

The University of Sydney

### **Copyright in relation to this thesis\***

Under the Copyright Act 1968 (several provision of which are referred to below), this thesis must be used only under the normal conditions of scholarly fair dealing for the purposes of research, criticism or review. In particular no results or conclusions should be extracted from it, nor should it be copied or closely paraphrased in whole or in part without the written consent of the author. Proper written acknowledgement should be made for any assistance obtained from this thesis.

Under Section 35(2) of the Copyright Act 1968 'the author of a literary, dramatic, musical or artistic work is the owner of any copyright subsisting in the work'. By virtue of Section 32(1) copyright 'subsists in an original literary, dramatic, musical or artistic work that is unpublished' and of which the author was an Australian citizen, an Australian protected person or a person resident in Australia.

The Act, by Section 36(1) provides: 'Subject to this Act, the copyright in a literary, dramatic, musical or artistic work is infringed by a person who, not being the owner of the copyright and without the licence of the owner of the copyright, does in Australia, or authorises the doing in Australia of, any act comprised in the copyright'.

Section 31(1)(a)(i) provides that copyright includes the exclusive right to 'reproduce the work in a material form'. Thus, copyright is infringed by a person who, not being the owner of the copyright, reproduces or authorises the reproduction of a work, or of more than a reasonable part of the work, in a material form, unless the reproduction is a 'fair dealing' with the work 'for the purpose of research or study' as further defined in Sections 40 and 41 of the Act.

Section 51(2) provides that "Where a manuscript, or a copy, of a thesis or other similar literary work that has not been published is kept in a library of a university or other similar institution or in an archives, the copyright in the thesis or other work is not infringed by the making of a copy of the thesis or other work by or on behalf of the officer in charge of the library or archives if the copy is supplied to a person who satisfies an authorized officer of the library or archives that he requires the copy for the purpose of research or study'.

\*'Thesis' includes 'treatise', dissertation' and other similar productions.



Clinical Psychology Unit, School of Psychology  
& Medical Psychology Research Unit  
The University of Sydney

**PSYCHO-SEXUAL ADJUSTMENT  
following TREATMENT for early stage  
CERVICAL and ENDOMETRIAL CANCER**

*Ilona Juraskova*

*A dissertation submitted in fulfilment of the combined degree of  
**Master of Psychology / Doctor of Philosophy**  
2003*

***Supervisors:***

***A/Prof Phyllis Butow, Director of Medical Psychology Research Unit  
Departments of Psychological Medicine & Medicine***

***Dr. Louise Sharpe, Senior Lecturer, School of Psychology***

I certify that the work in this thesis has not been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged.

A handwritten signature in cursive script, reading "Steve J. Smith", is written above a horizontal line.

## Acknowledgments

So many people have made it possible for this Ph.D. to be written that it would probably take a volume of similar size to mention them all. I'm deeply grateful to all those people, family, friends, colleagues, who have given so freely of their time and expertise to help me undertake this study. Every one of you deserves my heartfelt thanks. Some people do, however, need a special mention...

My principle supervisor, Associate Professor Phyllis Butow. You have inspired me to reach for academic excellence. Thank you for always being there, to give me direction and generously share with me the wealth of your knowledge. Your encouragement and belief in me was essential for me through the challenging times. I have the greatest admiration for you and feel privileged to have had the opportunity to learn from you.

My associate supervisor, Dr. Louise Sharpe. Your knowledge, clarity, insight and enthusiasm have been invaluable to me. You never ceased to motivate me to go that "extra mile" and actually enjoy it. Thank you for your constructive feedback and for giving so freely of your time. Your academic confidence in me helped me to grow not only as a researcher but also as a person.

My clinical supervisor, Ms. Rosalind Robertson. This Ph.D. thesis would not exist without your instigation. You recommended the topic, helped with the design of the study as well as recruitment and have stood by me with unfaltering support the whole way through. Your clinical expertise and your caring and empathetic nature inspire me.

My research assistants, Evril Freckleton and later Monika Dzikowski. Thank you for all your dedication to the project, your patience with recruitment and your accuracy and attention to detail during data entry. Your readiness to help was admirable, relieving a lot of stress and pressure during demanding times.

My present and past colleagues at the Medical Psychology Research Unit (MPRU), particularly Judy, Rebecca, Penny, Natasha and Laura. The MPRU was a great source of support on all levels, from academic and administrative to social and personal. I feel grateful that I can count my colleagues as my close friends.

My cherished friend and mentor, Tricia Mark. You offered me unconditional support through all the ups and downs of this PhD journey. Thank you for always believing in me, for correcting my endless drafts, for patiently listening to my latest Ph.D. dramas and then turning them into advantages. I feel blessed to have you in my life.

My dear friends, Pete, Alison, Deb and Joanna. You supported, rescued and revived me, encouraging me to persevere in achieving my goal. You played such an important part. Thank you for all your help, your understanding and tolerance with my Ph.D.-driven lifestyle.

This study would not have been possible without the willing co-operation of the patients who shared their experiences with such openness and candour. Thank you. Many other women will benefit in the future from your contribution. My thanks also extend to the many health professionals who contributed to this study, particularly at the Gynaecological Cancer Centre, Royal Hospital for Women.

Last but not least, I would like to thank those closest to me, my partner Darek and my family. Thank you, Darek, for your patience, understanding and encouragement throughout the time of this Ph.D. You have seen me at my best and my worst and loved me nevertheless. I am truly grateful. Thank you to my beautiful family in Czech. You believed in me and wanted the best for me, even though it meant we could not see each other as often as we would have liked. Your belief in me is so important.

I acknowledge and appreciate partial funding for this research project provided by the Departmental Research Grant and the Completion Scholarship from the School of Psychology at the University of Sydney, and by the Department of Radiation Oncology at the Royal Prince Alfred Hospital.

# TABLE OF CONTENTS

<i>Table of Contents</i>	iii
<i>List of Figures</i>	ix
<i>List of Tables</i>	xiii
<i>List of Abbreviations</i>	xviii
<i>Abstract</i>	xix
<b>CHAPTER I</b>	<b>1</b>
<b>1. Gynaecological Cancer &amp; Psycho-oncology</b>	<b>1</b>
<b>1.1 AIMS OF THE CURRENT STUDY</b>	<b>2</b>
<b>1.2 EARLY STAGE CERVICAL &amp; ENDOMETRIAL CANCER</b>	<b>4</b>
1.2.1 EPIDEMIOLOGY AND AETIOLOGY	4
1.2.1.1 <i>Cervical cancer</i>	4
1.2.1.2 <i>Endometrial cancer</i>	8
1.2.2 TREATMENT OPTIONS FOR EARLY STAGE CERVICAL AND ENDOMETRIAL CANCER	10
1.2.2.1 <i>Gynaecological surgery</i>	11
1.2.2.2 <i>Adjuvant radiotherapy</i>	13
1.2.2.3 <i>Common side effects of surgery versus radiotherapy</i>	16
<b>1.3 FEMALE SEXUAL FUNCTIONING</b>	<b>19</b>
1.3.1 FEMALE REPRODUCTIVE SYSTEM	20
1.3.2 SEXUAL RESPONSE CYCLE	23
1.3.3 SEXUAL RESPONSE OF OLDER WOMEN	24
1.3.4 MENOPAUSE AND SEXUALITY	26
1.3.5 CONCEPTUALISATION OF FEMALE SEXUAL FUNCTIONING: WHAT SHOULD WE MEASURE?	28
<b>1.4 PHYSICAL IMPACT OF CANCER TREATMENTS ON SEXUAL ADJUSTMENT</b>	<b>31</b>
<b>1.5 FACTORS IMPINGING ON SEXUAL ADJUSTMENTS OTHER THAN TREATMENT: MEDIATING VARIABLES</b>	<b>36</b>
1.5.1 MODELS OF SEXUAL ADJUSTMENT FOLLOWING GYNAECOLOGICAL CANCER	37
1.5.2 SATISFACTION WITH RELATIONSHIP	41
1.5.3 PSYCHOLOGICAL STATUS	43
1.5.4 ADJUSTMENT STYLES TO GYNAECOLOGICAL CANCER AND ITS TREATMENT	45
1.5.5 INFORMATIONAL NEEDS OF GYNAECOLOGICAL CANCER PATIENTS	47
1.5.5.1 <i>Dilators</i>	51

<b>1.6</b>	<b>SEXUAL FUNCTIONING OUTCOMES IN EARLY STAGE GYNAECOLOGICAL CANCER PATIENTS</b>	<b>53</b>
1.6.1	RETROSPECTIVE STUDIES	54
1.6.2	PROSPECTIVE STUDIES	56
1.6.3	SEXUAL OUTCOMES PERTINENT TO VARIOUS TREATMENT MODALITIES	69
<b>CHAPTER II</b>		<b>74</b>
<b>2.</b>	<b>Overall Design of the Study</b>	<b>74</b>
<b>2.1</b>	<b>FORMULATIONS OF THE STUDY DESIGN</b>	<b>74</b>
2.1.1	A COMBINATION OF QUALITATIVE & QUANTITATIVE METHODOLOGY	74
2.1.2	LONGITUDINAL CONTROLLED STUDY	78
<b>2.2</b>	<b>CONTROL GROUP I: PATIENTS WITH BENIGN GYNAECOLOGICAL CONDITIONS</b>	<b>79</b>
2.2.1	AETIOLOGY	79
2.2.2	PSYCHOLOGICAL CONCOMITANTS OF HYSTERECTOMY FOR BENIGN GYNAECOLOGICAL CONDITIONS	80
2.2.3	SEXUAL ADJUSTMENT FOLLOWING HYSTERECTOMY FOR BENIGN GYNAECOLOGICAL CONDITIONS	81
<b>2.3</b>	<b>CONTROL GROUP II: PATIENTS WITH PRE-INVASIVE CERVICAL ABNORMALITIES</b>	<b>85</b>
2.3.1	AETIOLOGY	85
2.3.2	PSYCHOLOGICAL CONCOMITANTS OF CERVICAL SCREENING AND FOLLOW-UP TREATMENT	88
2.3.3	SEXUAL OUTCOMES FOLLOWING PRE-INVASIVE CERVICAL ABNORMALITIES	90
<b>2.4</b>	<b>FORMULATIONS OF AIMS &amp; HYPOTHESES</b>	<b>92</b>
<b>CHAPTER III</b>		<b>96</b>
<b>3.</b>	<b>Phase 1a: A Qualitative Insight into Post-treatment Psycho-sexual Adjustment following Treatment for Cervical and Endometrial Cancer</b>	<b>96</b>
<b>3.1</b>	<b>METHOD</b>	<b>96</b>
3.1.1	PARTICIPANTS	96
3.1.2	DATA COLLECTION	97
3.1.3	DATA ANALYSES	98

<b>3.2</b>	<b>RESULTS</b>	<b>99</b>
3.2.1	IMPACT OF TREATMENT MODALITY	101
3.2.2	PATIENT & PARTNER ISSUES	101
3.2.3	PATIENT – DOCTOR ISSUES	106
<b>3.3</b>	<b>DISCUSSION</b>	<b>109</b>
3.3.1	IMPACT OF TREATMENT MODALITY ON SEXUAL FUNCTIONING	109
3.3.2	PATIENT & PARTNER ISSUES	110
3.3.3	PATIENT – DOCTOR ISSUES	112
3.3.4	DILATORS	114
<b>3.4</b>	<b>CONCLUSION</b>	<b>117</b>
<b>CHAPTER IV</b>		<b>119</b>
<b>4.</b>	<b>Phase 1b: A Qualitative Insight into Post-treatment Psycho-sexual Adjustment following Treatment for Pre-Cancerous Cervical Abnormalities</b>	<b>119</b>
<b>4.1</b>	<b>METHOD</b>	<b>120</b>
4.1.1	PARTICIPANTS	120
4.1.2	DATA COLLECTION	120
4.1.3	DATA ANALYSES	122
<b>4.2</b>	<b>RESULTS</b>	<b>123</b>
<b>4.3</b>	<b>DISCUSSION</b>	<b>130</b>
<b>4.4</b>	<b>CONCLUSION</b>	<b>136</b>
<b>CHAPTER V</b>		<b>137</b>
<b>5.</b>	<b>Method: Quantitative Phase</b>	<b>137</b>
<b>5.1</b>	<b>METHODOLOGICAL DESIGN</b>	<b>137</b>
<b>5.2</b>	<b>SAMPLE</b>	<b>138</b>
5.2.1	CANCER PATIENTS	139
5.2.2	PATIENTS WITH BENIGN GYNAECOLOGICAL CONDITIONS	148
5.2.3.	PATIENTS WITH PRE-INVASIVE CERVICAL ABNORMALITIES	151

<b>5.3</b>	<b>DATA COLLECTION</b>	<b>155</b>
5.3.1	BASELINE ASSESSMENT	155
5.3.1.1	<i>Cancer and Benign patients</i>	155
5.3.1.2	<i>Pre-invasive cancer patients</i>	156
5.3.2	FOLLOW-UP ASSESSMENTS	158
5.3.2.1	<i>Letter of thanks</i>	158
<b>5.4</b>	<b>ETHICAL CONSIDERATIONS</b>	<b>158</b>
<b>5.5</b>	<b>MEASURES</b>	<b>159</b>
5.5.1	BASELINE MEASURES	160
5.5.1.1	<i>Derogatis Sexual Functioning Inventory (DSFI)</i>	160
5.5.1.2	<i>Functional Analysis of Cancer Treatment (FACT) scale – version 3</i>	164
5.5.1.3	<i>Relationship satisfaction interaction scale</i>	167
5.5.1.4	<i>Mini-mental Adjustment to Cancer (Mini-MAC) scale</i>	168
5.5.1.5	<i>Hospital Anxiety and Depression Scale (HADS)</i>	172
5.5.2	FOLLOW-UP MEASURES	174
5.5.2.1	<i>Sexual Functioning After Gynaecologic Illness Scale (SFAGIS)</i>	174
5.5.2.2	<i>Treatment-specific measures addressing side effects, psychological responses and main issues of cervical and endometrial cancer patients</i>	175
<b>5.6</b>	<b>PILOT TESTING AND ARRANGEMENT OF THE QUESTIONNAIRE SETS</b>	<b>179</b>
<b>5.7</b>	<b>DATA ANALYSES</b>	<b>181</b>
5.7.1	CHECKING ASSUMPTIONS AND CHOICE OF STATISTICS	181
<b>CHAPTER VI</b>		<b>187</b>
<b>6.</b>	<b>Cross-Sectional Analyses of Baseline Data</b>	<b>187</b>
<b>6.1</b>	<b>RESULTS</b>	<b>188</b>
6.1.1	DEMOGRAPHIC CHARACTERISTICS	188
6.1.2	SEXUAL FUNCTIONING	189
6.1.3	QUALITY OF LIFE	190
6.1.4	SATISFACTION WITH RELATIONSHIP	194
6.1.5	PSYCHOLOGICAL STATUS	195
6.1.6	ADJUSTMENT STYLES	197
6.1.7	A SUMMARY OF RESULTS	197
<b>6.2</b>	<b>DISCUSSION</b>	<b>198</b>
6.2.1	DEMOGRAPHIC VARIABLES	198
6.2.2	BASELINE: PERIOD PRIOR TO ONSET OF GYNAECOLOGICAL SYMPTOMS / DIAGNOSIS	200
6.2.2.1	<i>Satisfaction with relationship</i>	200
6.2.2.2	<i>Sexual functioning</i>	200



6.2.3	BASELINE: PERIOD DURING THE MONTH PRIOR TO SURGERY / COLPOSCOPY	202
6.2.3.1	<i>Sexual functioning</i>	202
6.2.3.2	<i>Quality of Life</i>	202
6.2.4	BASELINE: POST-SURGERY / LLETZ (OR EQUIVALENT FOR PRE-INVASIVE PATIENTS)	206
6.2.4.1	<i>Psychological status</i>	206
6.2.4.2	<i>Mental adjustment styles of cancer patients</i>	208
6.3	<b>SUMMARY OF BASELINE FINDINGS</b>	<b>209</b>

## **CHAPTER VII** **210**

### **7. Prospective Longitudinal Study** **210**

#### **7.1 RESULTS I: PROSPECTIVE FINDINGS AT 6 MONTHS FOLLOW-UP** **210**

7.1.1	HORMONAL CHANGES	210
7.1.2	SATISFACTION WITH RELATIONSHIP	212
7.1.3	CHANGES IN SEXUAL FUNCTIONING	213
7.1.4	POST-TREATMENT CHANGES IN SEXUAL FUNCTIONING	222
7.1.5	SHORT-TERM TREATMENT SIDE EFFECTS	230
7.1.6	SIDE EFFECTS PERTINENT TO SPECIFIC TREATMENT MODALITIES	232
7.1.7	MAIN ISSUES PERTINENT TO SURGICAL TREATMENT	234
7.1.8	PSYCHOLOGICAL RESPONSES PERTINENT TO SPECIFIC TREATMENT MODALITIES	236
7.1.9	CHANGES IN PSYCHOLOGICAL FUNCTIONING	239
7.1.10	CHANGES IN QUALITY OF LIFE	243

#### **7.2 RESULTS II: Longitudinal data of the cancer group** **250**

7.2.1	HORMONAL CHANGES	250
7.2.2	SATISFACTION WITH RELATIONSHIP	250
7.2.3	CHANGES IN SEXUAL FUNCTIONING	251
7.2.4	POST-TREATMENT CHANGES IN SEXUAL FUNCTIONING	259
7.2.5	LONG-TERM TREATMENT SIDE EFFECTS	265
7.2.6	MAIN ISSUES PERTINENT TO SPECIFIC TREATMENT MODALITIES	269
7.2.7	PSYCHOLOGICAL RESPONSES PERTINENT TO SPECIFIC TREATMENT MODALITIES	272
7.2.8	CHANGES IN PSYCHOLOGICAL FUNCTIONING	275
7.2.9	CHANGES IN MENTAL ADJUSTMENT STYLES OF CANCER PATIENTS	277
7.2.10	CHANGES IN QUALITY OF LIFE OF CANCER PATIENTS	278

#### **7.3 RESULTS III: PROGNOSTIC VARIABLES FOR PSYCHO-SEXUAL ADJUSTMENT AND QUALITY OF LIFE FOLLOWING EARLY STAGE CERVICAL AND ENDOMETRIAL CANCER** **283**

7.3.1	INTRODUCTION	283
7.3.2	PRELIMINARY ANALYSES	284
7.3.3	RESULTS	285
7.3.3.1	<i>Predictors of sexual satisfaction at 6 months follow up</i>	287
7.3.3.2	<i>Predictors of relationship satisfaction at 6 months follow up</i>	288
7.3.3.3	<i>Predictors of quality of life at 6 months follow up</i>	289
7.3.3.4	<i>Predictors of anxiety levels at 6 months follow up</i>	290
7.3.4	SUMMARY OF RESULTS	291

<b>CHAPTER VIII</b>	<b>292</b>
<b>8. Discussion</b>	<b>292</b>
8.1 OVERVIEW OF FINDINGS	293
8.2 PHYSICAL OUTCOMES	294
8.2.1 HORMONAL CHANGES	294
8.2.2 VAGINAL CHANGES	295
8.2.3 DILATORS	299
8.2.4 OTHER SIDE EFFECTS	300
<b>8.3 THE IMPACT OF SPECIFIC TREATMENT MODALITIES</b>	<b>302</b>
8.3.1 MAIN ISSUES PERTINENT TO SPECIFIC TREATMENT MODALITIES	302
8.3.2 PSYCHOLOGICAL RESPONSES PERTINENT TO SPECIFIC TREATMENT MODALITIES	304
<b>8.4 PSYCHOLOGICAL OUTCOMES</b>	<b>306</b>
<b>8.5 RELATIONSHIP SATISFACTION</b>	<b>315</b>
<b>8.6 SEXUAL OUTCOMES</b>	<b>316</b>
8.6.1 SEXUAL DRIVE	316
8.6.2 SEXUAL SATISFACTION	324
<b>8.7 QUALITY OF LIFE</b>	<b>333</b>
<b>8.8 INFORMATIONAL NEEDS</b>	<b>338</b>
<b>CHAPTER IX</b>	<b>344</b>
<b>9. Overview of Limitations and Strengths of the Project</b>	<b>344</b>
9.1 LIMITATIONS OF THE STUDY	344
9.2 STRENGTHS OF THE STUDY	352
<b>CHAPTER X</b>	<b>356</b>
<b>10. Summary and Clinical Implications</b>	<b>356</b>
Reference List	361
Appendix	393

# List of Figures

<b>Chapter I</b>	<b>Pages</b>
Figure 1.1. <i>A graphical representation of the incidence of cervical and uterine cancers in Australia between 1994 and 1999</i> .....	5
Figure 1.2. <i>Internal female genitalia and other pelvic organs</i> .....	21
Figure 1.3. <i>Female reproductive anatomy</i> .....	21
Figure 1.4. <i>Andersen's (1993) model for predicting the risk of psychological and behavioural morbidity (p.1679)</i> .....	38
Figure 1.5. <i>A model of the evaluation of sexual functioning after cancer treatment by Weijmar Schultz and van de Wiel (2003, p.126)</i> .....	39
Figure 1.6. <i>Weijmar Schultz &amp; van de Wiel's (2003) model linking psychological and physiological consequences of cancer and its treatment (p.124)</i> .....	40
<b>Chapter II</b>	
Figure 2.1. <i>Overview of design employed in the quantitative stage</i> .....	92
<b>Chapter III</b>	
Figure 3.1. <i>The proposed model incorporating components believed to influence sexual outcomes following gynaecological cancer</i> .....	116
<b>Chapter IV</b>	
Figure 4.1. <i>Initial reactions to the diagnosis of abnormal cervical smear</i> .....	125
Figure 4.2. <i>Main concerns at the time of diagnosis versus post-treatment</i> .....	127
Figure 4.3. <i>Summary of findings</i> .....	131
<b>Chapter V</b>	
Figure 5.1 <i>Cancer group: Recruitment sample and data collection overview</i> .....	140
Figure 5.2. <i>Benign group: Recruitment sample and data collection overview</i> .....	149
Figure 5.3. <i>Pre-invasive cancer group: Recruitment sample and data collection overview</i> .....	152

## Chapter VI

Figure 6.1. <i>Quality of Life: Differences of group means in pre-treatment physical wellbeing</i> .....	191
Figure 6.2. <i>Quality of Life: Differences of group means in pre-treatment social wellbeing</i> .....	192
Figure 6.3. <i>Quality of Life: Differences in group means for satisfaction with the doctor-patient relationship</i> .....	193
Figure 6.4. <i>Quality of Life: Differences of group means in pre-treatment overall quality of life</i> .....	194
Figure 6.5. <i>Baseline group differences in anxiety levels (clinical cases vs. non-cases)</i> .....	196
Figure 6.6. <i>Baseline group differences in depression levels (clinical cases vs. non-cases)</i> .....	197

## Chapter VII

Figure 7.1.1. <i>Changes in relationship satisfaction over time</i> .....	212
Figure 7.1.2. <i>Changes in sexual satisfaction over time</i> .....	214
Figure 7.1.3. <i>Group comparisons of the itemised Sexual Satisfaction subscale at 6 months post-treatment</i> .....	216
Figure 7.1.4. <i>Percentage of true cases of the itemised Sexual Satisfaction subscale reported by a) cancer group, b) benign group and c) pre-invasive group at baseline and 6 months follow up</i> .....	217
Figure 7.1.5. <i>Changes in levels of sexual drive over time</i> .....	219
Figure 7.1.6. <i>Changes in global evaluation of sexual life over time</i> .....	221
Figure 7.1.7. <i>Percentage of various side effects experienced by cancer and benign patients at 6 months post-treatment</i> .....	231
Figure 7.1.8. <i>Changes in anxiety levels over time</i> .....	240
Figure 7.1.9. <i>Changes in clinical levels of anxiety over time</i> .....	241

Figure 7.1.10. <i>Changes in depression levels over time</i> .....	242
Figure 7.1.11. <i>Changes in clinical levels of depression over time</i> .....	243
Figure 7.1.12. <i>Changes in physical wellbeing over time</i> .....	245
Figure 7.1.13. <i>Changes in functional wellbeing over time</i> .....	245
Figure 7.1.14. <i>Changes in emotional wellbeing over time</i> .....	246
Figure 7.1.15. <i>Changes in social wellbeing over time</i> .....	247
Figure 7.1.16. <i>Changes in doctor-patient relationship over time</i> .....	247
Figure 7.1.17. <i>Changes in overall quality of life over time</i> .....	248
Figure 7.1.18. <i>Changes in wellbeing related to a gynaecological condition over time</i> .....	249
Figure 7.2.1. <i>Changes in relationship satisfaction of cancer patients over time</i> .....	251
Figure 7.2.2. <i>Changes in sexual satisfaction of cancer patients over time</i> .....	252
Figure 7.2.3. <i>Graphical representation of the percentage of true cases of the itemised Sexual Satisfaction subscale</i> .....	253
Figure 7.2.4. <i>Changes in levels of sexual drive of cancer patients over time</i> .....	255
Figure 7.2.5. <i>Mean scores for individual items of the Sexual Drive subscale</i> .....	256
Figure 7.2.6. <i>Changes in global evaluation of sexual life (i.e. GSSI) of cancer patients over time</i> .....	258
Figure 7.2.7. <i>Percentages of long-term side effects experienced by cancer patients treated with surgery alone versus surgery and radiotherapy at 12 months post-treatment</i> .....	267
Figure 7.2.8. <i>Percentages of side effects reported by cancer patients who had undergone surgery alone at 6 and 12 months post-treatment</i> .....	268

Figure 7.2.9. Percentages of side effects reported by cancer patients who had undergone surgery with adjuvant radiotherapy at 6 and 12 months post-treatment.....	269
Figure 7.2.10. Changes in anxiety and depression levels over time.....	276
Figure 7.2.11. Changes in clinical levels of anxiety and depression over time.....	276
Figure 7.2.12. Changes in the five Quality of Life dimensions of cancer patients over time.....	279
Figure 7.2.13. Changes in overall quality of life of cancer patients over time.....	281
Figure 7.2.14. Changes in cancer-related wellbeing of cancer patients over time.....	282

# List of Tables

<b>Chapter I</b>	<b>Pages</b>
Table 1.1. <i>The staging criteria of invasive cervical carcinoma established by the International Federation of Gynaecological Oncologists (FIGO)</i> .....	6
Table 1.2. <i>The staging criteria of endometrial cancer established by the International Federation of Gynaecological Oncologists (FIGO)</i> .....	9
Table 1.3. <i>Brief overview of longitudinal studies on sexual adjustment during first year post-treatment</i> .....	58-59
<b>Chapter II</b>	
Table 2.1. <i>Evolving guidelines for publication of qualitative research studies in psychology and related studies</i> .....	77
<b>Chapter III</b>	
Table 3.1. <i>Interview Questions</i> .....	98
Table 3.2. <i>Demographic and disease characteristics of sample (n = 20)</i> .....	100
Table 3.3. <i>Proposed components facilitating effective post-treatment sexual adjustment</i> .....	117
<b>Chapter IV</b>	
Table 4.1. <i>Interview Questions</i> .....	122
Table 4.2. <i>Characteristics of the sample (n=21)</i> .....	123
Table 4.3. <i>Practical suggestions to facilitate positive adjustment</i> .....	135
<b>Chapter V</b>	
Table 5.1. <i>Demographic and disease characteristics of “decliners” versus participants</i> .....	144
Table 5.2. <i>Demographic characteristics of sample (n = 197)</i> .....	145-146
Table 5.3. <i>Clinical characteristics of sample (i.e. diagnosis and treatment)</i> .....	147
Table 5.4. <i>Internal Consistency for the FACT subscales based on the current sample</i> .....	167

Table 5.5. <i>Internal consistency for the Mini-MACS subscales based on the current sample</i> .....	171
Table 5.6. <i>Overview of baseline and follow-up measures</i> .....	180
<b>Chapter VII</b>	
Table 7.1.1. <i>Changes in menopausal status and HRT use over time</i> .....	211
Table 7.1.2. <i>Group means (and standard errors) of relationship satisfaction and the sexual functioning variables, adjusted for age and psychological status</i> ...	213
Table 7.1.3. <i>Group percentage of true cases of the itemised Sexual Satisfaction subscale at baseline and at 6 months follow up</i> .....	215
Table 7.1.4. <i>Group means (and standard errors) of individual items of the sexual drive subscale, adjusted for age</i> .....	220
Table 7.1.5. <i>Post-treatment changes in sexual functioning reported at 6 months follow up</i> .....	222
Table 7.1.6. <i>Patients' post-treatment reports of the incidence and degree of vaginal stenosis</i> .....	223
Table 7.1.7. <i>Patients' post-treatment reports of the incidence and degree of reduced vaginal lubrication when having sexual relations</i> .....	224
Table 7.1.8. <i>Patients' post-treatment reports of the incidence and degree of genital sensations</i> .....	225
Table 7.1.9. <i>Patients' reports of degree of sexual excitement since the end of their treatment</i> .....	225
Table 7.1.10. <i>When sexual issues were discussed during consultations</i> .....	226
Table 7.1.11. <i>Patients' preferences of discussing sexual issues during consultations</i> .....	226
Table 7.1.12. <i>Patients' preferences regarding from whom to receive information about potential post-treatment sexual changes</i> .....	227
Table 7.1.13. <i>The preferences for time periods during the illness trajectory related to discussions of sexual issues during consultations</i> .....	228



Table 7.1.14. <i>Assessment of prevalence of misconceptions and myths among patients regarding contagiousness of the illness.....</i>	228
Table 7.1.15. <i>Patients' reports of misconceptions and myths among partners regarding contagiousness of the illness.....</i>	229
Table 7.1.16. <i>Cancer patients' reports of receiving a vaginal dilator.....</i>	229
Table 7.1.17. <i>Cancer patients' reports of receiving instructions on how to use a vaginal dilator.....</i>	230
Table 7.1.18. <i>Cancer patients' reports on the frequency of use of a vaginal dilator.....</i>	230
Table 7.1.19. <i>Perceived causes of side effects of various treatments reported by patients experiencing these side effects.....</i>	233
Table 7.1.20. <i>A summary of group frequencies (percentages) associated with the impact of surgery / LLETZ procedure on common issues identified by gynecological patients.....</i>	236
Table 7.1.21. <i>Factor analysis of psychological responses to gynaecological cancer treatments, revealing three components.....</i>	237
Table 7.1.22. <i>Descriptive statistics for surgery-related psychological responses analysis.....</i>	238
Table 7.1.23. <i>Descriptive statistics for the factor structure of psychological responses of cancer patients related to specific treatment modalities.....</i>	239
Table 7.1.24. <i>Group means (and standard errors) of the psychological status variables, adjusted for age.....</i>	240
Table 7.1.25. <i>Group means (and standard errors) of Quality of Life dimensions, adjusted for age and psychological status.....</i>	244
Table 7.2.1. <i>Group means (and standard errors) of the relationship satisfaction and sexual functioning variables.....</i>	251
Table 7.2.2. <i>Percentage of true cases of the itemised Sexual Satisfaction subscale.....</i>	253
Table 7.2.3. <i>Means (and standard errors) of individual items of the Sexual Drive subscale.....</i>	256

Table 7.2.4. <i>Cancer patients' reports of the incidence and degree of vaginal stenosis at 6 and 12 months post- treatment</i> .....	259
Table 7.2.5. <i>Cancer patients' reports of the incidence and degree of reduced vaginal lubrication when having sexual relations at 6 and 12 months post-treatment</i> .....	260
Table 7.2.6. <i>Cancer patients' reports of the incidence and degree of genital sensations at 6 and 12 months post-treatment</i> .....	260
Table 7.2.7. <i>Cancer patients' reports of degree of sexual excitement at 6 and 12 months post-treatment</i> .....	261
Table 7.2.8. <i>When sexual issues were discussed during consultations</i> .....	261
Table 7.2.9. <i>Patients' preferences for discussing sexual issues during consultations</i> .....	262
Table 7.2.10. <i>Cancer patients' preferences regarding from whom to receive information about potential post-treatment sexual changes</i> .....	262
Table 7.2.11. <i>Cancer patients' preferences for time periods regarding discussions of post-treatment sexual issues during consultations</i> .....	263
Table 7.2.12. <i>Prevalence of misconceptions and myths among cancer <u>patients</u> regarding contagiousness of their illness or its treatment</i> .....	264
Table 7.2.13. <i>Cancer patients' reports of misconceptions and myths among <u>partners</u> regarding contagiousness of the patient's illness or its treatment</i> .....	264
Table 7.2.14. <i>Cancer patients' reports of receiving a vaginal dilator</i> .....	265
Table 7.2.15. <i>Cancer patients' reports of receiving instructions on how to use a vaginal dilator</i> .....	265
Table 7.2.16. <i>Cancer patients' reports on the frequency of use of a vaginal dilator</i> .....	265
Table 7.2.17. <i>A comparison of the incidence of side effects at 6 and 12 months post-treatment</i> .....	266
Table 7.2.19. <i>The impact of various cancer treatments on common issues reported by cancer patients at 6 and 12 months follow ups</i> .....	272

Table 7.2.20. <i>Descriptive statistics for surgery-related psychological responses of cancer patients at 6 and 12 months follow up.....</i>	273
Table 7.2.21. <i>The mean scores (and standard deviations) for the factor structure of psychological responses of cancer patients related to specific treatment modalities at 6 and 12 months follow-up.....</i>	274
Table 7.2.22. <i>Group means (and standard errors) of the psychological status variables.....</i>	276
Table 7.2.23. <i>Group means (and standard errors) of the mental adjustment styles of cancer patients.....</i>	278
Table 7.2.24. <i>Means (and standard errors) of Quality of Life dimensions of cancer patients....</i>	279
Table 7.3.1. <i>Correlation matrix for baseline measures of sexual satisfaction, relationship satisfaction, quality of life and anxiety scores of cancer patients at 6 months follow up .....</i>	286
Table 7.3.2. <i>Multiple regression tables for backwards step-wise hierarchical regression to predict levels of sexual satisfaction at 6 months follow up.....</i>	287
Table 7.3.3. <i>Multiple regression tables for backwards step-wise hierarchical regression to predict levels of relationship satisfaction at 6 months follow up.....</i>	288
Table 7.3.4. <i>Multiple regression tables for backwards step-wise hierarchical regression to predict levels of Quality of Life at 6 months follow up.....</i>	289
Table 7.3.5. <i>Multiple regression tables for backwards step-wise hierarchical regression to predict levels of anxiety at 6 months follow up.....</i>	290

**Chapter XIII**

Table 8.1. <i>Studies measuring anxiety levels in women with gynaecological cancer as identified in the review by Thompson &amp; Shear (1998) supplemented by additional studies identified by the Ph.D. candidate.....</i>	310-311
---	---------

## List of Abbreviations

NSW	-	New South Wales
FIGO	-	Federation of Gynaecological Oncologists
CIN	-	Cervical Intraepithelial Neoplasia
SSC	-	Squamous cell carcinoma
BSO	-	Bilateral Salpingo-Oophorectomy
HDR	-	High Dose Rate
LDR	-	Low Dose Rate
WHO	-	World Health Organisation
HRT	-	Hormonal Replacement Therapy
DSM	-	Diagnostic and Statistical Manual for the Classification of Mental Disorders
CBT	-	Cognitive Behavioural Therapy
HADS	-	Hospital Anxiety and Depression Scale
NU*DIST	-	Non-numerical Unstructured Data by Indexing, Searching and Theorising
HPV	-	Human Papilloma Virus
LLETZ	-	Large Loop Excision of the Transformation Zone
QoL	-	Quality of Life
PLND	-	Pelvic Lymph Nodes Dissection
TAH	-	Total Abdominal Hysterectomy
DSFI	-	Derogatis Sexual Functioning Inventory
FACT	-	Functional Analysis of Cancer Treatment
GSSI	-	Global Sexual Satisfaction Index
EORTC QLQ	-	European Organisation for Research and Treatment Quality of Life Questionnaire
FLIC	-	Functional Living Index Cancer
POM	-	Profile of Mood States
MAC	-	Mental Adjustment to Cancer
GHQ	-	General Health Questionnaire
RSCL	-	Rotterdam Symptom Checklist
M-CSDS	-	Marlowe-Crowne Social Desirability Scale
SFAGIS	-	Sexual Functioning After Gynaecologic Illness Scale

## *Abstract*

The present multi-centre study provides a comprehensive assessment of the psycho-sexual adjustment and quality of life of patients undergoing various treatments for early stage cervical and endometrial cancer. It was comprised of a preliminary qualitative phase (Stage 1) and a main quantitative phase (Stage 2). Stage 1 included two in-depth qualitative studies. The first study (Phase 1a) was conducted to explore psycho-sexual issues relevant to post-treatment adjustment in early stage cervical and endometrial cancer patients and to inform measures used in the following quantitative stage. The second qualitative study (Phase 1b), conducted with patients diagnosed with pre-invasive cervical abnormalities, was designed to examine the suitability of including these patients as an additional control group. The second stage of the project involved a longitudinal assessment of early stage cervical and endometrial cancer patients using standardised and newly developed measures. Cancer patients' outcomes were compared to those of two control groups; i) benign gynaecological patients controlling for the effect of gynaecological surgery and ii) pre-invasive cancer patients controlling for the "threat of cancer" and related psychological issues.

The obtained findings indicated that treatment for early stage cervical and endometrial cancer does not result in major, continuing sexual upheaval and sequelae. The only lasting, albeit mild, decline seen in sexual satisfaction was an island of disruption in a scenario that otherwise represented a good post-treatment adjustment for these women. Psychological factors and the doctor-patient relationship/communication were identified as key predictors of post-treatment psycho-sexual adjustment. Patients treated for non-oncological gynaecological conditions reported poorer adjustment to their diagnosis and treatment than expected, pointing to a danger that the impact of such conditions may be underestimated by health care professionals. These findings have important implications for clinical practice and future research.

# 1. GYNAECOLOGICAL CANCER & PSYCHO-ONCOLOGY

Research into sexual outcomes following gynaecological cancer can be classified as a discipline within psycho-oncology. Psycho-oncology is a multi-disciplinary research and clinical sub-speciality focusing on the psychological, behavioural, social, and ethical components of cancer. These components are being addressed within two main dimensions: a) the psychological impact of cancer and its implications on patients, their partners/caretakers, family and friends, and health professionals, and b) the psychological, behavioural, and social aspects influencing the disease and recovery process (Holland & Watson, 1995).

Over the years, gynaecological cancer has progressed from being a terminal disease to a chronic illness with high survival rates. Despite a high incidence of gynaecological cancers, particularly in third world countries, the mortality rate from cervical cancer has decreased dramatically, in fact by more than 50%, over the past 30 years (American Cancer Society, 2002). The overall improvement in survival rates has led to a change in research emphasis. The majority of early published trials reported treatment outcomes predominantly in terms of survival and tumour response. Although the relevance of these quantitative factors is important, it is now clear that they alone are not sufficient data by which to judge the efficacy of treatment. Rather, issues defined as "quality of life" are now seen as important factors in determining the cost-benefit ratio of treatment. This has been illustrated in the medical literature by cases where radical surgery and/or highly toxic treatment has produced substantial suffering with only minimal benefit to the patient (Moorey & Greer, 1989).

As the likelihood of long-term survival has increased, the initial quantitative orientation of cancer research has become complemented by studies investigating qualitative aspects of patients' post-treatment life. These data allow physicians to base their treatment recommendations on wider criteria and assist patients in making informed decisions regarding their treatment options. Such data also facilitate the development of interventions aimed at improving patients' quality of life, which include not only physiological, but also psychological, sexual and sociological dimensions of life. Over the past two decades, increased research interest in the post-treatment adjustment process of gynaecological cancer patients pointed to the adverse impact of gynaecological cancer and its treatment on sexual functioning and/or sexual satisfaction (Weijmar Schultz, Branfield, van de Weil & Bouma, 1992; Andersen & Van der Does, 1994; Auchincloss, 1995). Although having received increased attention, the areas within quality of life relating to sexual functioning are still not well understood or documented. Novel findings and unexplored aspects continually surface as research progresses utilizing rigorous methodologies. This is illustrated by the use of a wider definition of sexual function/dysfunction in women and recognition of the psychological components of sexual functioning (Weijmar Schultz, van de Weil & Bouma, 1991). Consequently, the areas of quality of life and sexual health following gynaecological cancer form the main emphasis of this study.

## **1.1 Aims of the current study**

The purpose of the current research was to extend the available data in the area of sexual outcomes of patients undergoing treatment for early stage cervical and endometrial cancer. This was to be achieved by comparing outcomes of cancer patients with patients undergoing comparable surgical procedures for benign gynaecological conditions and patients diagnosed with pre-invasive cervical cancer, who are confronted with the threat of possibly developing a cancerous condition.

*The general aims of the study were:*

- to document the pattern of various facets of sexual functioning following early stage cervical and endometrial cancer within the first post-treatment year
- to explore differences in the process of psycho-sexual adjustment following early stage gynaecological cancer compared to other (benign and pre-invasive) gynaecological conditions
- to identify underlying psychological and physiological mechanisms regulating the process of sexual adjustment following early stage cervical and endometrial cancer, including internal (e.g. adjustment style) and external (e.g. health-care related) factors
- to evaluate the impact of different treatment modalities on post-treatment psycho-sexual functioning
- to explore the impact of psycho-sexual functioning on overall "quality of life"

Prompted by these research aims, a thorough literature review, two in-depth qualitative studies and a controlled prospective longitudinal study were conducted to provide findings which would contribute to the current understanding of post-treatment sexual adjustment following early stage cervical and endometrial cancer. The potential for practical implementation of the findings relevant to improving patients' quality of life and post-treatment sexual health was a prime consideration.



## **1.2 Early stage cervical & endometrial cancer**

### **1.2.1 Epidemiology & Aetiology**

Gynaecological cancer encompasses a number of primary carcinomas occurring in the female reproductive system. These include cancer of the vulva, vagina, cervix, the uterine corpus and ovaries. The most common site for gynaecological cancer is the uterus, with invasion of the cervix and the endometrium accounting for 70% of all gynaecological tumours (Andersen, Anderson & deProsse, 1989a).

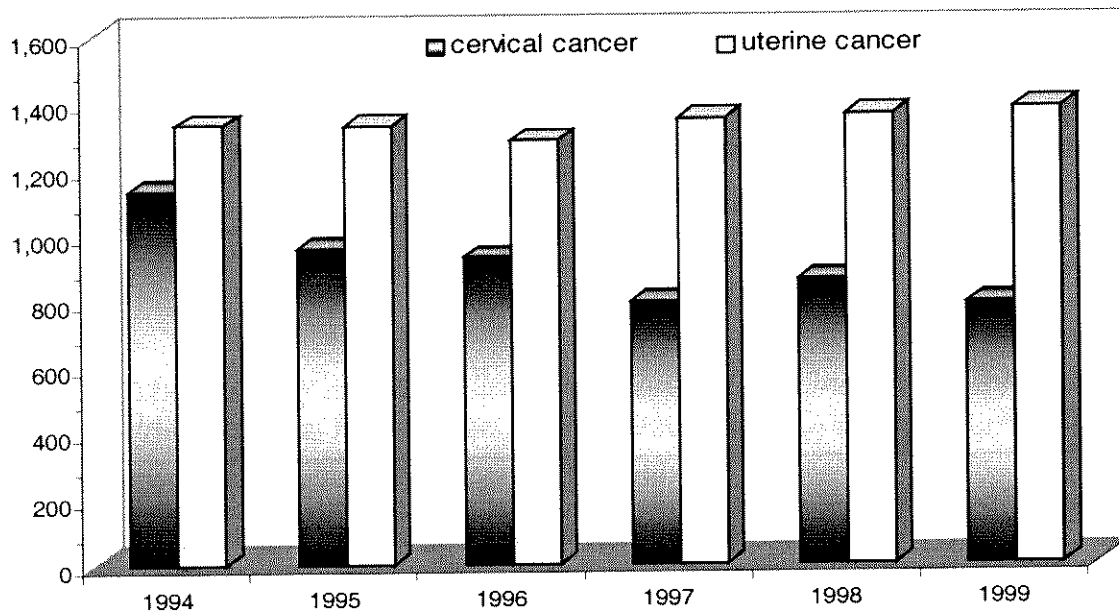
*Incidence* (or the crude incidence rate) refers to “the number of new cases in a given population during a specific period” (Tracey & Supramaniam, 2002, p.124). *The age-standardized incidence rates* refer to “the estimation of the age-specific rates as applied to the reference population” (Tracey & Supramaniam, 2002, p.124).

#### **1.2.1.1 Cervical Cancer**

In 2000, 285 new cases of cervical cancer were diagnosed in NSW, representing 2.2% of all cancers in females. Compared to Australian population data from 1991, the age-standardised incidence rate of cervical cancer was 8.1. The 88 deaths from cervical cancer represented 1.7% of female cancer deaths. The age-standardised mortality rate was 2.2 (Tracey & Supramaniam, 2002). Based on figures from 2000, approximately 1 in 150 females (0.7%) was expected to develop cervical cancer by the age of 75. Although the incidence of cervical cancer has been declining throughout the period from 1972 to 2000, this trend has accelerated in recent years since the introduction of population screening (see Figure 1.1. for Australian data; Tracey & Supramaniam, 2002). In the ten years, from 1990 to 2000, the incidence and mortality rates of cervical cancer both fell by 40%. The median age at diagnosis of cervical cancer in 2000 was 51. The 5-year survival rate experienced between 1994 and 1998 in NSW

was 73% for females diagnosed with all stages of cervical cancer (NSW Cervical Screening Program & The NSW Pap Test Registry, 2001). The 5-year survival rate of *early stage* cervical cancer is 91% and of *pre-invasive* cervical abnormalities 100% (American Cancer Society, 2002).

Figure 1.1. A graphical representation of the incidence of cervical and uterine cancers in Australia between 1994 and 1999



Cervical cancer is defined as a group of malignant cells in the cervix, the cervix forming the lower part of the uterus. This condition needs to be differentiated from the presence of non-malignant abnormal cells occurring in the cervix, which is termed cervical intraepithelial neoplasia (CIN). The severity of the latter condition is evaluated by the percentage of abnormal epithelial cells identified. Involvement of the inner one-third of the epithelium represents mild dysplasia (CIN I), involvement of the inner one-half to two-thirds represents moderate dysplasia (CIN II), and full thickness involvement represents severe dysplasia (CIN III). Although cervical intraepithelial neoplasia may progress (from CIN I to CIN III), or regress, once the process reaches severe dysplasia, a spontaneous regression rarely occurs (Nelson, Averette & Richart, 1989; Reid & Campion, 1989). The progression of non-malignant cervical abnormalities, such as CIN, has been suggested as a precursor to squamous cell carcinoma (SSC).

Of the 852 new cases of cervical cancer among all women in NSW between 1997 and 1999, 75% were classified as squamous cell carcinoma (NSW Cervical Screening Program & the NSW Pap Test Register, 2001). Adenocarcinomas and adenosquamous carcinomas, which appear to be increasing in incidence, account for approximately 15-20% of cases. A more accurate differentiation of cell types due to improved diagnostic techniques may account for the increased percentages in recent years. The staging criteria of invasive cervical carcinoma established by the International Federation of Gynaecological Oncologists (FIGO) are presented in Table 1.1. The present study includes cervical cancer patients diagnosed with FIGO Stages I and II only.

Table 1.1. *The staging criteria of invasive cervical carcinoma established by the International Federation of Gynaecological Oncologists (FIGO)*

---

**Stage 0 – Cervical Intraepithelial Neoplasia (CIN I-III)**

The abnormal cells are in the surface layer of the cervix and have not invaded deeper tissues  
This stage is also called pre-malignant, pre-invasive or pre-cancerous

**Stage I – The carcinoma is strictly confined to the cervix**

IA - Invasion of the cervical tissues can be identified only microscopically (not clinically)  
(Further classified into 1A1 and 1A2, depending upon depth)

IB - Lesions wider than 7 mm or deeper than 5 mm, or that can be identified clinically  
(Further classified into 1B1 and 1B2 for tumours larger or smaller than 4cm)

**Stage II – The carcinoma has extended beyond the cervix, but not onto the pelvic wall**

IIA - Extends to upper part of the vagina, but not to the surrounding tissues (parametria)

IIB - Extends to the parametrial tissues (but not to the pelvic wall)

**Stage III - The carcinoma has extended beyond the pelvic wall, but not beyond the pelvic area**

IIIA - Spread to the proximal third of the vagina, but not onto the pelvic wall

IIIB - Spread onto the pelvic wall, or has blocked a ureter (carrying urine from the kidneys to the bladder)

**Stage IV – The carcinoma has spread beyond the true pelvis, or has clinically involved the mucosa of the bladder or rectum**

IVA - Spread to the rectum or bladder

IVB - Spread (metastasis) to distant organs such as the lungs or liver

---

Although pre-invasive cervical disease (dysplasia) is mostly asymptomatic, invasive cervical cancer is commonly characterised by abnormal bleeding during

coitus, post-coitus, inter-menstruation and post-menopause. Vaginal discharge and dyspareunia can also occur. Other symptoms such as pelvic pain, swelling of the legs and urinary infrequency are often evident with advanced disease (Andersen, 1986). Since symptoms are not always present, particularly in the early stages of the condition, it is imperative that Papanicolaou smear (Pap smear) tests are undertaken regularly (i.e. every two years) to identify abnormalities before the condition deteriorates, thus allowing for earlier treatment.

Available literature suggests a multifactorial aetiology for cervical cancer (Ho *et al.*, 1998; Schiffman *et al.*, 1993). Research findings point to an infectious agent being responsible for cervical cancer, with Human Papilloma Virus (HPV, especially types 16 and 18) currently identified as the major causative factor (Ho, Bierman, Beardsley, Chang & Burk, 1998; Schiffman, Bauer, Hoover, Glass, Cadell *et al.*, 1993). The aetiology of cervical cancer has been closely linked to the individual's sexual life. Women whose male sexual partner reports multiple sexual partners appear to be at an increased risk, as are partners of men who report previous sexual partners diagnosed with cancer of the cervix (Bosch, Munoz, de Sanjose, Guerrerro, Ghaffari *et al.*, 1994; Nelson *et al.*, 1989). Further, women who become sexually active at an early age and who have multiple sexual partners appear to be at greater risk of developing cervical cancer (Stone, Zaidi, Rosero-Bixby, Oberle, Reynolds *et al.*, 1995; Bosch *et al.*, 1994; Schiffman, 1992; Slattery, Overall, Abbott, French, Robison & Gardner *et al.*, 1989; Brinton, Hamman, Huggins, Lehman, Levine *et al.*, 1987). Prostitutes are reported to have more than a fourfold relative risk (Brinton & Fraumeni, 1986; Nelson *et al.*, 1989), whilst cervical cancer is uncommon in virgins and no cases of cervical cancer were found in a study of 13,000 nuns (Gagnon, 1950). Further research is needed to determine whether there really is an increased risk factor associated with early onset of sexual intercourse and whether this is independent of, or in addition to, the increased risk that occurs with multiple sexual partners. Similarly, marriage at an early age and divorce have appeared as cervical cancer risk factors in some studies, but may merely serve as

markers for other factors such as number of sexual partners and early instigation of sexual intercourse (Brinton & Fraumeni, 1986). Such close association between the development of (pre-)cancerous cervical abnormalities and the patients' and partner's sexual history may challenge the couple's relationship and compromise their sexual life following the diagnosis.

Other factors implicated as potential risk factors for cervical cancer include advancing age, cigarette smoking, nutritional factors and the use of oral contraceptives (Coker, Bond, Williams, Gerasimova & Pirisi, 2002; Derchain, Roteli-Martins, Syrjanen, de Abreu, Martinez & Alves, 1999; Slattery *et al.*, 1989; Eddy, 1990). Women of a lower socioeconomic status, older women, women of non-English speaking background, Aboriginal and Torres Islander women and women from isolated rural areas, are commonly under-screened or unscreened and are therefore seen as having an increased risk of developing cervical cancer (McCormick, 1989; Baileff, 2000).

### **1.2.1.2 Endometrial cancer**

Whilst pre-menopausal women are diagnosed predominately with cervical cancer, endometrial cancer is the most prevalent form of gynaecological cancer among peri- and post-menopausal women (Andersen, 1986). In 2000, the incidence of endometrial cancer among women living in NSW was 465, corresponding to 3.5% of all cancers in females. The 83 deaths from endometrial cancer accounted for 1.3% of female cancer deaths (Tracey & Supramaniam 2002). Compared to the Australian population in 1991, the age-standardised incidence rate was 12.1 and the age-standardised mortality rate was 2.0. Based on the year 2000 data, approximately 1 in 86 females (1.2%) would develop endometrial cancer by the age of 75 years. In the ten years from 1990-2000, there was no significant trend in age-standardised incidence or mortality rates of endometrial cancer (Tracey & Supramaniam 2002, also see Figure 1.1.). The median age at diagnosis of endometrial cancer in 2000 was 65. The 5-year survival rate experienced between 1994 and 1998 in NSW was 80% for females diagnosed with endometrial cancer. The 5-year survival rate for

women diagnosed with Stage I endometrial cancer has been reported to be as high as 95%.

Approximately 75% of endometrial cancer cases are adenocarcinomas. When squamous elements are present, the tumour is considered to be an adenosquamous carcinoma, and carries a poorer prognosis. Less often, clear cell, squamous or serous carcinomas occur in the endometrium (American Cancer Society, 2002). The staging criteria of endometrial cancer, established by the International Federation of Gynaecological Oncologists (FIGO), are presented in Table 1.2. The present study includes endometrial patients diagnosed with Stages I and II only.

Table 1.2. *The staging criteria of endometrial cancer established by the International Federation of Gynaecological Oncologists (FIGO)*

---

**Stage I – The tumour is limited to endometrium**

IA – Invasion of the endometrium (uterine lining) only

IB – Invasion into the muscular layer under the endometrium (called the myometrium), but has invaded less than half of its thickness.

IC – Invasion extended to more than half of the thickness of the myometrium

**Stage II - The tumour has extended to the cervix**

IIA - The cancer is only in the glands of the endocervix (the part of the cervix nearest the body of the uterus).

IIB – Cervical stroma invasion

**Stage III - The tumour has spread beyond the uterus (but has not extended into the pelvic area)**

IIIA - Cancer spread to the tissues around the uterus, or fallopian tubes, or cancer cells are found in the fluid of the peritoneum

IIIB - Vaginal metastases

IIIC – Metastases to pelvic or para-aortic lymph nodes, or both

**Stage IV - More distant spread of the tumour**

IVA – Invasion of the rectum or bladder mucosa, or both

IVB – Distant metastases including extra-abdominal organs or the lungs

---

*Note: Histological tumour grade (i.e. Grade 1 = well differentiated, Grade 2 = moderately differentiated, Grade 3 = poorly differentiated) does not change the stage*

The most common symptom of endometrial cancer is abnormal uterine bleeding and dyspareunia. Pelvic pain, palpable mass and weight loss usually occur in later stages of the disease. Endometrial cancer is considered an oestrogen-dependent disease. Many of the risk factors of endometrial cancer are

associated with prolonged stimulation of the endometrium by unopposed oestrogen. These include early menarche, late menopause (later than 50 years), increased total years of menstruation, prolonged use of tamoxifen (anti-oestrogen drug used in the treatment of breast cancer), and use of oestrogen replacement therapy (without progesterone). Other risk factors include a genetic predisposition to gynaecological cancers and family history of polycystic ovarian disease, history of infertility, obesity, diabetes, a diet high in animal fats and advancing age (American Cancer Society, 2002).

### **1.2.2 Treatment options for early stage cervical and endometrial cancer**

In the present study only patients with stages I and II cervical and endometrial cancer took part. According to the protocol of the Gynaecological Oncology Study Group in Sydney (1995), the following treatment options for each subgroup of patients are recommended.

The options for treatment of *invasive carcinoma of the cervix* are:

- *Surgery* (i.e. radical hysterectomy with or without bilateral salpingo-oophorectomy, with or without pelvic lymph node dissection)
- Radiotherapy alone (i.e. *intracavitary radiation (brachytherapy) and/or external beam radiotherapy*) or in combination with surgery
- *Chemotherapy*, generally in combination with either or both of the above

The treatment of *endometrial cancer* can take the form of:

- *Surgery* (i.e. Total abdominal hysterectomy with or without bilateral salpingo-oophorectomy, with or without pelvic lymph node dissection)
- Additional *external beam radiotherapy* if the lymph nodes are positive
- Additional *brachytherapy* if the lymph nodes are negative but a deep invasion or poor staging is present
- *Chemotherapy*, generally in combination with any or all of the above

(Hacker & Moore, 1998)

It should be noted, however, that over the last decade the use of radiation as a single treatment modality had declined (Jones, Shingleton, Russell, Chmiel, Fremgen *et al.*, 1995), whilst the adjuvant chemo-radiation has become increasingly used. At the time the current project was being designed, the option of adjuvant chemotherapy was still in its experimental phase, with clinical trials being carried out to provide evidence for its effectiveness. As a result only a very small percentage of early stage cervical and endometrial cancer patients were expected to receive chemotherapy. It was therefore decided that the current review of psycho-sexual outcomes would focus on the impact of two main treatment options, namely surgery and adjuvant radiotherapy.

#### **1.2.2.1 Gynaecological surgery**

Surgery is the primary treatment for early stage cervical and endometrial cancer. Surgical treatment not only allows for the removal of cancerous cells from the body, but also allows for an accurate staging of the disease, which in turn determines whether adjuvant treatment will be required. Exploring the physiological impact of gynaecological surgery on a woman's sexual life requires a basic understanding of the main approaches to gynaecological surgery and the hysterectomy procedure itself.

During the hysterectomy, the uterus can be removed via the abdomen (i.e. *abdominal hysterectomy*), or through the vagina (i.e. *vaginal hysterectomy*). The apparent advantages of a vaginal approach are the lack of an abdominal scar and lesser postoperative discomfort compared to the abdominal procedure (Gutl, Greimel, Roth, & Winter, 2002). However, a number of conditions need to be fulfilled before a patient is eligible for a vaginal hysterectomy. These include, among others, having a mobile uterus which is not larger than a ten-week gestational size, and no evidence of adhesions due to pelvic inflammatory disease/endometriosis (Hatch, 1994).



Two types of hysterectomies can be performed, *subtotal* and *total*. Patients with early stage endometrial cancer commonly undergo a total abdominal hysterectomy, involving the removal of both the body of the uterus, cervix and other tissues where appropriate. Abdominal hysterectomies are commonly performed for resistant benign gynaecological diseases, such as fibroids, endometriosis and persistent uterine bleeding. A subtotal abdominal hysterectomy involves the removal of the uterus whilst preserving the cervix intact. Radical hysterectomy is the primary surgical treatment for cervical cancer patients. It includes the removal of the uterus, cervix, and the fallopian tubes, possibly ovaries, as well as the tissue between the uterus and the pelvic side walls and one third of the proximal vagina (Hatch, 1994).

Early stage cervical and endometrial cancer may require further pelvic and, if necessary, periaortic lymphadenectomy (the surgical removal of lymph nodes located around the aorta), allowing assessment and prevention of possible spread of the cancerous cells by the lymphatic system. Many post-menopausal women also allow for the removal of their ovaries whilst undergoing hysterectomy, a procedure called Bilateral Salpingo-Oophorectomy (BSO). The option of conservation of the ovaries, where medically appropriate, is particularly relevant for pre-menopausal women. A controlled longitudinal study by Vuorento, Maenpää, & Huhtaniemi (1992) assessed the serum progesterone levels of 41 patients during the month prior to and following the surgery and at one and six months post-operation. At 6 months follow up, normal cyclic ovarian function was restored. Consequently, long-term ovarian dysfunction seems unlikely in the absence of BSO procedure or functional impairment of the ovaries as a side effect of the operation.

The significant impact of hysterectomy on women's psychological and physical functioning becomes apparent with the description of the procedure. Since all surgically treated women in the current study had undergone an abdominal hysterectomy, the procedure of abdominal hysterectomy will be briefly outlined.

An abdominal hysterectomy is considered major surgery requiring general anaesthetic. The procedure is extensive and intricate. Incision through, and subsequent repair of, the abdominal wall often means the patient experiences pain on movement during recovery. Scar tissue forms along the incision line and can be visibly disfiguring. Invasive procedures to ensure the identification and removal of cancerous growths cause trauma to internal abdominal organs, possibly impairing their function for some time post operative. Since the removal of any organ requires the dissection of nerve pathways, veins and arteries, unintentional severance of any of these structures can cause significant damage in the short and long-term. Infection, including pelvic abscess, can also occur with symptoms of elevated temperature and lower abdominal pain and is usually evident within seven days of surgery (Smith & Bigrigg, 1994). Discharge from hospital usually depends upon an observable return to normal functioning of the bladder and bowels, allowing any *in situ* catheter to be removed. Postoperative hospital recovery takes approximately three to eight days, depending on a number of factors such as the type of surgery and the patient's preoperative health status.

#### **1.2.2.2 Adjuvant radiotherapy**

Adjuvant radiation treatment is recommended for some patients to ensure adequate destruction of any cancerous cells not removed by surgery, with the aim of reducing, possibly preventing, any further cancerous growth in that area. An increased risk of a recurrence is indicated by traces of cancer cells within the lymph nodes (i.e. positive lymph nodes), deep cervical invasion, tumour growth in the para-cervical tissue, or inadequate surgical margins (Thomas, 1994). However, no persuasive evidence exists that post-operative radiotherapy *per se* considerably increases the 5-year survival rate (Kinney, Alvarez, Reid, Schray, Soong *et al.*, 1989). Prior to recommendation of adjuvant radiation treatment, a number of clinical variables need to be considered, including age of the patient, diameter of the lesion and the number of positive lymph nodes (Alvarez, Soong, Kinney, Reid, Schray *et al.*, 1989) as well as the location of any lymph node metastases (Inoue, Chihara, & Morita, 1986). Postoperative radiotherapy is

performed in approximately 60% of early stage cervical and endometrial cancer patients and is considered to have only a limited beneficial effect.

Radiotherapy is defined as the use of high-energy ionizing rays or particles to treat cancer (Iwamoto, 1997), which in the treatment of Stages I and II cervical and endometrial cancer is commonly delivered in the form of external telecobalt therapy and/or intracavitary radium treatment (i.e. brachytherapy) (Nunns, Williamson, Swaney & Davy, 2000; Krumm & Lamberti, 1993). Ionizing radiation has a direct effect on the highly radiosensitive basal layer of the vaginal epithelium as well as on the endothelium of the small vessels and on the fibroblasts of the connective tissue in the sub-epithelium, both of them moderately radiosensitive (Weijmar Schultz *et al.*, 1991). Consequently, any vaginal changes following radiotherapy are, to a large extent, related to the dose of radiation and tissue radiosensitivity (Krumm & Lamberti, 1993; Hamberger, Unal, Gershenson & Fletcher, 1983).

The dosage of rays determined for treatment is specific to each patient. Prior to the procedure of *external beam radiation*, the skin is marked at the points where the rays are to be applied. Megavoltage therapy by linear accelerators (4-35meV) and betatrons (20-42meV) is used, since they are deemed to provide maximum dosage to deeper layers of tissue, with minimal skin damage and no bone necrosis. These are efficient over larger areas such as the abdomen and require shorter treatment times (Hacker, 1986). The entire treatment of external radiotherapy takes four to six weekly sessions.

*Brachytherapy* (i.e. intracavitary radiation) is another primary component of radiation treatment for gynaecological cancer. It can be used either alone or in combination with a course of fractionated, external beam radiation treatments. There are two methods of brachytherapy: High dose rate (HDR) implants or Low dose rate (LDR) implants (Wright, Jones, Whelan & Lukka, 1994). LDR involves prolonged (approximately 30 hours) irradiation with a single insertion of the rods into the vagina under general anesthetic. In contrast, HDR involves brief,

approximately 15-20 minutes long, irradiation of the tumour mass and/or surrounding tissues with repeated insertion of rods (3-4 times) in an outpatient clinic (Karlsson & Andersen, 1985; Wright *et al.*, 1994; Velji & Fitch, 2001). Wright *et al.* (1994) explored patient preferences for HDR or LDR brachytherapy in cervical cancer patients. When both methods were assumed to be isoeffective, only a third of patients preferred three fractions of HDR to one fraction of LDR. This, however, increased to 50% when HDR was assumed to be 2% more curative or 6% less toxic (Wright *et al.*, 1994).

The invasive nature of both intracavitary methods becomes apparent with the mere description of the procedure of LDR brachytherapy. The procedure involves a continuous or pulsed-dose treatment over one or two days, requiring admission to hospital. The implantation of irradiation rods into the vagina and uterus is carried out under general anaesthetic with full preoperative procedures including enema. Internal irradiation requires the insertion of three 15-inch (38.10 cm) metal rod-like instruments, one into the uterus, the other two in the cervical fornices. The position of the instruments is radio-graphically ascertained prior to the loading of the rods with radioactive pellets. Patients usually remain isolated in a special room designed to contain radiation procedures. Due to the radioactive nature of the treatment, protective measures need to be taken, such as restricted contact with nursing staff and visitors. It is essential that there be no disturbance to the positioned rods and pellets, therefore the patient is obliged to remain immobile, lying on her back. A urinary catheter is inserted and bowel movement, where necessary, requires the use of a bedpan. Eating and drinking is awkward. Thus, the distress commonly experienced, despite the option of heavy sedation, can make this a most arduous ordeal for most patients. During the active implantation time, patients have reported experiencing anxiety, physical discomfort/pain, physiological arousal, fatigue, varying degrees of loneliness and isolation (Andersen, Karlsson, Anderson & Tewfik, 1984; Nail, 1993; Velji & Fitch, 2001). The removal of metal rods and radioactive material is carried out in the patient's

room with the patient under heavy sedation; a general anaesthetic is not usually required (Andersen *et al.*, 1984).

Clearly, the experience of any type of adjuvant radiotherapy and its possible complications and/or side effects places an additional burden on the cancer patient, who is already forced to cope with removal of reproductive organs, an alteration of anatomical structures as well as various adverse vaginal changes and side effects as a result of surgery. To facilitate accurate understanding of the impact of various treatment modalities, the most common side effects pertinent to surgery and radiotherapy are described.

### **1.2.2.3 Common side effects of surgery versus radiotherapy**

Any discussions regarding treatment regimes with cancer patients need to include the evaluation of possible side effects of each treatment modality (Bertelsen, 1983; Andersen & Hacker, 1983c). Since during radical hysterectomy approximately one-third of the proximal vagina is removed, cervical cancer patients commonly complain of subjective feelings of a *shortened vagina* (Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 1999; Flay & Matthews, 1995; Andersen, 1995). *Sensory loss* in the vagina and surrounding areas related to surgery has also been noted, particularly in women undergoing pelvic lymph nodes dissection (Weijmar Schultz *et al.*, 1991). Since reproductive organs are removed during hysterectomy, the woman loses her ability to bear children. Patients undergoing lymph node dissection are at risk of developing *lymphoedema* (causing swelling of the legs). A common side effect following the surgery is *bladder dysfunction*, with the degree of urinary dysfunction depending on the extent of the surgery (Haes & van Knippenberg, 1985). Although normal bladder function is usually restored within 1-3 months following surgery, dysfunction can be prolonged and occasionally becomes permanent.

*Radiation treatment* has been shown to have *delayed side effects*, occurring as long as one year post-treatment (Schover, Fife & Gershenson, 1989). Late

effects of radiotherapy may be serious and can jeopardize the success of any other therapies. Therefore, possible side effects need to be considered when assessing the benefits of various therapeutic modalities. In the Australian study evaluating the results of adjuvant pelvic radiation for early stage cervical cancer (n=81), 14% of irradiated patients experienced *late radiation effects (toxicity)* requiring medical or surgical intervention, which was greater than with hysterectomy or pelvic irradiation alone (Vinod, MacLeod, Dalrymple, Elliott, Atkinson *et al.*, 2000; Cull, Cowie, Farquharson, Livingstone, Smart *et al.*, 1993). Common physiological problems induced by radiation treatment include the *inhibition of vasocongestion, lubrication and the sensory nerve responses*, which are integral to arousal and the achievement of orgasm (Weijmar Schultz *et al.*, 1991, Andersen, 1995). *Diarrhoea* is another commonly reported acute side effect following external radiotherapy. This may become chronic (Nunns *et al.*, 2000, Klee, Thranov & Machin, 2000b). Research findings suggest that patients who experience increased acute toxicity and diarrhoea during radiation therapy are at greater risk of future rectal complications (Wang, Leung, Chen, Sun, Fang *et al.*, 1998; Uno, Itami, Aruga, Kotaka, Fujimoto *et al.*, 1998). A recent study by Carlsson, Strang & Bjurstrom (2000) assessed long-term treatment-related effects on quality of life and symptomatology in gynaecological cancer patients. Significantly more problems with flatulence and diarrhoea were reported in women treated with external radiation and/or brachytherapy than with surgery or chemotherapy (Carlsson *et al.*, 2000).

*Bladder irritation* may also occur, although it is more common following surgery as described previously (Klee *et al.*, 2000b). Another consequence of radiotherapy is the cessation of ovarian functioning, thus inducing menopausal symptoms, unless the ovaries have been transplanted out of the radiation field prior to the radiotherapy. Oestrogen deficiency is in turn associated with *reduced vaginal lubrication, vaginal atrophy and stenosis* (Andersen, 1995; Bruner, Lanciano, Keegan, Corn & Hanks, 1993; Seibel, Freeman & Graves, 1982). The use of Hormonal Replacement Therapy (HRT) does not fully compensate for radiation-induced vaginal atrophy and stenosis (Andersen & Hacker, 1983c).

*Vaginal stenosis* (i.e. hardening and narrowing of vagina) is a common side effect following post-operative radiotherapy, brachytherapy in particular, with reported frequencies ranging from 54.7% to as high as 80% (MacLeod, Fowler & Duval *et al.*, 1999; Nunns *et al.* 2000; Vasicka, Popovich & Brausch, 1958; Abitbol & Davenport, 1974a). To counteract the occurrence of vaginal stenosis, atrophy and adhesions, the use of a dilator and topical oestrogen are considered important treatment requirements for irradiated women (Decruze, Guthrie, & Magnani, 1999). Pelvic radiation treatment also causes *damage to the skin* in the radiation field, which may look and feel sunburned, gradually fading to a tanned look, returning to a normal appearance within 6 to 12 months (Kagan, Nussbaum, Gilbert, Chan, Rao *et al.*, 1979).

Differentiating between side effects originating solely from pelvic radiation as opposed to brachytherapy is very difficult. Nevertheless, instances of vaginal atrophy and stenosis seem more severe in women treated with brachytherapy than in those treated with external beam radiation (Andersen, 1995). Since vaginal irradiation (i.e. brachytherapy) directly affects vaginal mucosa, qualitatively different changes in vaginal elasticity, lubrication and sensation compared to vaginal changes following pelvic radiation, have been noted (Lamb, 1990). A study by Nunns *et al.* (2000) found that the incidence of vaginal stenosis does not seem to change when external beam radiotherapy is given in addition to brachytherapy or when only brachytherapy treatment is given. This study also found that all patients treated with brachytherapy alone initially developed radionecrotic ulcers of the vulva, which healed with conservative treatment (although for one patient this took a total of 9 months).

Interestingly, the type of cancer treatment had little if any effect on the prevalence of specific long-term vaginal changes in the Swedish retrospective study by Bergmark *et al.* (1999). Similarly, Weijmar Schultz *et al.* (1991), in their longitudinal controlled study did not find radiation-induced changes in patients treated with combined modalities of surgery and radiotherapy (i.e. no vaginal stenosis or fibrosis). Neural denervation as a result of radical hysterectomy was

noted, having a detrimental effect on vasocongestion, lubrication and perception of genital sensations, particularly during arousal, coitus and orgasm.

In summary, the physiological mechanisms underlying sexual responses are likely to be impaired as a result of the radical nature of cancer treatments and the many side effects that patients undergoing such treatment procedures commonly experience (Bergmark *et al.*, 1999). Indeed, even a simple hysterectomy for benign disease has been found to result in significant sexual disruptions (Andersen *et al.*, 1989a). However, prior to evaluating the physical impact of various treatments on sexual functioning, description of sexual responses and functioning in healthy women as well as the impact of menopause on sexuality needs to be considered.

### **1.3 Female sexual functioning**

Human sexuality is not simply the act of sexual intercourse (Horden, 1999), but a complex multidimensional aspect of human behaviour which contributes to a person's quality of life (Lamb, 1996). The World Health Organisation (WHO) defined human sexual health as: *"...the positive integration of the somatic, emotional, intellectual, and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love"* (WHO, 1975). Sexuality is an essential component of every human being throughout their life, regardless of age (Shell & Smith, 1994). It is not a static, but rather a constantly changing, experience (Topping, 1996) affecting how we feel about ourselves and our bodies (Robinson, 1998). The diagnosis of cancer and its treatment can, therefore, have a dramatic effect on a person's sexuality, challenging many beliefs, sexual behaviours and issues of intimacy as well as confronting the patient and her partner with issues of mortality and survival (Wellard & Joyce, 1998).



### **1.3.1 The female reproductive system**

An understanding of the anatomy and physiology of the female genital tract is essential for a clearer understanding of the changes that can take place following various treatments for gynaecological conditions.

The female genital tract comprises the vulva (labia majora and minora), the vagina, the cervix, the uterus, fallopian tubes and ovaries (see Figures 1.2. & 1.3.). Other significant structures are the clitoris, and the Grafenberg (G) spot, both rich in sensory nerve supply and believed to be integral in stimulating orgasm. Parting the labia exposes the clitoris, beneath which is the urethra and the vaginal opening. The urethra lies anterior to the length of the vaginal wall and in close proximity to it. Posterior to, and along the length of, the vagina is the rectum. Damage to any of these structures due to surgery or radiation can cause a disturbance in their functioning and can contribute to sexual difficulties, not only preventing pleasure, but possibly causing pain and discomfort (McCance & Huether, 1998).

The length of an intact vagina can vary between 7 and 9 cm when at rest, with the cervix protruding 1-2 cm into the proximal end of the vagina sealing it off from the uterus. The walls of the vagina are lined with squamous cell epithelium resting on rich vascular connective tissue. The vaginal epithelium is a mucous membrane arranged in folds or rugae, which allows the muscles of the vagina to stretch and lubricate during sexual intercourse and childbirth. The thickness of the epithelial layer is influenced by hormones, oestrogen in particular (McCance & Huether, 1998).

Figure 1.2. *Internal female genitalia and other pelvic organs*

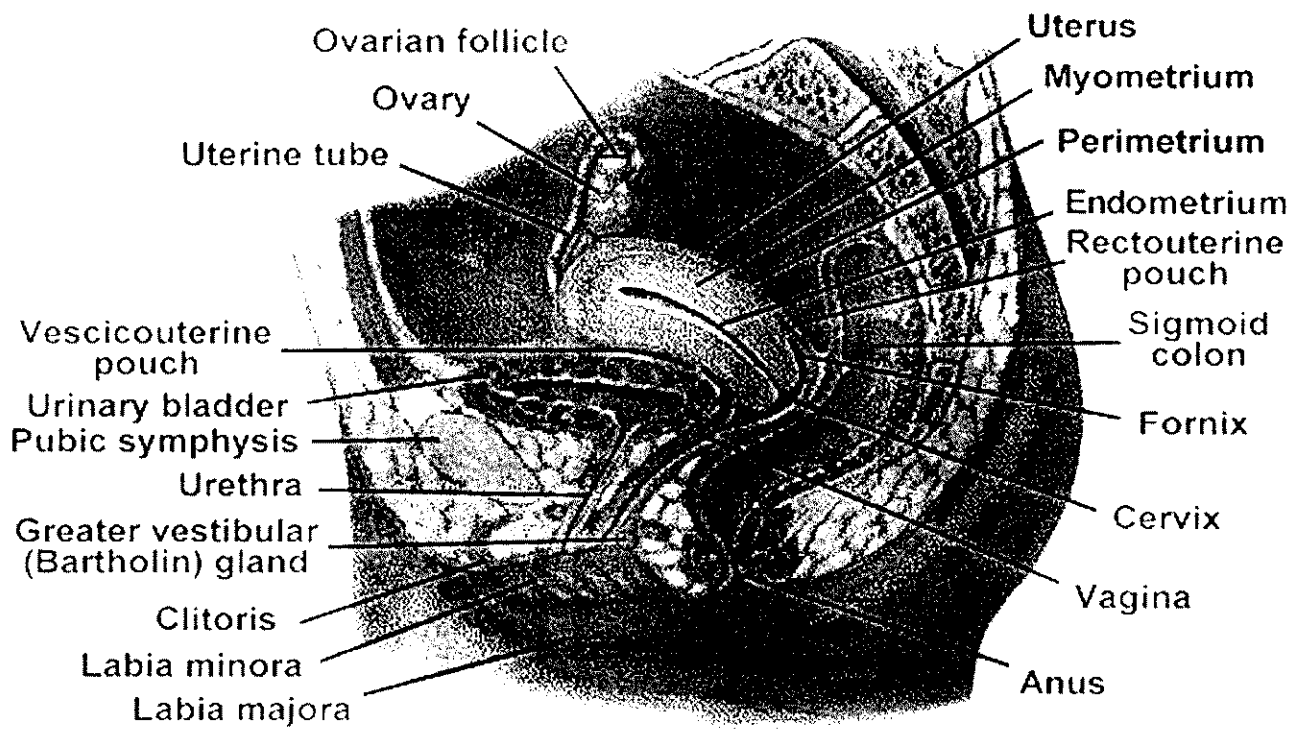
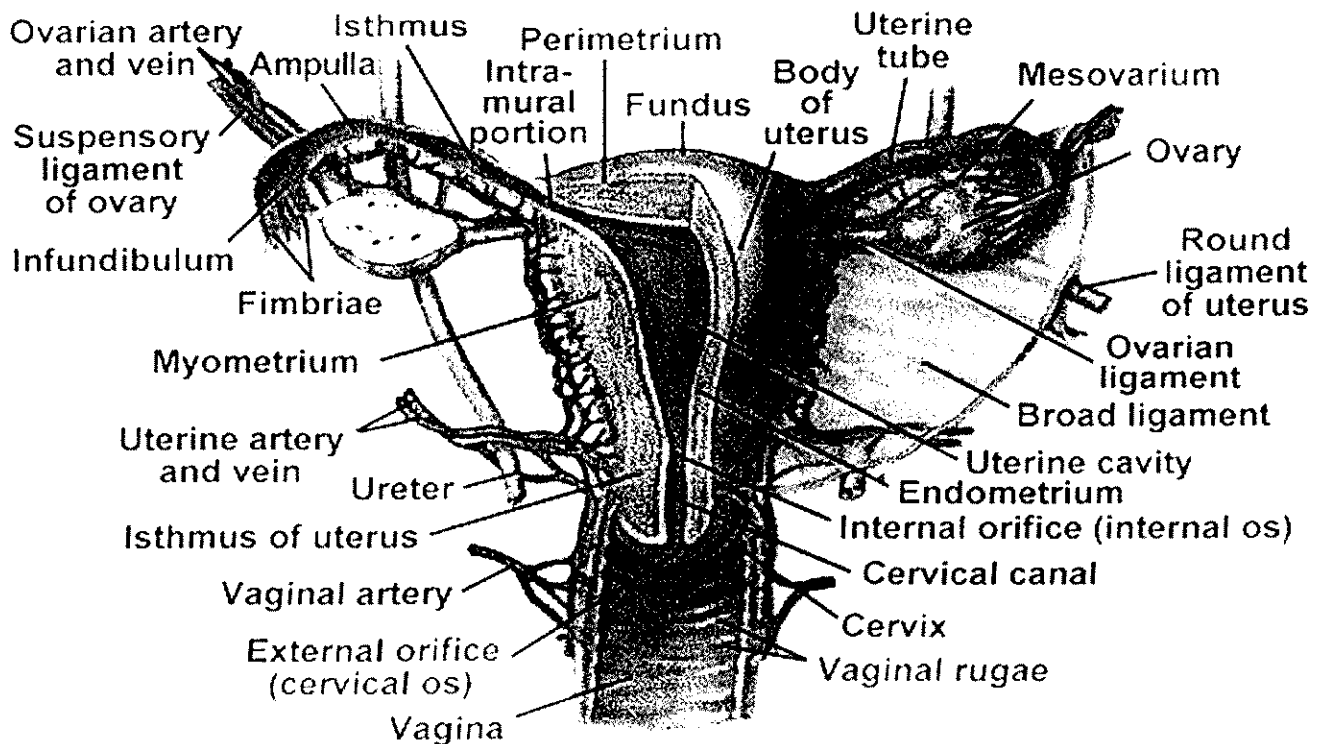


Figure 1.3. *Female reproductive anatomy*



The vagina contains secretions derived partly from the glands of the cervix, partly from the Bartholin glands and from the vaginal mucosa. These secretions increase considerably during sexual excitation producing lubrication to ease penetration and friction of the penis. The fluid is mucoid and acidic, and contributes to the maintenance of a healthy environment within the vagina. Damage to the integrity of any of these structures compromises their ability to perform their functions adequately and can detract from sexual competency and enjoyment (McCance & Huether, 1998).

The uterus at rest is a muscular, pear-shaped organ, roughly 7cm long, 2cm wide with walls 1-2cm thick and a potential cavity inside. At the distal end of the uterus is the cervix protruding into the proximal end of the vagina (see Figures 1.2. & 1.3.). The main function of the body of the uterus is to provide an optimal environment for the development and maturation of a fertilised ovum into a baby. The uterine wall has three layers. The endometrium is sensitive to the influence of hormones, particularly oestrogen, proliferating then shedding when pregnancy does not occur. This shedding is termed menstruation (McCance & Huether, 1998).

Two Fallopian tubes 0.5cm in diameter and 9-10cm long arise from either side of the upper lateral aspects of the uterus, terminating in fringed ends suspended above the right and left ovaries (see Figures 1.2. & 1.3.). Ova are drawn into the fallopian tubes where fertilisation usually takes, the fertilised ova then traveling to the uterus for implantation (McCance & Huether, 1998). Aside from producing ova carrying reproductive chromosomes, ovaries are responsible for producing various hormones including progesterone and oestrogen. The ovaries and the adrenal glands also produce small amounts of the male sex hormones known as androgens, important for the maintenance of libido (McCance & Huether, 1998). Consequently disruption to production of any of these hormones can interfere with sexual motivation and libido. Damage to the uterus, fallopian tubes and/or ovaries can cause infertility; removal of any of these organs certainly does (McCance & Huether, 1998).

### 1.3.2 Sexual response cycle

The normal physiological sexual response cycle is dependent upon an intact neurological system and an adequate supply of hormones (Lamb, 1996). The most prominent pioneers of human sexual response, Masters & Johnston (1966), proposed a four-phase sexual response cycle consisting of sexual excitement, plateau, orgasm, and resolution. This classification has since been challenged, particularly the plateau and resolution phases (Kaplan, 1970). Nowadays a four-phase sexual response cycle is seen as comprising of sexual desire, sexual excitement/arousal (which includes plateau phase), orgasm and sexual resolution. This is the most common concept of human sexual response used in psycho-sexual research (American Psychiatric Association, 1994).

The female sexual response cycle commences with the **desire** phase, manifesting itself as a need for intimate and sexual contact, thus activating sexual behaviour. The female then becomes sensitive to physiological and psychological cues that best lead her to the next phase of sexual **excitement/arousal**. To reach the stage of sexual arousal causing increased vaginal lubrication, stimulation needs to be consistent and appropriate and of an intensity that produces the desired results of progression to the next phase (Lamb, 1996). Signs of successful sexual arousal and excitement include engorgement of the breasts with erection of the nipples, enlargement of the clitoris and vasodilation within the vagina. Progression to the plateau phase results in more engorgement of the primary and secondary sex organs, with an increase in the heart and respiratory rate. Muscle tension throughout the body increases and flushing of the skin usually occurs. The smooth vaginal muscles expand which allows the vaginal vault to extend and the uterus to rise. **Orgasm** takes place when sexual excitement is intensified to its maximum level. It is an involuntary reflex, characterised by rhythmic contractions of the circum-vaginal muscles, accompanied by involuntary contractions of various other muscles. Following orgasm the increased respiratory and heart rate may persist for some time and may be accompanied by an elevation in blood pressure. A decrease in hormonal levels concurrent with the decrease of physiological tension allows

relaxation to take place. This is called the **resolution** phase and is characterised by the return of the breasts and nipples to normal size, the disappearance of any flushing of the skin and the relaxation of circum-vaginal and other muscles (Topping, 1996). Ultimately the heart rate, respiration rate and blood pressure, all return to normal levels. When orgasm does not occur, despite significant levels of sexual excitement, the resolution phase takes longer to manifest, with sexual tension persisting for an extended period (Masters & Johnson, 1980).

This accounts for the physiological components of a sexual encounter but does not include an evaluation of the emotional and psychological components involved.

### **1.3.3 The sexual response of older women**

Masters and Johnson (1980) differentiate the sexual responses of younger women (in their 20's - 40's) and older women (in their 50's - 70's). The comparison between the sexual responses of each group reflects the understanding of sexual matters prevalent at the time (first edition was published in 1966) Masters and Johnson conducted their investigations. However, their publications were influential and provided information relevant to the older women in our study.

Sexual **desire** has been said to decrease in older women due to a natural aging process that sees the efficiency of sexual hormone production diminish and a deterioration in the vigour of genital organs and tissue. This can be reflected in a lessening of libido, a retardation of response rates and a lack of intensity of sensation and orgasm (Masters & Johnston, 1980). Symptoms similar to the natural aging process are said to occur after disruption of hormonal levels following damage to, or removal of, ovaries in particular and genitalia in general. Hormone replacement therapy is seen as having the potential to rectify some of these degenerative changes enabling former levels of sexual desire and proficiency to return. However, these conclusions are drawn from an evaluation

cannot be continued throughout life, providing both partners are capable and wish to benefit from continuing this activity (Gress, 1978).

### **1.3.4 Menopause and Sexuality**

The physical consequence of undergoing a hysterectomy with Bilateral Salpingo-Oophorectomy (BSO) can be one of an induced menopause. This may have varying effects, depending on the age of the woman and the stage of her reproductive life. In order to guarantee that age-related sexual alterations are not confounded with surgically induced sexual concomitants, some knowledge of menopause is required.

Menopause is the term applied to the cessation of menstruation. A menstruation free period of at least six months is considered an adequate time to conclude that menopause has occurred. The average age of menopause is approximately 51 years (Speroff, Glass, & Kase, 1994). However, this may vary from the early forties to the late fifties (Mackay, Beischer, Pepperell & Wood, 1990). For some women there is an abrupt cessation of ovulation and menstrual activity. However, for the majority of women menstruation becomes erratic in occurrence with variations in flow from scant to profuse, as hormonal levels destabilise and re-establish. This readjustment can take several years and is referred to as perimenopause. Eventually, oestrogen production is too low to induce shedding of the uterine lining and menstruation ceases (Speroff *et al.*, 1994). Menopause occurs naturally for all women with or without attendant 'menopausal symptoms' such as emotional lability, night sweats and hot flushes. Surgical or radiation induced menopause causes an immediate cessation of menstruation, often with the onset of menopausal symptoms such as vaginal dryness and inelasticity as well as those previously mentioned (Mackay *et al.*, 1990; Auchincloss, 1995). If menopause occurs before age 40, it is said to be premature menopause. Autoimmune problems (e.g. thyroid disease, diabetes mellitus) and cancer treatments (e.g. surgery, radiotherapy, chemotherapy) can be possible causes of premature menopause.

In a naturally occurring menopause the continuing decrease in oestrogen production results in atrophy of oestrogen-dependent tissues, in particular the uterus and the ovaries. The vagina can become drier, less elastic, and appears to shrink. Vaginitis (an inflammation of the vagina characterized by discharge, odour, and itching) may result, as may occasional coital bleeding due to reduced lubrication and tearing of the now thinned vaginal lining. The atrophic process also affects the lower urinary tract, often resulting in stress incontinence. Loss of muscle tone and ligamentous insufficiency may account for an increase in the incidences of antiversion, retroversion of the uterus, prolapse of the uterus and stress incontinence, particularly in women who have had multiple pregnancies. The onset of osteoporosis is more prevalent during this time as is a dramatic increase in the risk of coronary heart disease (Eden, 1995). Hot flushes, vasodilation, particularly of the neck and face, are common symptoms of a destabilised hormonal status (Speroff *et al.*, 1994).

Direct hormonal influences on the physiology of postmenopausal women are better understood and differentiated than the indirect effects, which are often psychological in nature. Recent data from controlled studies shows that many psychological problems occurring around the time of menopause are consequences of changes in a woman's family and social circumstances rather than a direct result of the process of menopause. Events such as loss of family members, children reaching adulthood and leaving home, loss of friends and loss of social life, have been attributed to menopause *per se* rather than concomitant with it (Speroff *et al.*, 1994; Robertson, 1996). Nevertheless, some psychological symptoms seem to be related to hormonal changes. It has long been postulated that emotional lability and depressive states fluctuate according to hormonal levels in some women. Certain types of headaches, palpitations, poor concentration and poor memory have also been said to have an hormonal component (Eden, 1995). Hormonal involvement in these symptoms seems likely since they appear to respond well to hormone replacement therapy (HRT). Addition of testosterone to regular HRT is known to improve sexual arousal and

frequency of orgasm (Sherwin & Gelfand, 1987; Walling, Andersen, & Johnson, 1990). However, it is possible that severe psychological and psychosomatic problems evident post-menopause may be based on pre-existing dysfunctional coping styles and a history of long-standing psychological difficulties. Information and education are valuable aids to allay some fears, myths and misconceptions regarding cessation of menstruation and the onset of menopause.

It is inaccurate to assume that an interest in sexual activity ceases with advancing years (Speroff *et al.*, 1994). This is one of many misconceptions that exist concerning the impact of menopause on female sexuality. Those women experiencing difficulties and attending a menopausal clinic seeking consultation for severe menopausal symptoms have formed the basis for many studies in this area (Speroff *et al.*, 1994). These patients, however, do not necessarily reflect the average menopausal woman. Thus the high incidence of peri- and post-menopausal difficulties reported in the literature may be misleading. It has been found that in many cases it is not physiological factors that cause a decline in sexual activity in older people but psychological variables (Frank, Andersen, & Rubinstein, 1978; Masters & Johnson, 1980; Speroff *et al.*, 1994; Robertson, 1996). Where difficulties do occur, psychological components such as inadequate communication and difficulty with inter-personal relationships need to be taken into account. It is therefore reasonable to conclude that sexual functioning in older women is a complex and multifaceted issue that warrants further research interest.

### **1.3.5 Conceptualisation of female sexual functioning: What should we measure?**

Considering the complex and dynamic nature of sexual functioning, it is not surprising that one of the main factors hindering research into sexuality to date has been a difficulty with the operationalisation of sexual functioning variables.



Studies commenting on the early clinical treatment of sexual problems in gynaecological cancer have been mainly orientated towards the resumption of coitus (Cain, Kohorn, Quinlan, Schwartz, Latimer, & Rogers, 1983; Capone, Good, Westie, & Jacobson, 1980; Harris, Good, & Pollack, 1982; Lamberti, 1979; Seibel, Freeman, & Graves, 1980), whilst ignoring other non-coital possibilities, which may, in fact, be much more in accordance with the actual preferences of most women (Bos, 1986). This traditional approach to sexual problems has been underpinned by stereotyped beliefs about women's sexual functioning such as the assumption that women focus on intact genitalia and the capacity for coitus and orgasm as indicative of sound sexual health. Accordingly, research methodology and outcome criteria have focused on issues such as the frequency of vaginal intercourse and orgasm rather than considering a broader range of sexual experiences and beliefs defined by women, such as intimacy between partners, including open communication about sexual matters and sensuous activities (Cairns & Valentich, 1986; Boss, 1986). Von Eschenbach & Schover's (1984) study represented one of the first attempts to assess a broader range of sexual attitudes and beliefs using the triphasic (desire, excitement, and orgasm) model of sexual response for the evaluation of sexual dysfunction after cancer treatment in both men and women. Findings of this study indicated that female cancer patients are more likely to lose interest in sex (desire phase) whilst male patients with cancer are more likely to lose erection response (excitement phase). These gender differences highlight the need to investigate female sexual functioning in a more comprehensive manner.

In an attempt to assess the complex nature of female sexual functioning whilst improving methodological rigour and reliability of research into sexual outcomes following gynaecological cancer, a number of longitudinal studies have operationalised sexual dysfunctions according to the diagnostic criteria of the Diagnostic and Statistical Manual for the Classification of Mental Disorders (DSM-III & IV, American Psychiatric Association, 1994) (Andersen *et al.*, 1989a; Grumann, Robertson, Hacker & Sommer, 2001). However, it is questionable

whether DSM-IV criteria can be considered as reliable guidelines for the diagnosis of sexual difficulties following treatment for early stage cervical and endometrial cancer. Close inspection of the criteria of various dysfunctions revealed that these are not clearly defined and instead rely heavily on the clinician's interpretation of the obtained information. For instance, sexual dysfunctions following cancer treatment may have been caused by changes in the sexual behaviour of the partner such as avoidance of sexual intercourse due to misconceptions regarding the contagiousness of cancer via sexual activities or due to fear of causing pain. One of the criteria necessary for the diagnosis of sexual dysfunction, namely the presence of personal or relationship distress resulting from a disruption of a specific phase of the sexual response cycle, may not be applicable to the targeted population due to the possible bias inherent in the exceptional circumstances of a life threatening disease and consequent distress. Taking these issues into account, the DSM-IV classification of sexual dysfunctions, although useful in a clinical setting, was not considered to adequately assess changes pertinent to post-treatment sexual life of gynaecological cancer patients due to its limited scope. Neither does it seem to reflect the shift in the conceptualisation of women's sexual problems, away from quantitative and towards qualitative aspects of sexual relating (Bancroft, Graham, & McCord, 2001).

Psychological factors commonly overlooked in the literature include the symbolic importance of the uterus (often seen as representative of womanhood and femininity) and the role of intimacy in sexual adjustment (Lilley, 1987; Botelho, 2000). Li, Samsioe & Iosif (1999) found that many younger survivors of endometrial cancer suffered from what they termed "post-castration syndrome", even 5 years after their surgically induced sterility. Based on these findings, research has begun to focus on a more "female-oriented" view of sexuality emphasising intimacy, sensuality and physical closeness rather than coital behaviour *per se* (Bos, 1986; Butler, Banfield, Sveinson, & Allen, 1998). Important data from the prospective controlled study by Weijmar Schultz *et al.* (1991) demonstrated that a woman's motivation for, and satisfaction with, sexual

interaction with a partner is not limited to the experience of sexual arousal but involves a whole range of emotions. For instance, satisfaction with sexual interaction with the partner in times of crisis was found to be more an expression of satisfaction with the intimate aspects than with the physiological aspects of the sexual relationship (Weijmar Schultz *et al.*, 1991). Moreover, Weijmar Schultz *et al.* (1991) found high levels of relational sexual satisfaction in women treated for cervical cancer despite the measures of sexual response showing significant deterioration at one year post-treatment. These findings suggest that the frequency of intercourse and orgasm or physiological aspects of the sexual response cycle can no longer be relied upon as primary indicators of post-treatment sexual adjustment. Consequently, research methods and measures in this area need to reflect the complex interplay of psychological, physiological and social/relational aspects that underlie post-treatment sexual life of gynaecological cancer patients.

## **1.4 Physical impact of cancer treatments on sexual adjustment**

Studies investigating post-treatment sexual functioning can be classified into two groups: those that compared the physical examination findings with the current level of sexual functioning (e.g. Vasicka *et al.*; 1958; Abitbol & Davenport, 1974b; Seibel *et al.*, 1982; Andersen *et al.*, 1989a; Weijmar Schultz *et al.*, 1991) and those that compared psychological variables with the current level of sexual functioning (e.g. Seibel *et al.*; 1982; Adelusi, 1980; Andersen & Jochimsen, 1985; Schover *et al.*, 1989; Grumann *et al.*, 2001). Whilst the impact of psychological variables will be discussed in the next section (1.5), data from studies assessing the physical status of patients indicate that sexual disruption is often associated with hormonal and/or vaginal changes such as vaginal shortening or stenosis and decreased vaginal lubrication (see Weijmar Schultz *et al.*, 1992 for review).

Considerable variations exist in the literature reporting the incidence of vaginal abnormalities following surgery and/or radiotherapy to the genital area: 4-100% of patients being aware of having a shortened vagina, 17-58% experiencing reduced lubrication (Bergmark *et al.*, 1999) and 1.5-98% reporting varying degrees of vaginal stenosis (e.g. MacLeod *et al.*, 1999, Abitbol & Davenport, 1974a). Such inconsistencies may be due to methodological differences such as the use of different designs (retrospective versus prospective), mixed samples of cancer patients and treatments, and/or different times of assessment. This has been illustrated in the study by Leenhouts, Kylstra, Everaerd, Hahn, Weijmar Schultz *et al.* (2002) who found that early stage gynaecological cancer patients with a mean time since treatment of 46 months, examined cross-sectionally, report significantly more problems related to sexual functioning and vaginal changes compared to prospectively assessed patients during the first year of rehabilitation (Bergmark *et al.*, 1999). Further, whilst the majority of studies rely on self-reports to assess the rate of changes, others are based on clinical examinations (e.g. vaginal stenosis findings). Clinical/physical examinations commonly overlook milder side effects, thus reporting lower rates of side effects compared to self-reports (Klee *et al.*, 2000b). Further, psychological aspects inherent in the patients' subjective evaluation of any vaginal changes need to be considered.

The adverse effect of cancer treatments has been shown in the retrospective study conducted by Bergmark *et al.* (1999). The study documented long-term changes in vaginal anatomy and function of 256 women treated for early stage cervical cancer (mean age at the time of treatment: 45, SE=0.78) compared to 489 controls matched for age and region of residence (mean age: 52, SE=0.80). All cancer patients had undergone treatment approximately five years prior to the commencement of the study. Patients who had undergone surgery alone were compared to patients treated with intracavitary and/or external radiation in place of, or in addition to, surgery. The results showed minimal effect, if any, of radiotherapy on the level of changes initially reported post-surgery. A higher

percentage of cancer patients than healthy controls reported insufficient vaginal lubrication (26% vs. 11%), shortened vagina (26% vs. 3%), insufficient elasticity of the vagina (23% vs. 4%) and absence of genital engorgement during sexual arousal (36% vs. 25%). Such post-treatment vaginal changes were stated to have caused moderate to high distress among 26% of the cancer patients compared to only 8% of the women in the control group. Similarly, Schover *et al.* (1989), in their longitudinal study found that 31% of cancer patients reported being aware of the effects of a shortened vagina at 6 months follow up. This percentage declined to 24% at 12 months follow up. A considerably lower percentage of women reported problems with insufficient lubrication in the longitudinal study by Kylstra, Leenhouts, Everaerd, Panneman, Hahn *et al.* (1999), although cancer patients reported an increase in problems involving lubrication (from 4% to 8%) and genital insensitivity (from 4% to 8%) at 6 and 12 months follow ups.

Flay and Matthews (1995) investigated the acute and short term effects of radiotherapy and surgery on the sexual functioning of women treated for cervical cancer (n=16), as assessed prior to radiotherapy, at completion of radiotherapy and at 6 and 14 weeks post-radiotherapy. They conclude that the deterioration of sexual activity and satisfaction were due to a number of physical and psychological causes, with vaginal shortening cited as the most common cause (73% and 64% at 6 and 14 weeks post-radiotherapy respectively). At 14 weeks follow up, 43% of women reported vaginal dryness, with the same percentage reporting varying amounts of vaginal narrowing/stenosis, both contributing to poorer sexual outcomes. It is also important to note that the findings suggest a higher risk of side effects for women receiving a combined treatment of radiotherapy and surgery compared to radiotherapy alone.

The majority of studies report that irradiated patients are more likely to develop dyspareunia related to radiation-induced vaginal stenosis and fibrosis, which in turn is assumed to lead to problems with sexual desire and arousal (see Weijmar Schultz *et al.*, 1992 for review; Andersen, 1995; Schover *et al.*, 1989).

Andersen *et al.* (1989a) evaluated incidences and changes in disruptions to coitus as a result of dyspareunia. Higher levels of “dyspareunia dysfunction” were found in cancer patients (21%) compared to benign patients (7%) and healthy controls (0%) at one year post-treatment. Over time cancer patients reported a general decline in disruptions to intercourse due to dyspareunia. Schover *et al.* (1989) found the frequencies of painful penetration 6 and 12 months post-treatment to be 28% and 21% respectively and pain during “deep thrusting” to be 39% and 45% respectively. Grumann *et al.* (2001) also longitudinally assessed the incidence of dyspareunia with early stage cervical patients undergoing radical hysterectomy only. In their study, 45% of patients reported a mild or severe dyspareunia at 4 months follow up and 39% at 8 months follow up. More importantly, no incidence of dyspareunia was reported pre-operatively by either cancer or benign gynaecological patients, supporting the notion that dyspareunia may be largely a physical concomitant of radical hysterectomy.

Further, patients undergoing oophorectomy (i.e. removal of ovaries) have been reported to experience a decrease in sexual desire, sexual enjoyment, and frequency of orgasm (Walling *et al.*, 1990). The use of HRT, where indicated, may facilitate some restoration of sexual desire and enjoyment (Dennerstein & Burrows, 1982; Walling *et al.*, 1990; Robertson, 1996). Oestrogen and testosterone have been shown to enhance sexual desire, whereas progesterone appears to have no, or an inhibiting, effect on sexuality and mood (Davidson & Myers, 1988; Walling *et al.*, 1990). Since women using HRT report recovery of both physical and psychological wellbeing, it is unclear whether the positive effect of HRT on sexuality is directly related to hormonal changes or is indirectly caused by increasing women’s physical and psychological well-being, which in turn might re-establish sexual interest and enjoyment (Walling *et al.*, 1990).

Nathorst-Boos, von Schoultz & Carlstrom (1993) compared 33 patients undergoing hysterectomy and oophorectomy without subsequent oestrogen replacement therapy, 33 patients undergoing hysterectomy plus oophorectomy

with the subsequent administration of HRT and 35 patients undergoing hysterectomy without removal of the ovaries. Patients undergoing hysterectomy with oophorectomy reported impairment of their sexual functioning, complaining of a decrease in levels of libido and vaginal dryness, which was not relieved by the administration of HRT. Reduced pleasure from sexual intercourse was also noted. Patients undergoing hysterectomy whilst retaining their ovaries and receiving HRT, reported less anxiety and depression with enhanced psychological wellbeing compared to women who had had their ovaries removed and were not treated with HRT. These results indicate that removal of the ovaries has a negative impact on a woman's sexual life. They also suggest that HRT cannot completely ameliorate the lack of ovarian hormonal secretions. Median testosterone levels were also measured in these patients and found to be higher in women who had their ovaries intact than in those with their ovaries removed, irrespective of the administration of HRT. The fact that following oophorectomy, irrespective of any treatment with HRT, women complained of a lower libido, fewer sexual fantasies and vaginal dryness, suggests the importance of testosterone in preserving adequate sexual functioning. It also supports the use of HRT combining oestrogen and testosterone for patients undergoing hysterectomy with oophorectomy. Further, these results indicate that the definition of hysterectomy, particularly whether or not that includes the removal of the ovaries, needs to be accounted for in any investigation of sexual functioning following hysterectomy. Since oophorectomy appears to have a stronger influence on patients' post-operative sexual functioning than removal of the uterus alone, consideration of the patients' ovarian status within any investigation of sexual functioning following hysterectomy is warranted (Bachmann, 1990).

Although bowel and bladder problems may indirectly impede the process of post-treatment sexual adjustment, it is the direct adverse effect of vaginal and hormonal changes as a consequence of various cancer treatments that has been shown to significantly interfere with post-treatment sexual functioning (Bergmark *et al.*, 1999; Weijmar Schultz *et al.*, 1992). Nevertheless, high levels

of sexual dysfunction following radiotherapy in the absence of vaginal stenosis have also been reported (Nunns *et al.*, 2000). In the study by Seibel *et al.* (1982), a positive correlation between radiation-induced vaginal stenosis and decreased coital frequency, orgasmic response and sexual desire was not found. These findings suggest that the vaginal changes *per se* cannot account for the significant decrease in sexual function among women who received pelvic radiation. Variations in the degree of sexual disruptions experienced by these women are likely to be mediated by psychological factors and education on sexual matters (Auchincloss, 1989). The role of these factors in post-treatment sexual adjustment will be discussed in the next section.

## **1.5 Factors impinging on sexual adjustment other than treatment: Mediating variables**

As mentioned previously, research into sexual functioning outcomes following gynaecological cancer requires consideration of multiple factors. Existing qualitative and quantitative findings have already indicated that sexuality is a complex multifaceted health issue underpinned by a range of inter-connected factors, both physiological and psychosocial (e.g. Butler *et al.*, 1998; Zagwaard, Gamel, Dugris & Logmans, 2000; Weijmar Schultz *et al.*, 1991; Schover, 1990). The occurrence of a life-threatening illness is seen as a traumatic event in most peoples lives and as such necessitates post-traumatic adjustment as well as adjustment to alteration to genitalia and sexual capability. Weijmar Schultz and van de Wiel (2003) comment that changes in sexual functioning need to be considered within the context in which they occur. Where these changes are considered out of context they run the risk of being designated psychological and/or sexual dysfunction, whereas within the context of adjustment to trauma they may be entirely appropriate. On the psychological level, gynaecological cancers and their treatments have a unique, direct impact on essential components of a woman's identity, femininity and sexuality (Bos, 1986; Cairns & Valentich, 1986; Lilley, 1987; Derogatis, 1986). Recent studies have highlighted



the need for developing treatment approaches that address the patient as a whole rather than mechanistic approaches focusing only on physical factors (Tucker, 1999).

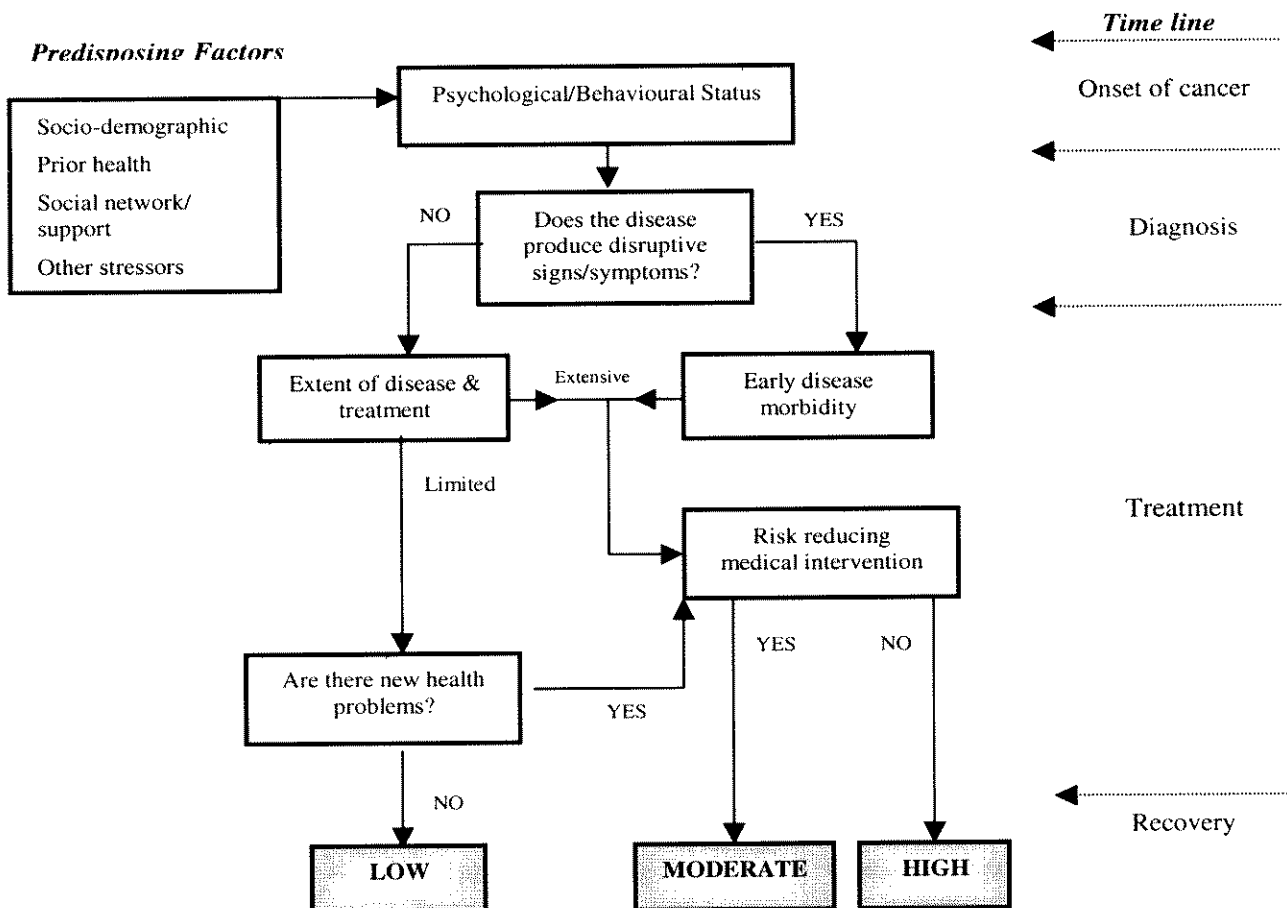
In her review of sexual problems in chronically ill patients, Schover (1990) outlines the importance of psychological factors, alongside physical factors, in sexual dysfunctions. She emphasizes the relevance of cancer patients' fears of sexual activity, such as fear of sexually transmitting the cancer to their partner, and of changes in their physical appearance following surgery, which may lead to loss of self-esteem and eventually to decreased sexual desire. Based on a comprehensive literature review, Weijmar Schultz *et al.* (1992) identified four factors necessitating consideration when investigating such a complex subject as psycho-sexual outcomes following gynaecological cancer treatments. These include *physical factors* (such as hormonal and vaginal changes, the magnitude of treatment interventions), *health-care-provider-related factors* (such as patient education, provision of multidisciplinary support), *partner-related factors* (such as availability/support, health, quality of relationship) and *psychological factors* (such as levels of anxiety/depression, adjustment styles). However, there are only very few models that attempt to explain the inter-relation of factors contributing to post-treatment sexual adjustment.

### **1.5.1 Models of sexual adjustment following gynaecological cancer**

Andersen (1993) in her prediction model emphasised the role of psychological mechanisms, alongside physiological mechanisms, in the process of post-treatment sexual adjustment (see Figure 1.4.). The model's timeline takes into account the occurrence, progress and interplay of stressors within socio-economic, social, health and other identified areas throughout the illness and recovery. Early disruptive signs (e.g. post-coital bleeding) during the onset of cancer can contribute to the emotional distress patients experience at diagnosis and may indicate the likelihood of continuing distress further into the illness.

However, irrespective of early disruptions, the extent of the disease and its treatment remains the major determinant of risk for the occurrence of psychological difficulties along the disease trajectory. Appropriate medical interventions (e.g. surgery, radiotherapy), pharmacological treatments (e.g. HRT, oestrogen cream) and mechanical devices (e.g. vaginal dilators) are seen as significant adjuncts in ameliorating stressors. The use of psychological interventions such as sexual education, information regarding female anatomy and possible sexual changes post-treatment, sexual therapy targeting specific sexual changes and Cognitive Behavioural Therapy (CBT) are also discussed.

Figure 1.4. Andersen's (1993) model for predicting the risk of psychological and behavioural morbidity (p.1679)

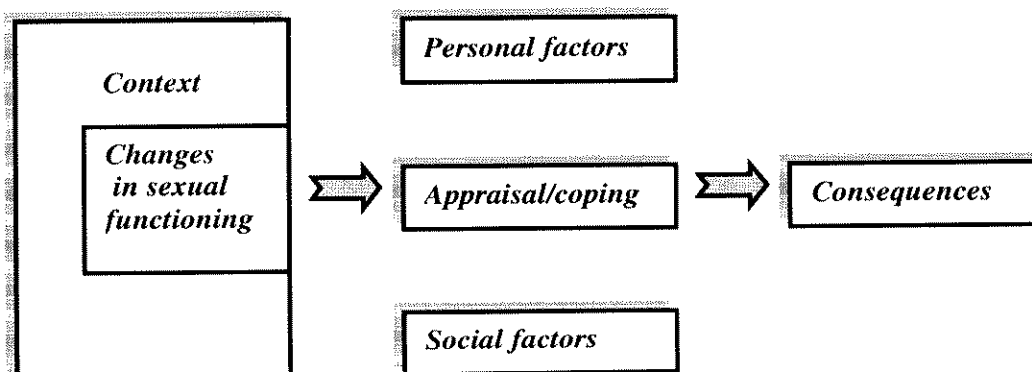


Although the model identifies many pathways that result in high or moderate morbidity risk, only those patients with limited disease or treatment modality and

who had no new or continuing problems, are hypothesised to have the lowest risk (Andersen, 1993). The validity of the risk model, which is theoretically based, was evaluated by a comparison of psychological intervention outcome studies targeting gynaecological patients with various risks (i.e. low, moderate or high). According to the model, the majority of patients in the current sample would be considered as having low-to-moderate morbidity risk since these patients have a localised disease with a favourable prognosis (e.g. 5-year survival rate estimates of 70-90%). A higher, moderate, morbidity risk would be predicted for women treated with combined treatment modalities compared to women receiving surgery alone (Andersen, 1993).

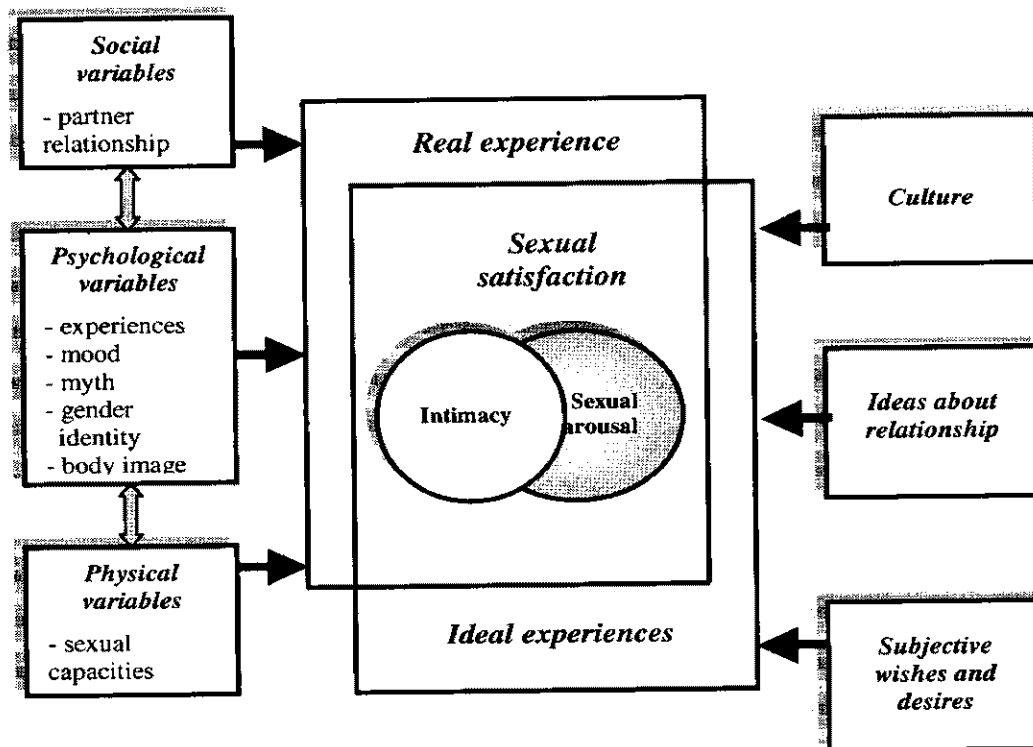
Recently Weijmar Schultz and van de Wiel (2003) outlined a model depicting an evaluation of sexual functioning following treatment for gynaecological cancer (see Figure 1.5.) This model is not restricted to anatomical and physiological aspects, but rather is based on the general model of adaptation following a traumatic experience devised by Kleber, Brom & Defares (1986, cited in Weijmar Schultz & van de Wiel, 2003). In this model, changes in sexual functioning are evaluated within the context in which they occur. The impact of personal factors, social factors and coping strategies are accordingly evaluated (see Figure 1.5.).

Figure 1.5. A model of the evaluation of sexual functioning after cancer treatment by Weijmar Schultz and van de Wiel (2003, p.126)



Viewed in this way, changes in sexual functioning do not automatically warrant definition as sexual dissatisfaction. Rather, they assume this status in as far as personal experiences differ from the individual's idealised experience. The extent to which a woman is able to realise her ideal desires depends upon her psychological ability to be aware of those desires and how realistic she evaluates them to be (see Figure 1.6).

Figure 1.6. *Weijmar Schultz & van de Wiefs (2003) model linking psychological and physiological consequences of cancer and its treatment (p.124)*



The authors identify two main motivations for sexual engagement evident in Western society; a) *the need for sexual arousal*, which is often transitory and more based in perception of genital sensitivity and physiological capabilities, and b) *the need for intimacy*, which is often longer lasting and more dependant on emotional and psychological factors. Depending on the predominant motive for

sexual engagement, the physical capabilities assume greater or lesser relevance. Although the degree of physical damage allows for a prediction of a loss of sexual arousal or orgasm, whether these losses will lead to a problematical sexual life seems to be determined by other, psycho-social, factors (Weijmar Schultz & van de Wiel, 2003). This model of post-traumatic adjustment highlights the importance of psychological, personal and social components in defining sexual dysfunction and methods of adjustment.

Consistent with these models, the current study aimed to explore the mediating role of psychosocial factors including satisfaction/quality of intimate relationship, psychological status, adjustment styles and informational needs, in post-treatment sexual adjustment of early stage gynaecological cancer patients.

### **1.5.2 Satisfaction with relationship**

Cancer is a stressful life-threatening condition requiring a substantial increase in social support to cope with ongoing stressors, such as invasive medical procedures, occurrence of treatment side effects and the persistent threat of cancer recurrence (Wortman, 1984). The amount and level of support the cancer patient receives from her partner has been shown to considerably influence the rate of her post-treatment adjustment (Goodwin, Hunt, Key & Samet, 1987; Gilbar, Steiner & Atad, 1995; Hann *et al.*, 1995; Grumann, 1998; Lichtman & Taylor, 1986). In line with these findings, married women have been found to adapt to the diagnosis of gynaecological cancer significantly better than single women (Gilbar *et al.*, 1995). This may be attributable to a consistent support partner with whom to share intimacy, including sexual intimacy. However, where problems arise within the relationship, particularly in the area of sexual activity, such activities can become a means of increasing stress rather than a stress-relief and comfort, thus exacerbating difficulties related to treatments and their side effects (Weijmar Schultz & van de Wiel, 2003). Hence,

the quality of and satisfaction with intimate relationship needs to be considered when investigating sexual adjustment following gynaecological cancer.

Although studies generally indicate marital adjustment for cancer patients following treatment is positive, heightened marital distress as a result of role changes, or a shift in the balance of power, has also been reported (Weijmar Schultz & van de Wiel, 2003). The extremely stressful time of cancer diagnosis and subsequent treatments often leaves the partner physically and emotionally overwhelmed. Since many partners are known to be reticent in discussing issues troubling them, they can become prone to the development of psychosomatic symptoms such as nervousness and fatigue, sleeping and eating disorders, and loss of concentration (Lalos, Jacobsson, Lalos & Stendahl, 1995). This may lead to a breakdown in communication between partners, which then contributes to marital difficulties. Indeed, the pre-existing quality of the relationship has been highly correlated with the quality of the relationship following cancer treatment (Weisman & Worden, 1976-7; Lichtman & Taylor, 1986). Another aspect of post-treatment relationship functioning reported in the literature, is the patient's and/or partner's overprotective behaviour possibly leading to an exceedingly high level of support given to shield their partners from the impact of cancer and ongoing worries associated with sexual functioning, fertility, and body image issues (Gilbar *et al.*, 1995; Auchincloss, 1995). Such behavioural patterns may result in the development of misconceptions and unreasonable expectations, which in the absence of open communication further disrupts the marital and sexual life of the couple (Lalos *et al.*, 1995; Krum & Lamberti, 1993).

Despite these potentially detrimental effects of cancer and its treatment on relationship satisfaction, longitudinal findings from methodologically sound studies point to unchanged or improved marital stability and satisfaction following treatment (Grumann *et al.*, 2001; Weijmar Schultz *et al.*, 1991; Andersen & Hacker, 1983a,b; Andersen & Jochimsen, 1985; Andersen, Anderson & deProse, 1989b; Schover *et al.*, 1989). Such positive outcomes

occur despite reported disruptions in the couple's sexual life. According to Bos (1986), a gynaecological cancer experience commonly leads to the development of a shift from coital to intimate behaviour, the latter being characterised by trust, physical closeness, sensuousness and warmth between partners. In accordance with this interpretation, couples in a relationship of short duration who have not yet reached a point of consolidated stability have been found to be at higher risk of marital difficulties (Auchincloss, 1995; Weijmar Schultz *et al.*, 1992). The quality of marital relationship for gynaecological cancer patients has also been shown to influence the rate of post-treatment adjustment, with a higher marital quality resulting in improved psychological wellbeing and a speedier recovery process (Rodrigue & Park, 1996; Spanier, 1976; Bloom, 1982).

In summary, the quality of the partnership plays a crucial role in the successful post-treatment adjustment of the gynaecological cancer patient (Glasdam, Jensen, Madsen & Rose, 1996; Goodwin *et al.*, 1987) and possibly the prolongation of her life (Spiegel, 1991). It is therefore necessary to consider and account for the quality of the patient's relationship with her partner when interpreting any findings regarding post-treatment changes in sexual functioning.

### **1.5.3 Psychological status**

There is a paucity of information regarding the post-treatment prevalence of depression, anxiety or adjustment disorders in gynaecological cancer patients. This omission is perplexing since several factors suggest that women suffering from gynaecological cancers are more vulnerable to experiencing psychological disorders. Firstly, anxiety and depression are more prevalent among patients diagnosed with cancer (Lesko, Massie, & Holland, 1993). Secondly, simply being female raises the risk of developing anxiety and depression (Cairney & Wade, 2002; Williams, Spitzer, Linzer, Kroenke, Hahn *et al.*, 1995). Thirdly, removal of organs of reproduction can destabilise hormonal levels to the point of precipitating the onset of symptoms of anxiety and depression (Thompson & Shear, 1998). A comprehensive literature review conducted by Thompson and

Shear (1998) identified only 13 studies focusing on rates and treatment of psychological disorders occurring in women with gynaecological cancer. The majority of these studies reported specific rates of depressive symptoms (mild to severe) in this population ranging from 4% to 90%. Only seven studies measured anxiety symptoms, with all reporting rates of anxiety higher than those in the general population. Indeed, gynaecological cancer patients nominated anxiety as one of the main factors contributing to post-treatment sexual disturbances (Corney, Everett, Howells & Crowther, 1992; Andersen, 1995). Since libido is known to be strongly influenced by depression levels, it is essential that levels of both depression and anxiety are assessed in studies of the post-treatment sexual outcomes of gynaecological cancer patients.

The fact that such important and often symbolic organs as the uterus and vagina have been affected by the disease and treatment may trigger specific fears for women concerning their sexual desirability and/or attractiveness. While heightened anxiety seems to be associated with reported decreases in the frequency of sexual intercourse, data from Andersen *et al.* (1989a) indicate that the arousal problems do not seem to be anxiety-based. Such data highlight the need to investigate a range of factors that might confound differing aspects of sexual response and satisfaction. Further, it is important that any future studies control for the levels of psychological distress in gynaecological cancer patients (e.g. anxiety regarding treatment) if reliable findings of post-treatment sexual adjustment are to be obtained.

Research data point to qualitative differences between fear of irradiation and the anxiety experienced pre-surgical intervention, the former causing more overall emotional distress (Munro, Biruls, Griffin, Thomas & Vallis, 1989; Andersen, 1996). *Radiation anxiety* is most commonly described as the fear of being burned or becoming sterile (Andersen, 1984). Further, patients may have misconceptions or fears regarding their cancer treatment; for example patients may think that their vagina is radioactive following radiotherapy or poisonous



following chemotherapy (Horden, 1999). Andersen *et al.* (1984) investigated changes in anxiety levels of patients undergoing brachytherapy. These patients reported continuously high levels of post-treatment anxiety throughout the repeated applications of brachytherapy, being more anxious following the second brachytherapy application than following the first application. Further, women who were least distressed prior to brachytherapy responded most anxiously post-treatment (Andersen *et al.*, 1984). Considering these findings, the systematic exploration of the interaction between physical, psychological and sexual aspects of functioning of women undergoing this treatment modality would be helpful. However, to our knowledge no study to date systematically compared the psychological responses (e.g. degradation, distress) pertinent to different types of radiation treatments for gynaecological conditions (i.e. brachytherapy versus external radiation).

#### **1.5.4 Adjustment styles to gynaecological cancer and its treatment**

Significant among the numerous factors that may influence a woman's psycho-sexual response to cancer, is her adjustment style. It has been shown that cancer patients who employ avoidant coping strategies experience greater anxiety, depression and fatigue post-treatment whilst women with an active coping style report greater social wellbeing, more positive relationships with care-givers and less distress overall (Lutgendorf, Anderson, Rothrock, Buller, Sood, & Sorosky, 2000). The cancer patient's style of adjustment has been shown to impact not only on her post-treatment psychological adjustment, but also on the quality of her collaboration with the treatment team and possibly on her chance of survival (Gotheridge & Dresner, 2002; Watson, Haviland, Greer, Davidson & Bliss, 1999).

It has been suggested that the incidence of progression from pre-cancerous cervical abnormalities to an invasive cancerous condition may also be influenced by emotional responses (Antoni & Goodkin, 1989; Goodkin, Antoni, &

Blaney, 1986). One explanation for this finding is the depressive effect of the response of anger and fear on the immune system (Antoni & Goodkin, 1988, 1989; Goodkin *et al.*, 1986). However, the evidence for such conclusions is not compelling due to the lack of methodological rigour in these studies.

The vast majority of studies investigating the role of psychological factors in the outcome of cancer have been conducted using breast cancer populations (e.g. Watson *et al.*, 1999; Buddeberg, Wolf, Sieber, Riehl-Emde & Bergant, 1991; Jamison, Burish & Wallston, 1987; Levy, Lee, Bagley & Lippman, 1988; Greer, Morris & Pettingale, 1979). Findings from an earlier prospective study by Greer *et al.* (1979) have linked high levels of psychopathology to the adjustment style of hopelessness-helplessness (HH), whereas low levels of psychopathology have been linked to a fighting spirit (FS). However, the study had a number of methodological shortcomings including no adjustment for the important prognostic variable of lymph-node status, and assessment of psychological response by brief open-ended question rather than standardised measures. To overcome these problems, Watson *et al.* (1999) conducted a large prospective population-based study using a cohort of 578 women diagnosed with early stage breast cancer. The disease status of women was monitored for a minimum of 5 years. Patients' levels of anxiety, depression, suppression of negative emotions related to the suggested type C cancer-prone personality, and mental adjustment styles were assessed, using standardized measures, at 4-12 weeks and 12 months post-diagnosis. Levels of clinically significant depressive symptomatology at baseline (HADS >11) were linked to a significantly reduced chance of survival. However, since only 2% of the sample was clinically depressed, this finding needs to be interpreted cautiously. Whilst a helpless response along with known clinical prognostic factors was found to have a modest association with poorer survival, fighting spirit and the suppression of negative emotions were not associated with improved survival. As Watson (2000) concludes: "It is not what may be added in by a fighting spirit but what is taken away by being helpless that seems important in the disease outcome" (p.849, cited in Greer, 2000). However, the role of adjustment styles in

mediating the impact of cancer and its treatment on post-treatment sexual adjustment following gynaecological cancer is unclear. In fact, review of the literature failed to identify any studies investigating adjustment styles of patients with gynaecological cancer. Considering the mediating role of adjustment styles in post-treatment sexual adjustment, including an assessment of mental adjustment styles within the current study, increases its originality and validity.

Since patients with a helpless/hopeless attitude may be less proactive in obtaining the amount of care needed to maximize their post-treatment psycho-sexual adjustment/quality of life, it is important that health care professionals are proactive in identifying patients at risk. Tucker (1999) points to a tendency evident in medicine in general to separate mental from physical health, which may result in the underestimation of the psychological needs of some patients. The modifying impact of adjustment styles on survival rate is of critical importance, considering that adjustment styles of patients, and HH style in particular, can be modified by a brief psychological intervention such as Cognitive Behavioural Therapy (CBT) (Greer, Moorey, Baruch, Watson, Robertson *et al.*, 1992). One important aspect of CBT is psycho-education. The provision of education can be important in challenging myths and misconceptions and facilitating patients' adjustment to post-treatment changes affecting their sexual life.

### **1.5.5 Informational needs of gynaecological cancer patients**

A universal theme encountered in many of the studies in the area of oncology is the importance of information for post-treatment recovery and the elevated levels of anxiety engendered by its lack. A large multi-centred study conducted by Jenkins, Fallowfield & Saul (2001, n=2331) provided strong evidence for the vast majority of cancer patients wanting a great deal of specific information concerning their illness and treatment, over and above that anticipated by their health care professionals. This was particularly pertinent for women and younger patients. A recent systematic review of informational needs of

gynaecological cancer patients by Gamel, Hengeveld & Davis (2000) confirmed the need for discussions concerning sexual matters with women treated for different types of gynaecological cancer.

The consequences of gynaecological cancer treatments often compel patients and their partners to redefine their sexual relationship and to extend and explore alternative possibilities within their sexual behaviour. By giving information, however threatening to a patient and her partner initially, the physician provides the patient with the possibility of realistically re-defining their sexual life (Weijmar Schultz & van de Wiel, 1992). For instance, misconceptions that cancer could be transmitted through intercourse, that intercourse could also precipitate a re-occurrence of the disease, have been cited in the literature as reasons for sexual abstinence (Lalos *et al.*, 1995; Krumm & Lamberti, 1993; Abitbol & Davenport, 1974b). The opportunity to share concerns and to dispel such misconceptions with the understanding of a competent physician and a supportive partner, has been shown to alleviate the woman's distress related to her treatment-induced physical changes and consequently enhance post-treatment psycho-sexual adjustment (Krumm & Lamberti, 1993).

Information concerning medical treatment is commonly divided into two types. While *procedural information* tends to increase the patient's understanding of what they can expect will happen during treatment and post-treatment, *sensory information* acquaints the patient with what they may expect to feel during and after the treatment process. It is suggested that the integration of these two types of information has a beneficial effect on patients' distress, coping and compliance with treatment regimes. In a meta-analysis of literature regarding the provision of procedural and sensory information of pre- and post-operative events, Johnston and Vogeles (1993) reported that procedural information and behavioural instructions show consistent and strong positive effects on post-operative recovery. Information about the procedure and possible bodily sensation during and post-treatment, as well as specific suggestions for coping with radiotherapy stressors, are particularly important for women undergoing

brachytherapy (Cochran, Hacker, Wellisch & Berek, 1987; Karlsson & Andersen, 1985). Based on their qualitative findings, Velji *et al.* (2001) emphasised the importance of providing sensory information to patients undergoing brachytherapy, helping patients to form more accurate expectations, which subsequently reduced patients' distress and facilitated post-treatment adjustment. Similarly, Klee *et al.* (2000a,b) concluded that the provision of information concerning possible side effects of radiation treatment (no matter how mild they may be) improves the patient's ability to cope with the symptoms should they occur. A study by Lasnik & Tatra (1986) found the least negative disturbance in the intimate relationship and sexual life of women who were well informed about the consequences of irradiation. Patients who were not informed about possible side effects were disappointed, fearful and in some cases angry (Cassileth, Volckmar & Goodman, 1980).

Despite a recognition of the importance of information regarding sexual consequences of gynaecological cancer and its treatments, the majority of studies point to health care professionals having inadequate knowledge, as well as an inability to communicate, about these changes to not only the patient (Bourgeois-Law & Lotocki, 1999; Cull *et al.*, 1993; Corney *et al.*, 1993; Jenkins, 1988; Bullard, Causey, Newman, Orloff, Schanche & Wallace, 1979) but also her partner (Lalos *et al.*, 1995; Van de Weil, Weijmar Schultz, Wouda, & Bouma, 1990c). For instance, Vincent, Vincent, Greiss & Linton (1975) found that 75% of gynae-oncology patients had received no information regarding sexual adjustment before, during or after treatment, although 80% of these women wanted this kind of information. A recent qualitative study by Stead, Fallowfield, Brown and Selby (2001) with ovarian cancer patients (n=15) revealed that sexual issues were discussed (briefly) with two patients only and no patients received any written information on this topic. This occurred although most women thought that health care professionals should provide written information or discuss sexual issues with them. Interestingly, all but one of the 43 health care professionals interviewed believed that medical staff should discuss

psycho-sexual issues; however, only four clinicians (25%) and five nurses (19%) did so (also see Stead, 2003). In contrast, a recent Dutch study by Leenhouts *et al.* (2002) found that 80% of patients were satisfied with the information provided on sexual rehabilitation and reported little need for extra care in the area of sexual health. The authors link such a relatively positive outcome to improved patient care and education on sexual aspects in the last decade. According to retrospective accounts of patients in the study by Bourgeois-Law and Lotocki (1999), gynaecological patients would prefer to receive sexual information (in order of priority) by a personal discussion with a caregiver (primarily with partner present), by pamphlet and small group discussion. Further, the topic should be addressed repeatedly in the course of treatment and recovery.

Patients cannot participate in decision making to the degree they may want unless they are provided with all the relevant information given in ways which they can understand. Women who receive adequate sexual information from their physicians report greater satisfaction with their sexual relationship compared to women who do not receive such information. Since the findings point to patients preferring health care professionals to initiate discussions concerning sexual matters, such dissatisfaction with the provision of information suggests that medical staff may not be sufficiently pro-active in raising sexual topics with their patients. There are several reasons why the sexual health of gynaecologic cancer patients has been neglected. Practitioners have frequently assumed that sexual concerns are irrelevant to many patients due to their age. This assumption is not tenable since it has been demonstrated that a high proportion of men and women over 70 remain sexually active (Read, 1999). A significant contributing factor inhibiting adequate communication concerning sexual matters, is perhaps insufficient training of doctors and nurses which, even when provided, rarely meets their needs (Fallowfield, Jenkins, Farewell, Saul, Duffy & Eves, 2002; Stead, 2003). In recognition of the need for training of health care professionals to help them communicate more comfortably about sexual issues, the NSW Cancer Council has developed an interactive skills-based training package "Talking about Sexuality, Body Image and Cancer: A

teaching resource for health professionals” (NSW Cancer Council, 2002). However, since the manual became available after the recruitment for the current study had ceased, this study’s outcomes were not expected to reflect the introduction of this valuable tool.

#### **1.5.5.1 Dilators**

For patients receiving adjuvant radiation therapy for gynaecological cancer a vaginal dilator has become an important rehabilitation tool. Although vaginal dryness and narrowing/stenosis are common side effects of external and internal radiation treatments, severe vaginal narrowing may be, to a large degree, preventable. As vaginal wounds heal, scar tissue forms. This tissue, being fibrous, stretches less than healthy tissue, thus reducing the ability of the vagina to elongate and widen during sexual excitement and intercourse. Early intervention is essential to lessen the effect of vaginal scarring, minimise vaginal adhesions and encourage the vagina to gain and maintain the maximum flexibility possible under the new circumstances. This not only allows for a more comfortable physical engagement in sexual intercourse but also enables adequate pelvic examinations to be carried out to monitor for any recurring changes in vaginal tissue (Pitkin & van Voorhis, 1971). Robinson, Faris & Scott (1999) reported that sexual intercourse occurring 3-4 times a week helps considerably in breaking down adhesions and fibrous filaments within the vagina, thus contributing to maximum vaginal patency. It is important to stress to the patient the critical need to maintain such maximum vaginal health and patency. Where the patient does not have a current partner with whom she can, or chooses to, engage in sexual intercourse, it is crucial that a vaginal dilator be substituted and used regularly, in conjunction with a lubricant, 3 to 4 times a week. In fact, irradiated patients with or without a partner, and irrespective of sexual implications, would benefit from the use of a dilator.

Robinson *et al.* (1999) commented that despite the benefits of vaginal dilators, very few women given dilators follow the recommended regime for their use. For

instance, in the longitudinal study by Schover *et al.* (1989), 57% women reported using a dilator with only 14% reaching the criterion for dilation of at least three times per week at 6 months follow up. By one year post-treatment, 33% women used the dilator with only 6% reaching recommended levels of usage. In the retrospective study by Krumm & Lamberti (1993), women who complied with the recommended use of dilators showed less pelvic pathology and more satisfaction with their sexual experiences. Indeed, these women showed more satisfaction with their sex life in general than women who did not use the dilator. Interesting findings were revealed in a controlled intervention study with patients following radiotherapy for early stage cervical and endometrial cancer conducted by Robinson *et al.* (1999). It was found that participation in a psycho-educational group, based on information-motivation-behavioural skills, increased compliance with the use of a vaginal dilator and reduced women's fears concerning sexual intercourse following cancer and its treatment. Younger women were less likely to follow the recommended regime for the use of a dilator unless they were taught the correct way to use it and were also given assistance to overcome their fears regarding its use (Robinson *et al.*, 1999).

In summary, the review of literature on psychological mechanisms underlying post-treatment sexual adjustment of gynaecological cancer patients points to a significant mediating effect of a number of factors (including quality of relationship, levels of psychological distress, adjustment styles of patients and quality of communication information provided by health care professionals) on post-treatment sexual outcomes. Therefore, research studies need to investigate these factors in relation to sexual outcomes in order to yield reliable and valid findings and enhance understanding of sexual functioning in this group of women.



## 1.6 Sexual functioning outcomes in early stage gynaecological cancer patients

Compared to other areas in cancer research, the exploration of the sexual rehabilitation of cancer patients is in its infancy (Paavonen, 1999; Horton, 1991). Although Bard and Sutherland (1952) first raised concerns about sexual problems following treatment for female cancers, it was not until the last two decades that substantial studies were conducted in the area of psycho-sexual adjustment following gynaecological cancer (e.g. Vincent *et al.*, 1975; Andersen *et al.*, 1989a; Weijmar Schultz *et al.*; 1991; Kylstra *et al.*, 1999; Grumann *et al.*, 2001). Data available to date highlight sexual functioning as a major area of disruption for patients undergoing treatment for gynaecological cancers (Lichtman & Taylor, 1986; Andersen & Van der Does, 1994; Andersen *et al.*, 1989a; Bergmark *et al.*, 1999).

The literature search for the current project was carried out using combinations of the terms: sexuality / sexual functioning / sexual outcomes / sexual problems /sexual adjustment and gynaecological / cervical / endometrial cancer. Three main databases were searched: Medline, PsychInfo and CINAHL. The following review of literature includes only those retrospective and prospective studies that have plausible methodological designs and/or results pertinent to the focus of the current study. Nevertheless, certain methodological shortcomings inherent in the sensitive nature of the research topic need to be taken into account. These include *measurement error* due to item refusal, underreporting, social desirability, or, conversely, sexual bragging; and *participation bias* due to differences in personality factors, sexual attitudes and behaviours of participants and non-participants (Auchincloss, 1989; Catania, Gibson, Chitwood, & Cootes, 1990; Abramson, 1990). For further reading on sexual outcomes following gynaecological cancer, reviews by Weijmar Schultz *et al.* (1992) and Andersen & van der Does (1994) are recommended.

### 1.6.1 Retrospective studies

For decades, data relating to sexual difficulties as a consequence of treatment of gynaecological cancer were gathered from broad surveys (Kaplan, 1970; Andersen 1986a; Schover, 1990; Auchincloss, 1995; Andersen, 1995) or taken from clinical evaluations (Roberts, Rossetti, Cone & Cavanagh, 1992). The majority of retrospective studies included mixed groups of gynaecological cancer patients, assessing sexual sequelae by contrasting treatments of surgery and radiotherapy (Bertelsen, 1983). The results indicated that variations in sexual functioning are more attributable to differences in treatment modality (e.g. surgery vs. radiotherapy) than the cancer site (e.g. cervix, endometrium, ovary). For example, levels of sexual dysfunction were found to be comparable between endometrial cancer patients and other gynaecological cancer patients who were treated with the same procedure (Cochran *et al.*, 1987). Furthermore, the majority of retrospective studies reported radiotherapy to be associated with more severe sexual dysfunction than other treatment modalities such as radical hysterectomy. In a study by Andersen & Jochimsen (1985), diminished or terminated sexual activity was found in only 6-19% of patients treated with radical hysterectomy compared to 44-79% of patients receiving radiotherapy. Although no distinction was made in their study between the different radiation modalities, it is likely that a higher percentage of sexual dysfunction in radiation patients would result from vaginally applied brachytherapy than from external beam irradiation.

An even greater rate of sexual dysfunction is associated with a more extreme treatment procedures, such as radical vulvectomy. Radical vulvectomy is a mutilating surgical procedure involving the removal of the clitoris, labia, distal third of the vagina and bilateral inguinal lymph node dissection with or without pelvic node dissection. Following vulvectomy, 50-80% of the patients abandon sexual activity altogether (Andersen & Hacker, 1983a; Moth, Andreasson, Jensen & Bock, 1983; Andreasson *et al.*, 1986). The most radical gynaecological surgical procedure is pelvic exenteration, which involves the removal of the urogenital organs including the uterus, cervix, vagina, bladder,

and rectum. Such invasive surgery is performed as a last curative attempt for centrally recurrent gynaecological cancers. It appears that virtually every such patient experiences major disruption to their sexual functioning; many abandoning any form of sexual activity despite the option of the construction of a rudimentary patent vagina (Andersen & Hacker, 1983b). Consequently, these patients would require extensive psycho-sexual support to assist them in achieving an acceptable quality of life.

A substantial volume of research regarding post-treatment sexual functioning in gynaecological cancer patients lacks reliable methodology. For instance, response bias may occur where reliance is placed on the treating doctor to also collect research data (Andersen & Hacker, 1983c). Further, data are commonly collected by various interview techniques (unstructured, semi-structured, or structured). In their review, Weijmar Schultz *et al.* (1992) identified only 9 (out of 44) retrospective studies that used standardised questionnaires when assessing sexual functioning of gynaecological patients. Often it appears that confounding variables (e.g. site and stage of the disease and treatment modality), are not adequately controlled for. For data regarding sexual functioning to be reliable, there needs to be a consensus as to definition of sexuality and sexual dysfunctions. Definitions are often found to be imprecise, being measured as one global score (Andersen & Hacker, 1983c). However, notwithstanding conflicting data, a majority of findings points to treatment of gynaecological cancer by radiotherapy as resulting in more severe sexual disruption than treatment with surgical procedures. A review of sexual outcomes in women with gynaecological cancer, using retrospective assessments, indicated that the range of incidence of sexual functioning-morbidity of patients treated for cervical cancer ranges from 6 to 100% (Weijmar Schultz *et al.*, 1992). However, with the recent emergence of prospective studies, a rather different picture of post-treatment sexual functioning has begun to emerge. These later studies indicated deterioration in sexual functioning during the symptomatic period preceding discovery of gynaecological cancer and the period immediately after diagnosis and treatment. Beyond this period, the deterioration in sexual

functioning seems less frequent, ranging from 0 to 40% (Weijmar Schultz *et al.*, 1992). Thus results regarding impact on sexual functioning post-treatment remain inconclusive.

### **1.6.2 Prospective studies**

In contrast to the high number of retrospective studies, only a few longitudinal prospective studies focusing on sexual functioning in patients treated for gynaecological cancer have been conducted to date (Vincent *et al.*, 1975; Andersen *et al.*, 1989a; Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991; Lalos *et al.*, 1995; Kylstra *et al.*, 1999; Grumann *et al.*, 2001). Findings from prospective studies often conflict with those reported in retrospective studies, although neither prospective nor retrospective studies show a trend for any particular disease modality. It is likely that the lower rates of sexual disruptions/dysfunctions in prospective studies result from more specific operationalisation of sexual variables, and more structured modes of analysis (Weijmar Schultz *et al.*, 1991; Schover *et al.*, 1989). However, prospective design also has some methodological constraints. Participation in a longitudinal study can, for instance, encourage patients to discuss possible sexual problems more openly, thus adding a bias to the results (Weijmar Schultz *et al.*, 1991). Most prospective studies conduct the first assessment either post-diagnosis or post-admission to hospital. In the period of time leading up to the first assessment, it is reasonable to assume that the patient has experienced some incapacitating symptoms such as increased bleeding, invasive diagnostic procedures, and psychological distress pending the outcome of those procedures, with a possibility of the diagnosis revealing a malignancy. Individually or collectively, these stressors can exert an influence on the patient's actual and/or perceived sexual life, which in turn could lead to an underestimation of levels of their premorbid functioning (Andersen *et al.*, 1989a; Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991). Further, the majority of studies fail to account for mediating factors in post-treatment sexual functioning, such as the patients' psychological status, coping styles, quality of relationship

with a partner and/or provision of information concerning post-treatment changes in sexual functioning. Nevertheless, providing appropriate control groups and employing more specific and reliable methods of operation and analyses of outcome variables, renders a prospective design more accurate than retrospective designs.

The literature review pointed to only seven well designed prospective longitudinal studies conducted to date in the area of sexual adjustment following treatment for the early stages of gynaecological cancer (Vincent *et al.*, 1975; Andersen *et al.*, 1989a; Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991; Lalos *et al.*, 1995; Kylstra *et al.*, 1999; Grumann *et al.*, 2001). Main findings from these studies will be presented below. Table 1.3. provides a summary of sample characteristics, design of each study, and main findings concerning post-treatment sexual functioning.

Table 1.3. Brief overview of longitudinal studies on sexual adjustment during first post-treatment year

Study	Sample (n)	Mean Age	Design (Response rate) Assessment times	Sexual activity / Intercourse	Disruptions of sexual response	Overall sexual satisfaction
Vincent <i>et al.</i> (1975)	- stage I-II cervical cancer patients: a) surgery alone (25) b) radiotherapy alone or surgery & radiotherapy (25)	41	Prospective interview study (98%): Pre-treatment, during 6- & 12- months post-treatment	Declined from pre- to post-treatment [Changes in coital positions post-treatment: surgery group (14%) radiation group (47%)]	Desire phase disrupted	-
Andersen <i>et al.</i> (1989a) USA	a) stage I & II ovarian, cervical (23) & endometrial (9) cancer patients b) benign patients (18) c) healthy controls (57)	42 39 42	Longitudinal controlled study (85-95%): Pre-treatment (retrospectively), 4-, 8- & 12-months post-treatment	Declined at 4 months normalised at 8 months No significant group differences in comparison with healthy women at 8 and 12 months follow ups	Desire phase stable Excitement phase disrupted the most (not anxiety based) 30% of cancer patients diagnosed with sexual dysfunction at 12 months	Declined
Schover <i>et al.</i> (1989) USA	- stage I-II cervical cancer patients: a) surgery alone (26) b) radiotherapy alone or surgery & radiotherapy (37)	38	Longitudinal study (80%): Pre-diagnosis (retrospectively), 6- & 12- months post-treatment	Stable at 6 months, declined at 1 year follow up	25% desire phase disrupted 19% arousal phase disrupted (more prominent in irradiated women than surgery alone group) Coital anorgasmia increased from 8% pre-diagnosis to 21% at 1 year post-treatment	Stable

Study	Sample (n)	Mean Age	Design (Response rate) Assessment times	Sexual activity / Intercourse	Disruptions of sexual response	Overall sexual satisfaction
Weijmar Schultz <i>et al</i> (1991) The Netherlands	a) stage I & III cervical cancer patients (21) b) benign patients (10) c) healthy controls (21) d) "testing" control group of cervical cancer patients (12) assessed only at 12 months post-treatment	39 43 42	Longitudinal controlled study (75%): Pre-treatment, 6-, 12- and 24- months post-treatment	Stable	Increased negative genital sensations during sexual arousal and orgasm in the patient groups, the frequency of dyspareunia (studied in cancer group) was low	General satisfaction stable, Relational satisfaction declined
Lalos <i>et al.</i> (1995) Sweden (Note: Mainly partner's data presented)	a) Cervical (30) and endometrial (30) cancer patients b) Partners of cervical cancer patients (23) and partners of endometrial cancer patients (24)	51 44 55 45	Prospective interview study (-): Pre-treatment, 6- & 12- months post-treatment (for patients) Pre-treatment, 12 months post-treatment (for partners)	Declined (reported by partners)	40% orgasmic phase disrupted (reported by patients)	-
Kyistra <i>et al</i> (1999) The Netherlands	a) stage I-II cervical (42), endometrial (10), vulvar (3), ovarian (2) and other (1) cancer patients b) healthy controls (103)	46 42	Longitudinal controlled study (37%): Post-treatment, 6- & 12- months post-treatment	Stable	The excitement phase disrupted due to lubrication problems, especially for irradiated patients Orgasm retarded over time	Stable
Grumann <i>et al</i> (2001) Australia	a) stage IB cervical cancer patients (20) b) benign patients (18) c) healthy controls (20)	38 45 49	Longitudinal controlled study (57-67%): Pre-treatment (retrospectively), 4- & 8- months post-treatment	Slight deterioration at 6 months follow up, stable between 6 and 12 months post-treatment Overall no significant changes over time	Downward trend across time in all four phases of sexual response cycle (i.e. desire, arousal, orgasm & resolution) No significant differences between initial and 8 months follow up on any phase	Stable

**Vincent, Vincent, Greiss & Linton (1975)** conducted one of the early prospective studies in this area, using a sample of 50 patients undergoing treatment for early stage cervical cancer (see Table 1.3.). Patients were randomly assigned to treatment by surgery (n=25) or by radiotherapy (n=25). Both subgroups were matched for age, socioeconomic status, parity and stage of disease. Patients were assessed using semi-structured interviews pre- and post-treatment and at 6 and 12 months post-treatment. Patients in both subgroups reported a decrease in sexual desire and activity between pre- and post-treatment assessments. Nearly half (47%) of patients treated with radiation engaging in sexual intercourse reported changing coital positions post-treatment, compared to only 14% of patients treated surgically. The majority of patients (70%) reported receiving no information related to sexual functioning from their oncologist, 68% wanted more information and 79% indicated they wanted the doctor to initiate a discussion concerning sexual matters.

This study is notable for initiating controlled prospective research into issues of sexuality following treatment for gynaecological cancer. Within this study less specific measures of operationalisation of sexual functioning were used and data were analysed descriptively, thus rendering the study exploratory in nature. There is a possibility that since the same interviewer discussed sexual functioning with the patients throughout the study, an element of positive intervention became part of the study. Nevertheless, Vincent *et al.*'s (1975) study is a milestone in the investigation of sexual functioning following gynaecological cancer, providing a basis and direction to be pursued by future prospective studies.

The main contribution of the study by **Schover, Fife & Gershenson (1989)** is the finding of delayed impact of radiotherapy affecting women's sexual functioning. This is in contrast with the findings of Vincent *et al.* (1975) who found no differences between surgery and radiotherapy patients in terms of post-treatment sexual adjustment. Patients in the Schover *et al.*'s (1989) study



were assessed by interview and standardized and non-standardised questionnaires (for clinical characteristics of subgroups see Table 1.7.). The data obtained showed no changes in sexual satisfaction, orgasmic capability, or frequency of masturbation. However, frequency of sexual activity with a partner and the range of those activities had declined by one year post-treatment. Assessment at this time revealed that women were less likely to initiate sexual activity with their partner. Time spent in foreplay did not diminish and psychological distress declined. No major differences in sexual adjustment between radiotherapy and hysterectomy patients were noted at 6 months follow up. However, by 12 months follow up, more radiotherapy than surgical patients developed severe dyspareunia, with a lessening of sexual desire and arousal. The higher incidence of dyspareunia in the radiotherapy group was correlated with narrowing and shortening of the vagina and post-coital soreness. Irradiated patients had a compliance rate of 57% for the use of vaginal dilators at 6 months follow up and 33% at 12 months follow up. Data indicated that patients receiving radiation treatment were less likely to resume a normal daily lifestyle, suggesting a poorer quality of life for the radiotherapy group compared to the surgical group at 1 year follow up. However, marital satisfaction/stability did not appear to relate to the treatment modality.

Authors acknowledge that the generally positive sexual outcome for their sample may have reflected a potential confounding effect of the brief sexual counselling that all patients received. Regrettably, no control group of patients with a benign gynaecological condition was used for comparison.

In a well designed study by **Andersen, Anderson & deProsse (1989a)**, the variable of sexual functioning is defined as a construct comprising of three components: sexual behaviour, sexual response cycle, and sexual dysfunctions according to DSM-III criteria. The authors developed a questionnaire assessing the sexual response cycle since no such standardized measure was available at the commencement of the study. This questionnaire was then subjected to

psychometric analysis. For clinical characteristics of the sample and design of the study see Table 1.3.

Patients in both the cancer and benign groups reported a significant decline in their sexual life post-treatment, including decline in frequency of intercourse and a less positive global evaluation of their sexual life. The incidence of sexual dysfunction in women treated for cancerous or benign conditions was three to six times higher than in healthy controls. It is of concern that half (50%) of the patients who had no sexual dysfunction pre-treatment, exhibited at least one sexual dysfunction at follow up assessments, with 30% of cancer patients still sexually dysfunctional at 12 months follow up. The rates of sexual dysfunctions in the cancer group at 12 months follow up included inhibited sexual desire (32%), sexual arousal (29%), orgasm (29%), and dyspareunia (29%). Over time, women in the two patient groups exhibited a lessening of sexual excitement, this being more pronounced and distressing in cancer patients compared to benign patients. The disruption of the excitement phase did not appear anxiety based (since no changes in sexual anxiety were noted) but rather appeared related to dyspareunia. Although changes also occurred within the desire, orgasm and resolution phases, they were of a lesser degree and duration. Thorough as this study is, it needs to be noted that the patient sample included cancer patients with different types of gynaecological cancers with various degrees of severity for which different treatment modalities were used. The distinct nature of different types of gynaecological cancers and the unique impact of various treatment modalities has to be taken into account when interpreting the results.

In their 2-year longitudinal controlled study, **Weijmar Schultz, van de Wiel & Bouma (1991)** investigated psycho-sexual functioning following treatment for cervical cancer, using data from 26 couples (see Table 1.3.). Sexual functioning was operationalised within the parameters of sexual motivation, sexual behaviour, perception of genital sensations in sexual arousal and sexual (dis)satisfaction. Whilst patients in the cancer and healthy control group

exhibited no major sexual difficulties pre-treatment, these difficulties were evident in the benign group, possibly as a consequence of symptoms associated with their gynaecological condition. By 12 months follow up, sexual functioning for cancer and benign patients was comparable for motivation, for sexual engagement and sexual behaviour, being within the healthy range (comparable to healthy controls). However, sexual response was considerably disrupted, areas most affected being arousal and orgasm, with heightened vaginal sensitivity and negative genital sensations during these phases. Interestingly, the overall sexual satisfaction of all patients was unaffected. In the second year, negative sensations during arousal and orgasm increased further for cancer patients. Vaginal sensitivity decreased slightly. Cancer patients reported they felt their vaginal was too narrow, too short or was feeling numb. On physical examination 70% of women showed vaginal shortening, however there was no evidence of vaginal stenosis. Reports of dyspareunia were infrequent, suggesting that the decrease in sexual response was not dyspareunia-based, as previously found in Andersen *et al.*'s (1989a) sample. According to Weijmar Schultz *et al.* (1991) the patients' poor sexual response was related to women feeling alienated from their vagina as a result of the disease and treatment. Post-hoc analysis did not reveal any significant differences in negative genital sensations during sexual arousal and orgasm between the patients treated with surgery alone (n=12) and patients undergoing combined radiotherapy and surgery (n=13). Conducting a single assessment at 12 months follow up of an additional control group treated by radical hysterectomy (see Table 1.3.) showed no differences in their sexual functioning compared to the cancer patients who were repeatedly assessed. Hence, it is unlikely that testing effects confounded the obtained results.

Based on the above findings, the authors conclude that a women's motivation for, and satisfaction with, sexuality is not limited to sexual arousal, but also includes a need for intimacy. Should the need for intimacy in a time of crisis be paramount and engaging in sexual activity meets that need, then the woman

may assess sexual activity as satisfactory despite the lack of physical sensations of arousal. The authors suggest that an increase in dependency and fear of losing their partner may account for the low level of relationship dissatisfaction reported by women post-treatment.

At one year follow up, assessment of sexual functioning in benign patients was similar to that in cervical cancer patients. This prompted the authors to suggest specific disease-dependent rehabilitation programs were not justified by their findings. Rather, greater emphasis could be paid to evaluating and enhancing coping strategies, such as communication skills and shared problem solving through the course of the illness and recovery. Since only cancer patients complained of negative genital sensations post-treatment, the possibility that these sensations are related to radiotherapy does seem to require particular attention. The lack of significant differences between the radiation group and the surgery patients may have been due to insufficient power. The recognition of the importance of the measurement of intimate aspects of sexual relating rather than the narrower focus on the physiological aspects, increases the value of this study. However, it is regrettable that psychological distress was not measured and controlled for as elevated levels of anxiety and depression may have confounded the obtained findings of sexual functioning.

In their prospective interview study, **Lalos, Jacobson, Lalos & Stendahl (1995)** investigated the social, psychological and sexual experiences of 47 partners of cervical and endometrial cancer patients within the first post-treatment year (see Table 1.3.). Although this study was mainly descriptive and provided only limited information regarding the post-treatment sexual functioning of patients themselves, the findings are considered important since this is one of the very few studies in this area to investigate the response of partners.

Prior to treatment, the majority of men (81%) were in a psychological crisis (e.g. feeling sad, anxious, helpless, restless) with the number of their psychological symptoms decreasing over time. This reduction was contrasted with a considerable increase of symptoms of a psychosomatic nature, such as muscular tension, headache, insomnia, over time. Most men did not obtain basic information about their partner's illness. Post-treatment, more negative experiences of intercourse and impaired sexual desire (30%) were reported by partners, whilst disruption of orgasmic phase was reported by 40% of patients. Some men reported noticing a decrease in lubrication, vaginal elasticity and vaginal length in their partners. The majority of men (89%) evaluated their relationship positively ("good" to "very good"), although the estimates became less positive over time (75% at one year follow up). Interpersonal problems were more evident in the cervical cancer group, whilst the endometrial group was characterized more by internal psychological problems (e.g. neurosis, poor self-confidence). Lack of open and honest communication with their partner about her illness and treatment was reported by approximately half the men. Many partners felt guilty that their deficient hygiene or their history of multiple sexual partners had caused their partner to contract cancer. Myths regarding the transmission of cancer through intercourse were also detected.

This study emphasises the importance of involving the partner in the health care program from the moment of the cancer diagnosis and the importance of open communication between partners and with health care professionals. Further, it supports Weijmar Schultz *et al.*'s (1991) findings that frequency of intercourse or orgasms are not necessarily a reliable measure of the quality of sexual functioning of a couple, since a reduced frequency of intercourse may imply an increase in other intimate behaviours that may give great satisfaction. More extensive reports on the social, psychological and sexual experiences of patients would have improved this important paper. Nevertheless, it provides a significant insight into the many aspects of the functioning of partners of gynaecological patients within the first post-treatment year.

**Kylstra, Leenhouts, Everaerd, Panneman, Hahn, Weijmar Schultz, van de Wiel & Heintz (1999)** found relatively positive sexual outcomes in patients treated for early stage gynaecological cancer (n=58; see Table 1.3.). Information regarding sexuality was given to 67% of the women and the majority of patients reported being satisfied with the information obtained (79%). Neither sexual activity nor sexual satisfaction changed from pre-treatment to 12 months follow up and was comparable to that of healthy controls (n=103). Cancer patients reported a higher frequency of "lubrication problems" over time, indicating a disruption of the excitement phase. Similarly to Schover *et al.* (1989) lubrication problems were particularly evident in the group of irradiated patients. Retardation of orgasm over time was also noted. Interestingly, cancer patients reported fewer sexual problems than healthy controls. The authors suggest this outcome may have arisen from the assessment of a non-representative sample of gynaecological cancer patients (response rate: 37%), a possible therapeutic effect of participation in the study and differing reasons for negative sexual changes of benign and cancer patients. The phenomenon of response shift is also introduced, response shift refers to a change in the meaning of patients' self-evaluation of quality of life in response to a life-threatening illness (Sprangers & Schwartz, 1999). As a result, sexual problems could be regarded as being of minor importance post-treatment, since cancer patients at that time still face existential issues. The authors also point to the possibility of having missed important changes in sexual functioning as a result of the chosen format for measurement, which did not target the treatment changes appearing some years following treatment. As with Weijmar Schultz *et al.*'s (1991) study, the patients' levels of psychological distress were not measured and controlled for, possibly allowing for the confounding effects of psychological distress on sexual functioning to be missed.

A controlled longitudinal study conducted by **Grumann, Robertson, Hacker & Sommer (2001)** in Australia also found no major sexual sequelae following

radical hysterectomy for Stage IB cervical cancer (n=20). Minor but steady deteriorations in sexual functioning among cancer patients were detected in contrast to consistent improvement in the benign group (parametric tests were not performed due to the small sample size). Minor decreases in intercourse frequency and sexual responsiveness were found, however neither reached a level of statistical significance. Levels of sexual anxiety and sexual satisfaction remained stable over time. Cancer patients raised more complaints related to oestrogen deficiency and dyspareunia than did benign patients. The main contribution of this in-depth comprehensive study lies in its methodological specificity regarding cancer site, stage and treatment. The authors acknowledge the problem of small sample size and a high attrition rate (see Table 1.3.) that precludes conclusive interpretation of the findings.

In summary, although retrospective studies reported an increased risk of sexual dysfunction, well-controlled prospective studies suggest that this may have been overestimated. The majority of prospective studies report disruption of *sexual response* over the first post-treatment year, especially in the excitement phase (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Andersen *et al.*, 1989a) and the orgasmic phase (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Andersen *et al.*, 1989a; Lalos *et al.*, 1995). *Sexual activity* remained stable in the studies of Weijmar Schultz *et al.* (1991), Kylstra *et al.* (1999) and Grumann *et al.* (2001), whereas a decline in sexual activity was reported in the studies by Andersen *et al.* (1989), Schover *et al.* (1989) and Lalos *et al.* (1995). Whilst sexual satisfaction remained stable in most studies (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Lalos *et al.*, 1995; Grumann *et al.*, 2001), deterioration in satisfaction has also been reported (Andersen *et al.*, 1989a).

These differences in results may be explained by measurement, time and/or cultural differences. Methodological shortcomings of the reviewed studies included: the use of mixed samples composed of patients with different types of gynaecological cancer (Andersen *et al.*, 1989a; Kylstra *et al.*, 1999), lack of

radical hysterectomy for Stage IB cervical cancer (n=20). Minor but steady deteriorations in sexual functioning among cancer patients were detected in contrast to consistent improvement in the benign group (parametric tests were not performed due to the small sample size). Minor decreases in intercourse frequency and sexual responsiveness were found, however neither reached a level of statistical significance. Levels of sexual anxiety and sexual satisfaction remained stable over time. Cancer patients raised more complaints related to oestrogen deficiency and dyspareunia than did benign patients. The main contribution of this in-depth comprehensive study lies in its methodological specificity regarding cancer site, stage and treatment. The authors acknowledge the problem of small sample size and a high attrition rate (see Table 1.3.) that precludes conclusive interpretation of the findings.

In summary, although retrospective studies reported an increased risk of sexual dysfunction, well-controlled prospective studies suggest that this may have been overestimated. The majority of prospective studies report disruption of *sexual response* over the first post-treatment year, especially in the excitement phase (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Andersen *et al.*, 1989a) and the orgasmic phase (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Andersen *et al.*, 1989a; Lalos *et al.*, 1995). *Sexual activity* remained stable in the studies of Weijmar Schultz *et al.* (1991), Kylstra *et al.* (1999) and Grumann *et al.* (2001), whereas a decline in sexual activity was reported in the studies by Andersen *et al.* (1989), Schover *et al.* (1989) and Lalos *et al.* (1995). Whilst sexual satisfaction remained stable in most studies (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991; Lalos *et al.*, 1995; Grumann *et al.*, 2001), deterioration in satisfaction has also been reported (Andersen *et al.*, 1989a).

These differences in results may be explained by measurement, time and/or cultural differences. Methodological shortcomings of the reviewed studies included: the use of mixed samples composed of patients with different types of gynaecological cancer (Andersen *et al.*, 1989a; Kylstra *et al.*, 1999), lack of



adequate controls (Schover *et al.*, 1989), and very limited sample sizes (Weijmar Schultz *et al.*, 1991; Grumann *et al.*, 2001). Since the course of the disease and treatment regimes differ with various types of gynaecological cancer, findings based on heterogeneous samples may lack sensitivity to the functioning of subgroups of women with a specific gynaecological cancer diagnosis.

An interesting viewpoint is suggested by Weijmar Schultz and van de Wiel (2003), utilising the process of trauma adaptation to explain differences in findings in this area. This process is described as being underpinned by an oscillation between two sub-processes: denial and intrusion. The authors propose that the severity of sexual problems reported in studies may depend on whether patients answer questions in the intrusion mode or in the denial mode of this process. Further, these two modes of adaptation possibly explain why a considerably higher rate of sexual problems is obtained using interviews compared to questionnaires (Weijmar Schultz & van de Wiel, 2003). Weijmar Schultz and van de Wiel (2003) illustrate this by reporting that when offered professional help, it took most patients two hours or more to decline the offer and state that they did not have a problem and could cope adequately with the situation. The authors conclude that the interpretation of sexual problems depends not only on the actual changes, but also on the theoretical background that the researchers use to interpret data. In summary, sexual outcomes cannot be evaluated exclusively at the level of content but rather must be considered within the context in which they occur.

In her review, Andersen (1996) concludes that during the first post-treatment year, the incidence of sexual morbidity is approximately 50%, with the possibility of chronic difficulty in upwards of 40% of women who are successfully treated. Consistent with other reviews, this outcome seems to occur in the context of satisfactory functioning in other areas of life (see Andersen & van der Does, 1994; Weijmar Schultz *et al.*, 1992 for reviews). In summary, sexual difficulties

are an island of disruption in an otherwise positive scenario of major life areas, including mental health and social adjustment (Andersen, 1996).

### **1.6.3 Sexual outcomes pertinent to various treatment modalities**

Since one of the aims of the current study was to investigate the impact of various treatment modalities on sexual functioning, it was important to evaluate research findings pertinent to psycho-sexual outcomes of the two main treatment modalities, namely surgery and radiotherapy. Since chemotherapy has only recently been included as an adjuvant treatment for early stage disease (only a small number of patients undergo this treatment), this section does not include chemotherapy outcomes. It is evident that the cervical cancer patient group has received the greatest amount of research interest to date (Weijmar Schultz *et al.*, 1992). This has been related to the high incidence of cervical cancer and to the controversy as to which treatment modality better controls cervical cancer: radical hysterectomy or radiotherapy. Since both treatment modalities have been found equally effective for an early stage disease, the studies focused on determining whether various treatment modalities produce different rates and types of psycho-sexual disruption (e.g. Vincent *et al.*, 1975; Weijmar Schultz *et al.*, 1992; Yeo & Perera, 1995; Flay & Matthews, 1995).

As previously discussed, the impact of radiotherapy treatment on women's sexual functioning is commonly delayed in comparison to surgery (Klee *et al.*, 2000b; Schover *et al.*, 1989). In the few studies that compared patients who received primarily radiation therapy to those who received primarily surgery, a higher incidence of sexual disruption/dysfunction (e.g. dyspareunia, disruptions of sexual desire and arousal phases) following radiotherapy was found (Decker & Schwartzman, 1962; Abitbol & Davenport, 1974a; Seibel *et al.*, 1982; Schover *et al.*, 1989; Yeo & Perera, 1995; Flay & Matthews, 1995). Seibel *et al.* (1980) conducted a retrospective study investigating the effects of radiotherapy and

surgery on sexual functioning in a cohort of 42 women of average age 40 years treated for cervical cancer (Stages I-III). The group treated with radiotherapy comprised of 22 patients and the surgery group of 20 patients. Data obtained by pelvic examination and interview showed all irradiated patients suffered some degree of vaginal damage, with 72% of women reporting a shortened and/or stenosed vagina. Irradiated patients reported a decline in several aspects of sexual activity including libido, excitement, ability to orgasm and frequency of intercourse, whereas those patients in the surgical group reported no significant changes in sexual functioning (also see Grumann *et al.*, 2001). Although these data clearly identify a greater disruption in sexual functioning for irradiated patients, insufficient data regarding stage and treatment modalities render this study less conclusive. It is noteworthy that this study revealed the disruptive nature of myths concerning cancer and pelvic irradiation, as destabilising the marital-sexual relationship for many women.

Using a cohort of 75 women aged 23-68 treated for cervical cancer (Stages I & II), Abitbol & Davenport (1974a) investigated the impact of specific treatment modalities on sexual functioning from 1 to 5 years post-treatment. The data was obtained by individual interviews and pelvic examination, both conducted by a gynaecological surgeon or a radiotherapist. The following treatment modalities were investigated: combined surgery and radiotherapy (n=15), radiotherapy alone (n=15), and surgery alone (n=32). Cessation or decline in sexual functioning in the combined group was reported by 33% of patients, in the radiation group by 79% and in the surgery group by 6% of patients. The very low rate of disruption in sexual functioning in the surgery group is rather surprising, considering the extensive nature of a hysterectomy. Indeed, other hysterectomy studies report higher rates of sexual disruption post-treatment (see Weijmar Schultz *et al.*, 1992 for review). Lack of libido was reported by 7% of patients in the combined group, 43% in the radiation group and 6% in the surgery group. The incidence of dyspareunia was greatest (39%) in the radiation group, followed by the combined group (13%) and the surgery group (3%). The inclusion of the internal pelvic examination revealed that alterations within the

vagina occurred in 60% of the combined group, 78% of the radiation group and 10% of the surgery group. These data reinforce the view that radiation treatment leads to higher levels of sexual dysfunction compared to surgical treatment. The fact that the interviews were carried out by the treating gynaecologists and radiotherapists raises the question of response bias in this sample. The fact that treatment groups were not matched for cancer stage further weakens the study's conclusions.

Flay & Matthews (1995) investigated short- and medium-term effects of pelvic radiotherapy on sexual functioning in women treated for cervical cancer (n=16; Stages I, II, or III). Six women had previously undergone hysterectomy. The women were assessed prior to radiotherapy, at completion of radiotherapy, and at 6 weeks and 14 weeks post-radiotherapy. Half of the women reported sexual disruption/dysfunction following radiotherapy. Further, combined treatment with radiotherapy and surgery resulted in a higher risk of sexual disruption than radiotherapy alone. Similarly, Seibel *et al.* (1982) reported statistically significant decrease in coital desire, coital opportunity, intercourse frequency, ability to attain orgasm, and sexual enjoyment following radiation treatment, with marked vaginal alterations recorded in the majority of irradiated patients (81%). Interestingly, the authors did not find positive correlation between the changes in sexual functioning and vaginal changes, thus supporting the view of multi-factorial nature of sexual function/dysfunction. It has to be kept in mind, however, that the incidence of sexual dysfunction may also depend on the method of radiation used. Unfortunately, no controlled study comparing sexual concomitants of external beam and intracavitary radiation exists so far.

Despite the traumatic nature of vaginal irradiation, until recently only a few studies systematically investigated brachytherapy in terms of the psychological effects of post-treatment changes in sexual functioning (Karlsson & Andersen *et al.*, 1985). Those few studies have reported conflicting findings. Bertelsen (1983) found that early stage cervical cancer patients treated with the combined modalities of surgery and brachytherapy (n=22) reported lower rates of sexual

dysfunction than patients treated with radiotherapy alone (i.e. brachytherapy and/or external radiotherapy, n=45). A study by Bruner *et al.* (1993) found a small to moderate change in sexual activity pre/post brachytherapy with 22% of the women reporting a decrease in coital frequency (n=90). Many studies investigated sexual functioning mainly on the basis of coital frequency, which is a poor indicator of overall satisfaction with post-treatment sexual life (Weijmar Schultz *et al.*, 1991). To our knowledge, no study has yet tried to systematically investigate the traumatic impact of the experience of brachytherapy on post-treatment quality of life, self-concept and body image.

An interesting result was found in the study by Tamburini, Filiberti, Ventafridda, Bianchi & Volterrani (1984). Twenty two early stage cervical cancer patients treated by radical hysterectomy, 61 patients receiving combined surgery and radiotherapy, and 15 patients having radiotherapy as a single treatment modality, were interviewed and completed a personality inventory (Minnesota Multiphasic Personality Inventory) to investigate post-treatment sexual outcomes. Patients had completed their treatment six months to ten years prior to the commencement of the study. Although all groups showed a significant reduction in sexual desire and enjoyment, no significant group differences were found. Work activity and emotional relationships also deteriorated. Despite the lack of significant differences, the authors noted the influence of psychosocial factors on adverse sexual functioning outcomes in hysterectomy patients compared to radiation patients, whose sexual disruptions seemed to be more closely related to radiotherapy-induced anatomical and physiological changes.

Schover (1990) commented on the importance of psychological factors in sexual dysfunctions in her review of sexual problems in chronically ill patients. Fears related to sexual activity, particularly the fear of sexually transmitting the cancer to their partner were highlighted, as were issues related to physical attractiveness and a loss of self-esteem following surgery. These factors were seen as possible contributing to a reduction of sexual desire. Similar misconceptions were highlighted in the study by Krumm & Lamberti (1993). This

study also demonstrated that women who did not follow advice regarding the use of vaginal dilators and who did not resume their pre-illness level of sexual activity were more likely to develop physical and sexual difficulties (Krumm & Lamberti, 1993).

Overall, little is known about the differential effects of various forms of radiotherapy on sexual functioning. This is mainly due to the fact that studies in this area have focused solely on one type of radiotherapy (e.g. Adelusi, 1980), have combined the two types of radiotherapy (Schover *et al.*, 1989; Krumm & Lamberti, 1993; Klee *et al.*, 2000a,b), or failed to specify what type of radiotherapy patients received (e.g. Vincent *et al.*, 1975). The majority of studies did not use a broad definition of sexual functioning and/or a prospective design. Most studies appear to suggest that radiation therapy has a more detrimental effect on sexual functioning, however the effects are delayed.

## 2. OVERALL DESIGN OF THE STUDY

The two common criticisms of research concerning psycho-sexual adjustment following gynaecological cancer have been: i) the paucity of concepts and theories that would explain and predict sexual behaviour and ii) the lack of methodological rigour in conducting research in this area (Abramson, 1990; Andersen, 1995). To overcome these shortcomings and to ensure that this study addressed actual, rather than theoretically derived or outdated issues and needs of treated women, the relevance of various scientific methods was evaluated in the light of their ability to provide meaningful and useful answers to the proposed research questions. The strengths and weaknesses of quantitative and qualitative methodologies were considered.

### 2.1 Formulations of the study design

#### 2.1.1 A combination of qualitative & quantitative methodology

In recent years, qualitative research has been steadily gaining respect and acceptance within the scientific community, particularly in health sciences, challenging the long-standing dominance of quantitative research (Jones, 1995). Traditionally, qualitative methodology was not seen to fit the paradigm of scientific methodology. In fact, a qualitative approach based on an *epistemological* philosophical standpoint has been perceived as antithetical to, and incompatible with, the quantitative methods based on a *positivist* philosophical stance. The latter approach is underpinned by the laws of cause and effect, perceiving reality as consisting of objectively derived facts that can be universalised (Henwood & Pidgeon, 1993). The use of quantitative research methods is particularly valuable in testing hypothesised relationships or causal explanations, thus verifying earlier theories and conclusions. In addition, its value lies in assessing reliability, validity and the underlying factor structure of

psychological measures, and in measuring the degree of generalisability across samples (Elliott, Fischer & Rennie, 1999). By using pre-determined responses in standardised questionnaires, however, quantitative research tends to reduce human experience to observable, manipulable and measurable variables. The method of quantification is thought to be necessary for the research findings to be generalisable and used for prediction (Henwood & Pidgeon, 1993). Such reductionist use of quantitative methods has been particularly evident in research relating to sexuality and cancer.

Until recently, the criteria for assessing post-treatment sexual functioning centered around the frequency of coitus and the achievement of orgasm, which lend themselves to a multitude of assessments by existing quantitative measures. Such measures, however, have been increasingly shown to lack sensitivity in accurately depicting the complexity of sexual functioning and female sexual satisfaction in particular (Weijmar Schultz *et al.*, 1991). Considering the paucity of *well validated* theoretical models in the area of post-treatment sexual functioning, the immediate application of quantitative methodologies was thought to be premature and inappropriate, potentially failing to identify factors that could prove important. Since the initial objective of this research was to explore important issues and dynamics that underlie post-treatment sexual adjustment, qualitative research with its main aim to revise and enrich the understanding of social concepts was selected as the most appropriate methodology for the initial stage of the project (i.e. Stage 1: Phase 1a & Phase 1b). A limitation of previous research has been a failure to measure important correlates of sexual functioning, which are necessary for an identification of patients likely to be at risk of developing sexual disruptions/dysfunctions. Such correlates can be identified using qualitative methodology.

Qualitative research offers a variety of methods of data analysis. Theory-building analysis is represented mainly in the "Grounded Theory" (GT) approach



developed by Glaser & Strauss (1967). This approach is rooted in the symbolic interactionist tradition, which holds that people are in a continual process of interpretation and definition as they move from one situation to another (Chenitz & Swanson, 1986). The term “grounded theory” is used to describe the process of identifying analytical categories as they emerge from the data. These categories may be derived inductively, that is obtained gradually from the data, or deductively, by setting in advance aims and objectives of the investigation (i.e. the “theoretical framework” approach). The data collection within the “framework approach” is more structured than in other qualitative research. Regardless of the reasoning process used, the grounded theory is built from elicited data through a process of constant comparative analysis of events, situations or settings (Glaser & Strauss, 1967). The GT approach can be used to: i) elaborate and modify existing theories rendering them more appropriate in various and specific contextual settings, or ii) generate new explanatory models of human behaviour (Strauss & Corbin, 1994). The latter is particularly valuable where there is little or no adequate existing theory and where generation of new theory is paramount, such as in the area of post-treatment sexual functioning following gynaecological cancer.

Two different types of theories can be obtained, depending on the number of situational contexts explored. A “*substantive theory*” emerges from the exploration of the phenomenon observed in one particular situational context such as post-surgery recovery, whilst a “*formal theory*” emerges from a study of a phenomenon examined in various types of situations such as pain during childbirth and pain in arthritis. The GT approach was selected as the most appropriate for the first qualitative stage of this study. The literature review and discussions with clinical staff at the gynae-oncological clinics, formed a basis for the development of the theoretical framework setting out hypothesised associations between concepts in the current research area. The obtained findings were then to be integrated into a “substantive theory” which, in turn, was to form a basis for hypotheses to be tested in the second quantitative phase.

The main criticisms of qualitative methods have been a lack of agreement regarding criteria for assessment and a lack of scientific rigour (Jones, 1995; Pope, Ziebland & Mays, 2000). In response to these criticisms, Elliot *et al* (1999) published a set of evolving guidelines with the aim of clarifying, unifying and therefore legitimising the methodological rigour of qualitative research (see Table 2.1.). This set is composed of seven guidelines common to both qualitative and quantitative research and seven guidelines specifically pertinent to qualitative investigation in psychology and related social sciences. These guidelines were closely observed and followed when conducting the Phase 1a and Phase 1b qualitative studies (see Chapters III & IV). The rigour of the current qualitative analysis was further enhanced by using the QSR NUD\*IST software designed for systematic analysis, complex organisation and retrieval of data. The computer software provides useful assistance in the dynamic process of gathering, organising and re-organising data. However, it is important that the hypotheses and the theoretical framework are generated by the process of computer-assisted analytical induction rather than *solely achieved* by the computer software.

Table 2.1. *Evolving guidelines for publication of qualitative research studies in psychology and related studies*

- 
- A. Publishability guidelines shared by both qualitative and quantitative approaches**
1. Explicit scientific context and purpose
  2. Appropriate methods
  3. Respect for participants
  4. Scientification of methods
  5. Appropriate discussion
  6. Clarity of presentation
  7. Contribution to knowledge
- B. Publishability guidelines especially pertinent to qualitative research**
1. Owning one's perspective
  2. Situating the sample
  3. Grounding in examples
  4. Providing credibility checks
  5. Coherence
  6. Accomplishing general vs. specific research tasks
  7. Resonating with readers
-

Rather than exclusive or competitive, qualitative research can be seen as complementary to quantitative methods. Qualitative methods are predominantly used for generating hypotheses rather than defining them *a priori* as in quantitative research. Qualitative findings rate highly on validity since they explore social concepts in a natural rather than contrived environment, thus facilitating a greater understanding of the concepts and terminology used to express them (Pope & Mayes, 1995). The linguistic aspect of qualitative research was considered particularly significant for the second stage of the study, where the sexual terms to be used in the battery of questionnaires needed to be familiar to, and understood by, the targeted population. Using qualitative research as a preliminary tool was therefore considered beneficial, facilitating a better understanding of a vast range of issues that are significant to women treated for early stage gynaecological cancer.

Based on the above review of scientific methods, the project was designed to comprise of two parts: a preliminary qualitative phase (Stage 1) and a main quantitative phase (Stage 2). Stage 1 employed the theory-building GT approach, using a “framework approach”. This method was selected to identify and explore important issues and dynamics underlying the post-treatment adjustment of women diagnosed with gynaecological conditions. In order to demonstrate the degree to which factors identified in the qualitative phase predict post-treatment sexual adjustment, prospective methodology was employed in the second phase of the current project. In summary, a combination of qualitative and quantitative methodologies was considered optimal for obtaining valid and reliable research findings.

### **2.1.2 Longitudinal controlled study**

Hypothetical relationships generated during the qualitative GT approach were tested in the second longitudinal quantitative phase (Stage 2), using measures informed by the qualitative phase.

Two confounding factors, potentially interfering with post-treatment sexual adjustment in the cancer group, were noted: i) the possibility of psychological and/or sexual disruption due to gynaecological disease or surgery itself and ii) the psychological impact of the threat of a recurrence of cancer. Whilst patients treated for benign gynaecological conditions have often been used as a control for gynaecological surgery, previous studies have not controlled for the psychological threat of cancer. One such group is represented by patients treated for pre-invasive cervical abnormalities (i.e. women with abnormal Pap smear). Consequently, the interpretation of post-treatment changes in sexual functioning was achieved in this study by comparing outcomes of cancer patients with the outcomes of women in two control groups: i) a group of patients being treated surgically for benign gynaecological conditions and ii) a group of patients diagnosed with pre-cancerous cervical abnormalities. The total sample was thus comprised of three naturally occurring groups of patients with various types of gynaecological conditions. In the following section, a brief overview of the aetiology and psycho-sexual outcomes of benign gynaecological and pre-invasive conditions is presented.

## **2.2 Control group I: Patients with benign gynaecological conditions**

As stated previously, the gynaecologically benign control group has been included to account for the sexual outcomes of surgical procedures where the threat of cancer was not present.

### **2.2.1 Aetiology**

Some symptomatology of benign gynaecological conditions is comparable to that of gynaecological cancers and includes excessive uterine bleeding, pelvic and back pain and abdominal bloating (Kjerulff, Langenberg, Rhodes, Harvey, Guzinski & Stolley, 2000). Careful investigation of the nature of the conditions

affecting the cervix, vagina, vulva, uterus, ovaries and fallopian tubes is needed to eliminate the possibility of malignancy. Once this process is completed and the use of less invasive treatments has proved ineffective, hysterectomy becomes the preferred treatment option for benign conditions such as uterine fibroids (approximately 30%), endometriosis and adenomyosis (approximately 20%), uterine prolapse (about 15%) and some pelvic inflammation (Sharts-Hopko, 2001). The use of adjuvant drug therapy following hysterectomy may or may not be recommended.

For the description of treatment for benign gynaecological conditions, i.e. hysterectomy, see section 1.2.2.1. As previously stated, the procedures involved in performing a hysterectomy are invasive and cause trauma to the abdominal area, both externally and internally, with organs adjacent to the uterus being affected during the procedure, immediately post-operative, with some lasting long-term.

### **2.2.2 *Psychological concomitants of hysterectomy for benign gynaecological condition***

The majority of studies targeting psychopathological concomitants of hysterectomy for benign gynaecological conditions are based on retrospective data which does not allow for causal interpretation of findings. In their longitudinal controlled study, Andersen *et al.* (1989b) found that patients with benign gynaecological conditions being treated by hysterectomy were significantly more anxious and fatigued compared to a group of healthy women. Data from follow up assessments at 4-, 8- and 12- months post-operatively showed a considerable improvement in physical health, vitality and mood, to the extent that there was a lack of statistically significant differences between patients treated with hysterectomy and the healthy women. The findings imply that the prospect of surgery for a gynaecological condition gives rise to a

significant amount of psychological distress. This distress, however, appears to be transient, resolving within the first four months post surgery.

Some authors propose that since undergoing a hysterectomy removes the causative factors contributing to heavy bleeding, pain and lack of physical wellbeing, most patients benefit from their operation and their psychological state is improved as a result (Bachmann, 1990). Alexander, Naji, Pinion, Mollison, Kitchener *et al.* (1996) found that hysterectomy compared to less invasive hysteroscopic procedures such as curettage, did not lead to increased psychological distress in the long-term. In their prospective longitudinal study, pre-operative levels of depression and anxiety for benign patients correlated with post-treatment levels. This suggests that the increase in scores post-surgery is more closely associated with existing levels of psychological distress pre-treatment, rather than being influenced by direct treatment outcomes.

### ***2.2.3 Sexual adjustment following hysterectomy for benign gynaecological conditions***

Studies show that hysterectomy patients are concerned about the potential adverse impact of this procedure on their sexual functioning (Poad & Arnold, 1994; Lalinec-Michaud & Engelsmann, 1985). Such concerns are not unfounded since research findings point to a deterioration in post-treatment sexual functioning in a subgroup of patients (13-37%) treated with hysterectomy (e.g. Nathorst-Boos & van Schoultz, 1992; Helstrom, Lundberg, Sorbom & Backstrom, 1993; Andersen *et al.*, 1989a). However, the same studies also report that for many women sexual life does not change or may improve following hysterectomy (34%-70%). Bachmann (1990) maintains that adverse post-operative sexual outcomes may occur more readily in women who experienced some level of sexual difficulties and psychological disturbances, such as depression, pre-operatively. Factors that appear to predispose women to adverse post-treatment sexual outcomes are a lower education, a younger age, and insufficient information regarding the nature of the condition and/or

treatment outcomes. Women who are ambivalent about child bearing, and those for whom the uterus hold great significance as a symbol of their femininity and womanhood, are also at greater risk of poorer sexual outcomes. Overall, it is evident that the impact of hysterectomy on post-treatment sexual functioning is complex, showing both beneficial and detrimental effects (Rhodes, Kjerulff, Langenberg & Guzinski, 1999).

A prospective study by Eicher (1994) reported a decrease in libido in 27% and orgasmic capability in 32% of benign patients, whilst 8% reported the occurrence of dyspareunia (cited in Grumann, 1998). Interestingly, 25% of his patients reported an increase in their orgasmic ability. Alexander *et al.* (1996) found both hysterectomy and less invasive treatment of hysteroscopy lead to comparable deterioration in patients' evaluation of their sexual functioning. However, no adverse psychosocial effects, such as marital difficulties, were reported with either treatment. It is possible that these findings reflect the use of a global rating for sexual adjustment post-surgery. A more detailed investigation regarding the nature of any persisting sexual problems might have clarified reasons underlying such deterioration.

The rigorous study designs and methods of operationalisation of sexual functioning variables render the findings from the following four prospective studies highly valuable. Weijmar Schultz *et al.* (1991) (for design and sample characteristics see Table 1.3.) found that motivation for sexual interaction of patients with benign gynaecological conditions was similar to that of the healthy women, although benign patients experienced significantly more disruption in their sexual responses. An assessment at 12 months follow up showed this disruption persisted with an impaired ability to induce sexual arousal and/or orgasm. In fact, benign patients reported significantly more negative genital sensations during sexual arousal and orgasm compared to the healthy women. A higher number of physical symptoms identified by benign patients as impairing their sexual activity with their partner was also reported.

Andersen *et al.* (1989a) noted a significant post-operative decrease in the frequency of intercourse of patients treated with hysterectomy for a benign gynaecological condition. This decrease was still evident at 12 months post-surgery (for design of the study see Table 1.3). The mean pre-operative intercourse frequency of 9.5 times per month decreased to 6.1 times per month in the first 4 postoperative months, and remained between 6 and 7.5 times per month over the following eight months. The mean intercourse frequency for healthy women remained fairly stable over the same time period, fluctuating between 7.5-7.8 times per month, corresponding to the mean frequency of benign patients at 4 months follow up.

In contrast, a prospective longitudinal study by Grumann *et al.* (2001) indicated no significant changes in sexual functioning of benign patients (n=18) pre- and post-treatment (for sample characteristics/study design see Table 3). Indeed, comparisons of baseline (pre-treatment) and 8-month follow up data revealed tentative improvements on most of the fifteen sexual variables assessed. However, due to the small sample size, the interpretation of trends predominated, thus conclusions need to be drawn with caution.

Nevertheless, similar findings to those in Grumann *et al.*'s (2001) study were obtained from a 2-year prospective study by Rhodes *et al.* (1999) assessing sexual functioning in 1101 women prior to hysterectomy and at 6-, 12-, 18- and 24-months post-surgery. The majority of patients (65%) had undergone an abdominal hysterectomy. All patients had identifiable gynaecological pathology as a consequence of long-standing debilitating symptoms. The main data obtained by interview assessed frequency of sexual relations/intercourse, sexual desire, vaginal dryness, orgasm and dyspareunia. Overall, for the majority of women sexual functioning considerably improved following hysterectomy, alongside improvements in overall health status and quality of life. Significantly more women were sexually active post-hysterectomy than pre-hysterectomy and for each sexual functioning problem the rate of improvement exceeded 60%.



Pre-hysterectomy depression was associated with reports of low libido, vaginal dryness and dyspareunia.

Helstrom (1994) conducted a prospective study, interviewing women undergoing hysterectomy for non-malignant gynaecological conditions (n=104). Women were assessed one month prior to the hysterectomy and one year post-hysterectomy. Sexual data were analysed statistically and supplemented by responses from open-ended questions. Regarding sexual activity, the majority of women reported improvements (50%) or no changes (31%) following their hysterectomy. Interestingly, women who reported improved sexual functioning commonly described these improvements in terms of improved personal sexual capacity, whereas most cases of deterioration were described in terms of an absent, poor or dysfunctional relationship with a partner. Since the majority of women defined sexuality as a social function influenced by the quality of relationship between partners, studies focusing on frequencies of desire, intercourse or satisfaction may prove limited in their scope. This study highlights the importance of both qualitative and quantitative aspects of sexuality when assessing post-treatment sexual disruptions/dysfunctions.

In summary, the effects of hysterectomy on post-treatment sexual functioning remains inconclusive, with some studies reporting a deterioration in sexual life (Weijmar Schultz *et al.*, 1991; Andersen, 1989a), others indicating positive post-treatment sexual outcomes (Grumann *et al.*, 2001; Rhodes *et al.*, 1999; Helstrom, 1994). As the study by Helstrom (1994) indicated, this may be due to the differences in operationalisation of sexual variables, particularly in terms of a neglect of qualitative (interpersonal) aspects of sexual relating, as well as discrepancies in the design of the studies.

## **2.3 Control group II: Patients with pre-invasive cervical abnormalities**

It was considered important to control for the effects of the threat of a cancerous condition, as opposed to the impact of treatments for gynaecological cancer. To achieve this, a control group of women diagnosed and, in some cases, treated for pre-cancerous cervical abnormalities was considered for inclusion in the study. Since the treatment recommended for pre-cancerous cervical abnormalities is very conservative, causing minimal physical trauma, the emotional response to the threat of cancer in those women diagnosed and treated was compared with the responses of women treated for early stages of cervical and endometrial cancer.

Pre-cancerous conditions, like gynaecological cancers, pose a number of challenges to women. The incidence of pre-cancerous cervical abnormalities has been closely linked to the sexually transmitted Human Papilloma Virus (Ho *et al.*, 1998; Schiffman *et al.*, 1993). Thus, for both pre-invasive and invasive cervical cancer patients, the association with personal sexual history directly challenges the relationship of the patient, her partner and their overall sexual interaction. Furthermore, since pre-cancerous conditions are linked with an increased risk of developing cancer, a pre-invasive cancer diagnosis raises fears somewhat similar to the fear of cancer recurrence experienced by women treated for early-stage cervical cancer. The way a woman responds to these challenges may impact on her relationship, on her sexual life and her overall quality of life. The psychological response to the diagnosis and treatment of a pre-invasive cervical abnormality can be traumatic and very important (Palmer, Tucker, Warren & Adams, 1993).

### **2.3.1 Aetiology**

The abnormal changes in epithelial cells of the cervix is termed Cervical Intraepithelial Neoplasia (CIN), also referred to as "pre-cancerous" or "pre-

invasive" abnormalities (Palmer *et al.*, 1993). The majority of CIN appears to occur in women under 35 years of age, whilst invasive cancer is recorded mainly in women over 35 years (NSW Cervical Screening Program & the NSW Pap Test Registry, 2001).

Although the rates of detection of invasive carcinoma of the cervix have been consistently declining, the incidences of cervical intraepithelial neoplasia (CIN) have risen dramatically (Lambley, 1993). This increase may be, in part, attributable to improved screening rates as well as improved cytopathological techniques to detect pre-cancerous cervical lesions, leading to early treatment of the CIN conditions. This, however, does not prevent the view by some researchers that there may be cause to consider invasive cervical cancer to be on the increase overall (Campion & Reid, 1990, Eddy, 1990). Australia has utilised cancer screening by Pap smear test for the past 27 years. In 2000, 4% of women screened in NSW had abnormal cytological findings requiring a colposcopy examination. Of these, 42% of histological results were not confirmed (i.e. were negative or benign), 19% were of low grade (CIN I) and 23% of high grade (CIN 2 & 3). The remaining 16% included diagnosis of micro-invasive cancer, cervical cancer, Human Papilloma Virus (HPV) alone and abnormal cells not otherwise specified (NSW Cervical Screening Program & the NSW Pap Test Registry, 2001).

Should there be sufficient indication that abnormal cells are present, a further investigation of the cervix is undertaken to define the position and extent of areas suspected of containing abnormal cells. The procedure used is a *colposcopy*, which involves an examination by a physician using a pair of high-powered binoculars on a stand (i.e. a colposcope). This allows the physician a magnified view of the cervix. The actual procedure of the physician looking at the cervix through a colposcope requires minimal invasive techniques. However, prior to the examination the physician may discuss with the patient the possibility

of removing tissue samples from the cervix during the procedure, should that be considered advisable on closer inspection of the cervix.

The procedure of colposcopy is carried out in an outpatient clinic. The patient lies on her back with her knees bent up and apart. Some physicians offer the patient the option of having their legs supported in stirrups. A warmed lubricated speculum is gently inserted into the vagina and expanded. The cervix is painted with 3-5% vinegar or iodine based solution, to highlight abnormal areas on the cervix. The reaction of the tissue is observed through the colposcope. This is the extent of the examination. Significant reactions to the solution strongly indicate the advisability of cone biopsies (the extraction of small fragments of tissue from suspected areas of abnormality) for further histological examination. The cervix is a relatively insensitive area (containing no pain nerve cells), and the minute size of the tissue fragments taken suggests the procedure should cause minimal discomfort. Laboratory histological examination of the biopsies can identify the presence of abnormal cells such as squamous cell atypia, dysplasia, and HPV with dysplasia, their degree of abnormality, distribution and depth of penetration into the cervical tissue (Palmer *et al.*, 1993). With biopsies taken where necessary, the speculum is carefully removed and the procedure is finished. Should further investigation by a deeper biopsy, known as a cone biopsy, be advisable, then this procedure can be undertaken under a general anaesthetic in hospital.

The use of colposcopy and ablative techniques allow pre-invasive abnormalities to be treated by the destruction of identified areas of abnormality using methods causing minimum disruption to surrounding tissue. There are a number of *ablative treatment* options available such as freezing, laser, surgical excision and large loop excision of the transformation zone (LLETZ). The LLETZ is a common ablative treatment used to remove areas of abnormal cells from the cervix by excising them with a hot wire loop (National Cervical Screening Program, 1997). The procedure (usually taking 15-20 minutes) can be carried

out in the outpatient clinic. No general anaesthetic is required although sedation and local anaesthesia is used where necessary. Minimal inconvenience is experienced post-procedure, although some discharge and bleeding may be evident for a day or two. Complications and/or side effects are rare and healing usually takes place rapidly (National Cervical Screening Program, 1997). An overall cure rate of 95% after one treatment is claimed for ablation (Wright, 1983). Hence any changes in sexual functioning after pre-invasive treatment are likely to be a result of psychological factors associated with fear of cancer, rather than physical causes.

### **2.3.2 *Psychological concomitants of cervical screening and follow up treatment***

It is a commonly held belief by many women and members of the public that a Pap smear is to detect cancer (Lerman, Miller, Scarborough, Hanjani, Nolte & Smith, 1991). However, its primary function is to detect any early abnormal changes in the cells of the cervix. Not all of these cells have the potential to progress to cancer. Further tests are required to establish risk values and a diagnosis of actual cancerous cells. Women's understanding of the Pap smear test, its results and how they interpret those results, affects the amount of psychosocial distress the patient experiences. Psychosocial distress is especially linked to concerns about cancer, the possibility that the disease and its treatment may affect sexual functioning, fertility and body image, as well as the possibility of transmitting the disease to a partner (Kavanagh & Broom, 1997; Campion, Brown, McCance, Atia, Edwards *et al.*, 1988).

There is increasing evidence that the screening procedure itself, the detection of any abnormal cells, the follow up strategies and subsequent treatment, all have a significant psychosocial impact (Posner & Vessey, 1988). Surveys have demonstrated that Pap smear tests can engender various negative responses, such as embarrassment, feelings of vulnerability and powerlessness, discomfort

and pain in some women (Areskog-Wijma, 1987; Bailie & Petrie, 1990). Invasive medical procedures are known to induce elevated levels of anxiety. For instance, significant anxiety was associated with the experience of an abnormal Pap smear and its treatment in the study by Nugent, Tamlyn-Leaman, Isa, Reardon and Crumley (1993). The level of anxiety regarding undergoing the procedure and the fear of the anticipated result may deter some women from having the Pap smear test (Baileff, 2000). Irrespective of the procedure or diagnosis, women identified uncertainty as a primary concern (i.e. uncertainty about the meaning of an abnormal Pap result as well as about cancer and infertility) (Lauver, Kruse & Baggot, 1999).

It was reported by Posner & Vessey (1988) that many women responded to their diagnosis of various degrees of CIN and its subsequent treatment with feelings of annoyance, resentment and anger. Palmer *et al.* (1993) studied levels of state/trait anger as well as intrusive thoughts, avoidance, and health locus of control. They found high levels of intrusive thoughts, avoidance and anger related to receiving the diagnosis. Anger, intrusive thoughts and avoidance are believed to occur when an individual is processing information associated with a traumatic event (Horowitz, 1979). Hence, the presence of anger in this situation supports the proposition that receiving the diagnosis is a traumatic experience. Interestingly, the level of anger post diagnosis did not differ significantly from the level of anger post treatment (Palmer *et al.*, 1993). Interview data suggests that in part the traumatic impact of the diagnosis may be related to the assumptions made by women that CIN is associated with cervical cancer (a potentially life-threatening disease). Further traumatic effects may be associated with coming to terms with the possible involvement of the sexually transmitted HPV virus, which, it is postulated, can be a causative factor in CIN, and disclosing and discussing this with their partner. A sense of sexual contamination was a common theme reported as a difficulty within sexual functioning in the study by Palmer *et al.* (1993).

### **2.3.3 Sexual outcomes following pre-invasive cervical abnormalities**

Stress and sexual activity were two common explanations women used to account for their cervical abnormality (Kavanagh & Broom, 1997). It is of interest that although most women recognised the connection between sexual activity, sexually transmitted diseases and cervical abnormalities, few accepted sexual transmission as an explanation for their condition (Kavanagh & Broom, 1997, 1998). This occurred despite increased media attention regarding the role of sexual partners in the aetiology of the disease (Campion, Singer, Clarkson & McCance, 1985) and its association with HPV (e.g. Ho *et al.*, 1998). Interestingly, hostility directed towards sexual intercourse and/or towards their regular sexual partner developed among a number of women treated for CIN (Campion *et al.*, 1988). Furthermore, McDonald, Neutens, Fischer & Jessee (1989) reported that patients perceived their sexual partners as responding identical to them; when they held negative views about themselves or their body image they reported that their partners also held these views.

Following colposcopy, women were mainly concerned about the implications of this treatment on their relationship with their partners, particularly about possible sexually transmitted diseases (Lauver *et al.*, 1999). For many women a cervical abnormality undermined their sense of feeling feminine. These women associated the cervix with reproduction and considered reproductive capacity as a defining feature of womanhood (Kavanagh & Broom, 1997, 1998).

A large majority of women attribute the cause of the disease to sexual activity, with female promiscuity seen as important, whilst male promiscuity was not mentioned (Palmer *et al.*, 1993). At 3 months follow up, women who had had a positive Pap smear showed significant impairment in sexual interest, mood, daily activities and sleep patterns as well as an elevation in worries about cancer. These symptoms were more pronounced in women who had not accepted the recommended colposcopy examination (Lerman *et al.*, 1991). For those women

who did accept a colposcopy examination, the predominant concern prior to colposcopy was fear of cancer (100%). After the colposcopy and surgical treatment, however, the predominant concern shifted to that of a loss of attractiveness and sexual dysfunction (61% and 47% respectively) (McDonald *et al.*, 1989).

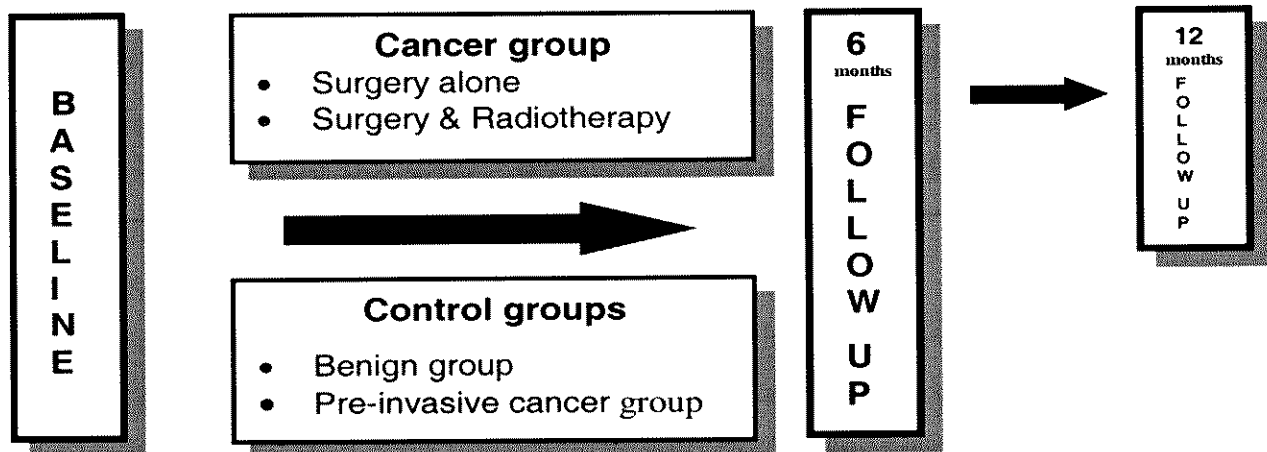
The first study which directly focused on sexual functioning and pre-invasive cancer, Champion *et al.* (1988), compared women diagnosed with CIN and HPV infection and women diagnosed with a sexually transmitted disease with no presence of CIN. Following treatment, women diagnosed with CIN and HPV reported reduced sexual interest and frequency of intercourse, reduction in vaginal lubrication and orgasm, as well as decreased sexual arousal. In addition, significant increase in negative feelings towards intercourse and sexual partners associated with the abnormal Pap smear was found in women treated for CIN and HPV. Similarly, a high percentage of sexual impairments following treatment was reported by Filiberti, Tamburini, Stefanon, Merola, Bandieramonte *et al.* (1993). The occurrence of sexual problems following major gynaecological surgery is readily understood (e.g. Andersen & Hacker, 1983c,d). The implication that sexual behaviour has contributed to and/or caused the problem has the potential to disrupt sexual functioning, as in gynaecological cancer. The threat of cancer is also a common concern. As such, it was suspected that there would be a large number of similarities in the psychological response between these two groups. To investigate this we conducted two qualitative studies, the first to explore the psychological issues relevant to post-treatment sexual adjustment in cancer (Phase 1a) and the second with pre-invasive patients to determine whether they represent an appropriate control group (Phase 1b).

This preliminary qualitative phase proceeded the main, quantitative phase of the project where psycho-sexual outcomes of early stage cervical and endometrial cancer patients were investigated using a prospective controlled design (see Figure 2.1.). In the second stage all patients were assessed at baseline and at 6 months follow up. The cancer group was additionally assessed at 12 months



post-treatment to account for any delayed impact of radiotherapy on sexual functioning.

Figure 2.1. Overview of design employed in the quantitative stage (i.e. Stage 2)



## 2.4 Formulations of Aims & Hypotheses

Methodologically rigorous research into sexuality following treatment for early stage cervical and endometrial cancer warrants a high priority as early stage cervical and endometrial cancer patients, given appropriate treatment, have a good prognosis for survival (American Cancer Society, 2002). Consequently, a satisfying quality of life, including areas pertaining to sexuality and fertility, represent one of the key issues for many of these patients. The focus of this research is to extend the present data available in the area of sexual outcomes and sexual dysfunction in patients undergoing treatment for endometrial and cervical cancer. Although short-term sexual disruption following early stage gynaecological cancer has been well documented, the role of psychological and physical factors in the development of chronic sexual morbidity within specific subgroups of gynaecological patients, remains unclear. The diversity and complexity of the physiological, psychological, social and sexual components of various therapies (e.g. surgery alone, surgery & radiotherapy) invite a more thorough qualitative and quantitative investigation. In order to address some of

the observed deficiencies in the previous reviewed research, the current project aimed:

- to document sexual outcomes for women with cervical or endometrial cancer receiving surgery alone, or receiving combined treatment modalities, compared to two control groups: benign patients and pre-invasive cancer patients.
- to document the areas of post-treatment sexual disruption for early stage cervical/endometrial cancer patients and to identify predictors of successful sexual adjustment
- to explore the impact of sexual functioning on quality of life
- to explore and describe the psychological status and adjustment strategies and their association with post-treatment sexual adjustment

Based on the literature review, the following **hypotheses** were formulated:

### **Sexual drive**

- 1) *It was hypothesised that sexual drive in **cancer patients** would significantly decline by six months post-treatment compared to pre-diagnosis levels, with lowered levels of drive remaining stable between 6 and 12 months follow up.*

This initial deterioration in sexual drive was expected to be due to the trauma of ongoing treatments, the ongoing impact of various side effects from both surgery, and later, radiotherapy, together with the challenge of facing approximately a 10-20% chance of cancer recurrence.

- 2) *In contrast, **benign patients** were expected to report no change or a slight improvement in their sexual drive by 6 months follow up.*

This outcome was predicted since by this time benign patients would have recovered from their surgery and the adverse physical effects of their condition would be largely ameliorated.

- 3) ***Pre-invasive patients** were expected to experience a slight decline in sexual drive by 6 months follow up.*

This outcome was predicted due to the psychological impact of patients' perceived increased risk of developing cancer and possibly to their adopting a somewhat more cautious approach to sexual expression due to an apprehension regarding uncertainty as to the aetiology of their condition (e.g. a possible link to the sexually transmitted disease of HPV).

### **Sexual satisfaction**

- 1) *It was hypothesised that the sexual satisfaction of **cancer patients** would remain stable over time, despite a reduction in sexual drive and the occurrence of post-treatment vaginal/hormonal changes and side effects.*  
It was predicted a positive influence of relationship and sexual satisfaction at baseline, as well as social support (psychological factors), would counteract the detrimental impact of treatment side effects and vaginal and hormonal changes (physiological factors), resulting in no changes in sexual satisfaction over time.
- 2) *Sexual satisfaction for **benign patients** was expected to improve over time with the reduction of debilitating gynaecological symptoms and a subsequent lessening of psychological distress associated with the condition.*
- 3) *Sexual satisfaction for **pre-invasive patients** was expected to slightly decline over time, due mainly to the psychological impact of a perceived threat of developing cancer and a more circumspect approach to sexual activities.*

### **Quality of life**

- 1) *It was hypothesised that the quality of life of cancer and benign patients at six months follow up would have improved compared to pre-treatment*

*levels, whilst the pre-invasive group would maintain high levels of quality of life.*

- 2) It was also predicted that disturbance in sexual functioning would have a significant impact on the reported quality of life.*

### **3. PHASE 1a: A qualitative insight into post-treatment psycho-sexual adjustment following treatment for cervical and endometrial cancer<sup>ψ</sup>**

A basic concern of research into sexual functioning following cancer therapy is the choice of appropriate instruments with which to measure this construct (Bruner & Boyd, 1999). Phase 1a was conducted in order to address this concern. It was planned that findings from this phase would allow for an appropriate selection of measures to be used in the quantitative stage, measures comprehensively covering those issues and concerns identified by women participating in Phase 1a.

#### **3.1 Method**

##### **3.1.1 Participants**

Women treated for cervical and endometrial cancer (Stages I & II) at two large teaching hospitals, were eligible to participate in this study. Ethics approval for this study was obtained from the Central Sydney Area Health Service, South Eastern Sydney Area Health Service and University of Sydney Human Ethics Committees. Patients with a command of English enabling them to understand and take part in an interview, who currently had a partner and who had no concurrent active disease, were included in the study sample. Patients were identified by their treating oncologist on the basis of the inclusion criteria and

---

<sup>ψ</sup> Data from Chapter III has been published in the *Psycho-Oncology* journal (see Juraskova, I., Butow, P., Robertson, R., Sharpe, L., McLeod, C., & Hacker, N. (2003). Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psycho-Oncology*, 12(3), 267-279.

were invited to participate. To ensure representation of all relevant experiences and views and to allow time for late onset side effects and the dynamics of post-treatment changes to be observed, women were stratified by: 1) treatment received (surgery alone, surgery plus external beam radiation, surgery plus brachytherapy, and surgery plus external beam radiation and brachytherapy) and 2) time since treatment (immediately post treatment, during the next two years and thereafter).

### **3.1.2 Data collection**

In order to obtain an accurate holistic picture of post-treatment dynamics we chose a qualitative methodology (Elliott *et al.*, 1999). Oncologists were approached to identify eligible patients based on the inclusion criteria. Eligible patients received a letter from their oncologist informing them of the study and requesting their permission to release their contact details to the researcher. Women who gave this permission were contacted by the researcher who explained more fully the nature of the study, obtained verbal consent and arranged an interview time. Information sheets and consent forms were then mailed to participating women, who returned them to the researcher in an enclosed reply paid envelope. At initial contact, women were also asked to invite their partners to participate in this study (although partner participation was not an eligibility criterion). If partners expressed interest, they were sent an information sheet and a consent form and an interview time was arranged. Data for evaluation were gathered by conducting conversational semi-structured telephone or face-to-face interviews with consenting patients and partners. Participants had the option to withdraw from the study at any time without detriment to the patient's treatment. The main interview questions are listed in Table 3.1. Interviews were audio-taped and transcribed in full. Recruitment continued until no new themes emerged (theoretical saturation, Strauss & Corbin, 1990).

Table 3.1. *Interview Questions*

- 
- ♦ *What sort of treatment did you receive for your gynaecological cancer?*
  - ♦ *Please tell me what was involved for each treatment.*
    - *What happened first, then, last?*
  - ♦ *What do you think are the benefits and costs of having treatment?*
  - ♦ *How did you feel while having the treatment?*
    - *For how long did you feel like that? How strong were those feelings?*
  - ♦ *Was the treatment explained to you (including the role of dilators)?*
  - ♦ *Overall, how did the treatment affect you?*
    - *While you were having it? Immediately after the treatment?*  
*Several months after the treatment?*
  - ♦ *Which part of the treatment did you find easier / harder?*
  - ♦ *What were the effects of the treatment on your relationship with your partner?*
    - *While you were having it? Immediately after the treatment?*  
*Several months after the treatment?*
  - ♦ *What were the effects of the treatment on your sexual functioning?*
    - *While you were having it? Immediately after the treatment?*  
*Several months after the treatment?*
  - ♦ *What helped you cope with the treatment and/or side effects of the treatment?*
    - *Was there something the staff did or something your partner, family or friends did?*
    - *Can you think of anything that may have reduced the side effects of treatment?*
  - ♦ *Is there any advice you would like to give to the hospital to improve the care of people like you in the future?*
- 

### **3.1.3 Data analyses**

A qualitative phenomenological approach based on grounded theory was used to explore women's experiences related to different types of treatment (Glaser & Strauss, 1967). Semi-structured, rather than structured, interviews were selected as the method of the current qualitative data collection. In comparison to structured interviews, semi-structured interviews have been shown to reveal extensive novel data rather than validating the frequency of thoughts or events predetermined by the researcher. The use of interviews as a method of qualitative data collection has been criticised for generating data which could be subjective and biased. This criticism, however, can be overcome by conducting

numerous interviews, constant comparison of collected data with data from other sources, inter-rater reliability testing and rigorous documentation. In addition, the quality of data generated is largely dependent upon the skills and expertise of the interviewer (Guba & Lincoln, 1992). Addressing sexual issues during interview is a specialised area of interviewing technique. In order to elicit a high quality of information whilst causing minimal distress, the interviewer in the present study was a clinical psychologist (IJ).

The author (IJ) read transcripts of the interviews to uncover essences, and generate broad descriptive categories (*open coding*). Subsequently *axial coding* was employed to identify relationships between the categories and subcategories within the contextual framework. At this level, key differences between groups of women were explored by comparing and contrasting subgroups, based on type of treatment and time since treatment (see Table 3.2). Two main categories emerged: issues concerning the Patient-Partner dyad and those concerning Patient-Doctor issues. The axial coding level involved continuous discussion between authors (IJ and PB) until consensus was reached regarding emerging (sub)themes and their position within the narrative framework. Coding of the data and searching for themes and segments was computer-assisted by the NUD\*IST software program (Non-numerical Unstructured Data by Indexing, Searching and Theorising). The accuracy and relevance of the proposed findings were reviewed and verified by the resident psychologist (RR) at the gynaecological cancer centre, since she was not actively involved in the process of qualitative analysis.

### **3.2 Results**

Twenty-five women satisfied the eligibility criteria, five declined to participate citing the sensitive nature of the inquiry. Of those five women, three received combined treatment for endometrial cancer and two had undergone surgery only for cervical cancer. Sixteen telephone interviews were conducted. Four face-to-



face interviews were conducted with women still hospitalised one week post-surgery. All twenty participating women (age 19 to 64) were in heterosexual partnerships, although sexual preference was not a criterion for eligibility. Formal assessment of the relationships was not undertaken; however in interview two women indicated some uncertainties regarding the permanency of their partnership. Only two partners (age 19 & 44) agreed to participate in the study. Their comments are not included since the sample was deemed too small to be representative of the remaining partners. The characteristics of the sample are shown in Table 2.

Table 3.2. *Demographic and disease characteristics of sample (n = 20)*

<i>Age (at the time of the treatment)</i>	
18 ~ 29	1
30 ~ 39	3
40 ~ 49	5
50 ~ 59	10
60 +	1
<i>Marital status</i>	
Married	18
De-facto	2
<i>Menopausal status (pre-treatment)</i>	
Pre-menopausal	11
Post-menopausal	9
<i>Type of treatment</i>	
Surgery alone	9
Surgery & Brachytherapy	3
Surgery & External radiotherapy	3
Surgery & Brachytherapy & External radiotherapy	5
<i>Type of cancer</i>	
Cervical cancer	11
Endometrial cancer	9
<i>Time since diagnosis</i>	
Immediately post-treatment	5
6 ~ 12 months	2
12 ~ 24 months	8
24 + months	5

### **3.2.1 Impact of treatment modality**

Although the current small sample was not intended for quantitative analysis, it is significant that the women interviewed substantiated many of the results obtained from larger quantitative studies. Women who received radiotherapy, particularly combined external radiation and brachytherapy, reported the greatest difficulties related to sexual activity and sexual satisfaction post-treatment. All patients treated with surgery alone resumed sexual activity post-treatment as opposed to only 50% of women in the combined treatment group. Reduced vaginal lubrication and dyspareunia were most prevalent among irradiated women (50%). Overall, 40% of women were aware of their vagina being shortened and attributed some of their sexual difficulties to this fact. No differences were found between the sexual outcomes of women treated with surgery & brachytherapy and women treated with surgery & external radiotherapy. Significant conclusions cannot be drawn from this data due to the limited sample size.

The following are the main themes that emerged in the course of qualitative analysis:

### **3.2.2 Patient & Partner issues**

#### *Perceptions of femininity and reproductive organs*

Data analysis pointed towards qualitative differences between women with differing perceptions of their femininity. Those who identified their femininity with their ability to bear children experienced a more acute sense of loss with the removal of their uterus, irrespective of whether or not they had yet produced children. They felt this loss might have a negative influence on their current partnerships and jeopardise their chances of forming any subsequent satisfactory partnerships (further discussed in the section "Perception of sexuality and intimacy"). They also reported a poorer body image and a lowering of self-esteem. These findings were more evident in younger (pre-menopausal) women who had not fully explored their femininity and established their families.

- ◆ *"Just a sense of loss...a grieving that I lost my femininity...(reproductive organs)...they are symbols of womanhood, I suppose". (age 30)*
- ◆ *" All I wanted was to know that I could have children at some stage...all of a sudden that was taken away from me... what if I want to get married and then I've got to face issues again, like with my husband ...it's a whole thing that I'm going to face again". (age 19)*
- ◆ *" These are my reproductive organs... this is my womanhood... this is what we are all about ...and if they would have said: "We have to take your breast away", that wouldn't have worried me". (age 41)*
- ◆ *"I was so angry, I just couldn't control it and I didn't want anybody near me because I felt dirty. I scrubbed my body, I scratched myself that bad that I bled and everything...I've got scars..." (age 41)*

Women who did not equate their femininity with their childbearing abilities did not report changes in their sense of being feminine following the removal of their reproductive organs. For them their femininity was expressed primarily through their capacity to nurture and care for their family. A positive aspect of treatment for these women was a sense of relief from disabling symptoms such as heavy bleeding and discharge. On the whole, these aspects were more commonly observed in older (peri- and post-menopausal) women.

- ◆ *"(radical hysterectomy)...it was the best thing that I ever did...I was no longer anaemic...I was so fed up with the discharges, the very heavy bleeding." (age 56)*
- ◆ *"It didn't affect me because I've been through life change anyhow. I thought to myself, what do I need it for? If I was given a choice, I would have hysterectomy anyhow...that's getting rid of that danger of maybe getting things...no, I coped fine, it was good to have it out of my body actually" (age 56)*
- ◆ *"(the issue of womanhood)...no it doesn't worry me...I don't have to be a woman for anyone." (age 54)*
- ◆ *"Making love was right out of question...it really does hurt and he couldn't have coped with that because he didn't want to hurt me... but (sexual life) it's not that important, it's not a main thing in our life...I have lots of grandchildren who I mind all the time, I'm kept fairly busy." (age 56)*

### *Attitudes regarding the initial re-commencement of sexual activity*

Sexual functioning was not a priority issue for women who had just undergone surgery and were still coming to terms with the diagnosis of a life-threatening disease. When sexuality was brought to their attention, many women reported fear and insecurity regarding future sexual interaction with their partners.

- ♦ *"Yes, I'm a bit scared about having sexual intercourse again but that's not our priority at the moment".*
- ♦ *"I suppose when it comes to that first initial having sex with him...I think that it's gonna be very hard".*
- ♦ *"I don't feel anything... I don't feel anything except fear".*

Similar apprehensions and fears were expressed by some women interviewed two and more years post-treatment who remembered psychological and physiological trauma when they first resumed sexual intercourse. A number of women reported that the fear was so great that they became emotionally detached during their early sexual experiences.

- ♦ *"Physically I had no problems, I think most of it was dealing with emotional pain. There were times when I actually just detached myself...like at the beginning there were a lot of times I don't even remember... like I just blanked myself out from it, when we were actually having sex".*
- ♦ *"It very hurt physically, and when he stopped I was really dry and plus my mind wasn't there either..."*
- ♦ *"Just after it (the operation), it was really, really sensitive because I sort of psychologically...because I didn't really have a cervix anymore and I didn't understand what was going to happen...I was really, really tense and nervous and really sort of scared...now though, I think it's better than ever before."*

### *Perceptions of Sexuality and Intimacy Issues from the patient's perspective*

For many women satisfactory sexual expression equated more with intimate aspects (sensuality, sharing of vulnerability, reassurance) than with coital aspects of their sexual relationship. However, the act of coitus was commonly

perceived by most women as the main indicator of a man's satisfaction with sexual interaction. Many indicated a need, despite their own difficulties, to provide their partner with what they thought he wanted, i.e. sexual intercourse. Some women felt if they could not fulfill their partner's desire for sexual intercourse, then they should not prevent his seeking sexual satisfaction elsewhere. Such responses were less profound or absent in couples who stated they were able to communicate openly, and who had had a broader sexual repertoire prior to the cancer diagnosis.

- *"With a woman, even a cuddle or a kiss is enough for me but for a man wouldn't be... you have to go to the full line".*
- *"Before we did it all the time...now...sometimes I feel like I'm not doing my duty".*
- *"He caresses me, we have a bath together all the time...we used to never do that ...and we've got vitamin E cream and he massages the cream into the scar and that arouses me more than getting into bed and having sex".*
- *"I think because there were a lot of really mutually satisfying sexual activities we normally indulged in, I had plenty of practice doing without penetration".*
- *"He started drinking...I felt because I wasn't, you know, able to have an intercourse or anything like that with him. I felt I had no right to say anything so I just let him go".*
- *We had not had intercourse for two years...and like most men I suppose he could have said, well I'm going and have a ... you know...a fling on the side... something like that. But no, he patiently waited and then I spoke to him last week and I said look I have to try to have an intercourse because the vagina is becoming smaller and so we did... and I thought I have to let him do whatever he wants to do now... because what can I offer him? ...it just sort of happened and we haven't spoken about it since.*

### *Women's perspectives on partners' coping with changes in sexual functioning*

Most women felt that their partners were reluctant to resume sexual intercourse. Some interpreted this behaviour as disinterest or a rejection of them as a woman. Patients prepared to discuss fears and anxieties with their partner found that their partners' distance was caused by fear of causing pain or further

physical damage. These concerns seemed more pronounced with partners of patients receiving radiotherapy.

- *"I had to speak to X. (patient's husband) last week because he was a bit teary on me and down...I've felt we've always had a great sexual life and I felt like he was sort of distant and so I asked him and he was worried about my welfare but he was worried about the sex side of it, he didn't want to hurt me, he wanted to wait but also I felt like he was backing off from me...I thought like it feels like I have some disease and he doesn't make it near me...but after we talked about it I realised that he was more concerned for me to get better"*
- *"He actually took off one weekend with somebody else, I didn't know what was happening...as I said, it's to do with mutilation as well... when the husband can't cope with that"*
- *(Did he talk about emotional difficulties at all?) ...No, he wouldn't, I would come out and approach him about something but he is not like that...I think he had a real fear that intercourse might hurt me physically"*

The participants' view was that their partners experienced difficulty coping with the diagnosis of cancer and its treatment. They described their partner's method of coping as a reluctance to discuss feelings, worries and concerns. According to these women, some symptoms experienced by the partner, such as insomnia, diarrhoea and aches and pains, were thought to be psychosomatic manifestations of the partner's difficulties.

- *"He felt really lost and helpless, I think that he felt really guilty too as if he, you know, in some way contributed to it"*
- *"Actually it was a lot harder on him than really me...he couldn't sleep, he was vomiting from the worry"*
- *"He was absolutely devastated. I've always been the strong one...I couldn't cope with making decisions and neither could he...he is very hesitant with me, he still treats me as if I'm a piece of china"*
- *He just wouldn't talk about it (cancer diagnosis & I)... you know I wanted him to sit down and talk with me about it... but he'd just do anything, like work in the garden rather than discussing this with me. He is just so quiet outwardly...but he is terribly anxious and gets agitated and over-reacts sometimes."*

### 3.2.3 Patient – Doctor issues

#### *Impact of treatment procedures and residual long-term side effects*

When reflecting on the experience of treatment modalities, the issues that caused high levels of distress in these women did not appear to lie in the treatment procedures, *per se*, but rather were related to coping with long-term side effects resulting from the treatment. Although these women no longer had an immediate life-threatening condition, they were left with life-long reminders of their cancer diagnosis. Some of these side effects influenced the way women saw their sexual desirability. Women dealt better with side effects when the possibility of these side effects had been explained to them and they were prepared for them to happen. Unforeseen side effects caused considerably more distress and anger. In this sample, these were more commonly experienced following surgical procedures than radiotherapy.

- *"The side effects were probably the worst half for me...it is a reminder every day".*
- *"...and as it turned out I've got lymphoedema and it's been very hard to deal with, I still can't accept it !"*
- *"The worst thing was...I went through a stage when I thought that I've never was going to be able to urinate myself...I had to self-catherise myself and that was...I wasn't prepared for that ...and also like during, through the surgery certain nerve endings have been cut off...I mean it's fine now but I wasn't prepared for all those things."*

#### *Lack of body knowledge and understanding of medical terms*

Most women felt that clinicians presumed women had a much greater knowledge and understanding of female anatomy and physiology than was actually the case. This allowed for many misconceptions regarding organs involved in treatment and possible side effects, particularly in the area of sexual matters.

- ◆ *"When you're a non-medical person, you don't realise what they (doctors) exactly mean".*
- ◆ *"When he explained it to me and told me that the carcinoma is in my cervix, I didn't quite understand, like I knew that, ok, babies are carried in your womb and so I thought, ok, I was fine... and I didn't realise that like it's all attached through your cervix... that means it affects everything, you know".*
- ◆ *" (after the first consultation)...I went home and I didn't have a clue what I was really coming up for".*
- ◆ *"At first I thought, there is going to be a great big hole there inside of me but the doctor explained that: "Your bladder moves over and this moves over", and you see, I didn't know all this and I think nobody really knows unless you're a doctor".*

### *Mediating effects of coping style on patients' perceptions of treatment and its side effects*

The initial acceptance of the diagnosis of cancer, its treatment and possible side effects was found to be an important component of the coping skills necessary to deal with the situation. It would appear that a determined and realistic attitude and active participation in the treatment process enabled some patients to confront the diagnosis, unpleasant procedures and side effects, with less distress.

- ◆ *"The thing is you just say that it has to be done... I don't like it, I don't feel like being prodded by a couple of people at a time and that but if it has to be done then it has to be done and it's for your own benefit, you know".*
- ◆ *"I'm having trouble with my bowel and apparently there is no cure for that I probably go to the toilet, oh, probably about 6 times in the morning so it just never stops...you just learn to cope with it ...it had to be done and that was it. In the end it's worth it...you've got to give yourself a chance."*
- ◆ *"(before the operation) ...I was really, really nervous but I was really positive ...it was just something I had to do and so I did it".*



### *Ongoing psychological support*

A significant number of women found that their need to debrief about their experience of having cancer, its treatment and side effects, assumed greater importance after six months or more, usually when physical recovery was well established. It was then that a need to interact with women who had undergone similar treatment was important, to talk with someone who would listen and understand, and to receive an acknowledgment of their improvement and progress. Receiving reassurance was significant from the time of diagnosis but became increasingly important at this later stage.

- ◆ *"Twelve months (following treatment)...that's when you start to think about it more, I'd say, it's not the first 12 months...you are still getting over the operation and anybody who had hysterectomy will tell you, the second 12 months are more important...and that's when, I say, I was last depressed, really depressed".*
- ◆ *"Then all of a sudden, like six months later (following treatment), when it finally hit me, I don't think people were prepared for it because I've been so strong. People looked at me and physically I'm fine and I can do everything again, I mean it took me 7 months before it hit me".*
- ◆ *"...You've been treated and: "Goodbye, see you in six months", you know...and he (doctor) didn't explain to me about the emotional part, he just sort of explained about the operation and scarring".*
- ◆ *"Well, the way I got through it was by talking to people...I've got other friends who had breast cancer... I think what helps you to cope with it sometimes is when you know somebody who got through it, I think that helps".*

### *Dilators & other aids*

Seven out of the eleven irradiated women in our study reported having received vaginal dilators with some brief information about their use and importance. Of the seven, three women tried to use the dilators but did not succeed (either due to painful insertion or because they felt embarrassed to use them) and four women did not attempt to use the dilator at all. Only two women mentioned the option of concurrent use of oestrogen cream as an aid to encourage healing.

No mention was made of an anaesthetic gel to ameliorate the initial dilation of the vagina in preparation for the re-commencement of sexual activity.

- ◆ *" They gave me an instrument thing...(dilator)...but I used to feel embarrassed, I didn't sort of... it's a degrading thing to do and I thought it is not that important".*
- ◆ *"The doctors were saying to me all the time: 'Are you sexually active?', you know...'if you are not, you are going to have to have a dilator!'... so we tried and tried twice but it was just unbearable...the top of vagina was just ... really tender...they removed a third of the vagina in surgery".*
- ◆ *"I don't like using them but I tried to use them before I had examination ... it hurts too much".*

### **3.3 Discussion**

#### **3.3.1 Impact of treatment modality on sexual functioning**

To a large extent the current qualitative data supported findings reported in the literature relating to sexual outcomes of various treatment modalities. Irradiated women, especially those treated with combined treatments (i.e. surgery plus external beam radiation plus brachytherapy), reported the highest levels of sexual dysfunction. Common physical changes, most pronounced in irradiated women, were decreased lubrication, loss of sensations, reduced libido and shortened vagina. Interestingly, no difference in sexual outcomes was found between the surgery & external beam radiation group and the surgery & brachytherapy group. It was speculated that brachytherapy would be experienced as more traumatic than external beam radiation. However, the majority of women receiving (high dose) brachytherapy coped reasonably well with this treatment, particularly when given adequate procedural and sensory information (also see Velji & Fitch, 2001). Given the small sample size, these findings need to be interpreted cautiously.

### **3.3.2 Patient & Partner issues**

Alterations in perceptions of femininity emerged as an important aspect of sexual readjustment following gynaecological cancer and its treatments. To a large extent these changes correlated with age and the stage of life at which the woman found herself. In this study older women (peri- or post-menopausal) tended to emphasise the more nurturing and companionable aspects of femininity, typified by more involvement with their extended families. Among these women, those who had suffered severe disabling symptoms pre-treatment commonly commented on the sense of relief from these disabling symptoms post surgery, thus seeing the removal of their uterus in a more positive light.

Women for whom the option to bear children and establish growing families was an important expression of their femininity, reported a poorer body image, lower self-esteem, and a lesser sense of being feminine, after the removal of their reproductive organs. Responses of these women seemed influenced by their perceived social role, which included an emphasis on satisfying their partner sexually, even if at their own expense. This mainly applied to younger women who had not yet reached an age for natural menopause, or satisfied their need to have children. These findings support the symbolic importance of the uterus to the concept of being feminine, as suggested in the literature (Botelho, 2000; Corney *et al.*, 1993). These findings are also consistent with Schain's (1986) model of socio-sexual development, advocating the main sexual concerns of adults (20-45 years old) being sexual adequacy and performance, fertility concerns and questions related to parenting. They also support the theory proposed by Derogatis (1986) that the passage through life's milestones can mediate sexual adjustment following gynaecological cancer.

Consistent with these models and other studies, the present interview data revealed that women often denied their own needs in order to satisfy perceived needs of their partner (i.e. engaging in sexual intercourse) (Weijmar Schultz *et al.*, 1991; Zagwaard *et al.*, 2000). However, most women perceived engaging in sexual intercourse without an adequate level of shared intimacy as

unsatisfactory. Emotions and fears about sexual issues were often not openly discussed or expressed by either the woman or her partner (also see Zagwaard *et al.*, 2000).

This study suggested that the coping style of patients influenced sexual re-adjustment and quality of life, regardless of treatment modalities. While we did not formally assess coping style, the interview data suggested that women using active coping strategies (e.g. fighting spirit, determination, co-operation) found the treatment and its side effects more tolerable and less distressing, even when faced with invasive procedures such as brachytherapy. These findings are consistent with the already established link between positive/active responses to diagnosis/treatment and more favourable outcomes of treatment for other cancerous conditions (Kraft, 1999; Morris, Pettingale & Haybittle, 1992). If psychological factors are contributing to health outcomes independently, rather than being merely confounded with the physiological status (Levy *et al.*, 1985), then psycho-educational interventions enhancing effective coping styles may be of significant value to patients and their partners as a part of general post-treatment care.

The role of partners at all stages of illness and recovery was reported by women to be significant and influential in promoting holistic healing and consolidating the integrity of their relationship. The current findings show that it is not uncommon for the patient to misinterpret their partner's hesitancy in recommencing sexual interaction post-treatment. This was particularly evident where there had been inadequate open communication, especially regarding sexual matters, and limited expression of physical and emotional intimacy within the relationship prior to the diagnosis of cancer. Failure to recognise and address their concerns was reported to produce psychosomatic symptoms for some male partners. A deficiency of intimate attachment and behavioural inhibition in sexual/romantic relationships have been identified as central

variables of a negative sexual self-schema (Andersen & Cyranowski, 1994) which have been linked to higher rates of sexual dysfunction in women following gynaecological cancer treatment (Andersen, Woods & Copeland, 1997). Such findings reflect views that despite post-treatment physical changes, a satisfactory sexual relationship is possible provided the intimate aspects of relating are present.

Women in this study were asked to invite their partners to be interviewed. However, only two partners agreed to participate, highlighting the difficulty of conducting research into sensitive issues such as sexuality. It has been reported by Lalos *et al.* (1995) that some men, despite their hesitancy, are interested in understanding and participating in sexual adjustment following their partner's treatment for gynaecological cancer. Further exploration of strategies to encourage men to participate in research of this kind (and indeed clinical care) is required to ensure that their views and experiences are heard and their needs addressed. Exploring experiences of partners, particularly of irradiated women, would prove invaluable in identifying the degree to which physical alteration to the genitalia and psychological factors were perceived as hindering the process of sexual adjustment.

### **3.3.3 Patient - Doctor issues**

Patients coped better with treatment procedures, no matter how traumatic they had been, than they did with unexpected complications that occurred thereafter. It may be that adequate preparation allowed patients to maintain a feeling of control during the treatment. Where side effects were unexpected, the patient's sense of control and dignity seemed undermined which may have resulted in feelings of anger and resentment (also see Carlsson & Strang, 1998). These results are consistent with previous studies, which found that psychological factors, such as a sense of control (related to informed decision making) and self-esteem, among others, rather than the nature of the treatment itself, are significant factors in sexual adjustment (Cochran *et al.*, 1987).

The majority of women in this sample felt that their knowledge of female anatomy and physiology was overestimated by their clinicians, which lead to misinterpretations of bodily and functional changes associated with various treatment modalities. Since patients in various stages of shock and distress perceive, understand and recall information differently, the displayed reactions of the patients need not accurately express their inner confusion and thus may mislead the clinician. Therefore, a closer inquiry by the clinician as to how clearly the patient has understood the anatomical and physiological implications of their treatment may prove useful. This area of study would greatly benefit from further investigation.

Obtaining adequate sexual information from clinicians is significantly correlated with psychological and sexual adjustment, even when the severity of the disease and subsequent treatment are taken into account (Cochran *et al.*, 1987; Klee *et al.*, 2000a). It seems that patients would benefit from discussions specific to sexual matters in follow up sessions when the recommencement of sexual activity is likely to have occurred (Corney *et al.*, 1993). However, there may well be a case for the introduction of sexual matters at the initial consultations prior to the commencement of treatment schedules, thus laying the foundation for future discussions (Corney *et al.*, 1993). It is particularly important that the patient is informed about any potential treatment-induced changes in her sexual responses, so that any misinterpretations can be prevented.

The current results indicated that patients may require the services of psychological and medical professionals long after the initial physiological healing is complete. This is consistent with other studies that found interventions enhancing coping with cancer are most effective when they are not presented immediately after the diagnosis but rather some months following treatment, at the time when patients focus more on emotional rather than existential issues (Klee *et al.*, 2000a; Edgar, Rosberger & Nowlis, 1992). It is possible that a component of the increased need to debrief stated by the women some six to

twelve months post-recovery may be an underlying anxiety regarding the return of the cancerous condition or the development of metastases. Hence, opportunities to tackle late-occurring physical and psychological difficulties in support groups or individual counselling, may prove valuable at this later stage.

### **3.3.4 Dilators**

Various studies have shown that women who did not follow advice regarding the use of vaginal dilators were more likely to develop physical and sexual difficulties (Krumm & Lamberti, 1993). Hence, the role of dilators is accepted by health professionals as being necessary following radiation treatment for gynaecological cancers, due to their effectiveness in the prevention of stenosis and adhesions (Auchincloss, 1989). It is therefore interesting to find that the current study confirms a well-established reluctance on the part of women to use this device (Decruze *et al.*, 1999; Flay & Matthews, 1995). The comments of women in this study indicate that some of the reasons for low level usage of dilators included embarrassment, expected or actual pain upon use, or a lack of emphasis placed on their importance by medical professionals. Other cultural and/or religious influences may also have impacted significantly on this process.

Therefore, since the role of the dilator is considered of value, it appears necessary to redesign this device, bearing in mind not only its physiological benefits but also the psychological components and associations of inserting a device into a painful and sensitive vagina. The dilator could be made of a softer flexible latex or plastic with a more rigid core, so that it is firm enough to allow insertion. It should be of an initial size that is not intimidating. It would be an advantage to be able to fill the dilator with air or warm water so that once it is *in situ*, the dilator itself could be gradually and comfortably expanded under the control of the patient. Sheaths of a lubricant with or without analgesic properties could be used to offset friction of the dilator. Aesthetically and carefully designed, this dilator could be used by either partner as a sex aid as well as a medical tool (Krumm & Lamberti, 1993). In this way intimacy could be deepened

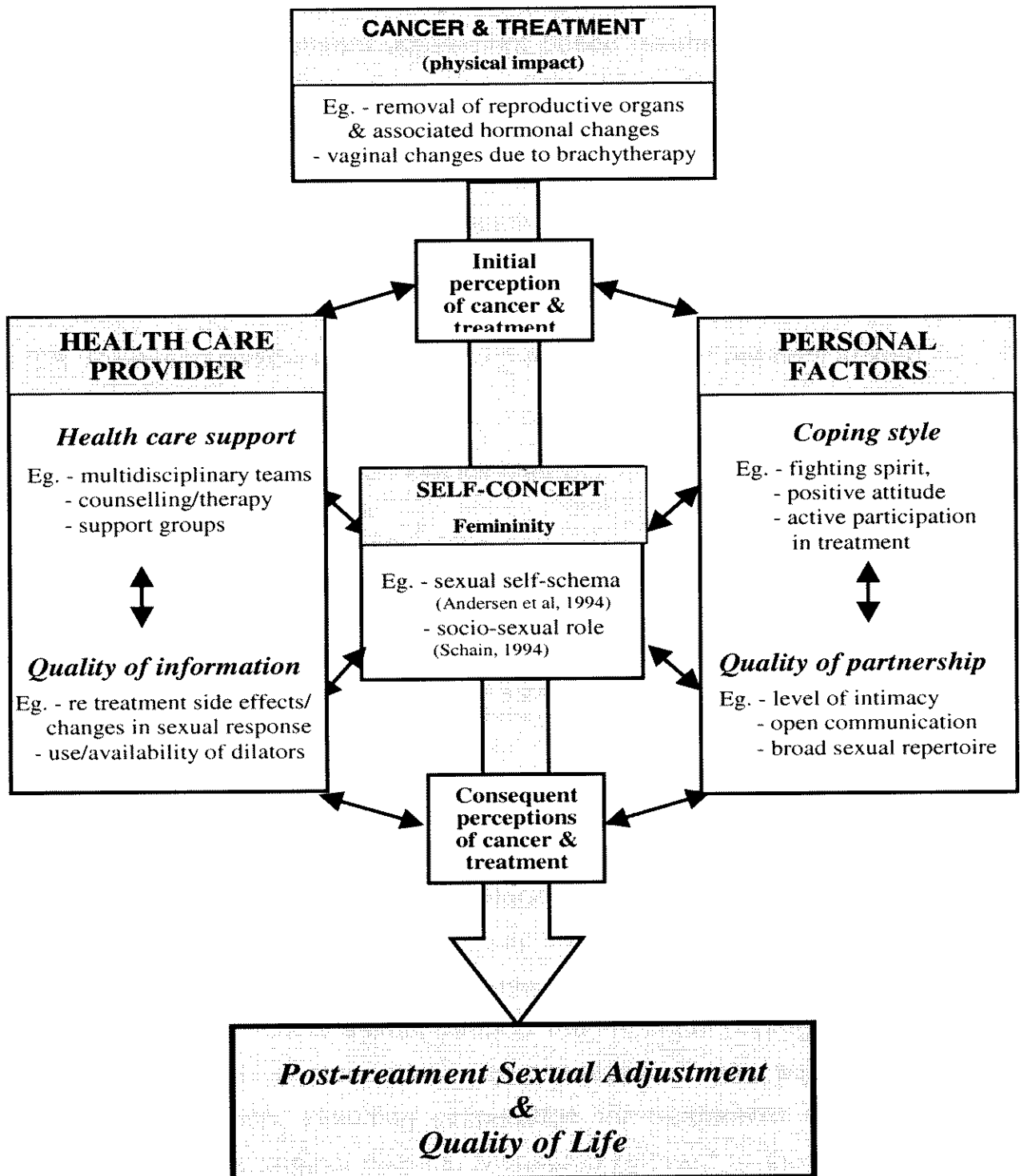
and a pleasurable sensation associated with the first attempts at vaginal penetration post-treatment. A study by Robinson *et al.* (1999) showed psycho-educational group intervention to be an effective means of disseminating information regarding the purpose and importance of vaginal patency together with the correct use of a vaginal dilator, particularly for younger women. This proved highly beneficial in allaying fears regarding sexual activity following cancer treatment.

It has been noted that immediately post-operatively and during radiotherapy the patient does not seem concerned with matters of a sexual nature and may even be antagonistic to suggestions of discussing issues relating to the recommencement of sexual activity. Therefore, knowledge of, and familiarity with, the concept and procedure of using dilators may be better included initially with pre-treatment information as a part of the possible treatment regimes (Crowther, Corney & Shepherd, 1994).

In conclusion, the generic themes that emerged in the course of the qualitative analysis can be conceptualised within the theoretical model outlined in Figure 3.1. The figure shows that the patient's sexual adjustment post cancer and its treatment results from an interaction between three main components; health care provider related factors (quality of information, support), personal factors (coping style, quality of partnership) and self-concept (body image, femininity). These components, together with influences from cancer/treatment-induced anatomical and physiological changes, are interdependent and potentiate each other.



Figure 3.1. *The proposed model incorporating components believed to influence sexual outcomes following gynaecological cancer*



Although many sexual difficulties following gynaecological cancer are inevitable outcomes of treatments required for the prolongation of life, it is possible to have an impact on their occurrence and magnitude. Recommended aspects that may facilitate effective post-treatment adjustment based on the current findings are listed in Table 3.3. Age and role related issues in particular need to be dealt with within the idiosyncratic profile of each patient and their partner. In essence, the emphasis of post-treatment care needs to be centered on the patient/partner and their resources, rather than being solely dictated by the type of cancer or the type of treatment received.

Table 3.3. *Proposed components facilitating effective post-treatment sexual adjustment*

- ♦ advocate active & positive style of coping
- ♦ promote positive sexual self-concept / intimate relating
- ♦ target couple's communication skills
- ♦ encourage sensuous activities other than intercourse
- ♦ provide information on any potential treatment-induced bodily changes & side effects
- ♦ elicit feedback regarding information given and understood
- ♦ provide opportunities to tackle late-occurring physiological / psychological difficulties
- ♦ educate irradiated gynaecological patients of the importance of the dilators

### **3.4 Conclusion**

The decision to include this qualitative Phase 1a as a component of the overall design of the current study proved advantageous. Responses elicited from this phase of the study helped determine key issues requiring inclusion in the following quantitative phase. Among these were the issues of fertility and femininity, intimate aspects of sexual relating, the impact of coping styles, quality of relationships and doctor-patient communication on adjustment, the importance of education, including preparation for treatments and their side effects, and the role of vaginal dilators. Measures relevant to these topics were identified for inclusion in Phase 2 of the study (see Chapter V). Where no validated standardised measures were available, new measures were

constructed to further determine the role of these factors in post-treatment adjustment. One such generated measure targeted the psychological impact of various combinations of treatment modalities including distress, disempowerment and degradation. Overall, the findings from this phase of the study warrant continuation of research to further evaluate the psycho-sexual impact of various treatment regimes following gynaecological cancer.

### **4. PHASE 1b: A qualitative insight into post-treatment psycho-sexual adjustment following treatment for pre-cancerous cervical abnormalities**

The second qualitative study (Phase 1b) was designed to examine the suitability of including pre-invasive cancer patients as an additional control group to control for the experience of a "cancer threat" and related psychological issues. Considering the decline in incidences of invasive cervical cancer concurrent with a dramatic increase in the detection of CIN evident in recent years, investigation of psycho-sexual outcomes of pre-invasive patients in this project was seen as an added advantage.

Our intention to control for the ongoing threat of cancer necessitated an exploration of the psychological issues raised by the experience of being diagnosed with and treated for CIN. We expected that an appropriate control group would show signs of being under threat characterised by an increase in the perception of being vulnerable to harm, with varying degrees of uncertainty as to how to remove the threat. We also anticipated there would be an initial and ongoing anxiety related to the quality and length of life. There would be a disruption in communication and activities, particularly in the area of sexual functioning and intimacy. We also expected that matters relating to socio-sexual roles would be challenged, as would the sense of self-worth. In summary, we hypothesised that many of the psychological issues would overlap with those found in cancer patients.

## **4.1 Method**

### **4.1.1 Participants**

Women with CIN who had undergone LLETZ treatment were eligible to participate in this study. Patients with an insufficient command of English to understand and take part in an interview, or who had a concurrent active disease and/or a co-existing psychiatric morbidity were excluded from study participation. To ensure representation of all relevant experiences and views and to allow time for the dynamics of post-treatment changes to manifest, women were stratified by time since treatment (immediately post-treatment & up to 8 months post-treatment) and by the degree of cervical abnormality (CIN 1-3). Ethical approval for this study was obtained from the South Eastern Sydney Area Health Service and University of Sydney Human Ethics Committees.

Participants for this study were recruited from a major colposcopy clinic in central Sydney. Women with a positive Pap smear are referred by their general practitioner to the consulting gynaecologist at this clinic and are given an appointment for a consultation and colposcopy. Patients are encouraged to return to, or telephone, the clinic three weeks following their colposcopy to obtain the histology results. Those with CIN 1-3 are asked to attend the clinic to discuss further treatment options. At this consultation patients selected, or opting, for treatment are provided with a pamphlet describing the disease, the treatment procedure, and post-treatment care. Possible short- and long-term consequences of treatments are described. Participants for this study were recruited prior to their initial consultation.

### **4.1.2 Data collection**

In order to obtain an holistic picture of post-treatment dynamics we chose a qualitative methodology (Elliot *et. al.*, 1999). Patients were identified by their treating gynaecologist on the basis of the inclusion criteria and were invited to participate. Eligible patients received a letter from their gynaecologist informing them of the study and requesting their permission to release their contact details

to the researcher. Women who gave permission were contacted by the researcher who explained more fully the nature of the study, obtained the participants' verbal consent and arranged an interview time. Information sheets and consent forms were mailed to participating women who returned the signed consent form prior to the interview. Conversational semi-structured telephone interviews were conducted with consenting patients. The main interview questions are listed in Table 4.1. Interviews were audio-taped and transcribed in full. Recruitment continued until no new themes emerged - theoretical saturation (Strauss and Corbin, 1990).

**Table 4.1. Interview Questions**

---

1. *How did you learn about your abnormal Pap smear?*
  2. *Were you satisfied with the information you were given regarding the results of the Pap smear and any procedures that might follow?*
  3. *When you think back, what went through your mind when you learnt that your Pap smear had some abnormalities?*
  4. *How did you feel about yourself right then?*
    - *How did you react to those feelings? What if anything did you do about them?*
    - *Did your feelings about yourself change – thinking about before and after the result, the diagnosis and the treatment?*
  5. *How did you feel about your body right then?*
    - *How did you react to those feelings? What if anything did you do about them?*
    - *Did your feelings about your body change – thinking about before and after the result, the diagnosis and the treatment?*
  6. *How did you feel about your partner right then?*
    - *How did you react to those feelings? What if anything did you do about them?*
    - *Did your feelings toward your partner change – thinking about before and after the result, the diagnosis and the treatment?*
  7. *What effect, if any, do you think the diagnosis and treatment had on your relationship with your partner?*
  8. *Were you able to talk openly to each other about this experience?*
  9. *What were the effects of the diagnosis and treatment on your sexual activities?*
    - *Did it change any part of your sexual activities – thinking about before and after the diagnosis/treatment?*
    - *How would you rate any change?*
  10. *Did you have any main concerns? If so, what were they?*
    - *Do you still have any concerns? What do you think about it all now?*
  11. *What do you think helped you and your partner to cope with the a) diagnosis, b) treatment?*
  12. *What else could have been beneficial to help you and your partner cope?*
  13. *Do you have any suggestions for the clinic as to how they could improve things?*
- 

### **4.1.3 Data Analyses**

A qualitative phenomenological approach based on grounded theory was used to explore women's experiences related to the diagnosis and treatment of CIN

(Strauss and Corbin, 1990). The investigator (IJ) read transcripts of the interviews to uncover essences, and generate broad descriptive categories (*open coding*). Subsequently *axial coding* was employed to identify relationships between the categories and subcategories within the narrative framework. At this level, key differences between groups of women were explored by comparing and contrasting sub-groups, based on the degree of cervical abnormality and time since treatment (see Table 4.2). The axial coding level involved continuous discussion between authors (IJ, PB and LS) until consensus was reached regarding emerging (sub)themes and their position within the narrative framework. Coding of the data and searching for themes and segments was computer-assisted by the NUD\*IST software program (Non-numerical Unstructured Data by Indexing, Searching and Theorising).

Table 4.2. *Characteristics of the sample (n=21)*

---

*Age (Mean = 34)*

20 ~ 29	10
30 ~ 39	6
40 ~ 49	2
50 ~ 59	3

*Degree of CIN*

CIN 1	5
CIN 2	7
CIN 3	9
HPV	19

*Time since treatment*

< 2 weeks	3
1-2 months	6
3-4 months	9
5-8months	3

---

## 4.2 Results

Twenty-three women were invited to participate in the study, two declined for personal reasons. Twenty-one telephone interviews, lasting 30-60 minutes, were conducted. Six participating women were single; the remaining fifteen were in



heterosexual partnerships (although sexual preference was not a criterion for eligibility). Formal assessment of their current relationships was not undertaken. The characteristics of the sample are shown in Table 4.2.

Eight categories emerged in the course of the qualitative analysis: 1) issues concerning initial reactions to the diagnosis, 2) impact on the sense of self, 3) impact on the sense of body, 4) reproductive concerns, 5) impact on partnerships, 6) impact on sexual functioning, 7) patients' reflections on "what helped them to cope" and 8) impact of time.

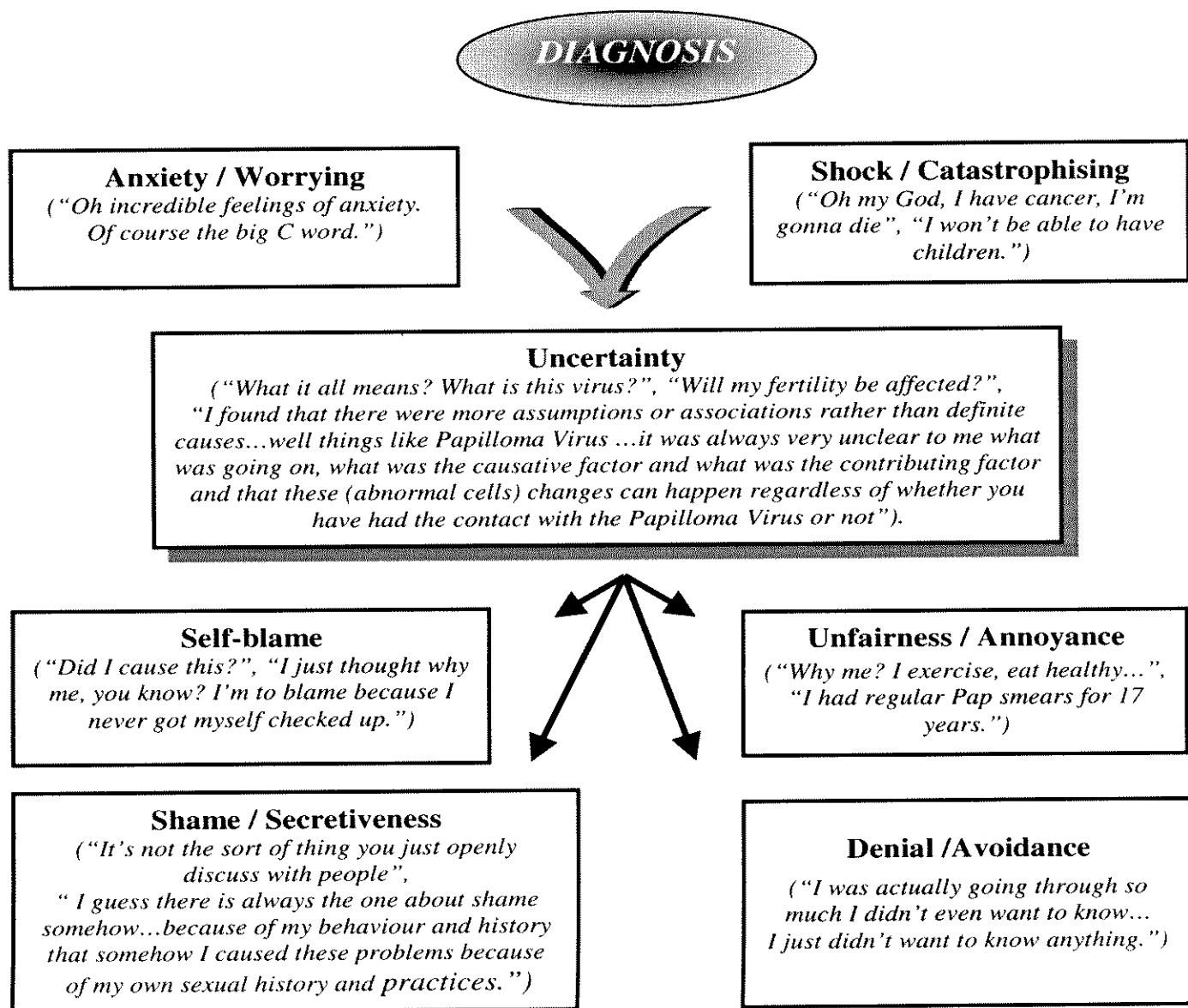
### **Theme 1: INITIAL REACTIONS to the diagnosis**

Women experienced a range of psychological reactions to the diagnosis of CIN (see Figure 4.1. for quotes). For many, the initial response was shock, fear and anxiety, most often based on the interpretation of CIN changes as indicative of invasive cancer. The potential threat to reproductive functioning was another commonly reported concern. In some cases, anxious responses carried aspects of catastrophising. The diagnosis also seemed to trigger prominent feelings of uncertainty regarding the causes of the cervical abnormalities and how these may impact on their health in the future. The degree of uncertainty appeared higher in women who experienced no symptoms prior to the diagnosis. As women tried to make sense of their condition, their uncertainties regarding the causes generated a spectrum of mostly adverse responses. In particular, a number of women: a) **blamed themselves** for causing these abnormalities in some way, b) **expressed anger and annoyance** with the diagnosis/condition as they had followed a healthy life-style and had undergone regular health checks, c) **felt ashamed** having been diagnosed with CIN pointing to the sexual implications of the condition or d) **avoided thinking about the condition** to "prevent" further distress.

Many women, in the process of trying to make sense of their diagnosis attributed the occurrence of CIN to the high levels of stress in their lives (*"I could actually tie it*

not just to specific events in my life but to a fairly extensive period of stress. And when I got the results that I had abnormalities, it didn't surprise me...because I thought it was an indicator of how my life has been for the previous year...yeah very much a lifestyle related issue and that as well as to have the treatment these were things that I needed to change as well"). Interestingly it appeared that adverse reactions to the diagnosis were not dependent on the severity of CIN.

Figure 4.1. Initial reactions to the diagnosis of abnormal cervical smear



## **Theme 2: Impact on the sense of SELF**

As evidenced in Theme 1, many women experienced adverse emotional responses at diagnosis, leaving them with an enduring sense of vulnerability (*"I think because it happens to young women, it's a real shock you know...you are not immortal and things can happen"*, *"I felt very mortal at such young age"*, *"I still have a fear that maybe everything hasn't gone"*, *"Is it going to come back?"*). Once the patient had undergone colposcopy and treatment, negative responses were frequently replaced by more positive reflections of the experience, including feelings of empowerment and relief (*"I feel quite lucky that I actually had a Pap smear and was treated when I was"*). However, some women felt an urge to have a child as soon as possible to make certain their fertility and childbearing capacities had not been adversely affected (*"You get this panic that you need to have a child now or it will be too late"*).

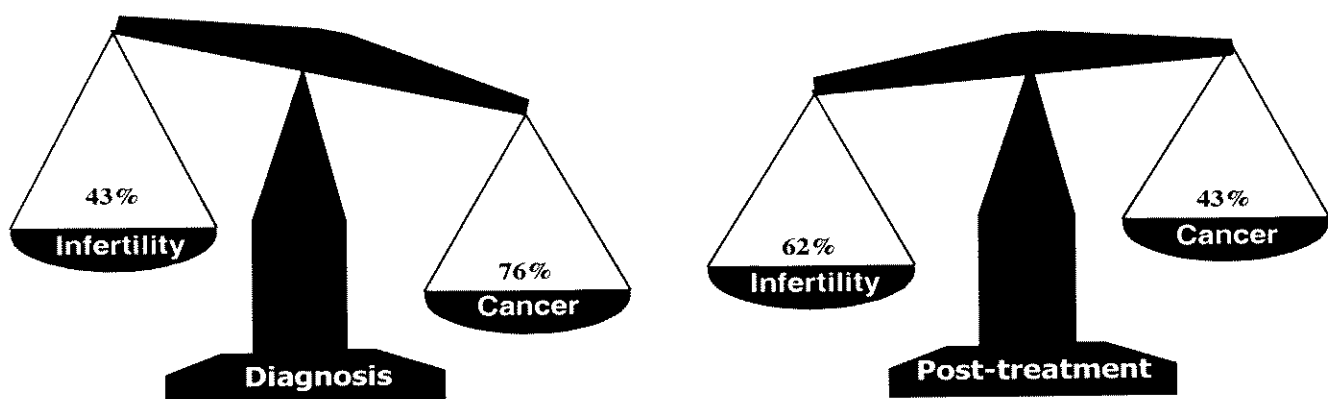
## **Theme 3: Impact on the sense of BODY**

Two responses to the development of cervical abnormalities were identified; a sense of trust vs. mistrust in the body. Feelings of mistrust were most commonly observed in women who had not experienced any symptoms related to their condition and had, in fact, felt fit and healthy prior to the diagnosis (*"My body let me down..."*; *"I felt so well, I felt really healthy and I looked healthy and fit and everything... and I think these sort of things are so sinister and betraying you because inside you these little cells are just, you know, multiplying away doing evil things and you wouldn't even know"*; *"I felt about my body, you know a love-hate kind of thing"*). Two women indicated that their body felt "dirty" (*"My partner, you know, always wants to get close to me and everything ...oh I'm just thinking, you know God as if you want to touch me and why would you want to touch me, I feel yuck. I feel like...don't go there, just don't go there...but my partner is very supportive, he always talks to me about it, he says you are the same as you were before."*). A sense of trust in the body was reported by those women who had experienced symptoms such as abdominal pains and lack of libido prior to diagnosis of CIN (*"...my body did it for a reason"*, *"...my body was signaling it"*, *"I didn't listen to my body"*). Another commonly reported response was a heightened awareness of themselves as women and potential mothers (*"I look at my body differently now, like potentially being a mother"*; *"I'm not just a human, I'm a woman...the woman in me woke up"*).

#### Theme 4: REPRODUCTIVE CONCERNS

Cancer fears and reproductive concerns were the two major issues reported by women in this study. At various times, however one or the other predominated (see Figure 4.2.). Following diagnosis, the fear of cancer was reported by 16 out of 21 women (*"In case it becomes cancerous is what worries me"*) whilst reproductive concerns were mentioned by 9 women (*"I was so worried, I kept talking about how I wanted to have children, it was like having an obsession"*). The reverse was true following treatment, with more women reporting reproductive concerns (13) compared to continuing cancer fears expressed by 9 women. This change of focus occurred despite women being informed by their doctor that the treatment is highly successful, conservative and very unlikely to affect reproductive functioning (*"I guess my biggest fear was that it may affect my future ability to conceive and carry a child. The doctor statistically went through all the different things and he said that even if it was a possibility that I might be infertile or might miscarry, then it was certainly fixable and the possibilities were very slim...that's yet to be tested"*, *"I'm in my early 40's and I haven't had children yet, so my fertility was the first concern because time is short for me and the risks associated with the procedure that I had are not high but there could be problems...but until I'm actively wanting to conceive, it's not really going to be known whether there's any problem or not. So, that's something that I just have to live with"*).

Figure 4.2. Main concerns at the time of diagnosis versus post-treatment



### **Theme 5: Impact on RELATIONSHIPS**

Partners were perceived as being supportive, reassuring, worried and apprehensive (*"I felt totally supported and am very glad at having this support"*). Generally, open communication with partners about fears and concerns was reported (*"He and I actually sat down, I was crying and telling him about how I felt and everything, it was quite sad but ah the main thing is that I got everything out", "...the two of us talked about how he felt, how he was dealing with it"*). Overall, many women stated there was a change for the better as relationships stabilised and intimacy levels increased following the treatment (*"Our relationship has really grown stronger, we tend to talk a lot"*). However, confronting issues related to cervical abnormalities had the potential to exacerbate any existing relationship difficulties for some women (*"My partner...he was not exactly the most supportive human being in the world but that was his character...he didn't choose to take on a nurturing role, I couldn't really expect anything more...but it became clearer what I want from the relationship"*). Some women also mentioned an initial distancing from their partner such as *"I pushed him away. I felt my partner would be better off with somebody else", "I was blaming him", "I considered leaving him"*. The majority of single women viewed not being in a relationship positively (*"I didn't have to deal with another person's emotions and concerns and whether they were supportive or not...I think it would be difficult with a partner at time like that."*).

### **Theme 6: Impact on SEXUAL FUNCTIONING**

Concerns for re-establishing sexual intercourse were present early on with an emphasis on the possible damage intercourse might do to the healing of the cervix (*"...intercourse could damage my cervix"*). A number of women reported an initial decrease in libido following treatment; however in this sample long-term sexual dysfunction was not observed. Interestingly, for many couples levels of intimacy did not decline, rather the depth of intimacy increased (*"...it's far more loving now", "when we couldn't have sex we had a massage, that kind of thing"*), an occurrence some women attributed to the recommended 4 weeks abstinence from sexual intercourse following the LLETZ treatment. Although many women commented upon the possibility of a sexually transmitted disease being a component of CIN, only one participant reported discussing this issue with her partner (*"I was worried about the doctor saying that it may have been caused by ah... um that"*).

*virus and so I think I went through a stage of sort of blaming him. Maybe because I know that I'm not promiscuous. And he sort of picked up that I was blaming him in a way and then I basically told him that that was probably subconsciously ...maybe that was what I was thinking. But once we spoke about it and discussed it, it was resolved after that.”).*

### **Theme 7: Patients’ reflections on “what helped them to COPE...”**

When asked what helped them to cope, the majority of women spontaneously identified their doctor’s positive communication and interpersonal skills as the most effective factor in reducing distress regarding their condition and its treatment. The following doctor’s attitudes were perceived as being helpful: expertise, compassion, honesty, patience, confidence, providing clear explanations, being easy to contact, inviting questions, encouraging the patient to invite the partner/friend to be present during consultations and promoting shared decision making (*“I was so frightened... so then I went to see him [doctor] and he invited my partner to come into the rooms as well and we went through a diagrams and he explained things and that made us totally confident ... He was patient and answered all the questions and it just took so much of the worry and fear out of it – to have spoken to him and to be treated that way”, “The main thing that helped us to cope I think was the support of the doctor. It was the way he communicated ...and you felt like you can make the right decision for yourself”*).

Having a support network was also identified as beneficial. Open communication with a partner, family and friends was strongly valued. Having a positive attitude and being invited to be pro-active regarding treatment was seen as helpful. Women advocated the benefits of early treatment (*“...being treated as soon as possible”*) as an important anxiety-reducing factor, as was education (*“Getting as much information as possible”, “...to be encouraged to be informed – it is important for women to know they have options and that other options can be successful”*). Being able to see their cervix on a video whilst undergoing colposcopy was perceived as very helpful, informative and empowering. It prevented potential catastrophising regarding physical changes related to their condition (*“...being able to see it’s just cells...not a big black furry thing or something huge...”*). Women highlighted the positive effects of normalising (*“...knowing that it is a common condition and procedure”*) and generalising (*“reassurance from other women who had undergone this procedure”*) their experience.

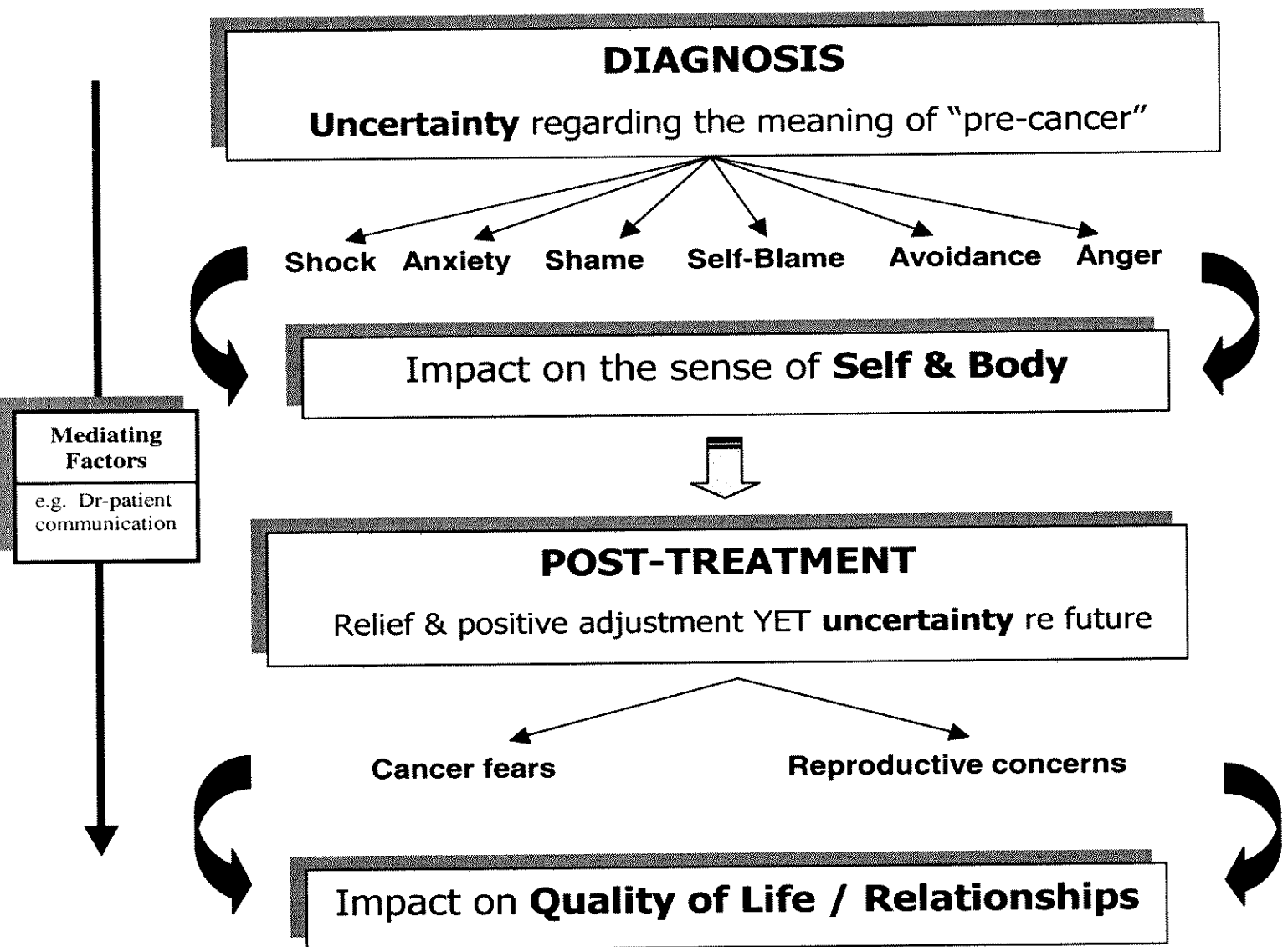
### **Theme 8: *Impact of TIME* (moving from survival to fertility)**

The impact of time emerged as an important factor determining the nature of main concerns. Faced with the possibility of a life-threatening disease (cancer), the initial response of most women was fear of confronting their mortality. Most women reported that this fear was relieved somewhat by explanation and subsequent treatment. However, over time many women experienced a greater concern regarding their fertility and childbearing capacities. This focus persisted for many women long after diagnosis and treatment. Indeed, women intimated that the fact that any problems with fertility would continue to be uncertain until such time as they planned to conceive, prompted them to take this decision sooner than they might otherwise have done. Despite reassurances from doctors that the minimally invasive treatment was unlikely to affect fertility, this remained a common concern for the women in this study and was the most commonly reported longer-term concern.

### **4.3 Discussion**

The present study aimed to determine whether there was a high rate of perceived cancer threat, allowing this group to be included in the second quantitative phase as a control group. The qualitative analysis of the interviews highlighted the dynamic nature of the process women diagnosed with an abnormal Pap smear experience from the time of that diagnosis, through treatment to recovery. Figure 4.3. summarises the issues that women reported retrospectively at each stage of this process.

Figure 4.3. Summary of findings



Consistent with previous studies, the diagnosis seemed to precipitate a range of difficult emotions/reactions including anxiety, self-blame, annoyance, shame, avoidance and/or catastrophising (Nugent *et. al.*, 1993; Lerman *et. al.*, 1991). These adverse responses, together with feelings of vulnerability, appeared to stem from the initial feelings of uncertainty regarding the meaning, implications and consequences of the diagnosis of cervical abnormalities. The two major findings of this study that add to our knowledge of women's experiences were: i)



the shift in the focus of concern over time from the threat of cancer to concerns regarding reproductive ability; and ii) the importance that women attributed to the role of health care professionals in providing reassurance that facilitated positive adjustment.

The initial concern centering on the risk of cancer is perhaps not surprising, since for many women in this study the diagnosis of CIN may have been the first potentially serious health threat that they had faced. The concerns reported in this group of women are strikingly similar to the initial feelings of uncertainty and confrontation with mortality that have been found within the cancer population. Little, Jordens, Paul, Montgomery & Philipson (1998) proposed a concept of liminality to capture the dynamic process of adaptation that cancer patients experience during their illness. Liminality defines the boundaries within which the patients identify themselves and the limiting conditions the patient sees as dictating the rest of their lives. Little *et. al.* (1998) argues that the initial phase of liminality is marked by disorientation, a sense of loss, sense of uncertainty and loss of control). The fact that patients in this study exhibited similar initial reactions indicates that even a relatively small possibility of a life-threatening condition is capable of inducing such responses.

In the current study, a shift in the focus of anxiety was evident in most women. The primary fear following diagnosis was related to cancer but changed to a more prominent concern with future reproductive issues in the post-treatment period. Our findings are consistent with Lauver *et al.* (1999) and Bennetts, Irwig, Oldenburg, Simpson, Mock *et al.* (1995) who also found uncertainty about the meaning of the abnormal Pap smear results, cancer and fertility to be the primary concerns of treated women. Neither group, however, reported a progressive shift from concerns regarding cancer to worries about fertility. Indeed, other authors, such as McDonald *et al.* (1989), did not find reproduction to be one of the main concerns of the participants. In their study, concerns about cancer were more pertinent than all other concerns except during the post-

surgery visit, at which time a loss of attractiveness was paramount. However, as this was a short-term outcome study, the shift from cancer to fertility issues may not have had time to manifest. Persistent concerns related to infertility/childbearing capabilities and the risk of cancer could exert significant pressure on women, their relationships and their quality of life.

Many women reported feelings of empowerment and psychological relief when actively participating in their treatment. However, being unable to visibly monitor any changes occurring in their cervical area post-treatment increased the anxiety for some women. Contributing factors to this anxiety were a perceived lack of control and lack of personal pro-active measures to regain that control, evidenced especially in women who had been asymptomatic before treatment. Over time concerns centered around diminished trust in their bodies, with some women now seeing their bodies as unreliable in indicating disease. Explanations and information given in a positive and supportive manner were helpful in decreasing uncertainty and therefore anxiety.

In the current study, a large number of women attributed the empathetic manner of the doctor as the most consistent determinant of their positive adjustment and subsequent compliance with treatment strategies. This is particularly noteworthy since no question specifically prompted patients to discuss their experiences with health care professionals or their medical management and yet the vast majority of women spontaneously mentioned those interactions positively. Somerset and Peters (1998) similarly found that nurses' interpersonal skills, particularly the manner in which the consultation was tailored to meet the needs of the patient, were important elements of care and a decisive factor in the women's responses to educational interventions. Khanna and Phillips (2001) reviewed barriers and interventions for improved adherence to care plans in this setting. Again, the most effective strategies for adherence involved a personalised approach such as case management, phone counselling (Lerman *et. al*, 1991), and personal invitation letters signed by women's general physicians (Segnan, Senore, Giordano, Ponti & Ronco, 1998). The present

results add further weight to the importance of interactions between patients and their health care providers.

In contrast to the universally positive experience that women reported of their consultations, no woman mentioned the usefulness of the written information that was provided routinely in the clinic. While the interview did not specifically ask about the provision of information, no woman commented on the pamphlet as a positive or negative aspect of her experience. It seems therefore that provision of access to general information about the condition is not always sufficient to allay women's specific concerns. The present results suggest that when information is communicated by health care professionals in a manner which is reassuring and appropriate to the needs of the patient, it is highly regarded and effective in facilitating positive adjustment. The communication of information regarding the possible involvement of sexually transmitted components of CIN in particular was viewed positively when provided in a non-threatening, non-moralistic fashion so that such information could be understood and integrated by the patient. The benefit of information being provided in different formats in an interactive style is exemplified by patients' positive response to seeing their cervix on video during colposcopy. This offered not only a very tangible reassurance that the abnormality was not extensive, but also provided an opportunity to discuss these fears with the doctor. The women in this study also emphasised the benefits of knowing responses and experiences of other women. The inclusion of patients' quotes in any supportive written information may improve the efficacy of that information. On the basis of these findings, we can make some recommendations for clinical practice, a summary of which is presented in Table 4.3.

**Table 4.3. *Practical suggestions to facilitate positive adjustment***

- ◆ provide information in simple and non-judgmental language
- ◆ discuss the content of written information to maximise understanding
- ◆ provide clear explanations, using diagrams and visual aids
- ◆ encourage patients to ask questions
- ◆ invite partner or friend to be present at consultation (and colposcopy)
- ◆ explain the advantages of watching colposcopy on a video
- ◆ normalise and generalise the condition
- ◆ raise potential concerns related to cancer and fertility
- ◆ promote an active & positive style of coping
- ◆ make the option of further counselling available at any time
- ◆ include personal quotes from treated patients in pamphlets

While the experiences of women in the current study have highlighted some important issues regarding their concerns and the communication of information, it is important to note that the women in this study were derived from only one clinic. All women in the clinic saw the same doctor and received the same written information. We cannot exclude the possibility that the particular characteristics of the clinic have affected the responses of women and therefore the generalisability of the results. Further, the interviews were retrospective. The degree to which the observations of the women in this study reflect recall biases can not be determined from this data. Clearly, prospective studies are needed to document more closely the changes that occur in adjustment over time.

These limitations notwithstanding, some interesting observations emerged from this study. The initial response to diagnosis in this sample was marked by negative emotions and concerns about cancer. While many women were reassured in the process of treatment, a sizeable minority remained concerned about cancer. However, concerns regarding fertility became further attenuated over time and women reported not being reassured in this regard. Reproductive issues by their very "time-dependent" nature appear likely to persist until a successful pregnancy and delivery has occurred. The need for a more stringent

follow up regime with frequent Pap smears is a constant reminder of the possibility of the recurrence of abnormal cells and their potential to become cancerous. The current findings point towards a more prolonged impact of CIN and its treatment than was originally thought. The length of time required to allay major concerns appears much longer than simply the repair of cervical tissue and the re-commencement of a normal life. There is a danger, therefore, that the impact of this “minor” condition with “minimal” treatment may be underestimated by health care professionals. The present study found that health care professionals can influence the impact of this condition. Sensitive communication that was tailored to the needs of patients was highly valued by women and was consistently reported to be the most important determinant of positive adjustment.

#### **4.4 Conclusion**

Since findings from the qualitative study (Phase 1b) indicated that many concerns of pre-invasive cancer patients are similar to those of patients with a cancer diagnosis, a pre-invasive cancer group was included in the study as a second control group to account for the experience of a “cancer threat” without the attendant experience of major invasive treatments. Components within the responses indicating the groups’ suitability for inclusion were; i) heightened anxiety regarding the condition, particularly the diagnosis of a positive Pap smear (many patients equated a positive Pap smear with a positive diagnosis of cancer despite reassurance from their gynaecologists that this was not so), ii) anxiety regarding the betrayal by their body since many were asymptomatic, iii) concerns regarding future effects on fertility and reproduction, iv) concerns related to alterations in sexual activity if not physical concerns then concerns related to the presence of HPV indicating a possible sexually transmitted disease implication, warranting a reassessment of sexual habits. The above data rendered pre-invasive patients eminently suitable for inclusion in the quantitative phase of the study.

# 5. METHOD: QUANTITATIVE PHASE

## 5.1 Methodological design

Typically, patients with gynaecological cancer undergo treatment as soon as possible following diagnosis, leaving an extremely small window of opportunity for a baseline assessment prior to surgery. Pre-operatively, the psychological trauma caused by the diagnosis and proposed treatment regimes was seen as having the potential to increase the refusal to participate and to impede the patient's understanding and recall of events under investigation. It was also considered inappropriate to risk increasing the patients' distress by intrusion at this time. Hence, assessment prior to surgery was deemed unfeasible. On the other hand, post-operative recruitment was considered optimal for a number of reasons. Firstly, this psychological trauma associated with diagnosis was likely to have reduced to some extent following the surgery. Secondly, since patients were recruited close to their discharge day, they were no longer taking post-operative medication such as morphine and therefore were cognitively and physically able to give informed consent for the study and complete assessments. In addition, histological investigation of the cancerous growth was complete by this time, so the inclusion/exclusion criteria could be assessed accurately.

Following the baseline assessment, subsequent measures were taken at 6 months for all groups, with an additional assessment for the cancer group taken at 12 months post-treatment. Longitudinal studies using such time spans have been shown to allow for identification of i) relevant issues occurring during a long-term recovery period and ii) the optimum time for clinical interventions should these be required (for review see Weijmar Schultz *et al.*, 1992).

## 5.2 Sample

The current study was designed to address the limitations identified in previous prospective studies, including the use of mixed samples, composed of patients with different types and stages of gynaecological cancer (Andersen *et al.*, 1989a; Kylstra *et al.*, 1999), lack of adequate controls (Schover *et al.*, 1989), and in some cases very limited sample sizes (n= 21, Weijmar Schultz *et al.*, 1991; n=21, Grumann *et al.*, 2001). Firstly, this study included a relatively homogeneous sample of women with early stage cervical and endometrial cancer (diseases for which the course and treatment are similar). This cancer group was further divided into two subgroups: i) patients undergoing surgery only and ii) patients undergoing surgery and adjunct radiotherapy/chemotherapy, in order to explore treatment specific outcomes. Secondly, an adequate sample size was recruited. Finally, two control groups were included: i) patients with benign gynaecological disease and ii) patients with pre-invasive cervical abnormalities. These groups were chosen in order to control for factors which were thought to possibly confound sexual functioning, surgery for gynaecological conditions and “the threat of cancer” respectively.

As the number of cases of cervical and endometrial cancer at any one hospital is relatively small, this was a multi-centred study. The following centres in NSW Australia participated in the study: Royal Prince Alfred Hospital, Royal Hospital for Women, Westmead Hospital, Royal North Shore Hospital and Liverpool Hospital. The main advantages of the multi-centre design were: i) the increased generalisability of the results and ii) maximisation of the sample size. Ethical approvals were obtained from all participating hospitals as well as The University of Sydney prior to data collection. Possible differences in socioeconomic status and treatment protocols between sites, potentially resulting in differences in baseline and follow up sexual responses across hospitals, were considered. Systematic differences by sites were explored by coding for different centres, with this variable included in analyses. Eligibility

criteria, recruitment rates and sample characteristics for each of the three groups are described below.

### **5.2.1 Cancer patients**

Eligibility for the study was based on the patient's disease (cervical cancer or endometrial cancer), disease stage (Stage I & II) and age (between 18 and 75 years). In order to strengthen the methodological rigour of the study, only patients who had undergone surgery as their first cancer treatment (i.e. radical or total abdominal hysterectomy with or without bilateral salpingo-oophorectomy) were included in the study. Exclusion criteria included non-English speaking, concurrent active disease and/or a psychiatric disorder (psychotic illness or drug addiction).

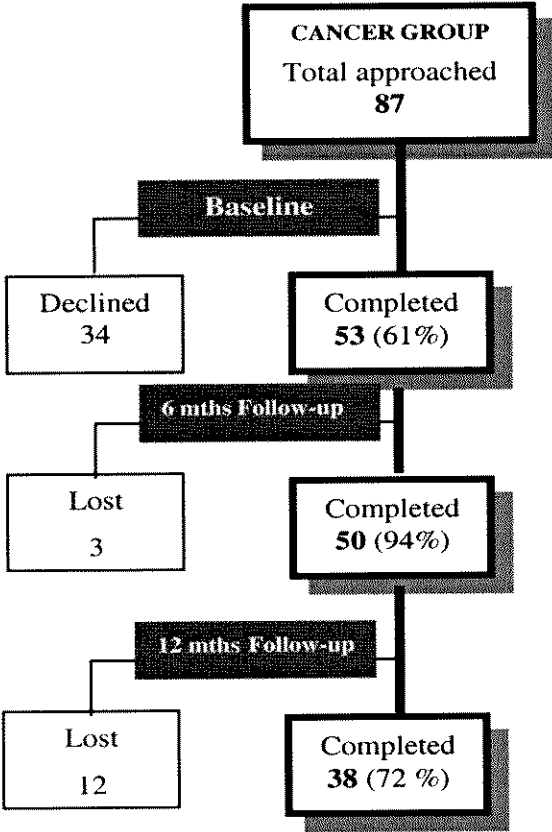
It was initially considered whether the study should include only women who were sexually active. In order to maximise the recruitment and to document quality of life of women who were not in a sexual partnership, it was subsequently decided to include any women interested in sexual activity, whether or not they were currently sexually active. Previous studies have been criticised for their narrow definition of sexual functioning and satisfaction. Since the baseline measures asked the participants to answer the sexual items in terms of their *usual* behaviour and feelings, women were able to complete study measures regardless of whether they were currently in a relationship. Women of both heterosexual and homosexual preferences were included. This decision was considered to allow for a greater generalisability of the results.

Consecutive patients at the five participating hospitals who fulfilled the eligibility criteria were invited to participate in the study. Consequently, 87 women who had undergone surgery for early stage cervical or endometrial cancer were approached (see Figure 5.1.). During the time of recruitment, health professionals treating potential study candidates identified 29 patients who were



ineligible for the study. Of the 87 eligible patients, 34 (39.1%) women declined to participate. Of these, 11 women gave no reason for non-participation, not responding to reminder letters or telephone calls. The remaining 23 volunteered the following reasons for their non-participation: 10 expressed lack of interest, 5 felt unwell/had post-operative complications, 5 considered the subject of enquiry too emotionally distressing (e.g. citing history of sexual abuse, recent divorce), and 3 reported having no time to participate (e.g. citing caring for young child(ren), the length of the questionnaire). Thus, the final sample of the cervical and endometrial cancer patients consisted of 53 patients, corresponding to a response rate of 61% of the 87 eligible patients approached to participate in the study. Of these, 50 women completed the 6 months follow up (94%) and 38 completed the 12 months follow up (72%).

Figure 5.1 Cancer group: Recruitment sample and data collection overview



A systematic sample bias was assessed by comparing patients who declined to participate and patients who agreed to participate. De-identified demographic and clinical characteristics of decliners were obtained from health care professionals at participating centres. In the cancer group, no significant differences between cancer decliners and participants were found in marital status (Fisher's exact test,  $p=0.228$ ), nationality (Fisher's exact test,  $p=0.444$ ) and cancer site ( $\chi^2(2)=3.504$ ,  $p=0.173$ ). There was, however, a trend for cancer decliners to be older (Mann-Whitney test,  $p=0.068$ ) and with a more severe cancer diagnosis (Fisher's exact test,  $U=p=0.091$ ). Since none of the differences between participants and decliners reached significance on any demographic and clinical variables, the current cancer sample was considered to be relatively representative of the targeted population (see Table 5.1.).

To explore whether continuing participants and patients who dropped out at each follow up assessment differed on any of the demographic, clinical and outcome variables, chi-square and t-test analyses were conducted. The three cancer patients who withdrew from the study at 6 months follow up differed from the participating patients on only one variable, the non-completers being more likely to be smokers than non-smokers ( $\chi^2=5.233$ ,  $p=0.022$ ). There was a trend for patients who dropped out at 12 months follow up ( $n=12$ ) to use a more anxious pre-occupation adjustment style at baseline, compared to participants, although the difference did not reach significance ( $t=1.903$ ,  $p=0.063$ ). No differences between "drop-outs" and participants at 12 months follow up were noted in any of the variables assessed at 6 months. Based on the high comparability of drop-outs and participants, with the possible exception of the anxious pre-occupation style of mental adjustment, the follow up sample of cancer patients was considered representative of the targeted population.

The overview of demographic characteristics of participating cancer patients ( $N=53$ ) is shown in Table 5.2. The average age of women in the cancer group was 51 years, ranging from 27 to 74 ( $SD=11.6$ ), with most participants aged between 46 and 65 (54.7%). The majority of cancer patients were married or in

a de-facto relationship (71.7%), had Anglo-Saxon ethnic origins (mother: 81.1%, father: 84.9 %), and spoke English at home (88.7%). Most patients reported Christianity as their religious denomination or spiritual belief (84.9%). More than half of the women considered their faith to be an important part of their lives (58.5%). Eight cancer patients had a university degree (17%), 22 women reported completing Year 10 as their highest educational level (41.5%). The predominance of lower educational levels was reflected in the large proportion of women employed in non-professional positions (such as trade persons, clerks, sales/personal services, labourers; 58.6%). Nearly ten percent of women were involved solely in home duties (9.4%). Half of the cancer group sample (50.9%) reported working at the time of assessment.

Most cancer patients had a regular sexual partner (85.5%). Only a small proportion of the women had no children (18.9%), with the majority of women having two or more children (69.8%). At the time of the study's commencement, 24 women were post-menopausal (45.3%), 8 were peri-menopausal (15.1%) and 19 women were pre-menopausal (35.8%). Self-reports regarding drinking and smoking habits revealed 8 cancer patients drank alcohol four or more times a week (15.1%) and most women were non-smokers (86.8%). The majority of cancer participants were not using HRT (86.8%), sedatives (92.5%) or antidepressants (94.3%). Only 4 women reported having a psychiatric history (7.5%) and 21 women reported having experienced a major stressful life event(s) (e.g. divorce, job change, moving house) in the past 12 months (39.6%).

Clinical information regarding the disease and treatment status of the participating cancer patients was obtained from their medical files and/or treating oncologists (see Table 5.3.). The cancer group consisted of relatively balanced subgroups of cervical cancer patients (n=25, 47.2%) and endometrial cancer patients (n=28, 52.8%). The majority of cancer patients were diagnosed with stage I malignancy (88.7%), with a smaller proportion diagnosed with a stage II malignancy (11.3%). The cancer sample was stratified into two treatment

groups: women who had undergone surgical treatment only (58.5%) and women who had undergone surgery in conjunction with radiation treatment (41.5%). The majority of cancer patients in this sample did not receive concurrent chemotherapy treatment (84.9%). A closer inspection of the radiotherapy group showed that 10 women had undergone surgery and brachytherapy (18.9%), 8 surgically treated women received adjuvant external beam radiation (15.1%), whilst only 4 women had undergone a combined treatment of surgery, external radiotherapy and brachytherapy (7.5%). In terms of surgery, the majority of endometrial cancer patients had undergone a Total Abdominal Hysterectomy (TAH) with the removal of both ovaries (Bilateral Salpingo-Oophorectomy, BSO) (89.0%) with or without Pelvic Lymph Nodes Dissection (PLND). In contrast, most cervical cancer patients had undergone a radical hysterectomy without removal of their ovaries (65.0%).

Table 5.1. Demographic and disease characteristics of “decliners” versus participants

	Cancer group		Benign group		Pre-invasive cancer	
	Participants (n=53)	Decliners (n=34)	Participants (n=60)	Decliners (n=34)	Participants (n=84)	Decliners (n=25)
<b>Mean Age</b> (Standard deviation)	50.9 (11.6)	55.8 (13.3)	47.6 (8.3)	48.2 (7.8)	30.4 (10.2)	31.8 (10.5)
	%	%	%	%	%	%
<b>Marital status</b>						
- never married	5.7	9.7	13.3	11.8	54.8	68.0
- married or de-facto	71.7	61.3	63.3	70.6	34.5	28.0
- widowed	5.7	12.9	0.0	2.9	3.6	0.0
- separated/divorced	17.0	16.1	23.3	14.7	7.1	4.0
<b>Nationality</b>						
- Anglo-Saxon	81.1	80.0	70.0	50.0	72.6	84.0
- Non Anglo-Saxon	18.9	20.0	30.0	50.0	25.0	16.0
<b>Diagnosis</b>						
- cervical cancer	48.0	46.9				
- endometrial cancer	52.0	53.1				
- fibroid(s)/cyst(s)			41.7	53.2		
- menorrhagia			23.3	25.0		
- other benign conditions			20.0	21.9		
- no CIN/no HPV					26.2	24.0
- no CIN/HPV					11.9	16.0
- CIN 1					30.9	28.0
- CIN 2					19.0	16.0
- CIN 3					11.9	16.0
<b>Cancer stage</b>						
- 1	88.7	75.0				
- 2	11.3	25.0				

\* Not all categories sum up to 100 due to missing data

\*\* Shaded areas indicate “not applicable”

Table 5.2. Demographic characteristics of sample (n = 197)

	<b>Cancer group (n= 53)</b>		<b>Benign group (n= 60)</b>		<b>Pre-Invasive group (n= 84)</b>	
<b>Age (Mean)</b> (Standard deviation)	50.9 11.6		47.6 8.3		30.4 10.2	
<b>Age group</b>						
- (18 - 25)	0	(0.0 %)	0	(0.0 %)	25	(29.8 %)
- (26 - 35)	8	(15.1 %)	3	(5.0 %)	42	(50.0 %)
- (36 - 45)	9	(17.0 %)	24	(40.0 %)	11	(13.1 %)
- (46 - 55)	17	(32.1 %)	26	(43.3 %)	3	(3.6 %)
- (56 - 65)	12	(22.6 %)	4	(6.7 %)	2	(2.4 %)
- (66 + )	7	(13.2 %)	3	(5.0 %)	1	(1.2 %)
<b>Marital status</b>						
- never married	3	(5.7 %)	8	(13.3 %)	46	(54.8 %)
- married or de-facto	38	(71.7 %)	38	(63.3 %)	29	(34.5 %)
- widowed	3	(5.7 %)	0	(0.0 %)	3	(3.6 %)
- separated or divorced	9	(17.0 %)	14	(23.3 %)	6	(7.1 %)
<b>Educational level</b>						
- Year 10 or below	22	(41.5 %)	10	(16.7 %)	7	(8.3 %)
- Year 12 – HSC	8	(15.1 %)	6	(10.0 %)	17	(21.2 %)
- TAFE diploma/Business College	15	(28.3 %)	21	(35.0 %)	23	(27.4 %)
- University degree	3	(5.7 %)	12	(20.0 %)	27	(32.1 %)
- Postgraduate degree	5	(9.4 %)	11	(18.3 %)	8	(9.5 %)
<b>Occupation</b>						
- managers/administrators	2	(3.8 %)	5	(8.3 %)	7	(8.3 %)
- professionals/paraprofessionals	11	(20.8 %)	26	(43.3 %)	30	(35.7 %)
- trades persons	2	(3.8 %)	2	(3.3 %)	2	(2.4 %)
- clerks	15	(28.3 %)	17	(28.3 %)	14	(16.7 %)
- sales/personal services	10	(18.9 %)	2	(3.3 %)	11	(13.1 %)
- labourers	4	(7.6 %)	0	(0.0 %)	1	(1.2 %)
- home duties	5	(9.4 %)	2	(3.3 %)	6	(7.1 %)
- students	0	(0.0 %)	0	(0.0 %)	9	(10.7 %)
<b>Working at present</b>						
- yes	25	(47.2 %)	47	(78.3 %)	62	(73.8 %)
- no	27	(50.9 %)	13	(21.7 %)	21	(25.0 %)
<b>Language other than English</b>						
- yes	6	(11.3 %)	10	(16.7 %)	13	(15.5 %)
- no	47	(88.7 %)	50	(83.3 %)	71	(84.5 %)
<b>Ethnicity of mother</b>						
- Anglo-Saxon	43	(81.1 %)	42	(70.0 %)	61	(72.6 %)
- Non Anglo-Saxon	10	(18.9 %)	18	(30.0 %)	21	(25.0 %)
<b>Ethnicity of father</b>						
- Anglo-Saxon	45	(84.9 %)	39	(65.0 %)	56	(66.7 %)
- Non Anglo-Saxon	8	(15.1 %)	21	(35.0 %)	27	(32.1 %)
<b>Religion</b>						
- Christian	45	(84.9 %)	37	(61.7 %)	43	(51.2 %)
- Other religion	3	(5.7 %)	3	(5.0 %)	13	(15.5 %)
- No religion	5	(9.4 %)	20	(33.3 %)	25	(29.8 %)
<b>Religion important</b>						
- yes	31	(58.5 %)	27	(45.0 %)	29	(34.5 %)
- no	20	(37.7 %)	33	(55.0 %)	53	(63.1 %)

	<b>Cancer group (n= 53)</b>	<b>Benign group (n= 60)</b>	<b>Pre-invasive group (n= 84)</b>
<b>Regular sexual partner</b>			
- yes	40 (75.5 %)	46 (76.6 %)	58 (69.0 %)
- no	12 (22.6 %)	14 (23.3 %)	26 (31.0 %)
<b>Number of children</b>			
- no children	10 (18.9 %)	20 (33.3 %)	57 (67.9 %)
- one child	6 (11.3 %)	13 (21.7 %)	9 (10.7 %)
- two children	14 (26.4 %)	13 (21.7 %)	14 (16.7 %)
- three or more children	23 (43.4 %)	14 (23.3 %)	4 (4.8 %)
<b>Stage of "life-change"</b>			
- pre-menopausal	19 (35.8 %)	33 (55.0 %)	74 (88.1 %)
- peri-menopausal	8 (15.1 %)	12 (20.0 %)	5 (6.0 %)
- post-menopausal	24 (45.3 %)	13 (21.7 %)	4 (4.8 %)
<b>Alcohol use</b>			
- never	7 (13.2 %)	5 (8.3 %)	6 (7.1 %)
- monthly or less	15 (28.3 %)	13 (21.7 %)	15 (19.0 %)
- 2-4 times a month	9 (17.0 %)	9 (15.0 %)	23 (27.4 %)
- 2-3 times a week	14 (26.4 %)	16 (26.7 %)	29 (34.5 %)
- 4+ times a week	8 (15.1 %)	17 (28.3 %)	9 (10.7 %)
<b>Smoking</b>			
- not smoking	44 (83.0 %)	49 (81.7 %)	55 (65.5 %)
- 10 or less	2 (3.8 %)	8 (13.3 %)	11 (13.1 %)
- 11-20	5 (9.4 %)	3 (5.0 %)	13 (15.5 %)
- 21-25	1 (1.9 %)	0 (0.0 %)	4 (4.8 %)
- 25 or more	1 (1.9 %)	0 (0.0 %)	0 (0.0 %)
<b>HRT</b>			
- not taking	46 (86.8 %)	43 (71.7 %)	78 (92.9 %)
- 1-7 days	2 (3.8 %)	3 (5.0 %)	0 (0.0 %)
- 1-4 weeks	2 (3.8 %)	1 (1.7 %)	0 (0.0 %)
- 1-6 months	0 (0.0 %)	3 (5.0 %)	0 (0.0 %)
- 6-12 months	0 (0.0 %)	2 (3.3 %)	0 (0.0 %)
- 12 + months	3 (5.7 %)	8 (13.3 %)	3 (3.6 %)
<b>Sedatives</b>			
- not taking	49 (92.5 %)	56 (93.3 %)	79 (94.0 %)
- 1-7 days	0 (0.0 %)	0 (0.0 %)	0 (0.0 %)
- 1-4 weeks	1 (1.9 %)	0 (0.0 %)	0 (0.0 %)
- 1-6 months	2 (3.8 %)	0 (0.0 %)	1 (1.2 %)
- 6-12 months	0 (0.0 %)	0 (0.0 %)	0 (0.0 %)
- 12 + months	0 (0.0 %)	4 (6.7 %)	1 (1.2 %)
<b>Antidepressants</b>			
- not taking	50 (94.3 %)	58 (96.7 %)	74 (88.1 %)
- 1-7 days	0 (0.0 %)	0 (0.0 %)	0 (0.0 %)
- 1-4 weeks	1 (1.9 %)	0 (0.0 %)	0 (0.0 %)
- 1-6 months	0 (0.0 %)	0 (0.0 %)	3 (3.6 %)
- 6-12 months	0 (0.0 %)	1 (1.7 %)	1 (1.2 %)
- 12 + months	2 (3.8 %)	1 (1.7 %)	3 (3.6 %)
<b>Psychiatric history</b>			
- yes	4 (7.5 %)	6 (10.0 %)	6 (7.1 %)
- no	49 (92.5 %)	54 (90.0 %)	76 (90.5 %)
<b>Major life events (last 12 months)</b>			
- yes	21 (39.6%)	30 (50.0 %)	21 (25.0 %)
- no	32 (60.4%)	30 (50.0 %)	62 (73.8 %)

\* Not all categories sum up to 100 due to missing data

Table 5.3. Clinical characteristics of sample (i.e. diagnosis and treatment)

	Cancer group (n= 53)	Benign group (n= 60)	Pre-invasive group (n= 84)
<b>Diagnosis</b>			
- cervical cancer	25 (47.2 %)		
- endometrial cancer	28 (52.8 %)		
- fibroid(s)/cyst(s)		25 (41.7 %)	
- menorrhagia		14 (23.3 %)	
- endometriosis		7 (11.7 %)	
- other benign conditions		5 ( 8.3 %)	
- no CIN <sup>1</sup> /no HPV <sup>2</sup>			22 (26.2 %)
- no CIN/HPV			10 (11.9 %)
- CIN 1			26 (30.9 %)
- CIN 2			16 (19.0 %)
- CIN 3			10 (11.9 %)
<b>Cancer stage</b>			
- 1	47 (88.7 %)		
- 2	6 (11.3 %)		
<b>Cancer treatment (grouped)</b>			
- surgery only	31 (58.5 %)		
- surgery & radiotherapy	22 (41.5 %)		
<b>Cancer treatment (detailed)</b>			
- surgery only	31 (58.5 %)		
- surgery & external radiation	8 (15.1 %)		
- surgery & brachytherapy	10 (18.9 %)		
- surgery & external & brachytherapy	4 ( 7.5 %)		
<b>Adjuvant chemotherapy</b>			
- yes	8 (15.1 %)		
- no	45 (84.9 %)		
<b>Type of surgery</b>			
- TAH <sup>3</sup>	0 ( 0.0 %)	34 (56.7 %)	
- TAH/BSO <sup>4</sup>	11 (20.8 %)	24 (40.0 %)	
- TAH/PLND <sup>5</sup>	1 (1.9 %)		
- TAH/BSO/PLND	14 (26.4 %)		
- Rad. Hyst. <sup>6</sup> /BSO	3 ( 5.7 %)		
- Rad. Hyst./PLND	17 (32.1 %)		
- Rad. Hyst./BSO/PLND	6 (11.3 %)		
- LLETZ <sup>7</sup> /laser treatment			25 (29.8 %)
- No treatment			59 (70.2 %)

\* Not all categories sum up to 100 due to missing data

\*\* Shaded areas indicate "not applicable"

<sup>1</sup> Cervical Intraepithelial Neoplasia

<sup>2</sup> Human Papilloma Virus

<sup>3</sup> Total Abdominal Hysterectomy

<sup>4</sup> Bilateral Salpingo-Oophorectomy

<sup>5</sup> Pelvic Lymph Nodes Dissection

<sup>6</sup> Radical Hysterectomy

<sup>7</sup> Large Loop Excision of Transformation Zone

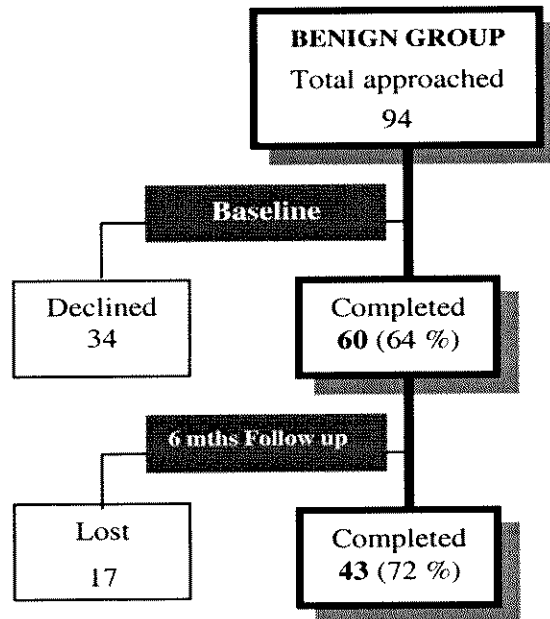


### **5.2.2 Patients with benign gynaecological conditions**

The first control group consisted of women undergoing total abdominal hysterectomy for benign gynaecological conditions (e.g. fibroids or endometriosis). This group was considered important as emotional distress and/or sexual difficulties have been implicated as possible complications following surgery for benign gynaecological diseases (Khastgir, Stud, & Catalan, 1999). Secondly, landmark articles in the literature addressing adverse sexual functioning outcomes following gynaecological cancer, advocate the inclusion of control groups of patients with different types of benign gynaecological diseases (Andersen *et al.*, 1989a; Weijmar Schultz *et al.*, 1991; Paavonen, 1999). The same exclusion criteria were employed as for the cancer group.

Based on health care professionals' reports, 11 patients treated for benign gynaecological conditions failed to satisfy the study's eligibility criteria. A total of 94 consecutive patients treated at the gynaecological wards of two participating hospitals were invited to participate in the study. Of these, 34 (36.2%) women declined participation, 12 women providing no reason for their refusal, not responding to the reminder letters and phone calls. Reasons for non-participation given by the remaining 22 women included: lack of interest (n=9), feeling unwell/having post-operative complications (n=2), finding the issues discussed in the questionnaire too emotionally distressing/personal (n=7), and being too busy/having no time to participate (n=4). The final sample of the benign group therefore consisted of 60 patients, representing a response rate of 64% of the 94 patients eligible to participate in the study (see Figure 5.2.). Of these, 42 patients completed 6 months follow up (70%).

Figure 5.2. Benign group: Recruitment sample and data collection overview



No significant differences were detected between benign participating patients and decliners in regard to age (Mann-Whitney test,  $p=0.206$ ), marital status (Fisher's exact test,  $p=0.506$ ), or type of benign condition ( $\chi^2(2)=4.128$ ,  $p=0.389$ ). There was a trend for women from a non-Anglo-Saxon background to be less likely to volunteer for the study in the benign group, although this effect failed to reach significance (Fisher's exact test,  $p=0.076$ ). Since no significant differences between benign participants and decliners reached significance on any of the available demographic and clinical variables, the current benign sample was likely to be representative of the targeted population with the possible exception of ethnicity (See Table 5.1.). At 6 months follow up, benign patients who dropped out of the study ( $n=17$ ) compared to continuing participants were more likely to be younger ( $t=-2.058$ ,  $p=0.044$ ) and did not undergo oophorectomy ( $\chi^2=7.194$ ,  $p=0.007$ ). There was a trend for patients who dropped out at 12 months follow up to have a poorer relationship with their doctor ( $t=-1.753$ ,  $p=0.085$ ). Thus the retained sample.

The demographic information of the benign patients are presented in Table 5.2. The age of benign patients ranged from 29 to 74, with a mean of 47.6 (SD = 8.3). The age distribution of the sample suggested that women aged 36-55 were over-represented in this group (83.3%). Of the 60 participating women, 38 were married or in a de-facto relationship (63.3%), whilst 14 were divorced or separated (23.3%). The majority of patients were of Anglo-Saxon origin (mother: 70.0%, father: 65.0%), and spoke English at home (83.3%). Approximately 62% of benign patients reported Christianity as their religious denomination, whilst 30% did not follow any religion or hold a spiritual belief. Just over half of the women did not consider faith an important part of their lives (55.0%). Twenty-three women had a university qualification (38.3%) whilst 16 women reached Year 12 or had a lower educational level (26.7%). This was reflected in the relatively high proportion of women employed as (para)professionals or managers (51.3%). Only 13 benign patients reported not working at present (21.7%).

Over three-quarters of women with a benign gynaecological condition reported having a regular sexual partner (76.6%). Twenty women had no children (33.3%), 26 women had one or two children (43.4%) and 14 women had three or more children (23.3%). At the time of the study's commencement, approximately half of the benign patients were pre-menopausal (55.0%), whilst 13 women were post-menopausal (21.7%). Nearly 30% of women reported drinking alcohol four or more times a week with the majority of women being non-smokers (81.7%). Nineteen benign patients were using some form of HRT (28.3%), 4 were taking sedatives (6.7%) and 2 were taking antidepressants (3.4%). Six women reported having a psychiatric history (10.0%) and half of the women (50.0%) reported having experienced major stressful life event(s) (e.g. job change, moving house, divorce) in the past year.

As with the cancer population, clinical information regarding the disease and treatment status of the participating benign patients was obtained from their medical files and/or treating gynaecologists (see Table 5.3.). Benign patients

presented with a variety of gynaecological conditions, with a number of patients having more than one diagnosis. Twenty-five patients were diagnosed with fibroid(s) or cyst(s) (41.7%), 14 women were treated for menorrhagia (often in combination with the diagnosis of fibroids) (23.3%), 11 women suffered from endometriosis (11.7%), whilst 5 women had other benign gynaecological conditions (8.3%). All participating benign patients had undergone a TAH. Of these, 34 women had retained their ovaries (60.0%), whilst 24 women had their ovaries removed (BSO, 40%).

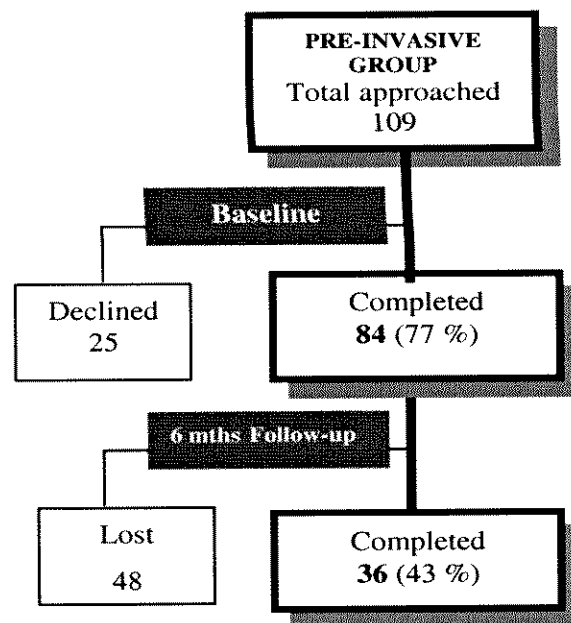
### **5.2.3 Patients with pre-invasive cervical abnormalities**

Based on the Phase 1b findings, patients with an abnormal Pap smear attending a colposcopy clinic were also invited to participate in the study in order to control for the experience of a “cancer threat” (see Chapter IV). Exclusion criteria for this group were the same as for the cancer group. In addition, only women for whom this was their first abnormal Pap smear were eligible to participate. Age-matching of pre-invasive patients with cancer patients was not feasible due to significant age differences between these two populations. It was noted that age-matching would result in an unusual and uncharacteristic sample of pre-invasive cancer population. Rather, age was controlled for in the subsequent analyses.

The group of pre-invasive cancer patients was recruited from two colposcopy clinics situated at the Royal Prince Alfred Hospital and Royal Hospital for Women in Sydney. Health care professionals treating potential participants for the study's pre-invasive group identified 11 women as ineligible to participate, based on information from their medical files. Of the 109 patients who fulfilled the eligibility criteria, 25 (13.2%) women declined to participate. Of these, 16 women did not return their baseline questionnaires and provided no reason for their non-participation. The remaining 9 patients gave the following reasons: a lack of interest (n=4), the questionnaire/topic being emotionally distressing (e.g. citing recent miscarriage) (n=3) and being too busy (e.g. caring for a young

baby, n=2). The final sample of the pre-invasive cancer group, therefore, consisted of 84 women attending colposcopy clinics at two of the participating hospitals, corresponding to a participation rate of 80% (see Figure 5.3.). Unfortunately, of these, only 34 patients completed 6 months follow up (40%), despite reminder letters and phone calls.

Figure 5.3. *Pre-invasive cancer group: Recruitment sample and data collection overview*



Pre-invasive cancer patients participating in the research did not differ from the decliners in demographic characteristics, as indicated by statistical analyses investigating age (Mann-Whitney,  $p=0.784$ ), marital status (Fisher's exact test,  $p=0.319$ ), nationality ( $\chi^2(2)=1.805$ ,  $p=0.405$ ) and degree of CIN ( $\chi^2(2)=0.336$ ,  $p=0.953$ ). Since no significant differences between pre-invasive participants and decliners were detected on any of the available demographic and clinical variables, the current pre-invasive cancer sample was considered representative of the targeted population at the initial baseline assessment (see Table 5.1.). Since just over half of the pre-invasive patients ( $n=48$ ) ceased participation in the study at 6 months follow up, it was important to determine whether the follow up pre-invasive sample encompassed any bias. Interestingly, pre-invasive

patients who dropped out from the study were comparable to continuing participants on all but two variables; drop-outs had a lower educational background ( $\chi^2=7.973$ ,  $p=0.019$ ) and were more likely to be smokers ( $\chi^2=4.261$ ,  $p=0.039$ ).

For the demographic information of the pre-invasive cancer patients refer to Table 5.2. The average age of women in the pre-invasive group was 30.4 years (range 18–75, SD = 10.2), closely reflecting the general population mean for this group of patients (NSW Cervical Screening Program & The NSW Pap Test Registry). The age distribution of the pre-invasive sample suggests that women aged 18-35 were over-represented in this group (89.3%). Of the 84 participating women, 46 had never been married (54.8%), a third were married or in a de-facto relationship (34.5%), whilst only a small proportion of women were divorced, separated or widowed (10.7%). The majority of pre-invasive patients were of Anglo-Saxon ethnic origin (mother: 72.6 %, father: 66.7%), and spoke English at home (84.5%). Just over half the patients (51.2%) reported Christianity as their religious denomination, whilst nearly thirty percent did not report a religious or spiritual bias (29.8%). More than half the women did not consider a religious faith an important part of their lives (63.1.0%). Regarding educational levels, over forty percent (41.6%) of women had completed an undergraduate/postgraduate university degree, whilst 29.5% of women reported completing Year 12 or lower as their highest educational qualification. A relatively high proportion of women were employed as (para)professionals or managers (44.0%), whilst only 7.1% of women reported home duties as their sole occupation. Nine women were students (10.7%). The majority of pre-invasive cancer patients were working at the time of assessment (73.8%).

Approximately two thirds of pre-invasive patients had a regular sexual partner (69.0%). A similar proportion of women had no children (67.9%), whilst 25 women had one or more children (32.2%). At the time of the study's commencement, the majority of pre-invasive cancer patients were pre-menopausal (88.1%), whilst 4 women were post-menopausal (4.8%). Regarding

drinking and smoking habits, 10.7% of women reported drinking alcohol four or more times a week and two thirds of the women were non-smokers (65.5%). Only 3 women have been using HRT (3.6%), 2 were taking sedatives (2.4%) and 7 were taking antidepressants (8.4%). Six women reported having a psychiatric history (7.1%). Twenty women reported having experienced major stressful life events in the past 12 months (25.0%).

As with the cancer and benign populations, clinical information regarding the diagnosis and treatment of the participating pre-invasive cancer patients was obtained from their medical files and/or the staff at the two colposcopy clinics (see Table 5.3.). Pre-invasive cancer patients presented with a range of degrees of CIN, with or without HPV infection. These patients were referred to the colposcopy clinic following abnormal findings from their last Pap smear test. The diagnostic information found in Table 5.3. is based on a combination of cytological and histological findings from a Pap smear re-test and examination performed at the colposcopy clinic. Despite the fact that previous Pap smear tests indicated the presence of cervical abnormalities for all participating women, the results from the Pap smear re-test at the colposcopy clinic indicated no CIN/HPV changes in 22 of these women (26.2%). Ten women had HPV infection in the absence of CIN abnormalities (11.9%) and 7 women were diagnosed with mild dysplasia (CIN 1) in the absence of HPV infection. Approximately half of the pre-invasive patients (53.5%) were diagnosed with CIN grades 1-3 epithelial changes in the presence of HPV infection. Of these, only 25 women had received treatment (i.e. LLETZ) for their cervical abnormalities (29.8%), whilst 59 were advised to undertake Pap smear tests 4-6 monthly in order to monitor the course of any cervical changes (70.2%). It is possible that these different outcomes may have affected women's psychological and sexual functioning post-consultation.

## **5.3 Data collection**

### **5.3.1 Baseline assessment**

#### **5.3.1.1 *Cancer and Benign patients***

At a time deemed appropriate, a specialist staff member and the investigator or research assistant approached patients who were recovering from operations for benign or cancerous conditions. In 90% of cases this occurred between the 4<sup>th</sup> and 8<sup>th</sup> day post-surgery and usually a day prior to discharge. Due consideration was given to the fragile condition of the patient. Those who agreed to participate were given an information sheet and asked to sign a consent form acknowledging their willingness to participate (see Appendix). Patients were reassured that they could withdraw from the study at any time without this affecting their treatment. It was emphasised that their data would be treated in the strictest confidence. Patients were given the option to complete the questionnaires whilst still in hospital or to take them home and return them to the investigator in the reply paid envelope provided.

Participating patients were asked to complete the baseline questionnaire battery from a retrospective point of view, except for the Hospital Anxiety and Depression Scale (HADS), which measured current levels of anxiety and depression. They were asked to recall the quality of their sexual functioning before experiencing the impact of their symptoms and diagnosis of cancer. Patients are commonly advised not to resume sexual intercourse for six weeks following surgery. Hence, this methodological design did not impose a considerable risk of confusing previous and current sexual practices. In addition, patients were asked to recall their physical, social, emotional and functional wellbeing as well as satisfaction with their doctor-patient relationship during the month prior to their surgery.

Those patients electing to complete their questionnaire at home were asked to return them in the reply paid envelope, within two weeks. If patients did not



return their questionnaires within that time, a letter was sent with a reminder to prompt their return. If a further week elapsed without the return of the questionnaires, the patient was contacted by telephone to inquire if she were experiencing difficulties with the questionnaire and needed help. At the end of a further week, contact by telephone was again established with the same options repeated. If the questionnaires were still not returned within the following week, the patient received a letter thanking her for her interest and informing her that she had been removed from the study.

#### **5.3.1.2 Pre-invasive cancer patients**

Since women with low grade pre-invasive abnormalities (CIN1) and the absence of HPV diagnosis, did not receive any treatment and did not return to the clinic for a check up for 6 months, it was decided to recruit women during their initial appointment at the colposcopy clinic. Previous studies have shown that recruitment and follow up of pre-invasive cancer patients is very difficult, with response rates averaging around 40-50% (Conaglen, Hughes, Conaglen & Morgan, 2001; Neilson & Jones, 1998). Further, approximately 30-80% of women diagnosed with an abnormal Pap smear fail to return for follow up medical care (Rajaram, 1998; Stewart, Buchegger, Lickrish & Sierra, 1994; Marcus, Crane, Kaplan, Reading, Savage *et al.*, 1992).

Patients were approached in the reception area of the colposcopy clinic whilst they waited for their consultation. These were new patients referred by their local GP, having received a positive Pap smear result. A specialist staff member initially approached the prospective patient and introduced the researcher. The patient was invited to accompany the investigator or research assistant to a private room where an outline of the study and its rationale was given. Those patients who showed interest and a willingness to participate were given further information and a consent form to sign. The battery of questionnaires was provided with instructions for their completion and return.

Women who agreed to participate in the study were informed that there were two parts to their baseline assessment. The first part (Part A) consisted of a retrospective report of their usual sexual functioning and relationship satisfaction prior to the abnormal Pap smear diagnosis. Quality of life during the past month was also assessed. Women were given an option to complete Part A either at the clinic (if time permitted), or at home. Women who chose to take their questionnaire home were encouraged to complete it within the next two weeks and return it in the reply paid envelope. The second part of the baseline questionnaire (Part B) consisted of an assessment of psychological wellbeing experienced during the two weeks following their treatment (i.e. LLETZ) or at equivalent time for non-treated women (i.e. approximately 6 weeks post-initial consultation, considering that the waiting period for the LLETZ procedure is about 4 weeks). Women were informed that Part B of the questionnaire would be posted to them later, for them to complete and return in the reply paid envelope provided.

The baseline questionnaire was divided into two parts for the following reasons: i) to maximise the recruitment of the pre-invasive cancer patients and ii) to re-establish the methodological uniformity of the assessment times across patient groups. Consequently, the retrospective assessments of sexual/relationship functioning and quality of life (Part A) were conducted post-initial consultation, which was considered an optimal recruitment time. An assessment of anxiety and depression (Part B) was conducted post-treatment (or at equivalent time for non-treated patients), at a time corresponding to the post-surgery assessment of the psychological distress of benign and cancer patients. Hence, all patients were informed about their diagnosis and had undergone adequate treatment for their condition (although some cancer patients were still awaiting adjuvant treatment).

### **5.3.2 Follow up assessments**

Six months later the first follow up questionnaire, together with a reply paid envelope, was mailed to the patients. In order to account for the delayed impact of radiotherapy on sexual functioning, an additional follow up was conducted with cancer patients at one year following surgery. To help the patients remember the relevance of the study, a letter summarising the aims of the investigation as well as the voluntary nature of the project was included. The process for the return of questionnaires was as for the baseline assessment.

#### **5.3.2.1 Letter of thanks**

Having returned the last set of questionnaires, the patients then received a letter thanking them for their support, patience and contribution to this study (see Appendix). Women were offered the option of receiving a brief summary of the study's final outcome, once the data was analysed. Continued contact with the department was offered should the patient feel a need for the services available.

### **5.4 Ethical considerations**

To maintain confidentiality, all participants were given a code number so that their name would not appear on the questionnaire or computer database. Responses were held in strict confidence and were not disclosed to any medical staff treating the patient. Questionnaires were kept in a locked cabinet to which only the investigator and a research assistant had access. A list of patient names linked to their IDs have been kept on a separate sheet, stored in a separate filing cabinet, in case clarification is sought on any issues. In accordance with the National Statement on the Ethical Conduct in Research Involving Humans issued by the National Health and Medical Research Council (2002), all questionnaires will be kept for seven years and then disposed of by shredding.

The possibility of some patients finding material contained in the questionnaire unsettling or offensive was considered. A reference to that effect was included in the Information sheet, with a suggestion that they call the investigators or contact the psychologist on their team if such material caused any distress. Only two patients contacted the researcher during the study to report increased distress related to the questionnaire's completion. They were offered counselling and support and took no further part in the study.

## **5.5 Measures**

During the design phase of this project, literature on post-treatment psycho-sexual functioning following cervical and endometrial cancer was reviewed extensively to provide a context for the present study. Qualitative interviews in the first phase of the study further assisted with the conception of appropriate hypotheses and informed methodological choices. Having formulated the research questions, introductory literature on concepts of measurement in the health setting was examined, followed by a comprehensive search to identify scales measuring the variables this study sought to assess. Psychometric data on those scales with the greatest potential to address the research questions, was then critically reviewed. The results of these inquiries for each measure, including the rationale for their selection, will now be described in detail. Measures used in the baseline assessment will be described first, followed by specific measures used at follow up, including newly developed scales.

Internal consistency scores calculated for all standardised instruments utilised in the current project are also presented. Cronbach's Alpha values were computed from the available scores of the entire sample. Alpha values between 0.600 and 0.800 were considered acceptable, values of 0.800 and beyond desirable (Anastasi, 1988).

## **5.5.1. Baseline measures**

### ***Demographic and general data***

At baseline, all participants were asked to complete 14 questions targeting the following demographic details: age, religion, ethnic origins of parents, occupation, marital status, number of children, menopausal status, alcohol/tobacco use, use of HRT/sedatives/antidepressants, recent psychiatric history and recent experience of major life events (e.g. divorce, job loss, moving house). Details of the disease (diagnosis and stage of disease) and treatment regime were obtained from medical case records.

### **5.5.1.1 *Derogatis Sexual Functioning Inventory (DSFI)***

*(Derogatis & Melisaratos, 1979)*

Measures exploring sexual functioning in women appear limited in scope and often fail to adequately discriminate between clinical and non-clinical samples (Taylor, Rosen & Leiblum, 1994). Sexual functioning has been shown to be a highly complex concept, with physical and emotional intimacy regarded as essential components within this concept (Weijmar Schultz *et al.*, 1991). Sexual functioning encompasses multiple domains and as such cannot be adequately assessed by unidimensional scales. In the current study, sexual functioning was measured using three independently validated subscales of the Derogatis Sexual Functioning Inventory (DSFI). The DSFI is a multidimensional test designed to measure an individual's level of sexual functioning (Derogatis & Melisaratos, 1979). The original inventory was developed by Derogatis (1975) and comprised of 8 subtests: I. Information, II. Experience, III. Drive, IV. Attitude, V. Symptoms, VI. Affects, VII. Gender Role Definition, VIII. Fantasy. Derogatis & Melisaratos (1979) revised and expanded the inventory by adding two subscales, Satisfaction (IX) and Body Image (X), in recognition of the importance and relevance of these domains in terms of determining effective and satisfying sexual behaviours. In addition to the 10 subscales, the Global Sexual Satisfaction Index (GSSI) (XI) was developed to represent the patient's overall evaluation of the quality of their sexual relationship (Derogatis &

Melisaratos, 1979). Each subscale generates a single raw score that is transformed to a standardised T-score distribution with the mean of 50 and standard deviation of 10. The DSFI area T-scores can be interpreted in the standard fashion as scores under the normal curve (Derogatis & Melisaratos, 1996). Separate norms have been developed for males and females due to gender differences in the scores distribution on 8 out of 11 subscales (Derogatis & Melisaratos, 1979).

DSFI has good psychometric qualities as demonstrated by multiple clinical applications and the reliability scores of the data. Internal consistency and test-retest reliability scores range from acceptable to very high (Derogatis, 1996). DSFI has a good face, content and criterion validity. The internal structure of the DSFI was confirmed by a factor analysis based on data from 380 subjects. The analysis provided strong support for the construct as it identified seven main factors that generally conformed to the primary subtests of the DSFI. In the comprehensive review of psychometric measures of sexual functioning, Conte (1986) found the DSFI to be the most comprehensive and potentially useful tool with the most complete psychometric data.

For the present study, the following scales of the DSFI were selected: Satisfaction, Drive and Global Sexual Satisfaction Index (GSSI). Description of each scale is provided below.

### ***Satisfaction Subscale***

The Satisfaction subscale is a 10-item rating scale that reflects the multifaceted basis of sexual satisfaction and fulfilment. The major themes of the satisfaction subtest are: degree of variation in sexual activities, communication between sexual partners, quality of foreplay, orgasm and resolution phase, and satisfaction with the frequency of sex. The participants are asked whether the positively and negatively oriented statements are true or false for them (Derogatis, 1996). The analyses of the test items have shown that qualitative

differences exist in terms of the male and female basis for feeling sexually satisfied. Whilst the basis of male satisfaction has been shown to be performance oriented, female satisfaction seems more broadly based, with an emphasis on the quality of the intimate relationship and sexual fulfilment (Derogatis & Melisaratos, 1979). The satisfaction subscale has a very strong discriminative power, being able to distinguish between sexual dysfunctions and normal functioning. The internal consistency of this subscale is adequate ( $\alpha=0.71$ ).

This multidimensional scale was selected for its support of the holistic view of sexuality, advocated in the current study. Namely, it recognises that sexual satisfaction is based on a broad spectrum of sexual relating including qualitative items such as open communication about sexual matters, and quality of sexual relating, rather than being restricted to the frequency of sexual intercourse. Qualitative findings from our Phase 1a and other studies indicate that not engaging in sexual intercourse does not necessarily equate with dissatisfaction with sexual relating (see Chapter III; Weijmar Schultz *et al.*, 1991). Since issues identified in the qualitative phase as being important for positive sexual adjustment are measured by test items of this scale, the satisfaction subscale seemed, therefore, an optimal measure to be used in the current study. The reliability analysis performed with the current cohort of patients ( $n=163$ ) supported the robust internal structure of the sexual satisfaction subscale, demonstrating Cronbach alpha of 0.731.

### ***Drive Subscale***

The Drive Subscale is a 5-item self-report inventory measuring an individual's level of interest or investment in sexual matters (i.e. libido). The participants are asked to reflect upon their frequency of intercourse, masturbation (self or mutual), kissing and petting, sexual fantasies, and the ideal or preferred frequency of intercourse. Each item is scored on a 9-point frequency scale, with scores ranging from "not at all" (0) to "4 or more a day" (8). These values are added to produce a total score (Derogatis, 1996). Although the authors

acknowledge the main weakness of this measure in failing to detect more subtle manifestations of drive, they recognise that the concept of sexual drive is fundamental to any consideration of sexual functioning and as such needs to be included. Further, this measure correlates significantly with clinical observations and has high discriminative sensitivity. The Drive subscale has an adequate internal reliability ( $\alpha = .60$ ) and test-retest reliability ( $\alpha = .77$ ), based on 14-day test-retest interval. The Cronbach Alpha calculated for the drive subscale using the current sample ( $n=163$ ) had adequate internal consistency ( $\alpha = 0.7626$ ).

As discussed in Chapter III, women seem more comfortable to engage in non-coital rather than penetrative sexual activities during their post-treatment recovery. By including items such as petting & kissing and masturbation, the Drive subscale appeared sensitive to the potential changes in women's libido where women seem more comfortable and interested in "outercourse" activities (e.g. masturbation, sensuous physical closeness) than in "intercourse" (i.e. penile vaginal penetration). Further, the Drive subscale was selected since decreased libido is one of the reported treatment side effects following gynaecological cancer (Weijmar Schultz *et al.*, 1992). Since a lowered sex drive is commonly seen in a causal rather than resulting role in sexual disorders (Derogatis, Lopez & Zinzeletta, 1988), it was imperative to accurately document and compare the levels of sexual drive at baseline, and at post-treatment follow ups.

### ***Global Sexual Satisfaction Index***

The Global Sexual Satisfaction Index (GSSI) is a one-dimensional 9-point scale measuring overall satisfaction with the present sexual relationship. The patient is asked to subjectively rate their sexual satisfaction by choosing a single score on a Likert-type scale. The ratings range from "could not be worse" (0) to "could not be better" (8) (Derogatis, 1996).

Regrettably, the test-retest reliability coefficient of GSSI subscale is not reported. By following a standardised procedure for application and scoring, this



scale's objectivity was enhanced. The GSSI was selected to ascertain a brief overall evaluation of sexual satisfaction within the participant's current relationship.

In summary, the assessment of sexual functioning in the current study focused on three main components:

1) *quantitative aspects of sexual relating*: sexual desire/libido measured as frequencies of overt sexual behaviours including intercourse, masturbation, sexual fantasies or kissing and petting

2) *qualitative aspects of sexual relating*: sexual satisfaction assessed by a range of factors including satisfaction with the individual phases of the sexual response cycle, with communication between partners about sexual matters and with sexual variety.

3) *global satisfaction*: conscious evaluation of a satisfaction with the emotional and physical aspects of sexual interaction and overall sexual life.

#### **5.5.1.2 Functional Assessment Of Cancer Therapy (FACT) Scales - Version 3 (Cella, Tulsky & Field, 1993)**

As with sexual functioning, quality of life (QoL) represents a multidimensional construct. Existing QoL measures as reviewed by Cella, Ingham & Portenoy (1998) describe seven dimensions sufficiently independent to warrant separate categorisation: physical ability, functional ability, family wellbeing, emotional wellbeing, treatment satisfaction, sexuality/intimacy and social functioning. The most widely used questionnaires assessing aspects of quality of life in cancer patients are: the European Organisation for Research and Treatment Quality of Life Questionnaire (EORTC QLQ C30) and the Functional Assessment of Cancer (FACT) scale. Both offer modules to supplement the core questionnaire with questions that are specifically relevant for patients with a particular cancer diagnosis, e.g. breast cancer. The FACT scale was chosen above the EORTC QLQ 30 as it contains a specific disease extension for cervical cancer patients.

The Functional Assessment of Cancer Therapy (FACT) scale is a self-report measure of quality of life consisting of a 29-item general version (FACT-G) with subscales for 12 different cancer sites (e.g. cancer of the cervix (FACT-CX), breast (FACT-B), ovaries (FACT-O), brain (FACT-BR)) (Cella *et al.*, 1993). These site-specific subscales have been developed to add substantial sensitivity to the instrument without loss of the ability to compare across chronic conditions. The FACT-CX disease-specific subscale consists of 14 additional items for cervical cancer that are added at the end of the general version. To account for the complexity of the quality of life concept, FACT-G addresses five dimensions of wellbeing: physical, functional, social/family, emotional wellbeing and as well as the relationship with doctor. Individual subscale scores, a total score and site-specific scores can be generated from this measure. The total score reflects the patients' overall quality of life and is gained by adding the scores of the five subscales. In addition to subscale total scores assessing specific functional impairment, patients estimate the perceived effect of that impairment on their overall quality of life. However, this evaluation needs to be interpreted with caution, as the FACT manual does not provide comparison scores from a validation sample. To reduce the number of comparisons in the current comprehensive study, the analysis and interpretation of FACT estimates was not included. The present study made use of the total score, the scores of five FACT-G subscales and the cervix-specific "additional concerns" score.

The concept of the FACT scales was confirmed in a factor analysis with a sample of 545 patients diagnosed with different types of cancer. Six significant factors accounting for 51% of the total variance were extracted: 1. physical functioning, 2. social wellbeing, 3. emotional wellbeing, 4. & 6. functional wellbeing and 5. doctor-patient relationship. The reliability and validity is reported for the global FACT score as well as for separate subscale scores. Reliability coefficients for the FACT subscales and a total FACT score are high, ranging from 0.65 to 0.89 for internal consistency and from 0.82 to 0.92 for test-retest reliability (3-7 days).

A sample of 316 patients with different sites and stages of cancer was used to investigate the convergent and discriminant validity of the scale. The FACT-G scale revealed a high Pearson correlation coefficient ( $r = .79$ ) with the Functional Living Index Cancer (FLIC, Schipper, Clinch, McMurray & Levitt, 1984) and a high correlation ( $r = .65$ ) with the profile of Mood States (POMS, McNair, Lorr & Droppleman, 1971), thus demonstrating its convergent validity. Both the FLIC and the POMS are respected instruments for the assessment of QoL and mood in oncological settings. Using the Marlowe-Crowne Social Desirability Scale (M-CSDS, Straham & Gerbasi, 1972), the association of the FACT scale with social desirability was assessed. The correlation was found to be low ( $r = .22$ ), demonstrating the discriminant validity of the scale. Cella, Hahn & Dineen (2002) investigated clinical usefulness of group change scores using the FACT inventory in a cohort of 308 cancer patients. They found that whilst relatively small gains in the quality of life have significant value, comparable declines may be less meaningful, possibly due to patients' minimisation of personal negative evaluation about their condition.

The FACT inventory has notable advantages over other QoL instruments. Firstly, the total QoL score can be broken down into five valid subscale scores. Secondly, no other measure specific to an oncological setting allows patients to assign personal weights to each life area, thereby simultaneously evaluating functional impairment and the perceived effect of that impairment on the overall quality of life. Thirdly, the ease of administration encourages patients' compliance with its completion. A further advantage is that the FACT-G scale has been shown to differentiate between metastatic and non-metastatic cancer, and to distinguish between FIGO (the International Federation of Gynaecological Oncologists) stages I, II, III and IV. More importantly, the inventory is sensitive to changes in the patient's clinical status over time (physical and functional well-being subscales in particular). Consequently, the FACT-CX was selected as the most appropriate measure to assess patients' quality of life.

As evident from the Table 5.4, internal consistency analyses performed with the current cohort of patients supported the reported robust internal structure of the FACT subscales. Half of the FACT subscales used in the current study demonstrated Cronbach's Alphas in the "desirable" range ( $\alpha > 0.800$ ), whilst the other half demonstrated an "adequate" internal consistency ( $0.600 < \alpha < 0.800$ ).

Table 5.4. *Internal Consistency for the FACT subscales based on the current sample*

Scale (number of items)	N	$\alpha$
FACT: Physical wellbeing (7 items)	195	0.8138
FACT: Functional wellbeing (7 items)	195	0.8312
FACT: Social wellbeing (7 items)	195	0.7320
FACT: Emotional wellbeing (6 items)	113	0.6958
FACT: Doctor-patient relationship (2 items)	195	0.8318
FACT-CX: Cervical cancer subscale (14 items)	195	0.6443

### 5.5.1.3 **Relationship Satisfaction Interaction Scale** (Buunk, 1990)

Since satisfaction with an intimate relationship was considered to be a potential confounder of sexual and quality of life outcomes, the Relationship Satisfaction Interaction Scale was included in the current battery of questionnaires. This scale is an efficient reliable measure for demonstrating the extent to which a close relationship is perceived as satisfactory (Buunk, 1982). The instrument does not try to assess various determinants of marital adjustment but rather how often interactions between intimate partners are perceived as rewarding (Touliatos, Perlmutter & Straus, 1990). The scale was developed according to reinforcement theory and proved applicable for married couples, cohabiting couples and those who consider themselves to be in a stable relationship.

The scale is comprised of 8 statements, rated on a 5-point Likert scale, ranging from 1 (“never”) to 5 (“very often”). Of the eight items, five relate to negative experiences often encountered in relationships e.g. “I feel our relationship will not last”, and three relate to positive experiences, e.g. “I enjoy the company of my partner”. The Total Relationship Satisfaction Score ranges from 0 to 40. The higher the score the greater the level of dissatisfaction with the current state of the relationship.

The Relationship Satisfaction Interaction scale has good psychometric properties. The internal consistency of the scale ranges from .83 to .88, which is adequate for research purposes in a scale consisting of as few as eight items (Buunk 1982, 1987; Buunk & Bosman, 1986; Buunk, Collins, Taylor, VanYperen & Dakof, 1990; Vanyperen & Buunk, 1991). The test-retest correlation of the scale, based on a three months retest interval, was .83, indicating the stability of the scale over time. Criterion validity was assessed using a sample of 365 married volunteers. Uncertainty about the future of the relationship, as measured by an uncertainty item, was correlated with marital dissatisfaction, as measured by the Relationship Satisfaction Interaction Scale ( $r = .50$ , Buunk *et al.*, 1990). Since Buunk and his colleagues have conducted the majority of the studies aimed at demonstrating the scale’s psychometric quality, further validation of their findings by other research groups would substantiate the validity of this scale. The scale was included in our battery of questionnaires due to its brevity whilst meeting the methodological prerequisites of this study. The Cronbach’s Alpha in this sample indicated internal consistency of the Buunk’s scale in the desirable range ( $\alpha = 0.886$ ).

#### **5.5.1.4 Mini – Mental Adjustment to Cancer (Mini-MAC) Scale**

*(Watson, Law, dos Santos, Greer, Baruch & Bliss, 1994)*

Mental adjustment to cancer is defined as the cognitive and behavioural responses made by an individual to the diagnosis of cancer (Greer, Moorey &

Watson, 1989). This definition differs from the definition of coping put forward by Lazarus & Folkman (1984). Whilst coping is defined as a wilful cognitive and behavioural effort, mental adjustment may also involve involuntary emotional reactions to threatening events such as cancer (Greer & Watson, 1987). Adjustment style has been indicated as a key determinant of quality of life and possibly related to improved clinical outcomes (Osborne, Elsworth, Kissane, Burke & Hopper, 1999). Previous studies suggested that women who initially respond to a breast cancer diagnosis with "fighting spirit" are more likely to be recurrence free at follow up whilst helplessness has been associated with a poor prognosis (Antoni & Goodkin, 1988, Greer *et al.*, 1979). Consistent with these findings, results of the current Phase 1a study indicated that one of the most pronounced psychological factors contributing to quality of life and sexual re-adjustment, regardless of treatment modalities, was the adjustment style of the patients (see Chapter III). If adjustment styles are contributing to quality of life and sexual outcomes independently, rather than being merely confounded with physiological status (Levy, Herberman, Maluish, Schlien & Lippman, 1985) then these need to be accounted for in any psycho-oncological research. Therefore, a multidimensional scale assessing various adjustment styles to cancer, the Mini-Mental Adjustment to Cancer (Mini-MAC) scale, was considered for incorporation into the current questionnaire battery.

The Mini-MAC scale is a refined measure of the original Mental Adjustment to Cancer (MAC) scale (Watson, Greer, Young, Inayat, Burgess & Robertson, 1988). The Mini-MAC provides a more economical evaluation of psychological responses to cancer than the original MAC scale without losing reliability (Watson *et al.*, 1994). The MAC scale is a widely used self-rating questionnaire developed by Watson *et al.* (1988) to assess "adjustment" or responses to the diagnosis and treatment of cancer (e.g. Schwartz, Daltroy, Brandt, Friedman & Stolbach, 1992; Lampic, Wennberg, Schill, Glimelius, Brodin & Sjoden, 1994; Schnoll, Harlow, Brandt & Stolbach, 1998). The MAC inventory is a 40-item scale, which has been developed using robust clinical research methods. Fifty-eight items were identified from interviews with cancer patients, covering four

primary response categories: fighting spirit, denial, stoic acceptance and helplessness/ hopelessness. Using exploratory factor analysis, five scales corresponding to the most common adjustment styles were derived: fighting spirit, helplessness/hopelessness, anxious preoccupation, fatalism and avoidance.

Due to the extensive length of the current battery of questionnaires, the abbreviated version of the MAC scale, the Mini-MAC scale, was chosen (Watson *et al.*, 1994). The Mini-MAC scale is a 29-item tool for obtaining a rapid and reliable assessment of adjustment styles of patients facing a cancer diagnosis and treatment. The Mini-MAC was developed using a rigorous factor analysis procedure based on a large cohort of heterogeneous cancer patients (N=573). In response to the analysis, the scope of the original scale was widened to include a 4-item "cognitive avoidance" scale and some original items were clarified and modified. As with the MAC scale, separate scores are calculated for each subscale indicating the extent to which this particular coping style is being employed. Scores on the various subscales can be converted to standardised T-scores (Watson *et al.*, 1994).

The Mini-MAC shows a good level of reliability, stability over time and validity. Watson *et al.* (1994) assessed the inter-correlations between the Mini-MAC and the original MAC subscales and found them associated to a highly significant degree. The psychometric properties of the original MAC scale were recently examined in an Australian study with breast cancer patients (Osborne *et al.*, 1999) and reliability coefficients similar to those originally reported were found (Watson *et al.*, 1989; Schwartz *et al.*, 1992).

The validity of the MAC scale has been determined by comparing patient ratings with spouse ratings (Watson *et al.*, 1989) and patient ratings with clinical ratings of patient mental adjustment (Greer *et al.*, 1989). The construct validity of the original MAC scale was assessed by Grassi, Rosti, Lasavia & Marangola (1993). A "fighting spirit" was found to be significantly related to a low external locus of

control and high social support, whilst the opposite associations were shown for “helplessness/hopelessness” and “fatalism”. A major criticism of the original MAC scale was its use of a single-item avoidance subscale, seen as insufficient to evaluate the use of avoidance/denial as a coping style (Grassi *et al.*, 1993). Developing a 4-item Avoidance scale in the Mini-Mac inventory rectified this weakness. The concurrent validity was assessed via correlations between the MAC scale and HADS anxiety and depression subscale scores. Fighting spirit was linked to low levels of psychopathology, whereas helplessness/hopelessness was consistently related to higher psychopathological levels (Watson *et al.*, 1994).

In the current study, Hopelessness/Helplessness, Anxious Preoccupation and Cognitive Avoidance subscales exhibited adequate internal consistency (see Table 5.5.). The only two subscales with low internal consistency were Mini-MACS subscales of Fighting Spirit and Fatalism ( $\alpha_{\text{Fighting Spirit}} = 0.5573$ ;  $\alpha_{\text{Fatalism}} = 0.4926$ ). An examination of the item-total statistical output of these subscales revealed that the scales’ reliability coefficients could not be increased by exclusion of any single item. To maintain confidence in the reliability of the findings, fighting spirit and fatalism subscales were therefore not included in the subsequent analyses.

Table 5.5. *Internal consistency for the Mini-MACS subscales based on the current sample*

Scale (number of items)	N	$\alpha$
Mini-MACS: Hopelessness/Helplessness (8 items)	52	0.8500
Mini-MACS: Anxious Preoccupation (7 items)	52	0.7728
Mini-MACS: Cognitive Avoidance (4 items)	52	0.7591
Mini-MACS: Fighting Spirit (4 items)	52	0.5573
Mini-MACS: Fatalism (5 items)	52	0.4926



**5.5.1.5 Hospital Anxiety And Depression Scale (HADS)**  
(Zigmond & Snaith, 1983)

The Hospital Anxiety and Depression Scale (HADS) is a 4-point, 14-item self-assessment scale developed to detect states and severity of depression and anxiety among physically ill patients (Zigmond & Snaith, 1983). Consequently, the HADS does not include any somatic items found in the usual psychiatric instruments assessing anxiety and depression. The inventory consists of two 7-item subscales, one measuring anxiety and the other measuring depression. The HADS is regarded as one of the most efficient and widely used screening instruments for assessing anxiety and depression in medical settings and in general population (Bjelland, Dahl, Haug & Neckelmann, 2002).

A score for each subscale can be divided into three categories indicating the severity of distress or anxiety. Subscale scores range from 0 (no distress) to 21 (maximum distress). Scores of 11 and higher indicate “probable” clinical cases of anxiety and depression, whilst scores of “possible” cases range from 8-10 and “non-cases” are indicated by a score of 7 or less. A recent Australian study investigating the diagnostic efficacy of HADS in early stage breast cancer patients found that these recommended cut off points may result in under-reporting of psychiatric morbidity in similar samples (Love, Kissane, Bloch & Clarke, 2002). In their sample, optimal accuracy of the scale (i.e. specificity and sensitivity) was achieved when the cut-off scores for the caseness were reduced to 5. However, a review of 747 studies that used HADS revealed that an optimal balance between sensitivity and specificity is achieved when caseness is defined by a score of 8 or above for both subscales (Bjelland *et al.*, 2002). Based on their review, the authors concluded that HADS performs well in assessing the symptom severity and caseness of anxiety disorders and depression in both somatic, psychiatric and primary care patients and in the general population.

Ibbotson, Maguire, Selby, Priestman & Wallace (1994) compared the screening ability of three questionnaires commonly used with the cancer population: the General Health Questionnaire (GHQ 28), Rotterdam Symptom Checklist (RSCL) & Hospital Anxiety and Depression Scale (HADS). The ability to detect anxiety and depression in an oncological setting was assessed using a heterogeneous sample of 513 cancer patients. The HADS performed best in the sample (closely followed by RSCL), with sensitivity of 80%, specificity of 76% and positive predictive value of 41%. Further, the HADS best identified affective disorders in those free of disease and when the disease was judged to be stable.

Psychometric properties of the scale are found to be robust across a wide spectrum of populations. According to a recent review of the literature, Cronbach's alpha for the anxiety subscale varied from 0.68 to 0.93 (mean 0.83) and for the depression subscale from 0.67 to 0.90 (mean 0.82) (Bjelland *et al.*, 2002). The inventory has been found sensitive to changes both during the course of the disease and in response to psychotherapeutic and pharmacological interventions (Herrmann, 1997). The HADS performs well in assessing symptom severity and caseness of anxiety disorders and depression not only in somatic and psychiatric primary care patients but also in the general population (Bjelland *et al.*, 2002; Aylard, Gooding, McKenna & Snaith, 1987; Moorey, Greer, Watson, Gorman, Rowden *et al.*, 1991).

The HADS was selected for the present study on the basis of its ability to target depressive and anxiety symptoms. Following cancer diagnosis and treatment, patients are at risk of developing depressive illnesses and anxiety disorders (Thompson & Shear, 1998; Derogatis, Morrow, Fetting, Penman, Piasetsky *et al.*, 1983). Since clinical depression or anxiety could be a precursor and/or a consequence of patients' sexual difficulties, the emotional state of the participants needed to be accounted for as a potential confounding variable. Furthermore, since patients in the current study were assessed following their treatment and thus were considered to be disease free, the HADS was selected

as the most sensitive measure to identify patients with psychopathological symptoms. Finally, since the HADS has been validated for the use with cancer patients as well as with a general population (Bjelland *et al.*, 2002), it was selected as the most appropriate measure to allow for the cross-sectional assessment of psychological distress across the three patient groups in the current study. The psychometric robustness of the HADS inventory was confirmed in the current study, with both anxiety and depression subscales demonstrating Cronbach's Alphas in the desirable range ( $\alpha_{\text{Anxiety}} = 0.8362$ ;  $\alpha_{\text{Depression}} = 0.8362$ ).

## **5.5.2 Follow up measures**

### **5.5.2.1 *Sexual Functioning After Gynaecologic Illness Scale (SFAGIS)*** *(Bransfield, Horiot, & Nabid, 1984)*

Sexual Functioning After Gynaecologic Illness Scale (SFAGIS) is a 30-item, site-specific, 4-point Likert-type self-report measure. The content of SFAGIS was devised to address the main themes that emerged from an extensive review of literature concerning sexual functioning and gynaecological cancer (Bruner & Boyd, 1999). The following 15 themes were identified and incorporated into the item pool: sexual desire, availability of a partner, patient's fears about sexual activity, sexual satisfaction, initiation of sexual activity, affectionate behaviour, frequency of sexual intercourse, frequency of orgasm, vaginal dimensions and mucousal conditions, potential for vaginal lubrication, desire for sexual information, changes in sexual activity after therapy, compliance with a recommendation for a dilator use and intervention of a health care provider. The scale has satisfactory content and face validity. The split-half reliability coefficient is .80 and internal consistency reliability alpha based on Kuder-Richardson formula, is 0.756.

The SFAGIS was selected as it addresses specific concerns revealed in the course of the Phase 1a qualitative analysis, which were not covered as

sufficiently by any of the other available scales. Critics of SFAGIS argue that this measure is too narrow in its focus, and does not target the broader aspects of sexual functioning (Bruner & Boyd, 1999). However, since subtests of DSFI were included as measures of broad sexual functioning, the specificity of SFAGIS proved to be advantageous for the current study. More importantly, the SFAGIS was the only scale we were aware of that included a combination of items such as the use of vaginal dilators and post-treatment mucousal changes, which emerged as important issues from the interviews with women in Phase 1a (see Chapter III). In order to reduce the burden for participants, items of SFAGIS that overlapped with the DSFI items were excluded from the scale (e.g. frequency of intercourse, sexual satisfaction, affectionate behaviour). Since the SFAGIS is designed to measure post-treatment sexual functioning, the modified 12-item scale was administered only at the two follow up assessments.

#### ***5.5.2.2 Treatment-specific measures addressing side effects, psychological responses and main issues of cervical and endometrial cancer patients***

The current qualitative study with cancer patients (Phase 1a) identified a number of areas that were not able to be addressed by the available questionnaires. These areas, mostly pertinent to the impact of various treatments, included patients' psychological responses, the importance of being prepared for and understanding side effects of various treatment modalities, as well as the main issues patients face following the treatment such as reduced femininity and fertility. To our knowledge, no standardised measures assessing patients' psychological responses pertinent to various types of gynaecological cancer treatments existed at the time of data collection. Similarly, no inventory targeting patients' perception of side effects and the impact of various treatment modalities on the main issues for gynaecological patients was available. Therefore, based on responses of women participating in the qualitative study (Phase 1a), new measures assessing the aforementioned issues were developed and piloted specifically for the present study. Our qualitative data

validated the relevance of items selected for each scale. A final draft of each scale was piloted and revised based on patients' feedback.

### **Side effects pertinent to specific treatment modalities**

The first newly designed scale related to common side effects pertinent to various treatment modalities. Side effects identified by cancer patients in the qualitative study were compared to those listed in the literature relevant to the subject (see section 1.2.2.3). The nine most common side effects that overlapped in both sources included: bowel problems (e.g. diarrhoea, constipation), bladder problems (e.g. levels of incontinence), shortened vagina, dry vagina, nerve damage, dyspareunia, onset of menopause, lymphoedema and damage to the skin (e.g. scarring or burns in the pelvic area). These items were arranged so that patients who indicated experiencing the side effect went on to indicate which treatment modality (i.e. surgery, external radiotherapy or brachytherapy) they believed contributed to the development of that particular side effect. Additional options included "I don't know" and "other causes", the latter requiring patients' to specify the perceived cause of the side effect. An additional question asked patients to include any side effects not listed in the questionnaire and to specify which treatment (if any) they believed predominantly contributed to the development of that side effect.

Since calculation of the total score was considered less informative, the incidence of each side effect in each of the two surgically treated groups of patients (i.e. cancer and benign groups) was evaluated separately. Further comparisons of side effects experienced by cancer patients undergoing surgery and those with adjuvant radiotherapy were also made. Importantly, the scale allowed for identification of patients who were unsure as to how their side effects originated. Qualitative data indicated that these patients are at risk of experiencing distress through being uninformed of the potential development of these side effects. The ultimate aim of this scale was to obtain a better understanding of women's perceptions as to how individual treatments influence

the development of particular side effects. Moreover, the scale was to control for a general influence of physiological factors on sexual functioning.

Obtaining extensive psychometric data on the scale was beyond the scope of the current study. When compiling the scale, methodological requirements were taken into consideration. Internal consistency data at both follow up assessments using the current sample were found well within the acceptable range (6 months follow up: Cronbach's alpha = 0.7019; 12 months follow up: Cronbach's alpha = 0.7311). This further endorsed the relevance and cohesiveness of the selected items as well as the high stability of the scale.

### **Psychological responses pertinent to specific treatment modalities**

A further under-researched area identified during the qualitative phase was the range of psychological responses related to various treatment modalities. The majority of studies focus on physiological changes associated with treatment, commonly neglecting the psychological impact of the actual treatment procedure. As mentioned in the literature review, brachytherapy in particular is a traumatic procedure which is often associated with feelings of fear, anxiety, lack of control, anger and/or isolation (e.g. Velji & Fitch, 2001; Cassileth *et al.*, 1980). It was hypothesised that these negative psychological reactions would interfere with patients' post-treatment adjustment, including their sexual life. To our knowledge, no specific inventory assessing this topic in cancer patients exists.

In the process of the scale's development, a list of common psychological responses was generated, prompted by responses given by women in the qualitative phase (1a). Related items were revised and combined by a team of clinical psychologists (including IJ) in order to minimise the number of items and to reflect the most common feelings and responses reported by the women. The final fifteen psychological responses identified included: feeling embarrassed, relieved, depressed, anxious/worried, informed, degraded, angry, accepting, revolted, in control, isolated, scared, numb, shocked and frustrated. Women were asked to indicate the degree to which each emotion/response best

described their feelings related to each treatment. This was achieved by putting a slash through the line ranging from “not at all” (0) to “very much” (10). Each line represented a specific treatment modality (see questionnaires, Appendix). Lines related to treatments that the patient did not receive were to be ignored. Data from this scale were reduced using factor analysis, which yielded three main factors: distress, disempowerment and degradation (for factor analysis calculations see Results section 7.1.8). Group comparisons were conducted using this factor structure.

As with the previous scale, obtaining extensive psychometric data was beyond the scope of this study. Internal consistency of the newly derived items at both follow ups was found to be in the desirable range, indicating adequate reliability and stability of the scale (Cronbach’s alpha = 0.8871; 12 months follow up: Cronbach’s alpha = 0.8125). Internal consistency was calculated using scores of cancer and benign patients related to the impact of surgery alone, as sample sizes of patients receiving different combinations of treatment modalities were very small. Nevertheless, it was considered unlikely that significantly different levels of internal consistency would emerge for different treatments.

Overall, the current scale was designed to generate empirically-based data that would elucidate the psychological impact of various treatment modalities in a gynaecological cancer population. Further, as the scale was administered at both follow ups, changes in perceptions of psychological reactions to various treatments could also be documented.

### **Main issues pertinent to specific treatment modalities**

The third newly developed measure reflected five issues identified by cancer patients during the qualitative phase as relevant and important for post-treatment adjustment. These included femininity/womanhood, physical appearance, sexual functioning, infertility and preparedness for the treatment. As further inspection of the data pointed to differences in treatment regarding patients’ “feeling confident that nothing would go wrong during treatment”, this

item was also included in the questionnaire. As with the previous measures, the aim of this measure was to determine whether the identified issues were pertinent to particular treatments. Accordingly, women were asked to rate (on the scale from “not at all (0) to very much (4)”) how much each treatment impacted on each of the six identified issues. Responses for each item were assessed individually. Patients were asked to leave blank columns for treatments they did not receive. As the selected items represented independent areas of inquiry, internal consistency of the items was not calculated. Data obtained from this questionnaire were analysed descriptively. Considering the lack of psychometric properties of the scale, in conjunction with the fact that each issue was assessed by a single item only, the obtained data need to be interpreted with caution.

In summary, the aforementioned newly developed measures were believed to provide a novel insight into the impact of specific treatment modalities on patients’ physical and psychological wellbeing.

## **5.6 Pilot testing and arrangement of the questionnaire sets**

Procedures for efficient identification of eligible patients, recruitment of patients and collection of data at the clinical centres, were developed and tested. A pilot test of the battery of questionnaires was conducted with 7 cervical and endometrial cancer patients who participated in the Phase 1a qualitative study. On the basis of the patients’ helpful comments, some items from the non-standardised scales were revised slightly. Table 5.6. outlines measures included in the sets of questionnaires at the baseline and at the two follow up assessments.



Table 5.6. Overview of baseline and follow up measures

Measures	Cancer group			Benign group		Pre-invasive group	
	Baseline	6 months follow up	12 months follow up	Baseline	6 months follow up	Baseline	6 months follow up
Demographic characteristics	✓ (14 items)	✓ (8 items)	✓ (8 items)	✓ (14 items)	✓ (8 items)	✓ (14 items)	✓ (8 items)
FACT-CX	✓	✓	✓	✓	✓	✓(a)	✓(a)
DSFI: - Satisfaction	✓	✓	✓	✓	✓	✓	✓
- Drive	✓	✓	✓	✓	✓	✓	✓
- GSSI	✓	✓	✓	✓	✓	✓	✓
Relationship Satisfaction Scale	✓	✓	✓	✓	✓	✓	✓
HADS	✓	✓	✓	✓	✓	✓	✓
Mini-MACS	✓	✓	✓				
SFAGIS		✓	✓		✓(a)		✓(a)
Treatment –specific side effects		✓	✓		✓(b)		✓(b, c)
Treatment –specific main issues		✓	✓		✓(b)		✓(b, c)
Treatment –specific psychological responses		✓	✓		✓(b)		✓(b, c)

(a) Cancer specific items modified or removed

(b) Only surgery/LLETZ-related items included

(c) Administered only to women who undergone treatment (i.e. LLETZ)

Separate questionnaire sets were arranged for each group of patients. Each set was adjusted depending upon its participants (i.e. cancer patients, benign patients or pre-invasive cancer patients) and time of the assessment (baseline, 6 and 12 months follow ups). Every set included an introductory letter, the required battery of questionnaires and a reply paid envelope. The introductory letter explained in easily understood language the purpose of the study as well as the procedure for the assessments. An information sheet and a consent form were included only at baseline. These were formatted in accordance with the requirements of each of the five area health ethics committees. The set was comprised of the battery of questionnaires. The names of the scales were not included in order to minimise the social desirability bias of the participants' responses. The questionnaire sets are included in Appendix.

## **5.7 Data Analyses**

All data analyses were conducted using the Statistical Package for the Social Science (SPSS) Version 10.0. Prior to conducting statistical analyses, the data set was closely inspected to assess the accuracy of input, plausibility of means and standard deviations, out-of-range values and missing values. This preliminary data inspection revealed that the pattern of missing data was random with less than twenty five percent of data missing. Consequently, missing values were estimated using group mean substitution as outlined by Tabachnick and Fidell (1996). The missing data of participants who did not have a partner (n=47), and therefore did not complete the Relationship Satisfaction Interaction Scale and a number of the DSFI items assessing sexual functioning, were excluded from the analyses.

### ***5.7.1 Checking assumptions and choice of statistics***

The assumptions of parametric univariate and multivariate analyses were checked using: a) graphical explorations (i.e. histograms with normal curves overlaid, stem-and-leaf plots, box plots and normal probability Q-Q plots) and b) statistical tests (i.e. the Kolmogorov-Smirnov (K-S) test with a Lilliefors significance level, Levene's test of homogeneity, skewness, kurtosis and measures of central tendency). Transformations for positively skewed data (square root, logarithm and inverse) and those distributed negatively (reflect and square root, reflect and logarithm and reflect and inverse) were computed to normalise distributions. Outliers were identified and replaced with a less extreme score, which was higher than the next most extreme score within the distribution (Tabachnick & Fidell, 1996). However, such re-scoring of outliers and transformations of continuous variables and residuals in the current sample did not lead to satisfactory normality in some variables, indicating that the data did not meet the assumptions that underlie parametric statistics.

It was considered whether the use of non-parametric analyses would be a suitable alternative for the analysis of the current data set. The problem with the use of non-parametric tests is their inability to control for systematic biases between the groups and within-groups error variance. Not controlling for the effect of potential confounding variables was believed to seriously jeopardise the validity of the current findings, especially since patient groups (by their nature) differed in a number of important demographic variables, such as age and marital status (see Table 5.2. and section 5.2.1). The Analysis of Covariance (ANCOVA) was therefore considered as an optimal statistical test. Further consideration, however, had to be given to the issue of the violation of assumptions of multivariate analyses. According to Howell (1997), the analysis of covariance is a very robust statistical procedure and its assumptions can be frequently violated with relatively minor effects. Further, Tabachnick and Fidell (1996) state that although data transformations are recommended as a remedy for failures of normality and outliers, they are not universally recommended since transformed values may be difficult to interpret and lose clinical meaning. This latter point was considered particularly relevant to the current data of sexual functioning and quality of life.

In summary, where appropriate, every attempt was made to normalise skewed distributions using transformation equations or by re-scoring outliers. In those cases where this could not be achieved and where confounding variables were presumed to affect the outcomes, the ANCOVA analysis was computed. To address the violation of multivariate assumptions, cautious interpretation of the findings is emphasised.

### ***Confounding variables # 1: Demographic and clinical data***

Descriptive statistics (frequencies, means and standard deviations) were used to summarise baseline demographic and clinical data. The normality of the **age** distribution, the only continuous demographic/clinical variable, was examined for each patient group. Both, graphical representations and K-S test supported normal age distribution for the cancer group ( $p = 0.200$ ), whilst benign and pre-invasive group distributions were positively skewed. An inspection of box plots pointed to five outliers in the benign group ( $n=60$ ) and five outliers in the pre-invasive group ( $n=84$ ). Square-root and logarithmic transformations of the skewed age data did not lead to satisfactory normality of data within the groups.

The re-scoring of the outliers from the sample was considered appropriate. A value of one greater than the highest non-outlying value was substituted for the outliers in those two groups. Consequently, a value of 59 was retained for all outliers in the benign group whilst a value of 48 replaced extreme age values in the pre-invasive group. Following such re-scoring, the distribution of age scores normalised in the benign group ( $p=0.200$ ) and substantially improved in the pre-invasive group. As the modified age variable now consisted of one non-normal and two normal distributions, the variable was treated as normally distributed and included in the subsequent univariate and multivariate analyses.

Group differences within categorical demographic variables were assessed using chi-square tests. The following categorical variables were explored (including collapsed categories within each variable, required to satisfy the chi-square's assumption of expected frequencies):

- ***Marital status*** (married versus other)
- ***Education*** (Year 12 or below, TAFE/business college, undergraduate degree and higher)
- ***Occupation*** (professionals, non-professionals and not-working)
- ***Menopausal status*** (pre-menopausal, peri-menopausal and post-menopausal)

- **Number of children** (no children, one child, two children, three or more children)

### ***Confounding Variables # 2: Satisfaction with intimate relationship***

The 8-item Relationship Satisfaction Interaction Scale was included in the study to control for the potential confounding effect of relationship satisfaction on sexual outcomes. The assumption of normality was not satisfied despite computations of square root and logarithmic transformations of this positively skewed variable. Therefore, a non-parametric (Kruskal-Wallis) test was used to investigate the comparability of patient groups regarding relationship satisfaction levels.

### ***Confounding Variables # 3: Psychological variables (HADS)***

Distributions of baseline anxiety and depression data were screened for the assumption of normality and were found positively skewed. Transformations of the skewed data did not lead to satisfactory normality. Therefore, non-parametric (chi-square) tests were used to determine group differences between clinical and non-clinical cases in the anxiety and depression baseline scores. The analysis of covariance was also computed to investigate group differences in baseline levels of anxiety and depression. HADS data were treated in this study as potential confounding variables as well as outcome variables.

### ***Confounding Variables # 4: Mental Adjustment to Cancer (Mini-MACS)***

Similarly to the HADS data, the Mini-MAC subscales were treated as potential confounding variables as well as outcome variables. As mentioned previously, the "Fighting Spirit" and "Fatalism" subscales were not included in the data analyses due to their low internal consistency. Therefore, of the five mini-MAC scales, only three were screened for the assumptions of normality. The K-S test supported normal distribution for the "Anxious Preoccupation (AP)" subscale ( $p=0.09$ ). Following the removal of two outliers from the "Cognitive Avoidance

(CA)" subscale, the initially slightly negatively skewed distribution normalised ( $p=0.118$ , based on the Shapiro-Wilk test of normality). The "Hopelessness-Helplessness (H-H)" subscale was positively skewed. Square root and logarithm transformations were used but did not result in satisfactory normality for this variable. The differences in the use of "AP" and "CA" adjustment styles over time were tested using repeated measures ANCOVA, whilst the use of "HH" style was assessed using the Friedman test.

### ***Outcome variable # 1: Quality of Life (FACT –CX)***

To assess whether the assumptions of multivariate analyses had been met, the distributions of residuals for all five quality of life (FACT) subscales as well as the total FACT scale scores were screened. All distributions (i.e. Physical, Social, Emotional, Functional wellbeing, Relationship with doctor subscales and Total FACT scores) were normally distributed. Group differences for each quality of life subscale were investigated using analysis of covariance in order to determine the source of the significance and whether the outcome was predicted by multiple covariates. The specific cervical cancer measure (FACT-CX) was also normally distributed. Therefore ANCOVA was used to examine baseline group differences whilst controlling for the effect of confounders (e.g. age, marital status).

### ***Outcome variable(s) # 2: Sexual functioning (DSFI)***

The histogram of sexual drive residuals revealed normally distributed data. Sexual satisfaction residuals, however, were moderately negatively skewed. As clarified earlier, it was considered inappropriate to transform sexual satisfaction values, as the clinical meaning of this variable was believed to become lost within the transformation process. Therefore, the analysis of covariance was used to investigate baseline differences among patient groups regarding their sexual satisfaction and drive whilst controlling for the effect of confounding variables. The violation of normality assumptions within the sexual satisfaction

scale calls for cautious interpretation of the results. Since the histogram of the Global Sexual Satisfaction Index (GSSI) residuals indicated normally distributed data, the values reported within GSSI were analysed using the analysis of covariance.

### 6. CROSS-SECTIONAL ANALYSES OF BASELINE DATA

The main aims of the first set of analyses were:

- To verify the comparability of patient groups regarding levels of various aspects of sexual functioning (i.e. sexual satisfaction, sexual drive and global satisfaction with sexual life) prior to the onset of gynaecological symptoms and diagnosis
- To document the pre-treatment quality of life (QoL) of patients diagnosed with various gynaecological conditions, focusing on the following dimensions of QoL: physical / social / emotional / functional wellbeing, gynaecological condition-related wellbeing as well as satisfaction with the doctor–patient relationship
- To explore the psychological status of patients immediately following their treatment (i.e. surgery for benign/cancer groups and the LLETZ procedure (or equivalent) for the pre-invasive group).

*It was hypothesised that:*

1. Prior to diagnosis, **sexual functioning** problems occur more frequently in patients with benign gynaecological disease than in cervical/endometrial cancer patients and pre-invasive cancer patients
2. Prior to surgery, **quality of life** of patients with benign gynaecological disease will be poorer than that of cervical/endometrial cancer patients and pre-invasive cancer patients



## 6.1 Results

### 6.1.1 Demographic characteristics

When reporting statistical values, the following abbreviations are used:

Ca = Cancer group/patients

Be = Benign group/patients

PI = Pre-Invasive group/patients

Demographic and clinical characteristics of the three groups are shown in Table 5.2 and 5.3. The three groups of patients were compared for *age*. A one-way ANOVA was conducted, which produced highly significant results ( $F(2,194)=120.512$ ,  $p=0.000$ ), with Tukey's post-hoc test indicating significant age differences among the three groups of women ( $p_{Ca-Be}=0.03$ ;  $p_{Ca-PI}=0.000$ ;  $p_{Be-PI}=0.000$ ). Pre-invasive patients were the youngest group (mean<sub>PI</sub>=30.4, SD=10.2), followed by benign patients (mean<sub>Be</sub>=47.6, SD=8.3) whilst cancer patients were the oldest group (mean<sub>Ca</sub>=50.9, SD=11.6). Given the likely importance of age as a confounding factor in sexual adjustment, it was decided to control for age in all outcome analyses.

The pre-invasive cancer groups significantly differed from the benign and cancer groups with respect to *marital status* ( $\chi^2=21.531$ ,  $p=0.000$ ). The pre-invasive group consisted mainly of single women whilst most cancer and benign patients were married. The three groups of patients also differed in their level of *education* ( $\chi^2=17.158$ ,  $p=0.002$ ), *occupation* ( $\chi^2=18.490$ ,  $p=0.001$ ), *number of children* ( $\chi^2=48.415$ ,  $p=0.000$ ) and *menopausal status* ( $\chi^2 = 46.388$ ,  $p=0.000$ ). The *ethnic origins* of patients' parents in each group were comparable ( $\chi^2_{mother}=1.87$ ,  $p=0.392$ ;  $\chi^2_{father}=7.947$ ,  $p=0.094$ ).

Rather than including all confounding demographic variables in subsequent multivariate analyses, theoretical considerations and a correlational matrix were used to select an optimal set of covariates. Age and menopausal status were highly positively correlated variables in all three groups ( $r_{Ca}=0.785$ ,  $r_{Be}=0.687$ ,

$r_{PI}=0.646$ , all  $p<0.01$ ). Therefore, it was not necessary to control for menopausal status in the subsequent analyses. Further, as groups had comparable ethnic origins and satisfaction with relationships, these variables were also not included in the outcome analyses. Therefore, the final set of confounding demographic variables included in all multiple linear models were; age, marital status, educational level, occupation and number of children. The confounding effects of anxiety and depression levels were also controlled for in subsequent analyses, since levels of anxiety and depression were believed to influence retrospective accounts of pre-diagnosis sexual functioning and relationship satisfaction and pre-treatment quality of life.

The group means reported below reflect values obtained after adjustment of covariates. Higher scores indicate better functioning in the assessed area of sexual functioning.

### **6.1.2 Sexual functioning**

An analysis of covariance revealed no baseline group differences in the levels of *sexual satisfaction* prior to the onset of symptoms/diagnosis associated with their gynaecological condition ( $F(2,114)=1.413$ ,  $p=0.248$ ). On the scale from 0 to 10, the mean satisfaction score of cancer patients was 7.78 (SE=0.49, T-score=50), benign patients scored 6.79 (SE=0.39, T-score=44) and pre-invasive patients 7.21 (SE=0.68, T-score=45), indicating satisfactory sexual relating pre-diagnosis.

The levels of *sexual drive* prior to the onset of gynaecological symptoms/diagnosis also did not differ across the three patient groups ( $F(2,118)=1.258$ ,  $p=0.288$ ). On the scale ranging from 0 to 40, the mean sexual drive score of cancer patients was 14.83 (SE=1.06, T-score =46), benign patients scored 14.87 (SE=0.90, T-score =46) and pre-invasive patients 11.91 (SE=1.47, T-score =42), implying rather low sexual drive in the overall sample.

Similar to sexual satisfaction and drive, no significant group differences in the *global sexual satisfaction* (GSSI) prior to the onset of gynaecological symptoms/diagnosis were found ( $F(2,123)=6.932$ ,  $p=0.651$ ). On the scale from 0 (could not be worse) to 8 (could not be better), the mean value of overall sexual satisfaction for the cancer group was 5.77 (SE=0.30, T-score=51), for the benign group 5.49 (SE=0.26, T-score=49) and for the pre-invasive group 5.38 (SE=0.29, T-score=48). According to the anchors of the scale, patients in all groups reported “above average” (5) to “good” (6) satisfaction with overall quality of their sexual relationships prior to their gynaecological symptoms/diagnosis.

Patients were additionally asked *how much* their *sexual life has changed since the diagnosis*. Significant differences among the groups were found ( $\chi^2(10)=36.765$ ,  $p=0.000$ ). Whilst pre-invasive patients reported little or no disruption to their sexual life (mean<sub>PI</sub>=1.92, SD<sub>PI</sub>=1.17), benign and cancer groups reported more significant deterioration of their sexual functioning post-diagnosis (mean<sub>Ca</sub>=3.25, SD<sub>Ca</sub>=1.78; mean<sub>Be</sub>=3.16, SD<sub>Be</sub>=1.62).

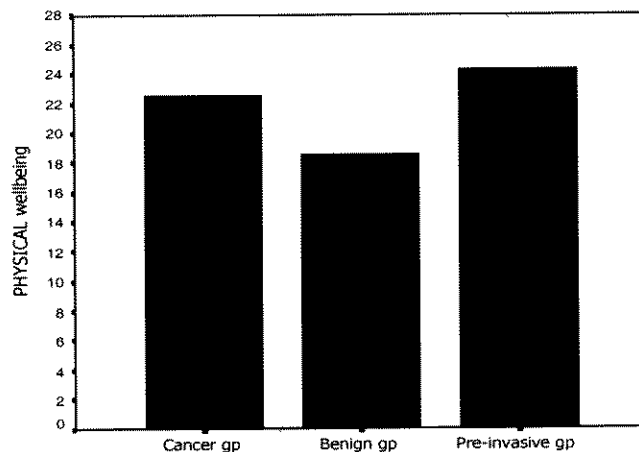
### 6.1.3 Quality of Life

Pre-treatment quality of life (referring to the month prior to the surgery/colposcopy) was assessed using the FACT scale, which includes a specific cervical cancer subscale measuring quality of life related to gynaecological symptoms/condition (FACT-CX). Higher values imply better outcomes in the assessed quality of life domain.

Pre-treatment quality of *physical wellbeing* significantly differed across the three groups of patients ( $F(2, 134)=18.103$ ,  $p=0.000$ ). According to the contrast matrix, pre-treatment physical functioning of benign patients was the poorest (mean<sub>Be</sub>=18.51, SE=0.627), being significantly more impaired than that of cancer patients (mean<sub>Ca</sub>=22.33, SE=0.738,  $p_{Ca-Be}=0.000$ ) and pre-invasive patients (mean<sub>PI</sub>=25.35, SE=1.03,  $p_{Be-PI}=0.000$ ). In turn, physical wellbeing of

cancer patients was significantly poorer than that of pre-invasive patients ( $p_{Ca-PI}=0.038$ ). See Figure 6.1. for graphical representations of group mean values.

Figure 6.1. *Quality of Life: Differences of group means in pre-treatment **physical wellbeing***

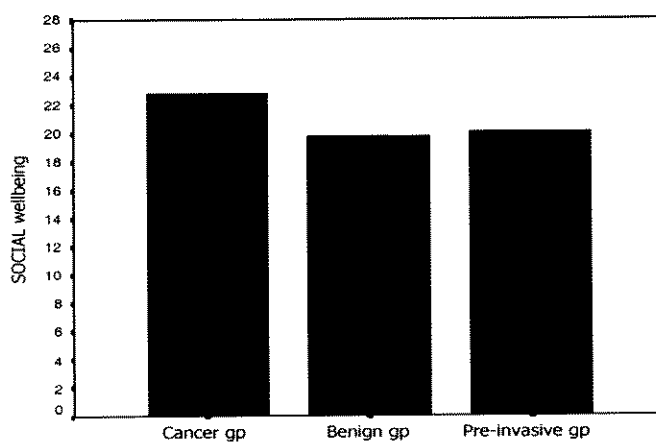


No differences in pre-treatment **functional wellbeing** among the three groups of patients were detected ( $F(2,134)=0.638$ ,  $p=0.530$ ). Although pre-invasive patients reported slightly higher levels of functional wellbeing (mean<sub>PI</sub>=19.93, SE=1.19), these were not significantly different from functional levels reported by cancer patients (mean<sub>Ca</sub>=18.90, SE=0.85) and benign patients (mean<sub>Be</sub>=18.30, SE=0.73).

After adjustment for covariates, reported levels of **social wellbeing** significantly differed across the three groups of patients ( $F(2,134)=4.498$ ,  $p=0.013$ ). The scope of possible social subscale scores ranges from 0 to a maximum of 28. All groups reported above average social support /wellbeing in the month prior to the surgery/colposcopy. According to contrast analyses, pre-treatment social wellbeing of cancer patients was the highest in the current sample (mean<sub>Ca</sub>=22.99, SE=0.79), being significantly better than that of benign patients (mean<sub>Be</sub>=19.96, SE=0.676,  $p_{Ca-Be}=0.003$ ). A trend for better social wellbeing of

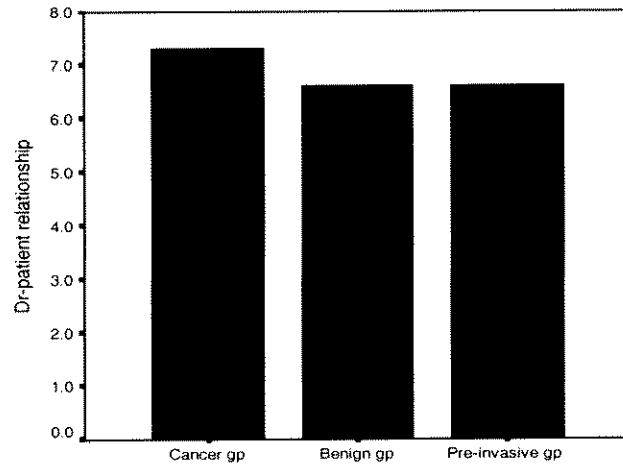
cancer patients compared to pre-invasive patients was noted, although this effect failed to reach significance ( $\text{mean}_{PI}=20.40$ ,  $\text{SE}=1.12$ ,  $p_{Ca-PI}=0.097$ ). Benign and pre-invasive patients reported similar levels of social wellbeing ( $p_{Be-PI}=0.756$ ). For graphic representations of mean group values see Figure 6.2.

Figure 6.2. *Quality of Life: Differences of group means in pre-treatment **social wellbeing***



A group trend for patients' perceived **satisfaction with the doctor-patient relationship** was detected, although this effect failed to reach significance ( $F(2,134)=2.847$ ,  $p=0.062$ ). In the baseline measures, the term "treating doctor" varied, depending on the group of patients (i.e. cancer patients were treated by a gynae-oncologist, benign patients by a gynaecologist and pre-invasive patients by a GP or gynaecologist). The total scores of this 2-item subscale range from 0 to 8. On average, all patients were highly satisfied with their treating doctors. Cancer patients ( $\text{mean}_{Ca}=7.3$ ,  $\text{SE}=0.24$ ) were significantly more satisfied with their doctors than were benign patients ( $\text{mean}_{Be}=6.58$ ,  $\text{SE}=0.21$ ,  $p_{Ca-Be}=0.021$ ). Benign and pre-invasive patients reported similar levels of satisfaction with their physician's care ( $\text{mean}_{PI}=6.58$ ,  $\text{SE}=0.34$ ,  $p_{Be-PI}=0.992$ ). Cancer and pre-invasive patients also reported comparable levels of satisfaction with their treating doctors ( $p_{Ca-PI}=0.131$ ). Group means are shown in Figure 6.3.

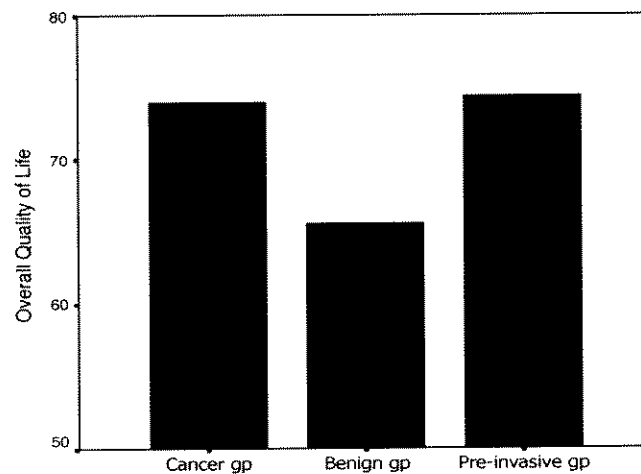
Figure 6.3. *Quality of Life: Differences in group means for satisfaction with the doctor-patient relationship*



Following adjustment of covariates, a trend in the levels of **emotional wellbeing** was detected across the groups of patients ( $F(2,134)=2.396$ ,  $p=0.095$ ). Pre-invasive patients reported significantly poorer emotional wellbeing than did benign patients ( $p_{Be-PI}=0.034$ ). Emotional wellbeing of cancer patients was comparable to benign and pre-invasive patients ( $p_{Ca-Be}=0.373$ ,  $p_{Ca-PI}=0.176$ ).

**Total Quality of Life (QoL)** prior to the treatment was found to differ across the groups of patients ( $F(2,134)=7.590$ ,  $p=0.001$ ). Benign patients reported significantly poorer overall QoL (mean<sub>Be</sub>=66.4, SE<sub>Be</sub>=1.58) than did cancer patients (mean<sub>Ca</sub>=74.50, SE<sub>Ca</sub>=1.86,  $p_{Ca-Be}=0.001$ ) and pre-invasive patients (mean<sub>PI</sub>=74.96, SE<sub>PI</sub>=2.6,  $p_{Be-PI}=0.011$ ). Total QoL of the latter two patient groups was comparable ( $p=0.898$ ). Figure 6.4. shows graphic representations of mean group values for overall QoL.

Figure 6.4. *Quality of Life: Differences of group means in pre-treatment overall quality of life*



The effect of *gynaecological conditions-related issues* on the pre-treatment wellbeing of patients was measured using the specific cervical cancer subscale of the FACT. No significant differences among the three groups of patients on this dimension were found ( $F(2,134)=0.069$ ,  $p=0.933$ ).

#### 6.1.4 Satisfaction with relationship

The participants' satisfaction with their intimate relationship was investigated using Buunk's Relational Interaction Satisfaction-Scale. A Kruskal-Wallis test for baseline satisfaction scores in the three patient groups was not significant ( $p=0.182$ ,  $\chi^2=3.405$ ), indicating similar levels of satisfaction across the groups prior to the diagnosis and treatment of gynaecological conditions. On average, cancer patients obtained a score of 13.7 (SD=4.96), benign patients a score of 14.6 (SD=5.8) and pre-invasive patients a score of 15.6 (SD=5.5). Possible scores on Buunk's Relational Interaction Satisfaction-Scale range from 0 to 40 with 0 indicating maximum satisfaction and 40 extreme dissatisfaction with the relationship. Women in the current sample reported an average score of 14.6, indicating a high degree of relationship satisfaction and support. Since no group

differences were found, this variable was not included in subsequent analyses as a covariate.

### 6.1.5 Psychological status

The following analyses are based on the data of only those pre-invasive patients who completed Part B of the baseline questionnaire assessing post-treatment psychological status (n=43). Data of all cancer and benign patients were available for analyses. For ease of reading, levels of clinically significant symptomatology of anxiety/depression will be abbreviated to “clinical anxiety/depression levels”.

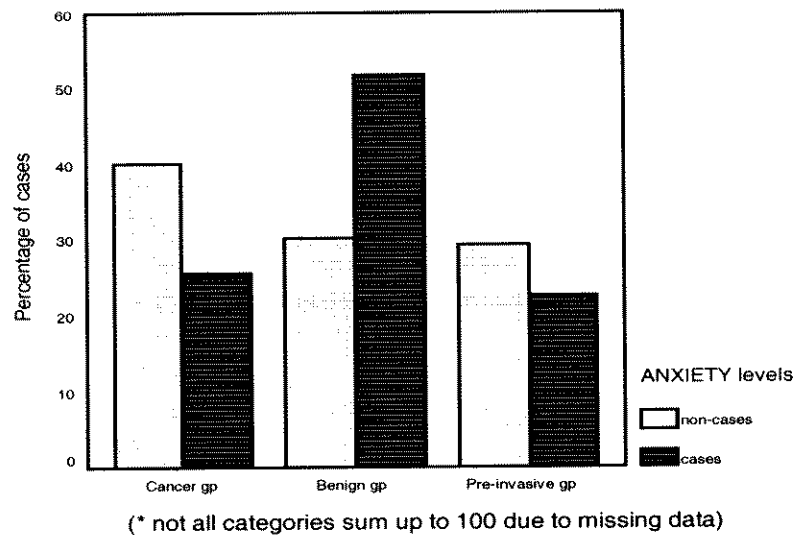
The analysis of covariance revealed significant differences in ***post-treatment anxiety levels*** of the three groups of patients ( $F(2,137)=7.094$ ,  $p=0.001$ ). Benign patients were significantly more anxious following their treatment than pre-invasive patients ( $F(2,137)=7.094$ ,  $p=0.001$ ). Interestingly, the analysis revealed a trend for higher post-treatment anxiety levels in the benign group compared to the cancer group, with the effect just failing to reach significance ( $p=0.058$ ). Similarly, a trend for cancer patients being more anxious than pre-invasive patients in the first two weeks following their treatment was noted, although this effect just failed to reach significance ( $p=0.058$ ). Following the adjustment for covariates, benign patients' mean anxiety score was 8.3 ( $SE_{Be}=0.58$ ,  $range_{Be}$  0-18), cancer patients scored 6.6 ( $SE_{Ca}=0.67$ ,  $range_{Ca}$  0-18) and pre-invasive patients' score was 4.25 ( $SE_{PI}=0.90$ ,  $range_{PI}$  0-20).

To evaluate ***clinical levels of anxiety***, patients' scores were categorised into non-clinical levels (0-7) and clinical levels (8-20). The chi-square test revealed significant clinical differences in baseline anxiety levels across the patient groups ( $\chi^2=7.136$ ,  $p=0.028$ ). Interestingly, more than half of benign patients



(53.3%) were clinically anxious following their hysterectomy compared to 30.2% of cancer patients and 34.1 % of pre-invasive patients (see Figure 6.5.).

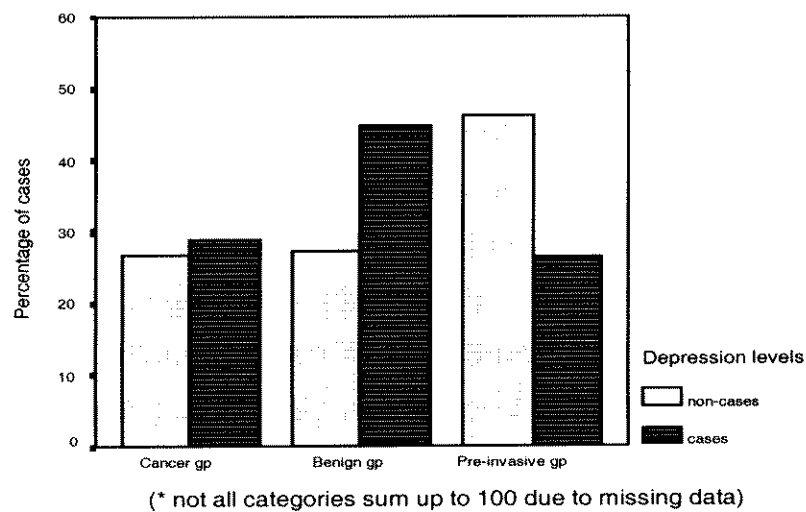
Figure 6.5. *Baseline group differences in anxiety levels (clinical cases vs. non-cases)*



Significant differences in **post-treatment depression levels** among the three groups of patients were also detected ( $F(2,137)=5.930$ ,  $p=0.003$ ). According to the contrast matrix, pre-invasive patients were significantly less depressed than cancer patients ( $p=0.002$ ) and benign patients ( $p=0.001$ ). The latter two groups reported comparable levels of depression ( $p=0.713$ ). Pre-invasive patients obtained a mean score of 2.4 (SE=0.78, range 0-14), compared to a score of 5.3 for cancer patients (SE=0.58, range 0-18) and a score of 5.1 for benign patients (SE=0.0.48, range 0-15).

A chi-square test revealed group differences in the clinical versus non-clinical levels of depression ( $\chi^2=6.711$ ,  $p=0.035$ ). Approximately twenty-eight percent (28.3%) of benign patients were clinically depressed, compared to 20.8% of cancer patients and 7.3% of pre-invasive patients (see Figure 6.6.).

Figure 6.6. *Baseline group differences in depression levels (clinical cases vs. non-cases)*



### 6.1.6 Adjustment styles

The adjustment styles of cancer patients were assessed following surgery using the Mini-MAC inventory. Anxious Preoccupation (AP) was the most commonly employed adjustment style (mean<sub>AP</sub>=19.0, SD=4.9), whilst Hopelessness/Helplessness (HH) and Cognitive Avoidance (CA) styles were less prominent (median<sub>HH</sub>=10.50, SD=3.76; mean<sub>CA</sub>=10.65, SD=3.05).

### 6.1.7 A summary of results

Prior to the onset of gynaecological symptoms/diagnosis, all patient groups experienced similar high levels of *satisfaction with their intimate relationships*. Further, all groups reported comparable levels of assessed components of *sexual functioning*, i.e. sexual satisfaction, sexual drive and global evaluation of sexual relationship. Pre-invasive patients reported little or no disruption to their sexual lives since their diagnosis, whilst cancer and benign patients identified a more significant deterioration in their sexual functioning.

Regarding assessment of pre-treatment levels of various dimensions of patients' quality of life, benign patients reported a poorer *overall quality of life* in comparison to cancer and pre-invasive patients. The latter two groups experienced similar high levels of quality of life. As expected, pre-treatment physical wellbeing of benign patients was the poorest, followed by cancer patients, whilst pre-invasive patients reported satisfactory physical wellbeing. Cancer patients reported the highest levels of perceived social support and satisfaction with their doctor-patient relationship. No group differences in emotional and functional wellbeing were found. Since the group mean scores across all dimensions of quality of life did not exceed the 55%-ile rank, it can be concluded that none of the assessed areas of pre-treatment quality of life was significantly impaired for any of the three patient groups.

Post-treatment assessment of patients' *psychological status* pointed to more than half of benign patients being clinically anxious, which was significantly higher than the percentage of patients in the cancer and pre-invasive groups. The majority of patients in this sample were not clinically depressed, regardless of the type of their gynaecological condition, although rates of clinically significant depressive symptoms were more frequent in the cancer and benign groups compared to the pre-invasive group.

## **6.2 Discussion**

### **6.2.1 Demographic variables**

The three groups of women differed on a number of demographic variables. It is evident that these differences were largely due to pre-invasive patients representing a much younger population than benign and cancer patients. Overall, the pre-invasive group consisted of young, mostly educated, single women working in professional positions. In contrast, the majority of cancer patients were married with children and came from lower educational and working backgrounds. Compared to cancer patients, a significantly higher

percentage of benign patients completed tertiary education and held professional positions. The majority of patients in all groups had Anglo-Saxon ethnic origins.

In the current study, age-matching of the two control groups with cancer group was not feasible. From a clinical point of view, questions can be raised as to whether it is desirable to aim for a perfect match for age since demographic variables can be controlled statistically. Had the pre-invasive group been matched to the cancer group, one of the groups would not have been representative of the population from which they were sampled. By including group samples that are representative of the respective populations, a more authentic picture of post-operative outcomes of patients undergoing various treatments for gynaecological conditions may emerge. In the current study, the problem of non-matched samples was accounted for by controlling for important demographic variables in the subsequent multivariate analyses. The current patient groups were believed to adequately reflect the characteristics of targeted populations and consequently their sexual and quality of life outcomes could be considered as characteristic of women undergoing treatment for similar gynaecological conditions.

The current study supported the general literature findings that cervical cancer is more prominent among women from a lower socio-economic background (Parham & Hicks, 1995). However, since no in-depth evaluation of the women's socio-economic situation or other risk factors was undertaken in this study, any conclusion needs to be drawn with caution. Whilst not unexpected, these results confirmed the importance of controlling for demographic factors in subsequent analyses exploring post-treatment outcomes in the three patient groups.

## **6.2.2 Baseline: Period prior to the onset of gynaecological symptoms / diagnosis**

### **6.2.2.1 Satisfaction with relationship**

No group differences regarding women's satisfaction with their relationship in the three months preceding the surgery/colposcopy were found, indicating comparability of groups at baseline. The average scores reported by women in the current sample (mean=14.6) were slightly superior to those reported in Buunk's group of married, healthy subjects (mean=16.3), implying a high degree of relationship satisfaction and support prior to the onset of gynaecological symptoms/diagnosis. Similar findings were obtained in Grumann *et al.*'s (2001) longitudinal study, where Buunk's scale was used to document changes in relationship satisfaction of early stage cervical cancer patients, benign patients and healthy controls. Consistent with the current study, no group differences in pre-treatment relationship satisfaction were noted, with the average score of Grumann's groups oscillating around 15. The current results are also in line with findings from the longitudinal studies of Schover *et al.* (1989) and Andersen *et al.* (1989b), which reported no major disruptions to intimate relationships following diagnosis in samples of early stage gynaecological cancer patients. The fact that patients in the benign and pre-invasive groups in the current study showed comparable baseline levels of relationship satisfaction to that of the cancer group, further supports previous findings that cancer diagnosis does not necessarily destabilise intimate relationships (Andersen *et al.*, 1989b, Weijmar Schultz *et al.*, 1991; Andersen, 1996).

### **6.2.2.2 Sexual functioning**

Prior to diagnosis, groups were comparably satisfied with their sexual lives. The mean value for **sexual satisfaction** of the current sample (mean=7.4) was slightly below that of Derogatis' sample of normal, healthy subjects (mean=8.9, SD=1.05), but considerably higher than the mean value of his female subjects

with sexual dysfunction (mean=4.2). As noted earlier, sexual satisfaction is no longer seen as limited to the experience of sexual arousal and coitus but rather as involving other aspects of relating such as emotional intimacy (Weijmar Schultz *et al.*, 1991). Whilst some women may experience substantial sexual changes pre- or post-treatment, these are not necessarily a source of distress. More specifically, less frequent coital activity does not necessarily compromise women's satisfaction with their sexual lives (also see qualitative Phase 1a findings). The intimacy levels, assessed by certain items included in the DSFI subscale of sexual satisfaction, indicated that the current sample of women experienced adequate pre-treatment levels of sexual satisfaction. Since pre-treatment satisfaction levels are known to be important predictors of post-treatment sexual outcomes, regardless of the treatment modality (Weijmar Schultz *et al.*, 1991), the fact that the current cancer patient sample did not report any major disruptions in sexual and relationship satisfaction indicates a potentially positive prognosis for post-treatment sexual adjustment for these patients.

Women in all groups reported comparable levels of **sexual drive** prior to the onset of their gynaecological symptoms/diagnosis. On the whole, patients in the current study experienced drive levels (mean =13.9) below Derogatis' sample of healthy women (mean=16.5). This difference in the levels of drive is most likely due to Derogatis' younger sample of women compared to the current sample. Since many of the cancer and benign patients were in their fifties, the relatively low level of sexual drive could be accounted for by hormonal changes associated with menopause and a possible decline in sexual activity related to reduced levels of sexual desire and arousability (Mackay *et al.*, 1990; Eden, 1995; Speroff *et al.*, 1994).

Women's **global evaluation of sexual life** (assessed by the GSSI subscale) was also comparable across all patient groups, falling into the "above average" (5) to "good" (6) band (mean<sub>Ca</sub>=5.77, mean<sub>Be</sub>=5.49, mean<sub>PI</sub>=5.37). Compared to

Derogatis' sample of 154 healthy female volunteers (mean= 4.81, SD=2.2), women in the current sample reported slightly greater satisfaction with their pre-diagnostic sexual lives. Grumann *et al.* (2001), using the GSSI subscale, reported close to identical levels of overall pre-treatment sexual satisfaction of cancer patients as found in the current study (mean=5.7, SD=2.41).

### **6.2.3 Baseline: Period during the month prior to surgery / colposcopy**

#### **6.2.3.1 Sexual functioning**

Cancer and benign patients reported moderate deterioration in their sexual life in the period following diagnosis and prior to surgery. Previous studies have found that women diagnosed with gynaecological cancer report lower levels of sexual functioning and poorer evaluation of themselves as a sexual person and partner (van de Wiel, Weijmar Schultz, Hallensleben, Thurkow & Bouma, 1988; Lamb & Sheldon, 1994). Zagwaard *et al.* (2000) in their qualitative study found that following diagnosis and before treatment, some women with cervical cancer recalled initiating sexual activity to farewell sexual life as they knew it, fearing a major change in their ability to engage in sexual activity post-operatively. It is possible that the patients in this study may have experienced a similar apprehension regarding their sexual capabilities post abdominal hysterectomy, resulting in disruption of their baseline sexual functioning.

#### **6.2.3.2 Quality of Life**

**Physical wellbeing** across the three groups of patients was in the expected direction, with pre-treatment physical functioning of benign patients being significantly more impaired than that of cancer and pre-invasive patients. In turn, physical wellbeing of cancer patients was significantly poorer than that of pre-invasive patients. When comparing the obtained mean scores (mean<sub>Ca</sub>=22.33, mean<sub>Be</sub>=18.51, mean<sub>PI</sub>=25.35) with those provided by Cella *et al.* (1993),

patients in the current sample leaned towards an average physical health state. Cella *et al.* (1993) report a mean value of 22.30 (SD=6.3) for cancer patients with stage I disease and value of 21.80 (SD=5.1) for stage II disease. Consequently, the score of cancer patients equaled that of Cella's stage I patients whilst pre-invasive patients' physical wellbeing was better than that of Cella's cancer patients. In contrast, benign patients reported poor pre-operative physical health, poorer than that of Cella's stage IV cancer patients (mean=19.6, SD=5.4).

These findings are consistent with the clinical findings for benign patients undergoing a hysterectomy, who commonly suffer from an immediate past history of incapacitating and debilitating symptoms (e.g. heavy bleeding) for which other treatments (e.g. dilatation & curettage and/or drug therapy) have been unsuccessful (Moore, 1986; Bachman, 1990). In contrast, early stage gynaecological cancer is largely asymptomatic although occasional dyspareunia, sporadic bleeding and vaginal discharge can occur (Hatch, 1994). Even fewer symptoms are associated with a pre-invasive condition (American Cancer Society, 2002). Hence, the less favourable pre-operative physical wellbeing of benign patients compared to cancer and pre-invasive patients further supports existing research findings.

The level of family and social support is known to impact on the recovery of patients treated for cancerous conditions (Gilbar *et al.*, 1995). In the current study, cancer patients reported a significantly better **social wellbeing** than benign and pre-invasive patients, prior to treatment. As with physical wellbeing, the scores of cancer patients on the social wellbeing subscale equaled those of Cella's stage I patients (mean=22.90, SD=5.3). Benign and pre-invasive cancer patients' social wellbeing/support was poorer than that of Cella's cancer patients, regardless of their disease stage. Since the cancer patient is in a physically and psychologically vulnerable position, the attitudes of those closest to them can exert a beneficial or detrimental effect on their recovery rate (Gilbar



*et al.*, 1995; Lichtman & Taylor, 1986; Hahn *et al.*, 1995). In fact, some argue that pre-treatment psychological and sexual variables are more crucial for post-treatment sexual rehabilitation than physical variables (Thranov & Klee, 1994). Therefore, the cancer patients' reports and perceptions of adequate social support indicate favourable conditions for the post-treatment sexual adjustment of these women.

The quality of the **doctor-patient relationship** has been postulated as an important component of quality of life assessment. Patients who are satisfied with doctor-patient communication understand more about their illness and its treatments, in turn facilitating patients' adjustment to the disease and their pre- and post-treatment quality of life (Butow, Kazemi, Beeney, Griffin, Dunn & Tattersall, 1996; Schofield, Butow, Thompson, Tattersall, Beeney & Dunn, *in press*). The communication style and personality of the oncologist/surgeon may have a marked, though sometimes unrecognised, influence on patients' psychological adjustment. For instance, Ong *et al.* (2000) found that the most prominent predictor of patients' quality of life and satisfaction has been the affective quality of consultations with their physicians/oncologists. In the current study, cancer patients expressed greater satisfaction with their treating doctor than patients from the other two groups. This could be related to a number of factors. Firstly, since cancer is a more serious condition, doctors may spend more time with patients, discussing their treatment options and attending to informational and emotional needs. Secondly, patients may want to have more confidence in their doctors as a means of decreasing their anxiety, considering their life-threatening situation and hence rate the relationship more positively. Their mean satisfaction score (7.3) was comparable with Cella's stage I cancer patients' value (mean=7.1, SD=1.8). Combined with the reported high levels of social support and relationship satisfaction, such positive perceptions of medical and social support in cancer patients indicate a favourable prognosis for the post-treatment physical recuperation and psychological adaptation of these patients.

Pre-invasive patients' pre-treatment levels of **emotional wellbeing** were comparable to that of cancer patients, whilst being significantly poorer than that of benign patients. The equivalence of cancer and pre-invasive patients in this respect further reinforces findings of the Phase 1b qualitative study, pointing to a notable initial impact of the diagnosis of pre-cancerous cervical lesions on the patients' emotional wellbeing. These findings are consistent with Andersen's (1993) reports of the transitory nature of cancer-related distress/negative emotional responses, which tend to resolve following treatment. The low to moderate levels of distress in the current sample of pre-invasive patients may have been indicative of a natural adjustment process to an uncertainty regarding the meaning of "pre-cancerous" and the diagnosis of a potentially life-threatening disease.

The current finding of relatively high pre-treatment levels of **overall quality of life** of cancer patients (which were comparable with pre-invasive patients) is consistent with previous studies reporting low rates of pre-treatment morbidity in main life areas in early stage gynaecological cancer patients (Andersen, 1993; Grumann *et al.*, 2001). In contrast to cancer and pre-invasive patients, benign patients reported rather poor overall pre-treatment quality of life. The low levels of emotional distress and high quality of life reported by cancer patients, perhaps counter-intuitive, could be explained by a phenomenon postulated by Sprangers & Schwartz (1999), called a response shift. This is defined as a change in the way one perceives quality of life. This change is deemed to be influenced by a) a change in the way the patient measures their quality of life, b) a change in their values, and c) a re-definition of what constitutes quality of life. The result of response shift is that cancer patients do not report a lower quality of life than the benign patients, due to a re-definition of their quality of life following their cancer diagnosis. The comparable levels of overall quality of life in the cancer and pre-invasive groups indicate a major impact of the diagnosis of pre-cancerous abnormalities on patients' overall wellbeing. This warrants further investigation.

## **6.2.4 Baseline: Post-surgery / LLETZ (or equivalent for pre-invasive patients)**

### **6.2.4.1 Psychological status**

Comparisons of patients' post-treatment levels of psychological distress yielded interesting findings. Whilst recovering from surgery, more than half of benign patients were clinically anxious, compared to 30 % of cancer patients and 34 % of pre-invasive patients. A strong (albeit non-significant) tendency of cancer patients to experience higher post-treatment anxiety levels than pre-invasive patients was also noted. Although the majority of patients were not clinically depressed, a significantly higher proportion of benign patients experienced clinical levels of depression compared to the other patient groups.

These findings fit Andersen *et al.*'s (1989b) suggestion of the transitory nature of psychological distress as the patient progresses through the gynaecological cancer trajectory. The generally high levels of distress characteristic of the time of cancer diagnosis and subsequent anticipation of surgery, may gradually dissipate as the patient recovers from the operation. Hence, the impact of successful removal of cancerous tissue and a positive prognosis may have accounted for relatively low post-treatment levels of distress in the cancer patients. However, although the total anxiety scores were in the "normal" range, this masks the fact that there was a high rate of clinically significant levels of anxiety (30%). It is recognised that up to a third of cancer patients become clinically anxious and depressed, which represents a three- to fourfold increase of clinically significant levels of distress in comparison to the general population (Li *et al.*, 1999).

Approximately half of the benign patients experienced clinical levels of anxiety within the first two weeks post-hysterectomy. It has been established in other studies that the incidence of depressed mood is higher among patients prior to hysterectomy than in an age-matched female population (Gath, Cooper & Day,

1982a). Prior to their treatment, benign patients are known to suffer from emotionally distressing and physically depleting symptoms such as heavy periods, chronic pelvic pain and/or severe pre-menstrual syndrome. These symptoms significantly compromise women's daily functioning, causing lethargy and diminished resistance to infections as well as resulting in secondary psychological problems such as elevated levels of depression/anxiety (Alexander *et al.*, 1996, Nathorst-Boos *et al.*, 1993). Moreover, the anticipation of any surgery is known to cause nervousness and anxiety (Anderson *et al.*, 1989b). In the study by Gottesman & Lewis (1982), similar feelings were reported by cancer and benign patients who were anticipating gynaecological surgery. Consequently, the post-treatment clinical levels of anxiety may have been a continuation of a chronic heightened distress experienced by benign patients prior to their hysterectomy.

Further, although benign patients consented to a hysterectomy in order to improve their quality of life, the operation may have temporarily exacerbated problems associated with a weakened physical and psychological system, compromising and retarding their recovery process. In addition, women may have felt vulnerable having had their reproductive organs removed or uncertain as to possible physical and psychological side effects of the surgery, including the onset of menopause, where this had not already occurred (Khastghir & Studd, 1998). It is possible that in cancer patients similar concerns would be overridden by existential issues since the patients' primary motivation for having surgery would be to rid themselves of a potentially fatal disease. Finally, the lower levels of anxiety and depression in cancer patients compared to benign patients could be related to the reassurance and quality of information provided by their respective treating doctors. Considering the significantly greater satisfaction of cancer patients with their treating doctors compared to benign patients, it is possible that cancer patients received a more thorough explanation of their treatment procedures and reassurance, resulting in reduced levels of psychological distress post-treatment.

#### **6.2.4.2 Mental adjustment styles of cancer patients**

Cancer patients reported *anxious preoccupation* (AP) with the disease as their most frequent adjustment style. The Mini-MAC anxious preoccupation subscale includes items that identify highly anxious patients engaging in information-seeking behaviour, thus sustaining the patient's anxiety and leading to excessive rumination about the disease and its impact. The predominance of anxious preoccupation responses is not surprising considering the assessment of adjustment styles took place immediately following surgery. Being anxiously preoccupied with the outcome of cancer treatment at that time could be seen as a normal adjustment response.

*Helpless/hopeless* (HH) responses were less prominent in the current cancer sample. Originally, HH responses were linked to high levels of psychopathology whereas fighting spirit (FS) was associated with low levels of pathology (Greer *et al.*, 1979). However, in a recent study by Watson *et al.* (1999) with breast cancer patients, FS was not found to have an impact on the long-term disease outcome, whilst a modest negative impact of HH adjustment style on a 5-year event-free survival was noted. Thus the absence of prominent HH responses in the current sample would be expected to contribute to a favourable post-treatment outcome for cancer patients. As mentioned previously, the FS subscale was not included in the analyses due to its low internal consistency (calculated using responses of the current sample). However, considering the findings of Watson *et al.* (1999), the omission of FS subscale in the current study should not have significantly compromised the validity of the current adjustment style results.

Similarly to HH responses, cancer patients infrequently used the *cognitive avoidance* (CA) adjustment style, as measured by the Mini-MAC scale. The CA subscale assesses patient's tendency to avoid actively thinking about the diagnosis and its implications. This response differs to a degree from denial, which was originally assessed by a single item in the MAC inventory (Watson *et al.*, 1994). The authors recognise the difficulty in stating that denial is present

when the patient actively participates in completing a questionnaire asking about responses to having cancer. Hence this single item was replaced by the CA subscale assessing the degree to which the patient avoids/denies the affective and cognitive *impact* of cancer diagnosis. The relatively low CA score obtained in the current sample indicates that cancer patients were not attempting to avoid/deny their feelings or thinking about their cancer diagnosis, treatment and its implications. The authors believe that the very act of completing a questionnaire that asks about responses to having cancer, suggests that the patient does not consciously deny their cancerous condition. It is possible to assess when a patient avoids/denies the affective and cognitive *impact* of the diagnosis. This is assessed by items in the CA subscale.

To our knowledge, no studies using Mini-MAC inventory were published at the time of the completion of this project. This rendered it difficult to compare the current findings with those in other studies. Therefore, interpretations of the current findings need to be made with caution.

### **6.3 Summary of baseline findings**

Pre-diagnosis, sexual functioning of the three groups of patients was comparable, allowing for reliable comparisons of post-treatment sexual outcomes at both follow ups. High levels of satisfaction with intimate relationships and doctor-patient relationships point to a favourable prognosis for cancer patients' post-treatment sexual and quality of life outcomes. Surprisingly low levels of quality of life and high levels of psychological distress were noted in the pre-invasive group. Poor quality of life and high levels psychological distress of benign patients were anticipated due to their long-standing debilitating gynaecological symptoms. There is a danger that health professionals may underestimate the impact of non-oncological gynaecological conditions on patients' quality of life including psycho-sexual wellbeing.

# 7. PROSPECTIVE LONGITUDINAL DATA

## 7.1 Results I: Prospective findings at 6 months follow up

For ease of reading, the following abbreviations are used:

CG = Cancer group / patients

BG = Benign group / patients

PG = Pre-invasive group / patients

As with the baseline analyses, theoretical considerations and a correlational matrix were used to select an optimal set of covariates. The matrix of selected demographic variables and changed scores for the outcome variables was generated. No significant correlations between demographic variables and changed scores were found for any variables, except for the sexual drive outcome. However, since these correlations were very low (i.e.  $r_{age} = -0.231$ ,  $r_{occupation} = -0.223$ ,  $r_{education} = -0.265$ ,  $r_{children} = -0.245$ ) and since age was inter-correlated with occupation, education and number of children, it was concluded that controlling only for age in the repeated measures analyses would be sufficient. The confounding effects of anxiety and depression levels at 6 months follow up were also controlled for in all subsequent repeated measures ANCOVAs.

### 7.1.1 Hormonal changes

As mentioned in Chapter VI, describing baseline data, 60% of our cancer patients were peri- or post-menopausal prior to their treatment compared to 42% of benign and 11% pre-invasive patients. By 6 months follow up, the difference between surgery groups diminished, with 74% of cancer patients and 66% of

benign patients reporting a peri- or post-menopausal status (see Table 7.1.1.). As expected, menopausal status of pre-invasive patients remained largely unchanged, with only two women reporting peri- or post- menopausal status at 6 months follow up.

With respect to the use of HRT, only 11% of cancer patients and 4% pre-invasive patients were using HRT at baseline compared to 28% of benign patients. By 6 months follow up, the use of HRT increased to 23% in the cancer group and 48% in the benign group. No changes in the use of HRT were detected for the pre-invasive group.

Table 7.1.1. *Changes in menopausal status and HRT use over time*

		<b>Cancer group</b>	<b>Benign group</b>	<b>Pre-invasive group</b>
<b>Menopausal status</b>	<i>Baseline</i>	60%	42%	11%
	<i>6 months F- up</i>	74%	66%	7%
<b>HRT</b>	<i>Baseline</i>	11%	28%	4%
	<i>6 months F-up</i>	23%	48%	5%

*Note: Baseline refers to pre-treatment assessment*

*Due to different sample sizes at each assessment only percentage are reported*

Bilateral Salpingo-Oophorectomy (BSO), involving surgical removal of both ovaries and fallopian tubes, is frequently performed with Total Abdominal Hysterectomy and Radical Hysterectomy. As a result the patient experiences a surgically-induced menopause, characterised by oestrogen deficiency symptoms of general aging of the genitals and atrophic vaginitis (Andersen *et al.*, 1989a). Whereas the option of HRT is given to patients with benign gynaecological conditions, cancer patients with oestrogen-sensitive tumours cannot be offered such hormonal replacements. In the current sample, 64% of cancer patients and 40% of benign patients had their ovaries removed (i.e. BSO). Of these, 32% of cancer patients and 30% of benign patients were pre-menopausal prior to the operation. At 6 months post-treatment, 58% of cancer patients and 48% of benign patients who had their ovaries surgically removed (i.e. BSO) were *not* using HRT.



### 7.1.2 Satisfaction with relationship

A repeated measures ANCOVA relationship satisfaction revealed no main effect for group ( $F(2,82)=0.159$ ,  $p=0.853$ ) and no group x time interaction effect ( $F(2,82)=0.187$ ,  $p=0.830$ ). There was, however, a significant effect for time ( $F(1,82)=4.736$ ,  $p=0.032$ ). Examination of means in Table 7.1.2. and Figure 7.1.1. indicates that the significant time effect was due to all patients, particularly those in the pre-invasive group, reporting lower satisfaction with their intimate relationship at 6 months follow up than at pre-diagnosis.

Figure 7.1.1. Changes in relationship satisfaction over time

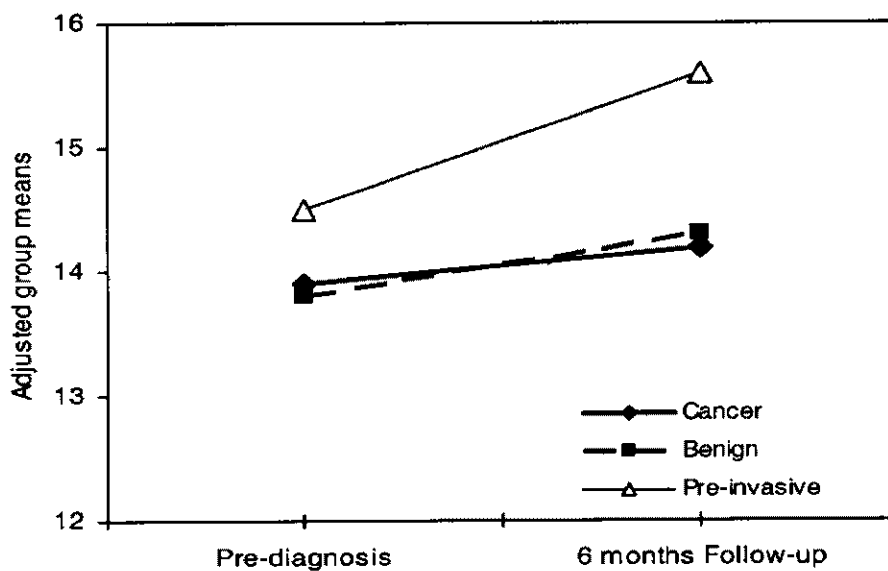


Table 7.1.2. *Group means (and standard errors) of relationship satisfaction and sexual functioning variables, adjusted for age and psychological status*

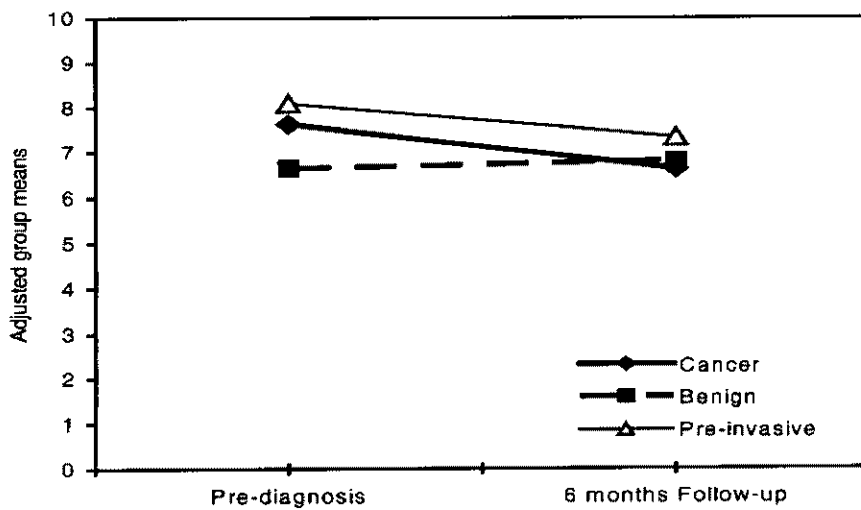
<b>Subscale</b>	<b>Group</b>	<b>Pre-diagnosis</b>		<b>6 months Follow up</b>	
		Mean (std. error)	DSFI T-score	Mean (std. error)	DSFI T-score
<b>Relationship satisfaction</b> <sup>§</sup> (max. score = 40)	Cancer	13.89 (0.94)		14.22 (1.01)	
	Benign	13.84 (0.96)		14.33 (1.03)	
	Pre-invasive	14.49 (1.47)		15.64 (1.57)	
<b>Sexual satisfaction</b> (max. score = 10)	Cancer	7.63 (0.48)	48	6.64 (0.51)	44
	Benign	6.65 (0.48)	44	6.82 (0.50)	45
	Pre-invasive	8.09 (0.75)	50	7.34 (0.79)	46
<b>Sexual drive</b> (max. score = 40)	Cancer	15.54 (1.07)	48	11.05 (1.18)	42
	Benign	15.49 (1.03)	48	12.33 (1.13)	42
	Pre-invasive	12.96 (1.54)	43	9.39 (1.69)	40
<b>GSSI</b> (Global Sexual Satisfaction Index) (max. score = 8)	Cancer	5.46 (0.33)	49	4.65 (0.40)	47
	Benign	5.73 (0.34)	51	5.22 (0.42)	48
	Pre-invasive	5.02 (0.48)	47	4.44 (0.58)	46

Note: Lower means indicate better outcomes for Relationship Satisfaction  
 Higher means indicate better outcomes for Sexual Functioning subscales  
 Baseline means/DSFI T-scores reported above differ from those cited in the Chapter VI due to different covariates used in the model (shaded areas indicate not applicable)  
 # = significant main effect for group, § = significant main effect for time, \* = significant interaction time x group effect

### 7.1.3 Changes in sexual functioning

A repeated measures 2 x 3 ANCOVA for **sexual satisfaction** revealed no main effects for time ( $F(2,82)=1.888$ ,  $p=0.173$ ) or group ( $F(2,82)=0.694$ ,  $p=0.503$ ) and there was no group x time interaction effect ( $F(2,82)=1.552$ ,  $p=0.218$ ). Although examination of means in Figure 7.1.2. and Table 7.1.2. indicates that cancer and pre-invasive patients reported slight deterioration in their level of sexual satisfaction in contrast to a marginal improvement in the benign group, these changes did not reach significance.

Figure 7.1.2. *Changes in sexual satisfaction over time*



Changes in patients' responses for *individual items of the DSFI Satisfaction subscale* at 6 months follow up compared to baseline, were inspected. Since, among others, these items evaluate satisfaction and changes within the four phases of the sexual response cycle (i.e. desire, arousal/excitement, orgasm, resolution), post-treatment disruptions pertinent to each response phase can be somewhat elucidated. Although Figure 7.1.3. and Table 7.1.3. indicate that cancer patients reported more adverse changes within various aspects of sexual relating than benign and pre-invasive patients over time, these differences were not significant. Except for the "frequency of sex", a slightly greater percentage of cancer patients was dissatisfied with all the assessed areas of sexual functioning at 6 months post-treatment compared to baseline (see Figure 7.1.4.). With respect to changes in the sexual response cycle, the greatest disruption was noted in the desire phase, with more than half of cancer patients reporting no interest in sexual activity at 6 months follow up. Satisfaction with orgasmic function was also adversely affected, declining over time from 78% to 62%. It is important to note that at 6 months post-treatment, half of the cancer patients often worried about their sexual performance, compared to only 32% of patients at baseline.

In contrast to cancer patients, the benign group did not report major changes in individual domains of sexual satisfaction over time, with the exception of the arousal phase (“foreplay is arousing for me”), which was adversely affected at 6 months follow up (see Figure 7.1.4.). The areas of greatest dissatisfaction in the benign group were: variety in sex (6 months follow up: 43%) and frequency of sex (6 months follow up: 46%), however discontent with these aspects was already evident at baseline. In the pre-invasive group, the only areas negatively affected over time were: “interest in sex” and “arousing foreplay”. As Figure 7.1.4. indicates, satisfaction of pre-invasive patients with certain areas of sexual relating improved over time.

Table 7.1.3. *Group percentage of true cases of the itemised Sexual Satisfaction subscale at baseline and at 6 months follow up*

	Cancer group (%)		Benign group (%)		Pre-invasive group (%)	
	Baseline	6 mths F-up	Baseline	6 mths F-up	Baseline	6 mths F-up
<i>I'm satisfied with my sexual partner</i>	95	78	89	85	96	91
<i>I feel I have sex frequently enough</i>	68	67	62	54	53	70
<i>There is enough variety in my sex life</i>	75	66	55	57	65	88
<i>After sex I feel relaxed and fulfilled</i>	85	75	84	76	89	87
<i>Sex lasts long enough</i>	88	75	75	76	81	91
<i>I'm interested in sex</i>	60	47	62	66	86	63
<i>I have satisfying orgasm with sex</i>	78	62	61	61	78	83
<i>Foreplay before intercourse is very arousing for me</i>	85	78	92	72	92	83
<i>I do not often worry about my sexual performance</i>	68	50	69	70	72	74
<i>My partner and I have a good communication about sex</i>	75	67	68	75	78	87

Figure 7.1.3. Group comparisons of the itemised Sexual Satisfaction subscale at 6 months post-treatment

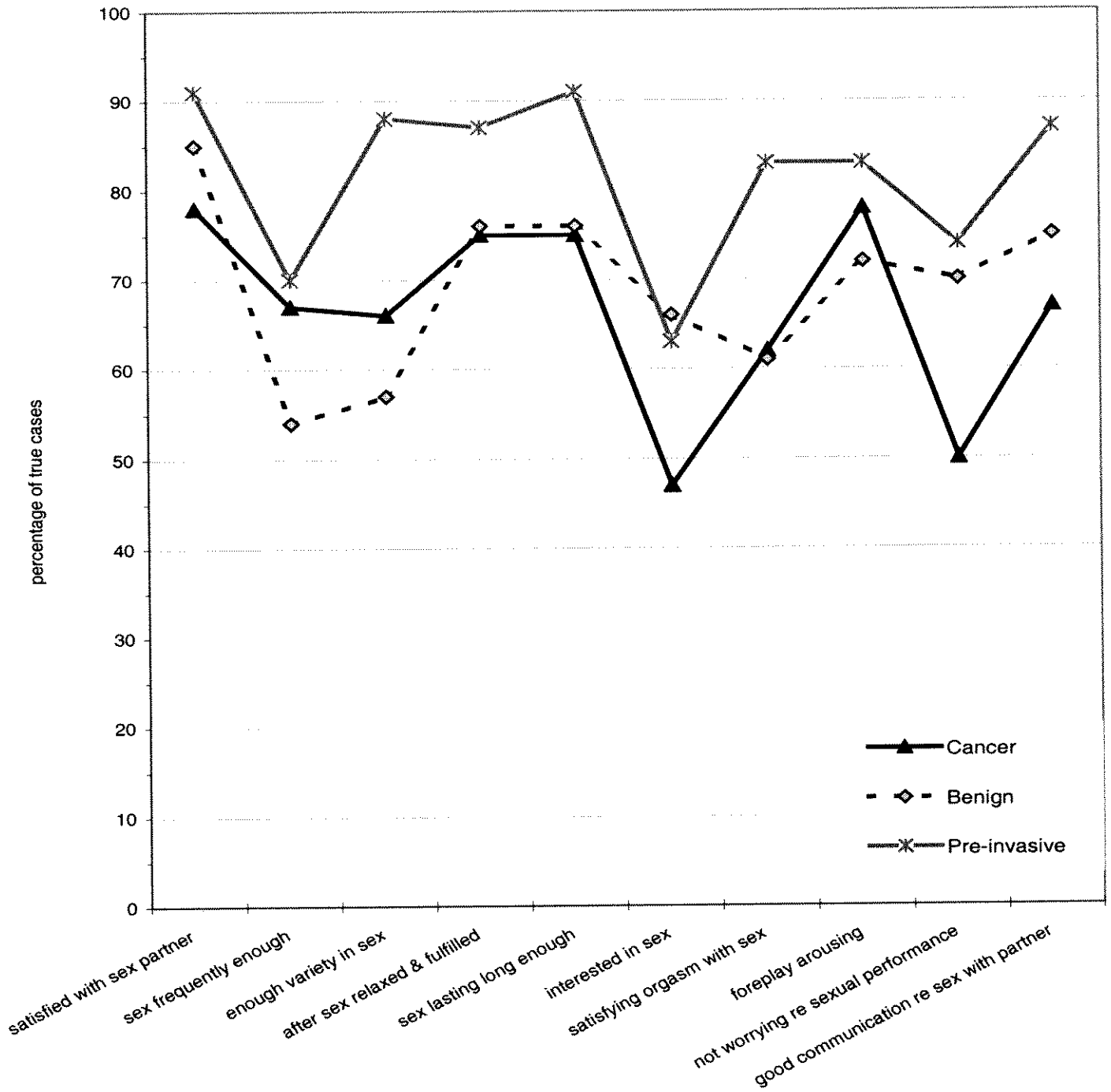
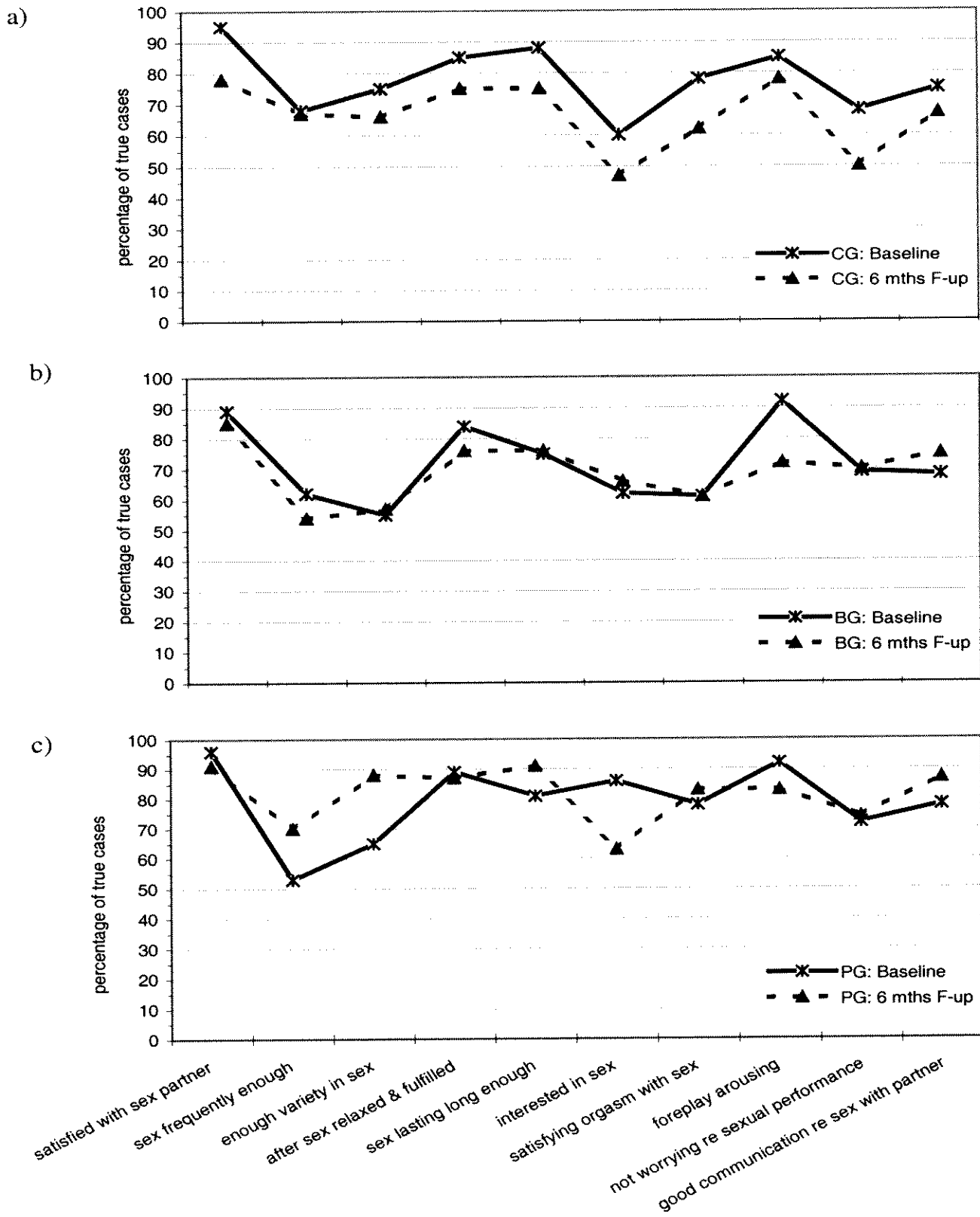


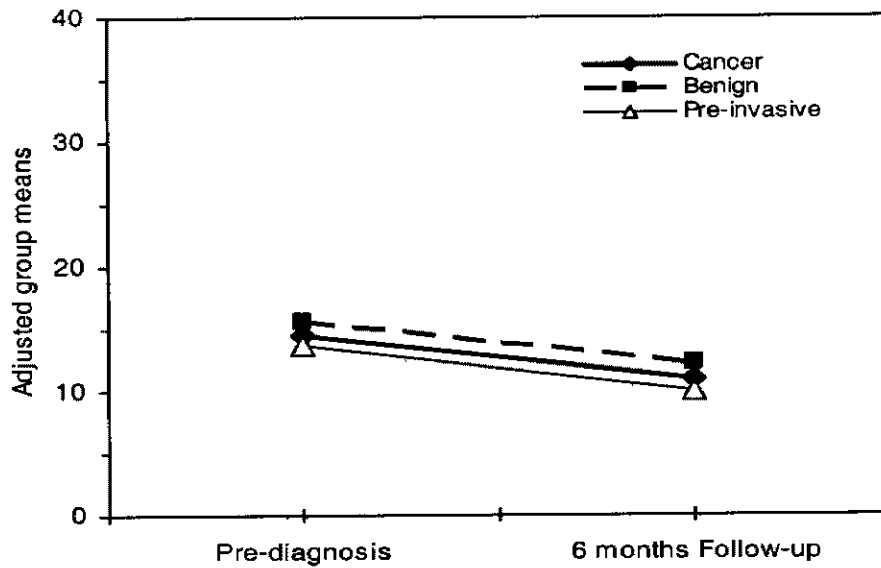
Figure 7.1.4. Percentage of true cases of the itemised Sexual Satisfaction subscale reported by a) cancer group, b) benign group and c) pre-invasive group at baseline and 6 months follow up



When further exploring the nature of the **first post-treatment sexual encounter**, a significantly higher percentage of benign patients (68%) compared to cancer patients (42%) indicated that this experience was satisfying (Fisher's exact test,  $p=0.049$ ). When asked who instigated the first post-treatment sexual encounter, 26% of cancer patients reported initiating the encounter themselves, 52% of encounters were initiated by their partner, and 22% of women indicated it was a joint decision. In the benign group, 46% of benign patients indicated that they initiated their first post-treatment sexual activity, 36% that their partner initiated it and 18% indicated it was by mutual agreement. No significant group differences were detected ( $\chi^2=2.540$ ,  $p=0.281$ ).

Regarding post-treatment levels of **sexual drive**, the 2 x 3 ANCOVA revealed no main effects for group ( $F(2,94)=0.937$ ,  $p=0.395$ ) and no group x time interaction effect ( $F(2,94)=0.004$ ,  $p=0.996$ ). However, a trend of deterioration of already low baseline levels in all three groups of patients was detected ( $F(2,94)=3.361$ ,  $p=0.070$ ) (see Figure 7.1.5.). A post-hoc analysis revealed that sexual drive scores were significantly lower at 6 months post-treatment compared to baseline only for the pre-invasive group of patients ( $F(1,25)=4.433$ ,  $p=0.045$ ).

Figure 7.1.5. *Changes in levels of sexual drive over time*



The Sexual Drive subscale is a summary measure of the libido in five behavioural domains of sexual interaction (intercourse, masturbation, kissing and petting, sexual fantasy, and ideal frequency of intercourse, see Table 7.1.4.). Repeated measures ANCOVA revealed a significant effect for time for two sexual drive items; frequency of intercourse ( $F(1,95)=4.637$ ,  $p=0.034$ ) and frequency of masturbation ( $F(1,94)=5.960$ ,  $p=0.017$ ). Examination of Table 7.1.4. indicates that these effects were due to a significant decline in post-treatment frequency of intercourse and masturbation in all patient groups compared to baseline (i.e. pre-diagnosis). The only significant effect for group was demonstrated in the frequency of masturbation ( $F(2,94)=4.325$ ,  $p=0.015$ ), with the benign group consistently reporting higher frequencies than cancer and pre-invasive patients. No other main or interaction effects were detected (all  $p>0.1$ ). Examination of Table 7.1.4. and results from paired t-tests point to interesting discrepancies between means for the real and ideal frequency of intercourse in all patient groups, indicating that patients desired more sexual encounters than they were experiencing ( $t=-7.924$ ,  $p=0.000$ ).



Table 7.1.4. Group means (and standard errors) of individual items of the sexual drive subscale, adjusted for age

Items (max. score=8)	Group	Pre-diagnosis	6 months Follow up
<b>Frequency of Intercourse</b> <sup>§</sup>	Cancer	2.88 (0.27)	2.03 (0.29)
	Benign	3.14 (0.97)	2.19 (0.29)
	Pre-invasive	3.12 (0.38)	2.12 (0.41)
<b>Frequency of Masturbation</b> <sup>§</sup>	Cancer	2.41 (0.28)	0.92 (0.19)
	Benign	2.90 (0.29)	1.64 (0.20)
	Pre-invasive	2.03 (0.39)	0.62 (0.27)
<b>Frequency of Kissing &amp; Petting</b>	Cancer	4.70 (0.40)	4.37 (0.49)
	Benign	4.34 (0.41)	3.36 (0.50)
	Pre-invasive	3.68 (0.54)	3.40 (0.66)
<b>Frequency of Sexual fantasies</b>	Cancer	1.32 (0.31)	0.78 (0.29)
	Benign	1.71 (0.32)	1.36 (0.30)
	Pre-invasive	1.49 (0.42)	1.35 (0.39)
<b>Ideal Frequency of Intercourse</b>	Cancer	3.57 (0.22)	3.27 (0.29)
	Benign	3.92 (0.22)	3.88 (0.28)
	Pre-invasive	3.68 (0.30)	3.16 (0.39)

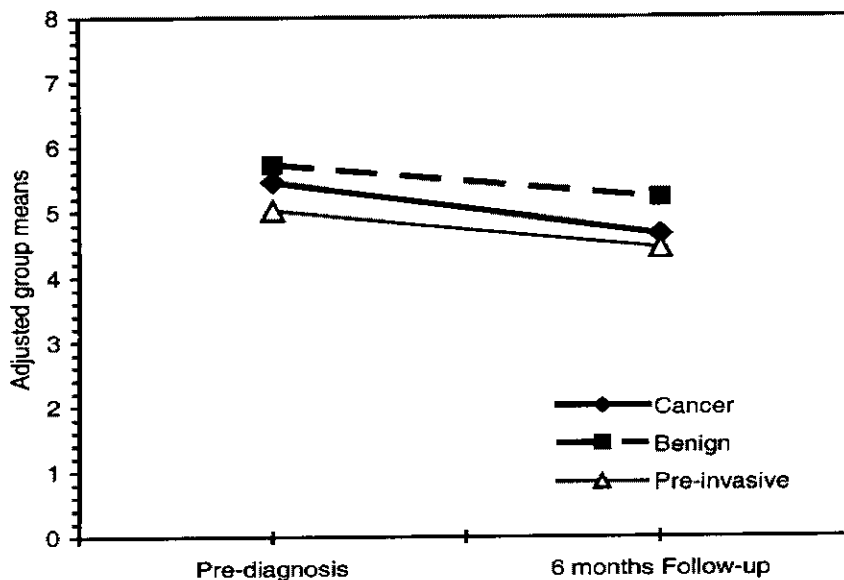
Note: (0) = not at all, (1) = less than 1x/month, (2) = 1-2x/month, (3) = 1x/week, (4) = 2-3 x/week  
 (5) = 4-6x/week, (6) = 1 x/day, (7) = 2-3 x/day, (8) = more than 4 x/day  
 # = significant main effect for group, § = significant main effect for time,  
 \* = significant interaction time x group effect

Detailed examination of the follow up findings revealed that four cancer patients (10%) who were sexually active at baseline did not **resume sexual intercourse after their treatment**, although they had a sexual partner. This is in contrast to the benign and pre-invasive groups where all patients resumed their sexual activity post- treatment. Inspection of the global evaluation of sexual life revealed that all four cancer patients reported that their sexual life had been "highly inadequate" or "could not be worse". Three of these women had undergone surgery alone, the fourth received adjuvant brachytherapy. This patient reported significant vaginal changes such as a considerable degree of vaginal stenosis, reduced vaginal lubrication and subsequent dyspareunia. This patient had not been given a vaginal dilator to use. The three patients who had undergone surgery alone did not report any adverse vaginal changes or other treatment side effects. However, interestingly, one patient reported that their partner was afraid that her treatment would harm him and two patients indicated

that their partners believed they could catch the “illness” from them during sexual intercourse. One patient also endorsed this misconception herself. Inspection of other outcome measures did not reveal impairments in any other areas. In addition, inspection of these three patients’ responses revealed that all three did not want to receive any information about post-treatment changes in sexual functioning and two women did not want the doctor to talk about sexual matters with them or their partner.

In contrast to the results for sexual drive, no significant results were evident for the 2 x 3 ANCOVA for **global evaluation of sexual functioning** (i.e. GSSI index), indicating no main effects for either time ( $F(1,81)=0.284$ ,  $p=0.595$ ) or group ( $F(2,81)=0.951$ ,  $p=0.391$ ) and no interaction effect ( $F(2,81)=0.153$ ,  $p=0.859$ ) (see Figure 7.1.6.). At both time points patients, on average, reported having an overall satisfactory sexual life, with anchors of the scale ranging from adequate (4) to good (6).

Figure 7.1.6. *Changes in global evaluation of sexual life over time*



Patients were also asked to indicate on a scale from 0 (not at all) to 5 (extremely), **how much their sexual functioning had changed since their treatment and whether this change was for the better or the worse.** Unfortunately, a number of patients did not complete this question. As Table 7.1.5. indicates, over three quarters of pre-invasive patients (78%) reported *no post-treatment changes* in sexual functioning compared to only about a quarter of cancer (26%) and benign (29%) patients. The majority of cancer patients (69%) indicated that their sexual life has changed *for the worse*, compared to 42% of benign patients and only 19% of pre-invasive patients. Of these, 17 cancer patients (63%), 5 benign patients (39%) and 5 pre-invasive patients (100%) reported slight (1) to moderate (2) changes in their post-treatment sexual functioning whilst 10 cancer patients (37%) and 6 benign patients (55%) indicated that their sexual life deteriorated “much” (3), “very much” (4) or “extremely” (5). Over a quarter of the benign patients reported *improvements* in post-treatment sexual life compared to only 5% of cancer and 4% of pre-invasive patients. Of these patients, the majority reported slight to moderate improvements, with only 1 cancer patient (50%) and 3 benign patients (33%) indicating considerable improvements in their post-treatment sexual life.

Table 7.1.5. *Post-treatment changes in sexual functioning reported at 6 months follow up*

	<b>No change</b>	<b>Change for better</b>	<b>Change for worse</b>
<i>Cancer group</i>	10 (26%)	2 (5%)	27 (69%)
<i>Benign group</i>	9 (29%)	9 (29%)	13 (42%)
<i>Pre-invasive group</i>	21 (78%)	1 (4%)	5 (19%)

### **7.1.4 Post-treatment changes in sexual functioning**

*(measured by SFAGIS)*

Post-treatment changes in women’s sexual functioning were assessed using the Sexual Functioning After Gynaecological Illness Scale (SFAGIS). The SFAGIS inventory was administered to those pre-invasive patients who had undergone the LLETZ procedure (i.e. a treatment subgroup) and had completed follow up

questionnaires (n=11). It was thought useful to include this group in preliminary analyses as the LLETZ procedure is so minor that objectively, no effects would have been anticipated. Therefore, a patient reporting any change suggests a psychological impact of the condition/treatment. Inspection of the data indicated that pre-invasive patients did not report any significant changes following their condition/treatment. Considering the lack of significant findings and a very high attrition rate in this group, it was decided to omit pre-invasive group's findings from this section. This exclusion was believed to facilitate detection of important trends in post-treatment vaginal changes in women treated with major gynaecological surgery, i.e. cancer and benign patients.

The following vaginal changes were assessed at 6 months follow up: vaginal stenosis (narrowing/closing of vagina), reduced vaginal lubrication, and reduced genital sensations during sexual arousal. Cross tabulations of post-treatment findings regarding the degree of **vaginal stenosis** revealed that only a third of cancer patients (33%) were *not* aware of any changes in vaginal elasticity, compared to over two thirds of benign patients (69%, see Table 7.1.6.). Fisher Exact test (2-sided) indicated that these differences were highly significant (p=0.002). Over a quarter (29%) of cancer patients compared to only 13% of benign patients indicated that they felt their vagina had become smaller/tighter post-treatment. Of particular concern was the report by one cancer patient (2%) who stated that her vagina had completely closed since treatment.

Table 7.1.6. *Patients' post-treatment reports of the incidence and degree of vaginal stenosis*

<b>"Since my treatment my vagina:"</b>	<b>Cancer group (n=45)</b>	<b>Benign group (n=39)</b>
<i>Became completely closed</i>	1 ( 2.2%)	0 ( 0.0%)
<i>Became smaller or tighter</i>	13 (28.9%)	5 (12.8%)
<i>Perhaps changed in size – I am not sure</i>	14 (31.3%)	6 (15.4%)
<i>Became larger or looser</i>	2 ( 4.4%)	1 ( 2.6%)
<i>Does not seem to have change in size</i>	15 (33.3%)	27 (69.2%)

Changes in **vaginal lubrication** during sexual relations within the first 6 months post-treatment were also assessed (see Table 7.1.7.). A number of patients did not complete this item as they did not have a sexual partner (CG: 17%, BG: 5%). Approximately a quarter of patients in both groups (CG: 27%, BG: 24%) reported having a “normally wet” vagina. The majority of remaining women (CG: 34%, BG: 57%) indicated that their vagina was a “little” dry following the treatment, with relatively few cancer patients (7%) and one benign patient (3%) reporting that their vagina felt completely dry. Chi-square test revealed no group differences regarding post-treatment changes in vaginal lubrication at 6 months follow up ( $\chi^2 = 1.227, p=0.542$ ).

Table 7.1.7. *Patients’ post-treatment reports of the incidence and degree of reduced vaginal lubrication when having sexual relations*

<b>“When I have had sexual relations after my treatment my vagina was:”</b>	<b>Cancer group (n=41)</b>	<b>Benign group (n=37)</b>
<i>Completely dry</i>	3 (7.3%)	1 (2.7%)
<i>I don’t know if my vagina was dry or wet</i>	6 (14.6%)	4 (10.8%)
<i>A little dry</i>	14 (34.1%)	21 (56.8%)
<i>Normally wet</i>	11 (26.8%)	9 (24.3%)
<i>This does not concern me because I do not have a partner</i>	7 (17.1%)	2 (5.4%)

A Fisher Exact test (2-sided) revealed a trend of higher incidence of reduced **genital sensations** during sexual arousal in the cancer group compared to the benign group at 6 months follow up ( $p=0.07$ ). As Table 7.1.8. indicates, 42% of cancer patients, compared to 73% of benign patients, reported *no change* in sensations. Only a small percentage of patients (CG: 7%, BG: 5%) reported substantial reductions in their genital sensations (i.e. “quite a bit” or “a lot”).

Table 7.1.8. *Patients' post-treatment reports of the incidence and degree of genital sensations*

<b>"Since the end of my treatment I have had reduced sensations in my genitals:"</b>	<b>Cancer group (n=41)</b>	<b>Benign group (n=41)</b>
<i>Not at all</i>	17 (41.5%)	30 (73.2%)
<i>A little bit</i>	11 (26.8%)	5 (12.2%)
<i>Somewhat</i>	6 (14.6%)	4 (9.8%)
<i>Quite a bit</i>	4 (9.8%)	1 (2.4%)
<i>A lot</i>	3 (7.3%)	1 (2.4%)

No significant group differences were detected between patients reporting normal levels of **sexual excitement** and those with reduced sexual excitement at 6 months post-treatment (Fisher Exact test (2-sided),  $p=0.509$ ). As Table 7.1.9. indicates, a greater percentage of cancer patients compared to benign patients reported having no sexual excitement since their treatment (CG: 22%, BG: 7%).

Table 7.1.9. *Patients' reports of degree of sexual excitement since the end of their treatment*

<b>"Since the end of my treatment, I have felt:"</b>	<b>Cancer group (n=42)</b>	<b>Benign group (n=41)</b>
<i>No sexual excitement or "turn on"</i>	9 (21.9%)	3 (7.3%)
<i>Little sexual excitement</i>	5 (11.9%)	12 (29.3%)
<i>Some sexual excitement but less than before treatment</i>	12 (28.6%)	7 (17.1%)
<i>Normally sexually excited</i>	16 (38.1%)	19 (46.3%)

A number of items focused on the provision of **information related to potential effects of the gynaecological illness and treatment on sexual functioning**, including patients' preferences for such discussions. In particular, patients were asked from whom they would like to receive sexual information, whether they would like their partner present during such discussions and to nominate the optimal time in the treatment trajectory for such conversations to take place.

In the current sample, just over half of the patients in both groups (i.e. CG: 53%, BG: 55%) reported that **the topic of post-treatment changes in sexual**

**functioning was addressed** at some stage during consultations. For detailed information on when these discussions took place see Table 7.1.10. It is important to note that 20% of cancer patients and only 5% of benign patients were unsure whether such discussions had taken place.

Table 7.1.10. *When sexual issues were discussed during consultations*

<b>"My doctor talked about my sex life:"</b>	<b>Cancer group (n=24)</b>	<b>Benign group (n=22)</b>
<i>Before treatment</i>	6 (25%)	6 (27%)
<i>During treatment</i>	2 (8 %)	2 (9%)
<i>End of treatment</i>	6 (25%)	4 (6%)
<i>Before &amp; after treatment</i>	10 (42%)	8 (36%)
<i>During &amp; after treatment</i>	0 (0.0%)	2 (9%)
<i>Before, during &amp; after treatment</i>	0 (0.0%)	0 (0.0%)

*Note: Numbers (percentages) in this Table are based on reports of only those patients who received information regarding sexual matters at some stage during their illness trajectory*

The majority of patients (CG: 74%, BG: 77%) indicated that they would **like to discuss relevant aspects of sexual life with their doctor**, with most patients wanting such discussions to occur with their partner present (CG: 81%, BG: 82%). Only 10% of cancer and benign patients preferred their doctor to speak separately to both of them or to speak only to their partner about possible changes in post-treatment sexual life (see Table 7.1.11.).

Table 7.1.11. *Patients' preferences of discussing sexual issues during consultations*

<b>"If I had a choice, I would like my doctor:"</b>	<b>Cancer group (n=43)</b>	<b>Benign group (n=39)</b>
<i>Not to speak about sexual matters</i>	11 (25.6%)	9 (23.1%)
<i>To speak about sexual matters</i>	32 (74.4%)	30 (76.9%)
<b>"If I had a partner, I would like my doctor:"</b>	(n=41)	(n=39)
<i>To speak to my partner only</i>	4 (9.8%)	4 (10.3%)
<i>To speak to both of us but not together</i>	4 (9.8%)	3 (7.7%)
<i>To speak to both of us together</i>	33 (80.5%)	32 (82.1%)

When asked *from whom* would they like *to receive sexual information*, most of the patients (CG: 48%, BG: 65%) reported no preference, being comfortable with either a male or a female health care worker (see Table 7.1.12.). The second most preferred choice was another female such as doctor, nurse, social worker or psychologist (CG: 37%, BG: 29%), followed by female doctor only (CG: 15%, BG: 6%).

Table 7.1.12. *Patients' preferences regarding from whom to receive information about potential post-treatment sexual changes*

<i>"If I had a choice I would like to receive sexual information from:"</i>	<i>Cancer group (n=27)</i>	<i>Benign group (n=17)</i>
<i>A female health care worker (e.g. doctor, nurse, psychologist, social worker)</i>	10 (37.0%)	5 (29.4%)
<i>A female doctor only</i>	4 (14.8%)	1 (5.9%)
<i>A male health care worker (e.g. doctor, nurse, psychologist, social worker)</i>	0 (0.0%)	0 (0.0%)
<i>Either a male or a female healthcare worker</i>	13 (48.1%)	11 (64.7%)

*Note: Only responses of patients who indicated that they would like to receive information about sexual matters are included*

Patients were also asked *when* they would like *to receive information about the possible impact of cancer and its treatment on sexual functioning*. As evident from Table 7.1.13., patients indicated a wide range of times for such discussions to occur. Nevertheless, the most common preference for discussion for cancer and benign patients was prior to the first treatment (CG: 31%, BG: 26%) and at their request should queries arise (CG: 22%, BG: 31%). Approximately one third of patients in both groups (CG: 34%, BG: 31%) did not want any information concerning their sexual life post-treatment.



Table 7.1.13. *The preferences for time periods during the illness trajectory related to discussions of sexual issues during consultations*

<b>"I would like to receive information about sexual expectations following treatment:"</b>	<b>Cancer group (n=41)</b>	<b>Benign group (n=39)</b>
<i>Not at all</i>	14 (34%)	12 (31%)
<i>Prior to the 1<sup>st</sup> treatment</i>	13 (32%)	10 (26%)
<i>Immediately following the 1<sup>st</sup> treatment</i>	1 (2%)	0 (0%)
<i>During the 1<sup>st</sup> follow up consultation</i>	4 (1%)	1 (3%)
<i>On my request when queries arise</i>	9 (22%)	12 (31%)
<i>All of the above</i>	0 (0%)	4 (10%)

Common myths and misconceptions, such as *patients' and partners' beliefs indicating a risk of "catching" the disease* from their partner were also explored. The vast majority of patients (CG: 95%, BG: 97%) understood that their partner could not be physically harmed by their illness in any way. However, one cancer patient believed that her partner could become ill or hurt if they had sexual relations and one patient from both groups reported that their partner could not be harmed so long as they did not have sexual relations (see Table 7.1.14.). Further, 2 cancer patients (4.5%) reported that their partner was afraid of "catching" cancer from them and 2 cancer patients (4.5%) reported partner's fears of being harmed by the patients' treatments such as radiotherapy (see Table 7.1.15.).

Table 7.1.14. *Assessment of prevalence of misconceptions and myths among patients regarding contagiousness of the illness*

<b>"Because of my illness, I believe a partner"</b>	<b>Cancer group (n=43)</b>	<b>Benign group (n=38)</b>
<i>Could "catch" my illness even if we did not have sexual relations</i>	0 (0.0%)	0 (0.0%)
<i>Could become sick or hurt if we had sexual relations</i>	1 (2.3%)	0 (0.0%)
<i>Could not be harmed provided we did not have sexual relations</i>	1 (2.3%)	1 (2.6%)
<i>Could not be harmed if we had sexual relations</i>	41 (95.3%)	37 (97.4%)

Table 7.1.15. *Patients' reports of misconceptions and myths among partners regarding contagiousness of the illness*

<b>"My partner:"</b>	<b>Cancer group (n=43)</b>	<b>Benign group (n=38)</b>
<i>This does not concern me because I do not have a partner</i>	7 (15.9%)	2 (5.4%)
<i>Is afraid that he/she will "catch" my illness</i>	2 (4.5%)	0 (0.0%)
<i>Is afraid that my treatment (such as radiotherapy) will harm him/her</i>	2 (4.5%)	0 (0.0%)
<i>Does not know very much about my illness and its treatment</i>	0 (0.0%)	9 (24.3%)
<i>Knows that neither my illness nor its treatment can harm him/her</i>	33 (75.0%)	26 (70.3%)

As mentioned earlier, radiation therapy can cause vaginal stenosis. It is possible to ameliorate the restrictions of scar tissue by stretching the walls of the vagina several times a week. This can be done by sexual intercourse three to four times a week or by using a vaginal dilator. Patients were therefore asked ***whether and when they had received a vaginal dilator***. If they had, ***did they receive instructions for its use and did they used this rehabilitation tool***. Interestingly, of the 22 cancer patients who had undergone adjuvant radiotherapy, only one woman reported being given a vaginal dilator (see Table 7.1.16.). Although she had been given adequate instructions for its use (see Table 7.1.17.), this patient reported having used the dilator less often than was advised (see Table 7.1.18.). The mean post-treatment frequency of intercourse for women who had undergone radiation was 1-2 times a month (SD=1.2), with only one woman reporting having intercourse 2-3 times a week.

Table 7.1.16. *Cancer patients' reports of receiving a vaginal dilator*

<b>"I received vaginal dilator:"</b>	<b>Cancer group (n=41)</b>
<i>Not at all</i>	40 (97.6%)
<i>Just after my radiation treatment</i>	1 (2.4%)
<i>One month after the end of my treatment</i>	0 (0.0%)
<i>Two to three months after the end of my treatment</i>	0 (0.0%)
<i>More than three months after the end of my treatment</i>	0 (0.0%)

Table 7.1.17. *Cancer patients' reports of receiving instructions on how to use a vaginal dilator*

<b><i>"I was given sufficient explanation on the use of a vaginal dilator:"</i></b>	<b>Cancer group (n=39)</b>
Yes	1 (2.6%)
No	0 (0.0%)
Not applicable	38 (97.4%)

Table 7.1.18. *Cancer patients' reports on the frequency of use of a vaginal dilator*

<b><i>"I use a vaginal dilator:"</i></b>	<b>Cancer group (n=41)</b>
<i>Not at all because it was not given or prescribed to me</i>	39 (96.6%)
<i>Not at all though it was given or prescribed to me</i>	0 (0.0%)
<i>Less often than recommended</i>	1 (2.4%)
<i>As often I was told to use it</i>	0 (0.0%)
<i>More often than I was told to use it</i>	0 (0.0%)

### **7.1.5 Short-term treatment side effects**

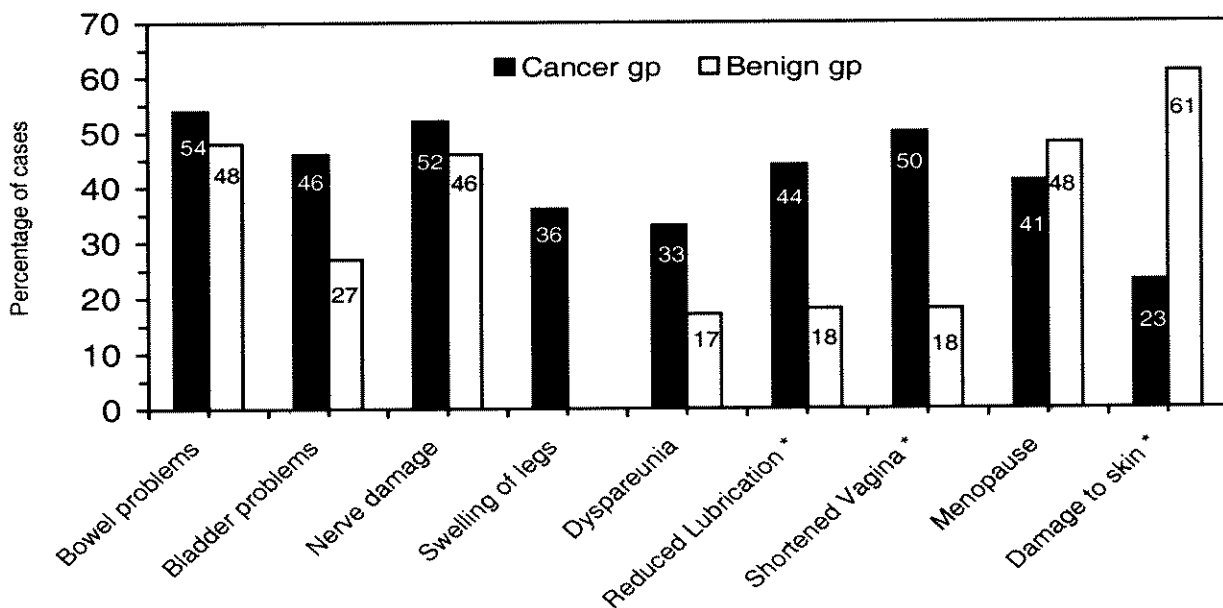
As discussed in the Method section, the qualitative study (Phase1a) with cancer patients, combined with the literature review, pointed to a number of side effects commonly experienced by cancer patients at various stages post-treatment. Based on these findings a new measure was developed, with the aim of obtaining a better understanding of women's perception as to how individual treatments influenced the development of particular side effects. This subjective information was then compared with known medical knowledge regarding the contribution of various treatments to the development of particular side effects. Only patients in the cancer and benign groups completed this measure.

As can be seen from Figure 7.1.8., a significantly greater percentage of cancer patients experienced various post-treatment side effects compared to benign patients. The Fisher's exact test (2-sided) revealed significant group differences in having a shortened vagina ( $p=0.005$ ; CG:  $n=21$ , 50%, BG:  $n=7$ , 18%) and reduced vaginal lubrication ( $p=0.010$ ; CG:  $n=20$ , 44%, BG:  $n=7$ , 18%). Lymphoedema was experienced only by cancer patients (CG:  $n=16$ , 35%, BG:

n=0) and therefore no statistical tests were computed. Interestingly, damage to skin such as scarring/burns in the pelvic area was the least prevalent side-effect reported by the cancer group (n=10, 23%), but the most reported side effect in the benign group (n=25, 61%), indicating significant group differences (p=0.001). A trend of bladder problems such as incontinence was more evident in the cancer group compared to the benign group, although this effect failed to reach significance (p=0.079; CG: n=21, 46%, BG: n=11, 27%).

No group differences between benign and cancer patients were detected regarding the side effect of bowel problems, such as constipation or diarrhoea (p=0.666; CG: n=25, 54%, BG: n=19, 48%), nerve damage or numbness in the pelvic area (p=0.669; CG: n=24, 52%, BG: n=19, 46%), dyspareunia (p=0.184; CG: n=13, 33%, BG: n=6, 17%) and the onset of menopause (p=0.661; CG: n=18, 41%, BG: n=19, 48%). It is important to note that, except for dyspareunia, nearly half of patients in each group reported these side effects (see Figure 7.1.7.).

Figure 7.1.7. *Percentage of various side effects experienced by cancer and benign patients at 6 months post-treatment*



Note: \* indicates significant differences

Patients were also given the option to include any additional side effects not listed in the questionnaire. The majority of patients did not report experiencing any additional side effects, which indicates that the most common side effects were covered by the questionnaire (CG: 67%, BG: 70%). Additional side effects reported by cancer patients included a lowered libido, loss of pubic hair, “partial loss of use of the right leg”, stomach pain/ache, an infected wound, and “drainage of lymph cysts in lower abdomen”.

### ***7.1.6 Side effects pertinent to specific treatment modalities***

An investigation of perceived causes of side effects was conducted with those patients experiencing such post-treatment side effects. Therefore, the percentages noted in the following section refer only to those women who had experienced any of the given side effects. For a review of short and long-term side effects pertinent to specific treatment modalities see section 1.2.3 within the literature review. Due to the small number of patients in individual radiotherapy subgroups, responses of brachytherapy and pelvic radiotherapy patients were combined.

As Table 7.1.19. indicates, most patients identified relevant side effects of surgery. Patients who had undergone a combined treatment of surgery and radiotherapy largely attributed bowel problems, dyspareunia and skin damage to radiotherapy. It is of concern that a small group of patients indicated they did not know what had caused their side effects.

Table 7.1.19. **Perceived causes of side effects of various treatments reported by patients experiencing these side effects**

Side effects	Treatment groups	Side effect attributed to:			
		Sx	Rx	Don't know	Other causes
<b>Bowel problems</b>	BG: Sx (n=19)	6		9	4
	CG: Sx (n=15)	9		1	0
	CG: Sx & Rx (n=15)	3	9	0	3
<b>Bladder problems</b>	BG: Sx (n=11)	8		2	1
	CG: Sx (n=8)	7		0	1
	CG: Sx & Rx (n=12)	4	6	0	2
<b>Nerve damage</b>	BG: Sx (n=19)	17		2	0
	CG: Sx (n=13)	12		0	1
	CG: Sx & Rx (n=11)	7	3	1	0
<b>Lymphoedema</b>	BG: Sx (n/a)	-		-	-
	CG: Sx (n=9)	8		1	0
	CG: Sx & Rx (n=6)	2	3	1	0
<b>Dyspareunia</b>	BG: Sx (n=6)	5		1	0
	CG: Sx (n=3)	3		0	0
	CG: Sx & Rx (n=8)	2	5	1	0
<b>Reduced lubrication</b>	BG: Sx (n=7)	4		2	1
	CG: Sx (n=10)	7		3	0
	CG: Sx & Rx (n=10)	3	4	2	1
<b>Shortened vagina</b>	BG: Sx (n=7)	6		0	1
	CG: Sx (n=9)	9		0	0
	CG: Sx & Rx (n=12)	10	2	0	0
<b>Onset of menopause</b>	BG: Sx (n=19)	16		1	2
	CG: Sx (n=9)	7		1	1
	CG: Sx & Rx (n=9)	3	3	3	0
<b>Skin damage</b>	BG: Sx (n=25)	23		2	0
	CG: Sx (n=3)	2		0	1
	CG: Sx & Rx (n=7)	2	4	1	0

Note: Sx = Surgery, Rx= Adjuvant radiation  
Shaded areas indicate not applicable

### **7.1.7 Main issues pertinent to surgical treatment**

A questionnaire exploring the perceived impact of treatments on 6 areas identified during the qualitative (Phase 1a) study as important was given to women at 6 months post-treatment. Women were asked to rate how much each treatment impacted on each of the six identified issues, namely femininity/womanhood, physical appearance, sexual functioning, infertility, feeling prepared for the treatment and feeling confident nothing would go wrong during treatment. For each issue, only group differences pertinent to the impact of surgery will be described in this section. An analysis of findings pertinent to various gynaecological cancer treatments (i.e. surgery versus external radiotherapy versus brachytherapy) will be examined within the longitudinal outcomes of the cancer group (Results section 7.2.7). It should be noted that only those pre-invasive patients who had undergone the LLETZ treatment were given this section of the follow up questionnaire. However, only 11 of the 25 patients returned the 6 months follow up questionnaire. Therefore, these findings need to be interpreted with caution. Nevertheless, responses of these women are included as they depict some interesting trends highlighted in the qualitative study (Phase 1b).

Table 7.1.20. describes a cross tabulation of patients' responses regarding various issues related to the impact of a gynaecological surgery. A greater percentage (40%) of cancer patients reported that their **femininity** was adversely affected by surgery, compared to benign patients (23%) and pre-invasive patients (18%). However, these differences failed to reach significance ( $\chi^2=4.769$ ,  $p=0.312$ ). Further, more than half of cancer and benign patients indicated surgery-related changes in their **physical appearance**, with 23% of cancer patients, 13% of benign patients 9% of pre-invasive patients reporting significant post-treatment changes. The chi-square statistics confirmed significant differences among patient groups ( $\chi^2=14.354$ ,  $p=0.006$ ). A high percentage of patients undergoing hysterectomy reported changes in **sexual functioning**, with a slightly higher number of cancer patients (62%) compared to

benign patients (54%) reporting mild to severe post-treatment changes in sexual functioning. No significant group differences on surgery-related changes in sexual functioning were noted ( $\chi^2=1.186$ ,  $p=0.880$ ). Interestingly, five of the ten pre-invasive patients who had undergone LLETZ treatment and who completed the follow up questionnaire reported that the procedure affected their post-treatment sexual functioning (see Table 7.1.20.). More importantly, 4 pre-invasive patients (44%) indicated that they believed the LLETZ procedure had made them “somewhat” or “very much” *infertile*. Five (12%) cancer patients and 9 (23%) benign patients reported that their hysterectomy had not affected their infertility. However, all but one of the benign patients were peri- or post-menopausal prior to their surgery. Although group differences were found among the three patient groups ( $\chi^2=31.271$ ,  $p=0.000$ ), a comparison of patient groups treated with hysterectomy (i.e. benign and cancer patients) showed comparable findings ( $\chi^2=2.848$ ,  $p=0.241$ ). The majority of patients reported being *prepared for the effect of surgery/LLETZ procedure* and its side effects, although 23% of cancer patients and 5% of benign patients indicated “not being prepared at all”. Indeed, significant group differences were identified by the chi-square test ( $\chi^2=13.911$ ,  $p=0.008$ ). Only a small percentage of patients reported not *feeling confident that anything could go wrong during surgery/LLETZ procedure* (CG: 16%, BG: 13%). No group differences were detected on this variable ( $\chi^2= 2.552$ ,  $p=0.635$ ).



Table 7.1.20. A summary of group frequencies (percentages) associated with the impact of surgery / LLETZ procedure on common issues identified by gynecological patients

	Group (n)	Not at all	Somewhat	Very Much
<b>Reduced Femininity</b>	CG (n=45)	26 (57.8%)	18 (40.0%)	1 (2.2%)
	BG (n=40)	29 (72.5%)	9 (22.5%)	2 (5.0%)
	PG (n=11)	9 (81.8%)	2 (18.2%)	0 (0.0%)
<b>Changed Physical Appearance</b>	CG (n=43)	19 (44.2%)	14 (32.6%)	10 (23.3%)
	BG (n=40)	14 (35.0%)	21 (52.5%)	5 (12.5%)
	PG (n=11)	10 (90.9%)	1 ( 9.1%)	0 ( 0.0%)
<b>Sexual Functioning affected</b>	CG (n=42)	16 (38.1%)	18 (42.9%)	8 (19.0%)
	BG (n=39)	18 (46.2%)	16 (41.0%)	5 (12.8%)
	PG (n=10)	5 (50.0%)	4 (40.0%)	1 (10.0%)
<b>The treatment and its side effects made me Infertile</b>	CG (n=41)	5 (12.2%)	0 ( 0.0%)	36 (87.8%)
	BG (n=39)	9 (23.1%)	1 ( 2.6%)	29 (74.4%)
	PG (n= 9)	5 (55.6%)	3 (33.3%)	1 (11.1%)
<b>Prepared for the treatment and its side effects</b>	CG (n=44)	10 (22.7%)	18 (40.9%)	16 (36.4%)
	BG (n=40)	2 ( 5.0%)	17 (42.5%)	21 (52.5%)
	PG (n=10)	0 ( 0.0%)	1 (10.0%)	9 (90.0%)
<b>Confident nothing could go wrong during the treatment</b>	CG (n=44)	7 (15.9%)	16 (36.4%)	21 (47.7%)
	BG (n=40)	5 (12.5%)	15 (37.5%)	20 (50.0%)
	PG (n=10)	0 ( 0.0%)	3 (30.0%)	7 (70.0%)

Note: CG = Cancer group, BG = Benign group, PG = Pre-invasive group

### 7.1.8 Psychological responses pertinent to specific treatment modalities

Psychological responses elicited by each treatment were analysed using a newly developed measure based on the qualitative findings from Phase 1a study. At 6 months follow up, patients were asked to what extent they felt any of the following emotions/psychological responses described their feelings related to a specific treatment: 1) embarrassed, 2) relieved, 3) depressed, 4) anxious/worried, 5) informed, 6) degraded, 7) angry, 8) accepting, 9) revolted, 10) in control, 11) isolated, 12) scared, 13) numb, 14) shocked 15) frustrated. Each item ranged from 0 (not at all) to 10 (very much). Items 2, 5, 8 and 10 were reverse scored. A factor analysis was conducted using scores of cancer and benign patients related to the impact of surgery alone (n=77), since very small

sample sizes of patients received different combinations of treatment modalities (e.g. surgery and adjuvant brachytherapy and/or external beam radiotherapy), making factor analyses with these groups invalid. Furthermore, it was considered unlikely that a different factor structure would emerge for different treatments.

The fifteen scores were assessed via factor analysis using principal component analysis for initial factor extraction and varimax rotation with Kaiser normalisation to explore the underlying factor structure and to decrease the number of variables tested. The results revealed that three components could explain 59% of the total variance. The first factor, "distress", explained 28% of the variance. The second factor, "disempowerment", explained a further 16% of the variance and the third factor, "degradation", explained an additional 15% of the variance (see Table 7.1.21.).

Table 7.1.21. *Factor analysis of psychological responses to gynaecological cancer treatments, revealing three components*

	<b>Distress</b>	<b>Disempowerment</b>	<b>Degradation</b>
<i>Embarrassed</i>	-	-	0.714
<i>Relieved</i>	-	-0.810	-
<i>Depressed</i>	0.515	0.427	-
<i>Anxious/worried</i>	0.737	-	-
<i>Informed</i>	-	-0.585	-
<i>Degraded</i>	-	-	0.899
<i>Angry</i>	0.653	-	-
<i>Accepting</i>	-0.521	-	-
<i>Revolted</i>	-	-	0.739
<i>In control</i>	-0.580	-0.471	-
<i>Isolated</i>	-	0.659	-
<i>Scared</i>	0.844	-	-
<i>Numb</i>	0.642	-	-
<i>Shocked</i>	0.789	-	-
<i>Frustrated</i>	0.599	0.460	-

*Note: Numbers presented in the table are rotated factor loadings.  
Only loadings of >0.4 are included.*

The first factor “distress” describes the negative emotions experienced by patients when undergoing surgical treatments, including feelings of numbness, fear, shock, frustration and subsequent anxiety/depression. The second factor, “disempowerment”, describes feelings associated with lack of active involvement, information and control. The third factor, “degradation”, describes intense negative emotions such as feeling degraded, revolted or embarrassed in the context of invasive treatment modalities. A total score for each of these three factors was generated by summing up variable scores that loaded on each factor. Descriptive statistics for all three factors are shown in Table 7.1.22.

Table 7.1.22. *Descriptive statistics for surgery-related psychological responses analysis*

		<b>Factor 1</b>	<b>Factor 2</b>	<b>Factor 3</b>
		<b>Distress</b>	<b>Disempowerment</b>	<b>Degradation</b>
<b>Cancer group</b> (n=39)	<i>Mean</i>	38.39	19.65	4.12
	<i>Std. Deviation</i>	20.95	13.50	5.09
	<i>Range</i>	0.00 – 85.60	0.00 – 57.60	0.00 – 19.80
<b>Benign group</b> (n=38)	<i>Mean</i>	30.06	17.88	2.97
	<i>Std. Deviation</i>	20.93	13.40	5.18
	<i>Range</i>	0.00 – 88.40	0.00 – 44.60	0.00 – 30.00

*Note: Maximum scores: Factor 1 = 90, Factor 2 = 60, Factor 3 = 30*

Group comparisons of the three factors pertinent to the impact of surgery were computed using the analysis of covariance, whilst controlling for the effect of age. The cancer group reported significantly higher levels of distress related to their hysterectomy treatment compared to benign patients ( $F(2,77)=4.385$ ,  $p=0.040$ ). However, there were no group differences in patients' feeling disempowered ( $F(2,77)=0.649$ ,  $p=0.423$ ) or degraded ( $F(2,79)=1.201$ ,  $p=0.276$ ) related to their experience of surgery.

Psychological responses of patients who had undergone combined treatment modalities were compared qualitatively based on the identified factor structure from "surgical outcomes". Examination of Table 7.1.23. indicates that cancer patients were feeling less distressed, disempowered and to a lesser degree degraded with individual treatments, the more cancer treatments they had received. In all treatment groups, both radiation treatments were associated with more disempowerment and degradation compared to the surgical treatment. When comparing the impact of both radiation treatments, brachytherapy appeared to evoke more distress and degradation than external radiation but surprisingly less disempowerment. However, it should be noted that any interpretation of the above tendencies should be made with caution due to very small sample sizes.

Table 7.1.23. *Descriptive statistics for the factor structure of psychological responses of cancer patients related to specific treatment modalities*

Treatment groups		DISTRESS related to			DISEMPOWERMENT related to			DEGRADATION related to		
		SR	ER	BR	SR	ER	BR	SR	ER	BR
<b>SR alone</b> (N=42)	Mean	38.4			19.7			4.1		
	Std. Deviation	21.0			13.5			5.1		
<b>SR &amp; BR</b> (N=6)	Mean	32.7		38.9	18.0		25.1	3.6		13.2
	Std. Deviation	19.7		20.2	10.6		15.1	3.2		7.8
<b>SR &amp; ER</b> (N=8)	Mean	34.6	36.4		22.0	29.8		3.8	10.1	
	Std. Deviation	16.9	19.2		16.2	18.8		3.9	10.0	
<b>SR &amp; ER &amp; BR</b> (N=4)	Mean	24.8	24.7	25.0	13.6	17.3	16.9	3.4	8.2	6.9
	Std. Deviation	24.8	20.8	18.8	10.4	12.2	11.4	6.9	9.6	7.7

Note: SR = Surgery, ER = External/Pelvic Radiotherapy, BR = Brachytherapy  
Maximum scores: Factor 1 = 90, Factor 2 = 60, Factor 3 = 30.

### 7.1.9 Changes in psychological functioning

Results for the 3 x 2 repeated measures ANCOVA for *anxiety levels*, whilst controlling for age, revealed a significant main effect for group ( $F(2,116)=3.230$ ,

$p=0.043$ ). There was no main effect for time ( $F(2,116)=2.222, p=0.139$ ) and no interaction effect for group x time ( $F(2,116)=0.659, p=0.520$ ). As evident from Figure 7.1.8. and Table 7.1.24., the significant group differences were due to higher anxiety levels of benign patients compared to cancer and pre-invasive patients.

Figure 7.1.8. *Changes in anxiety levels over time*

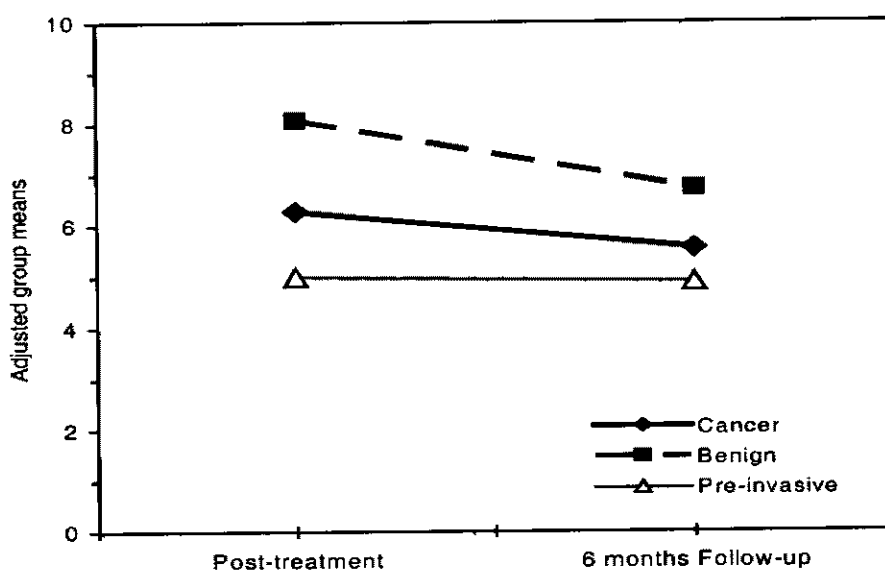


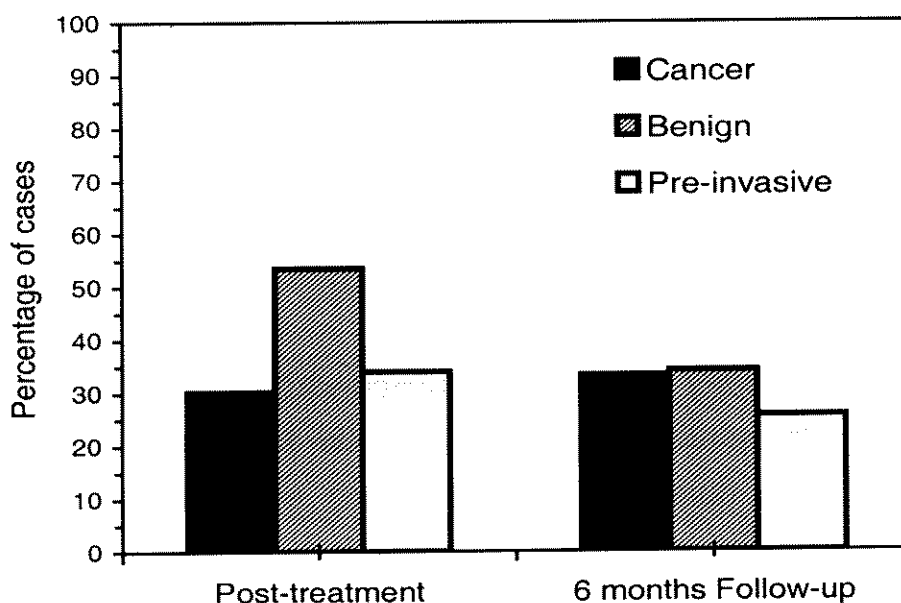
Table 7.1.24. *Group means (and standard errors) of the psychological status variables, adjusted for age*

Subscale	Group	Post-treatment	6 months Follow up
<b>Anxiety</b> <sup>#</sup> (max. score = 21)	Cancer	6.28 (0.64)	5.56 (0.68)
	Benign	8.08 (0.65)	6.73 (0.70)
	Pre-invasive	5.00 (0.94)	4.90 (1.01)
<b>Depression</b> <sup>*</sup> (max. score = 21)	Cancer	5.15 (0.57)	2.78 (0.43)
	Benign	5.37 (0.58)	3.45 (0.44)
	Pre-invasive	1.87 (0.84)	1.51 (0.63)

Note: Baseline means reported above differ from those cited in the Chapter 6 due to different covariates  
<sup>#</sup> = significant main effect for group, <sup>§</sup> = significant main effect for time, <sup>\*</sup> = significant interaction time x group effect

As with baseline analyses, patients' scores were categorised into non-clinical levels (0-7) and clinical levels (8-21). The chi-square test revealed comparable **clinical levels of anxiety** across the patient groups at 6 months follow up ( $\chi^2=0.751, p=0.687$ ). Interestingly, a slightly higher percentage of cancer patients reported clinical anxiety at 6 months post-treatment (33.3%) compared to immediately post-hysterectomy (30.2%). Whilst more than half of benign patients (53.3%) were clinically anxious immediately post-hysterectomy, by 6 months follow up the percentage of clinically anxious patients declined to levels comparable to those of the cancer group (34.1%). Similarly, a substantially smaller percentage of pre-invasive patients reported clinical anxiety at 6 months follow up (25%) compared to immediately post-treatment (34%). For graphical representation of group percentages see Figure 7.1.9.

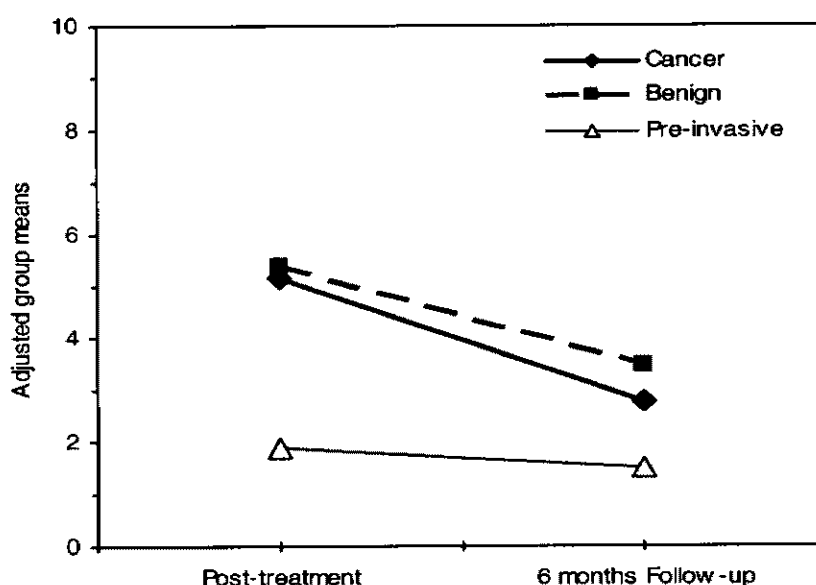
Figure 7.1.9. *Changes in clinical levels of anxiety over time*



A similar pattern emerged in levels of depression. The 2 x 3 ANCOVA revealed a main effect for group ( $F(2,116)=5.072, p=0.008$ ). A tendency toward a main effect for time was detected, although this effect did not reach significance ( $F(1, 116)=3.177, p=0.077$ ). The interaction effect of time x group pointed to a trend towards greater improvements in mood in cancer and benign patients in contrast

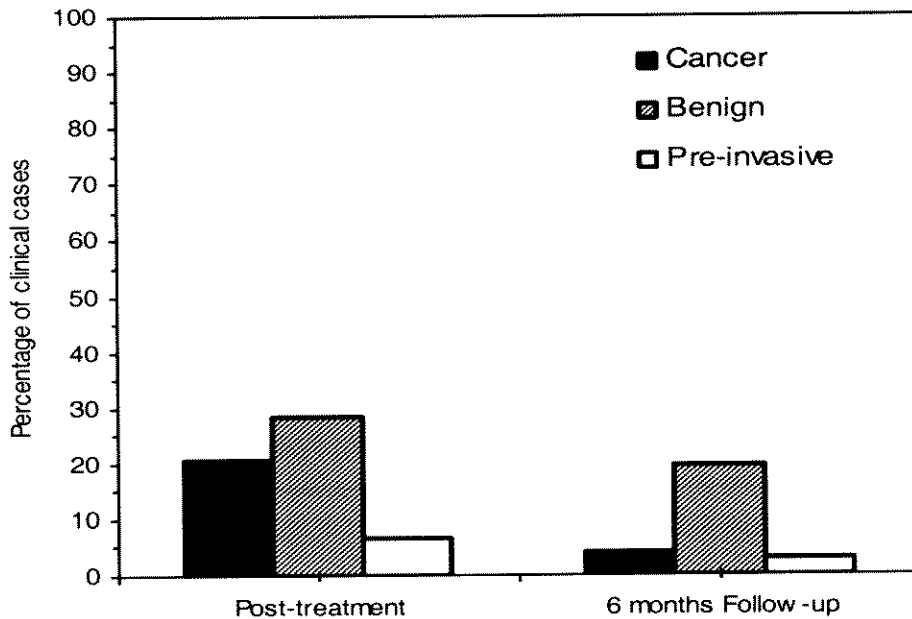
to only a marginal improvement in the pre-invasive group ( $F(2,116)=2.376$ ,  $p=0.097$ ), however this effect again failed to reach significance. Examination of the means in Table 7.1.24. indicates that the main effect observed over time is due to a tendency towards improvement of mood in all groups of patients. More specifically, the elevated post-treatment levels of depression of cancer patients substantially decreased by 6 month follow up with a similar pattern observed in the benign group (see Figure 7.1.10.).

Figure 7.1.10. *Changes in depression levels over time*



The relatively low mean depression scores in this sample indicate that the majority of patients were not clinically depressed during the first 6 months following their treatment. The chi-square test revealed group differences in **clinical depression levels** at 6 months follow up ( $\chi^2=8.623$ ,  $p=0.013$ ). A significantly higher proportion of benign patients (19.5%) reported clinical depression at 6 months follow up compared to cancer patients (4.2%) and pre-invasive patients (2.9%). As can be seen from Figure 7.1.11., all groups reported improvement in mood over time.

Figure 7.1.11. *Changes in clinical levels of depression over time*



### 7.1.10 *Changes in Quality of Life*

Changes in quality of life from baseline (i.e. pre-treatment) to 6 months follow up were also investigated. The assessed sub-areas included physical, functional, social and emotional wellbeing, satisfaction with doctor-patient relationship and specific concerns related to gynaecological illness. Between group and over time comparisons of total scores of these 5 subscales were analysed using repeated measures 2 x 3 ANCOVA. The mean scores presented refer to adjusted means for age and for psychological status.

The results of a 2 x 3 ANCOVA for *physical wellbeing* revealed a highly significant main effect for group ( $F(2,115)=10.225, p=0.000$ ) and time ( $F(1,115)=12.104, p=0.001$ ). A significant interaction for group x time effect was also found ( $F(1,115)=14.628, p=0.000$ ). Examination of means in Figure 7.1.12. and Table 7.1.25. indicates that these results were due to substantial improvements in physical wellbeing for the cancer and benign groups in contrast to no improvement in the pre-invasive group. Considering the maximum



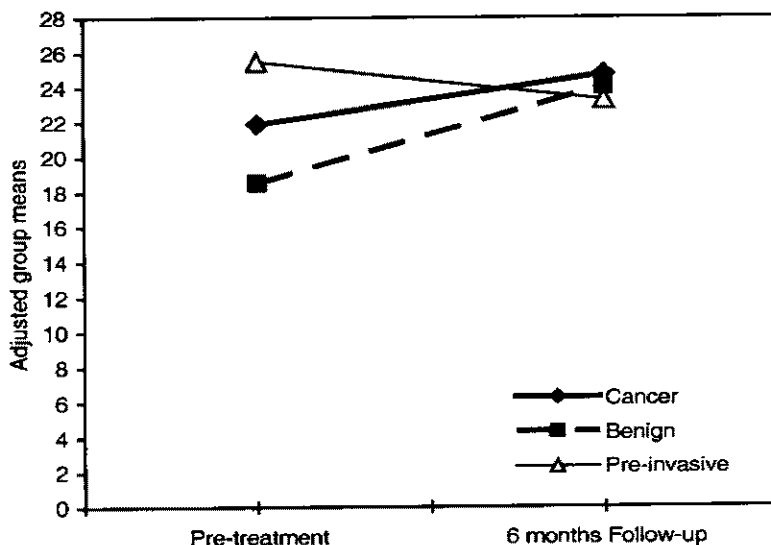
subscale score of 28, all patients in the present sample were located in the upper quartile of possible scale scores at six months follow up and for most affected women were, according to the anchors of the scale, "a little bit" impaired by physical concerns.

Table 7.1.25. *Group means (and standard errors) of Quality of Life dimensions, adjusted for age and psychological status*

<b>Subscale</b>	<b>Group</b>	<b>Pre-treatment</b>	<b>6 months Follow up</b>
<b>Physical wellbeing</b> <sup>#,§,*</sup> (max. score = 28)	Cancer group	21.90 (0.68)	24.75 (0.44)
	Benign group	18.53 (0.69)	24.02 (0.45)
	Pre-invasive group	25.48 (0.97)	23.27 (0.63)
<b>Functional wellbeing</b> <sup>§,*</sup> (max. score = 28)	Cancer group	17.71 (0.89)	22.49 (0.67)
	Benign group	18.54 (0.89)	22.17 (0.67)
	Pre-invasive group	21.58 (1.29)	20.07 (0.96)
<b>Emotional wellbeing</b> <sup>§</sup> (max. score = 24)	Cancer group	17.57 (0.58)	19.76 (0.44)
	Benign group	18.26 (0.59)	20.70 (0.45)
	Pre-invasive group	17.37 (0.83)	18.76 (0.64)
<b>Social wellbeing</b> <sup>#,§</sup> (max. score = 28)	Cancer group	22.81 (0.78)	23.96 (0.71)
	Benign group	19.71 (0.80)	21.69 (0.73)
	Pre-invasive group	20.33 (1.12)	20.93 (1.02)
<b>Dr-patient relationship</b> (max. score = 8)	Cancer group	7.41 (0.22)	6.93 (0.26)
	Benign group	6.80 (0.22)	6.81 (0.27)
	Pre-invasive group	6.43 (0.31)	6.25 (0.37)
<b>Total Quality of Life</b> <sup>§,*</sup> (max. score = 120)	Cancer group	87.17 (2.11)	97.77 (1.42)
	Benign group	81.93 (2.15)	95.40 (1.46)
	Pre-invasive group	91.22 (3.02)	89.49 (2.04)
<b>Gyn. condition – related wellbeing</b> <sup>#</sup> (max. score = 56)	Cancer group	36.31 (0.91)	40.18 (0.94)
	Benign group	38.46 (0.93)	44.83 (0.96)
	Pre-invasive group	40.05 (1.31)	42.14 (1.34)

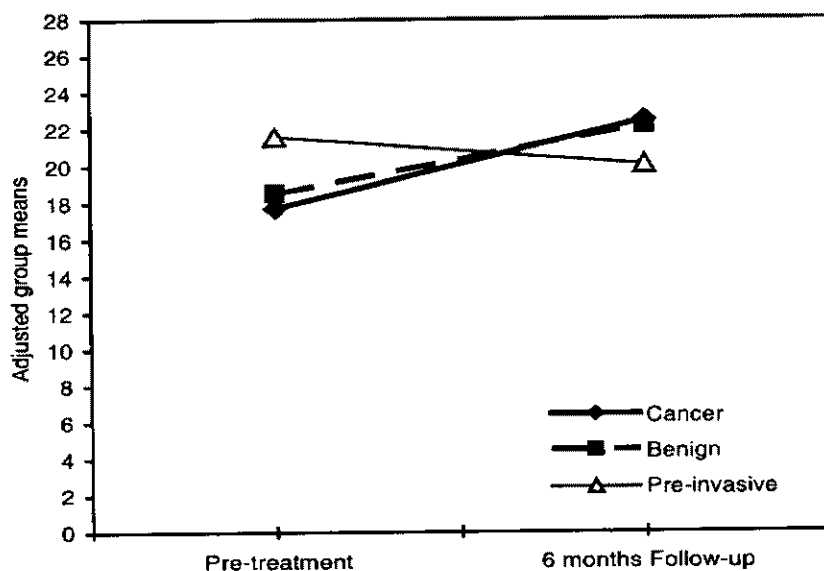
*\*Note: The above baseline means differ from those cited in the Chapter VI due to different covariates  
Higher means indicate better outcomes  
# = significant main effect for group, § = significant main effect for time, \* = significant interaction  
time x group effect*

Figure 7.1.12. Changes in **physical wellbeing** over time



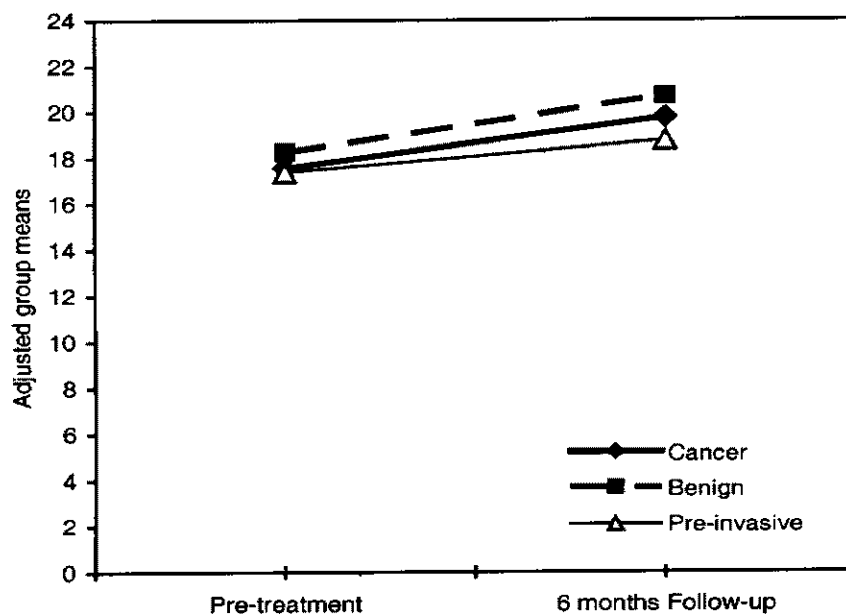
An assessment of **functional wellbeing** revealed no significant main effect for group ( $F(2,113)=0.168$ ,  $p=0.845$ ). However, the main effect for time ( $F(1,113)=14.799$ ,  $p=0.000$ ) and interaction effect for group x time ( $F(2, 113)=5.834$ ,  $p=0.004$ ) were both highly significant. The examination of means in Figure 7.1.13. and Table 7.1.25. indicates that these results are due to a notable functional improvement for cancer patients, compared with a less steep improvement for benign patients in contrast to a marginal deterioration of functional wellbeing in pre-invasive patients.

Figure 7.1.13. Changes in **functional wellbeing** over time



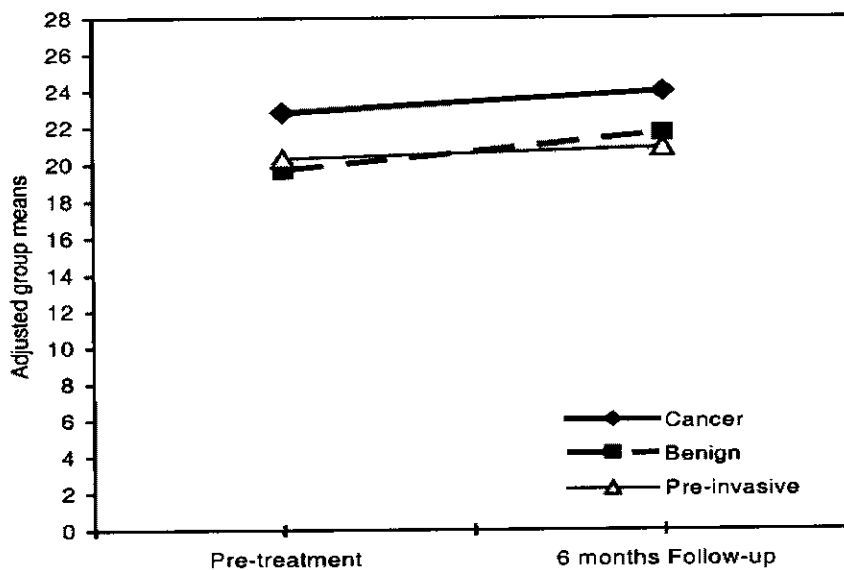
For the **emotional wellbeing** subscale, there was no main effect for group ( $F(2,115)=2.192$ ,  $p=0.116$ ), however a significant main effect for time ( $F(2,115)=13.953$ ,  $p=0.000$ ) was detected. Over the two assessments, the interaction effect was not indicative of differences between groups over time ( $F(2,115)=0.355$ ,  $p=0.702$ ). Examination of means in Figure 7.1.14. and Table 7.1.25. indicates that the significant time effect was due to considerable improvement in emotional wellbeing of all patients.

Figure 7.1.14. *Changes in emotional wellbeing over time*



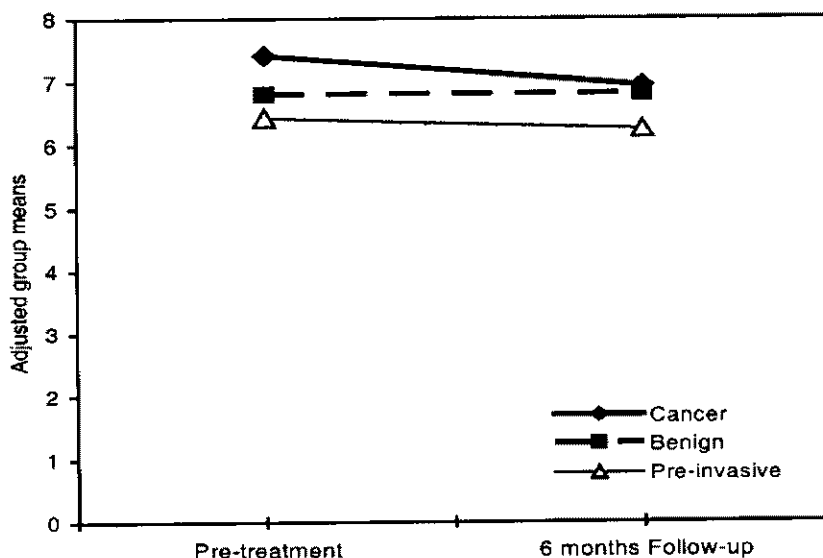
There were main effects in levels of **social wellbeing** for both group ( $F(2, 115)=5.17$ ,  $p=0.007$ ) and time ( $F(2,115)=5.87$ ,  $p=0.017$ ). However, no significant time x group interaction effect was found ( $F(2,115)=0.660$ ,  $p=0.519$ ). At both assessments, cancer patients reported a higher level of social wellbeing and support than the other two patient groups (see Figure 7.1.15. and Table 7.1.25.). Their already elevated baseline levels of social wellbeing further increased at 6 months follow up. Benign patients reported even greater improvement in social functioning/support than cancer patients whilst pre-invasive patients reported no change in social wellbeing over time.

Figure 7.1.15. *Changes in social wellbeing over time*



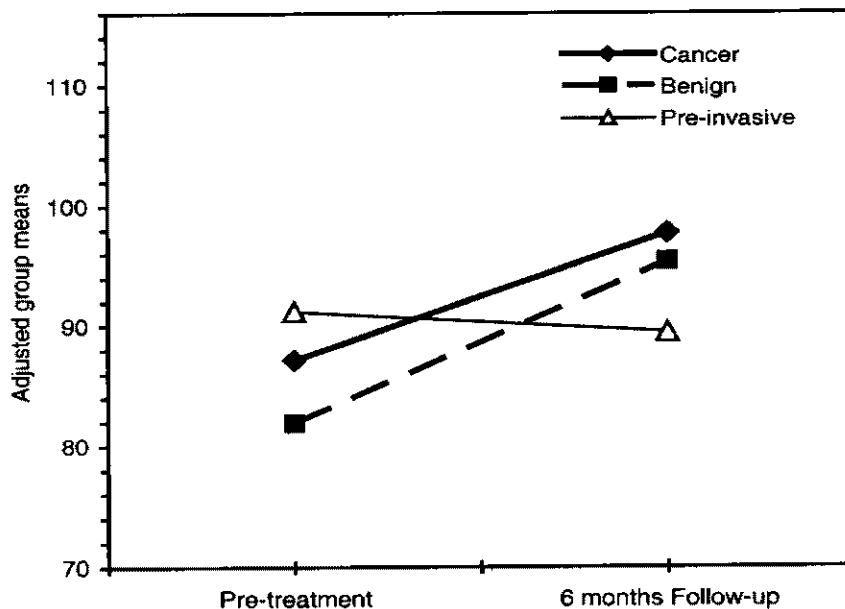
Repeated measures 2 x 3 ANCOVA for satisfaction with **doctor-patient relationship** revealed no main effect of time ( $F(1,115)=0.416, p=0.520$ ), group ( $F(2,115)=2.329, p=0.102$ ) and no time x group interaction effect ( $F(2,115)=2.329, p=0.102$ ). Examination of means in Figure 7.1.16. and Table 7.1.25. indicates that overall, all patients reported high satisfaction with their treating doctor, which remained stable at both time points.

Figure 7.1.16. *Changes in doctor-patient relationship over time*



The total scores of the above 5 quality of life subscales were summed up and analysed to investigate whether there were any significant changes in the **overall quality of life** of patients. A 2 x 3 ANCOVA revealed an interesting pattern of results. There was a main effect for time ( $F(1,115)=26.523, p=0.000$ ) but not for group ( $F(2,115)=1.802, p=0.170$ ). When comparing effects across the two time frames, a significant time x group interaction effect emerged ( $F(2,115)=7.723, p=0.001$ ). Examination of means in Figure 7.1.17. and Table 7.1.25. indicates that the significant main effect of time and the interaction effect were due to considerable improvements in the quality of life of cancer and benign patients in contrast to a slight deterioration of quality of life in pre-invasive patients. Group comparisons at 6 months follow up, whilst controlling for age, revealed a trend of higher levels of quality of life of cancer patients compared to pre-invasive patients ( $F(1, 76) = 3.265, p=0.075$ ).

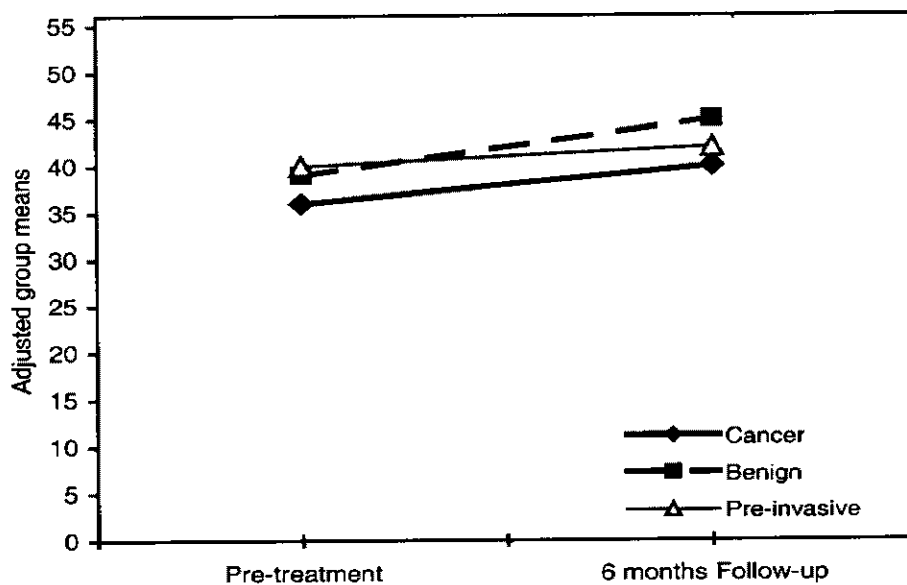
Figure 7.1.17. *Changes in overall quality of life over time*



A 2 x 3 ANCOVA for **wellbeing related to gynaecological conditions** revealed a main effect for group ( $F(1,115)=5.731, p=0.004$ ) but not for time ( $F(2,115)=0.921, p=0.339$ ). When comparing effects across the two time frames,

a trend for time x group interaction effect emerged ( $F(2,115)=2.909$ ,  $p=0.059$ ). Examination of means in Figure 7.1.18. and Table 7.1.25. indicates that the significant main effect of group and the trend of interaction effect were due to considerable improvements in the gynaecological condition-related wellbeing of cancer and benign patients in contrast to only a slight improvement of quality of life in pre-invasive patients. Group comparisons at 6 months follow up, whilst controlling for age and psychological status, revealed significantly better wellbeing related to the gynaecological condition of benign patients compared to cancer patients ( $F(1, 83) =15.793$ ,  $p=0.000$ ). Wellbeing levels of pre-invasive patients were comparable to cancer patients and benign patients.

Figure 7.1.18. *Changes in wellbeing related to a gynaecological condition over time*



## **7.2 Results II: Longitudinal data of the cancer group**

### **7.2.1 Hormonal changes**

In the current cancer sample, 60% of our cancer patients were peri- or post-menopausal prior to their treatment. At 6 months follow up, 74% of cancer patients described their "stage of life" as peri- or post-menopausal and this increased to 81% by one year post-treatment.

Investigation of the use of HRT showed 11% of cancer patients were using HRT at baseline; with the use of HRT increasing to 23% at 6 months follow up. A comparable percentage of cancer patients reported using HRT at 6 and 12 months follow ups (23% and 24%).

Surgically-induced menopause was experienced by 64% of cancer patients (those undergoing hysterectomy with BSO). Of these, 32% of cancer patients were pre-menopausal prior to the operation. At 6 months post-treatment, 58% of cancer patients who had undergone BSO were *not* using HRT. At 12 months follow up, 79% of cancer patients who had undergone the BSO procedure and completed the second follow up questionnaire were not using HRT.

### **7.2.2 Satisfaction with relationship**

A repeated measures 3x1 ANOVA for relationship satisfaction revealed no significant changes in cancer patients' levels of relationship satisfaction during the first year post-treatment ( $F(2,26)=2.409$ ,  $p=0.100$ ). However, examination of means in Table 7.2.1. and within-subject contrasts indicated a trend of lower satisfaction levels at 6 months post-treatment compared to pre-diagnosis ( $F(1,26)=3.975$ ,  $p=0.057$ ) and no change in satisfaction levels between 6 and 12 months follow ups ( $F(1,26)=0.087$ ,  $p=0.770$ ). A trend of lower satisfaction levels

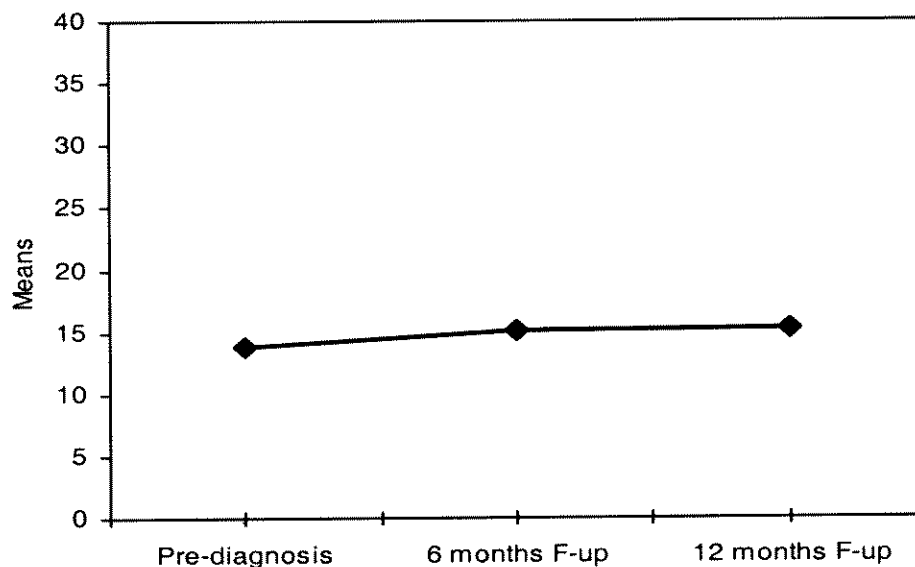
at 12 months post-treatment compared to baseline was also detected ( $F(1,26)=3.225, p=0.084$ ) (see Figure 7.2.1).

Table 7.2.1. Group means (and standard errors) of the relationship satisfaction and sexual functioning variables

Subscale (maximum score)	Pre-diagnosis		6 mths Follow up		12 mths Follow up	
	Mean (std. error)	DSFI T-score	Mean (std. error)	DSFI T-score	Mean (std. error)	DSFI T-score
<b>Relationship satisfaction</b> (40)	13.74 (0.98)		15.07 (1.07)		15.30 (1.07)	
<b>Sexual satisfaction</b> <sup>§</sup> (10)	7.56 (0.48)	48	6.12 (0.60)	42	6.36 (0.54)	43
<b>Sexual drive</b> (40)	12.74 (1.11)	43	9.39 (1.12)	40	14.20 (1.06)	45
<b>GSSI</b> (8)	5.24 (0.33)	48	3.84 (0.48)	44	3.92 (0.51)	45

\*Note: Baseline means reported above differ from those cited in the Chapter VI due to different covariates  
 Shaded areas indicate not applicable  
 Lower means indicate better outcomes for Relationship Satisfaction  
 Higher means indicate better outcomes for Sexual Functioning subscales  
 § = significant main effect for time

Figure 7.2.1. Changes in relationship satisfaction of cancer patients over time



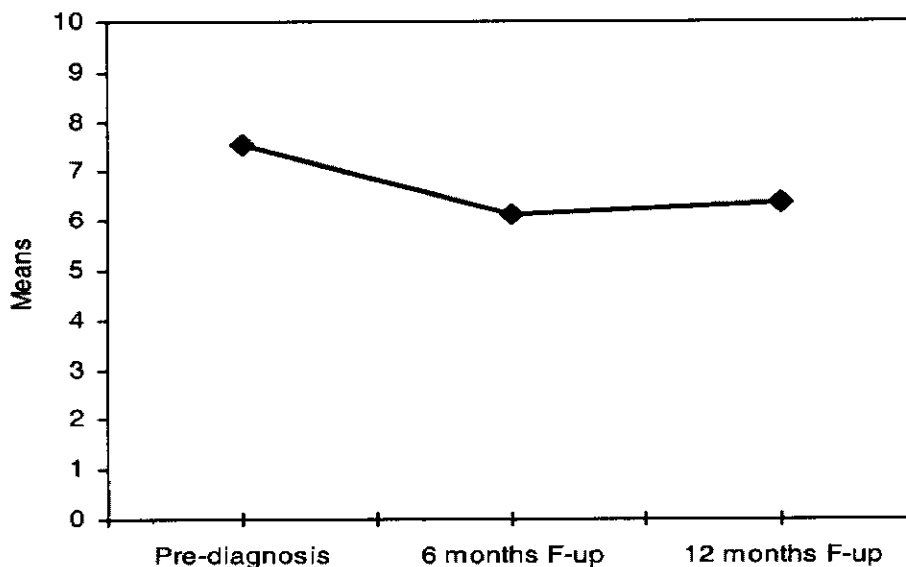
### 7.2.3 Changes in sexual functioning

A repeated measures ANOVA for **sexual satisfaction** revealed main effect for time ( $F(2,24)=5.780, p=0.006$ ). Examination of means in Figure 7.2.2 and within-subject contrasts indicated that this effect was due to a significant deterioration



in sexual satisfaction in the first 6 months post-treatment ( $F(1,24)=8.286$ ,  $p=0.008$ ), which remained lower in the second half of the post-treatment year ( $F(1,24)=0.373$ ,  $p=0.547$ ). Sexual satisfaction at 12 months post-treatment was significantly lower than at pre-diagnosis ( $F(1,24)=6.750$ ,  $p=0.016$ ).

Figure 7.2.2. *Changes in sexual satisfaction of cancer patients over time*

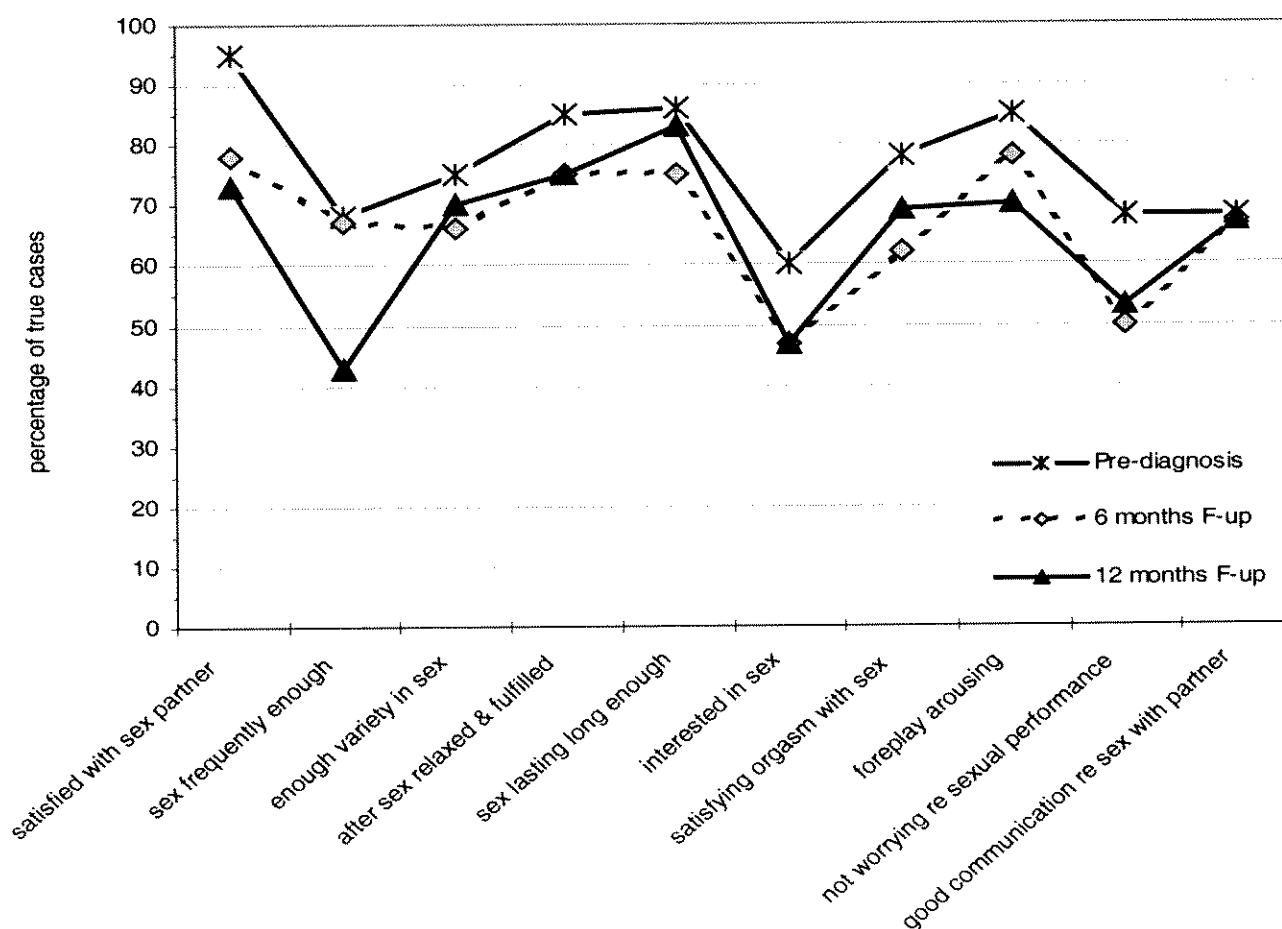


Changes in cancer patients' responses for *individual items of the Sexual Satisfaction subscale* over time were inspected. Examination of Table 7.2.2. indicates that cancer patients were dissatisfied with various aspects of sexual relating at 12 months follow up compared to baseline (i.e. pre-diagnosis). Sexual areas identified by cancer patients as the most adversely affected by 12 months follow up were: satisfaction with sexual partner, frequency of sex, arousal during foreplay, worry about sexual performance and interest in sex (see Figure 7.2.3.). The only aspects of sexual relating that did not appear to be affected were: communication between partners about sexual matters and a length of sexual encounters. The only areas that appeared to deteriorate between 6 and 12 months follow up were frequency of sex, arousal during foreplay and, to some degree, satisfaction with sexual partner (see Figure 7.2.3.).

Table 7.2.2. Percentage of true cases of the itemised Sexual Satisfaction subscale

	Pre-diagnosis (%)	6 months F-up (%)	12 months F-up (%)
<i>I'm satisfied with my sexual partner</i>	95	78	73
<i>I feel I have sex frequently enough</i>	68	67	43
<i>There is enough variety in my sex life</i>	75	66	70
<i>After sex I feel relaxed and fulfilled</i>	85	75	75
<i>Sex lasts long enough</i>	86	75	83
<i>I'm interested in sex</i>	60	47	47
<i>I have satisfying orgasm with sex</i>	78	62	69
<i>Foreplay before intercourse is very arousing for me</i>	85	78	70
<i>Often I worry about my sexual performance</i>	68	50	53
<i>My partner and I have a good communication about sex</i>	68	67	67

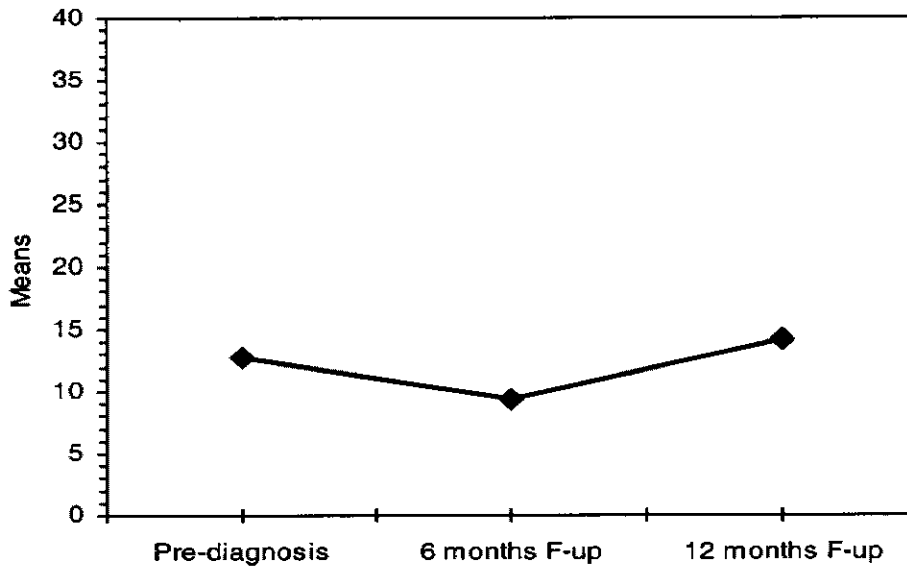
Figure 7.2.3. Graphical representation of the percentages of true cases of the itemised Sexual Satisfaction subscale



At 12 months follow up, patients were asked **whether post-treatment sexual encounters were on average satisfying**. More than a third (37%) of cancer patients reported that they were not satisfied in general with sexual encounters. More than half (58%) of cancer patients also reported that their *first* post-treatment sexual encounter was unsatisfactory. At baseline and at 12 months follow up assessments, patients were also asked to indicate **who usually instigates sexual encounters**. At baseline, only one (2.5%) cancer patient reported initiating the encounters herself whilst at 12 months post-treatment, no cancer patient reported initiating sexual encounters. According to cancer patients' reports, 60% of baseline encounters were initiated by partner, compared to 50% at 12 months follow up. Finally, 38% of baseline sexual encounters were based on a mutual decision and 42% at 12 months follow up.

The repeated measures ANOVA revealed significant changes in **sexual drive** levels over time ( $F(2,26)=12.315$ ,  $p=0.000$ ). There was a significant decline in drive levels at 6 months follow up compared to baseline ( $F(1,26)=8.569$ ,  $p=0.007$ ) whilst drive levels significantly increased in the second half of the post-treatment year ( $F(1,26)=31.352$ ,  $p=0.000$ ) (see Table 7.2.1. and Figure 7.2.4.). Drive levels at baseline and at 12 months follow up were comparable ( $F(1,26)=2.331$ ,  $p=0.139$ ).

Figure 7.2.4. Changes in levels of sexual drive of cancer patients over time



Changes in frequencies for *individual items of the Sexual Drive subscale* over time were also analysed. With the exception of frequency of kissing and petting, the repeated measures ANOVA revealed significant quadratic trends over time for all remaining sexual drive items. Examination of Table 7.2.3. and Figure 7.2.5. indicates that whilst women reported a significant decline in frequencies of intercourse ( $F(1,26)=9.953$ ,  $p=0.004$ ) and particularly masturbation ( $F(1,25)=30.780$ ,  $p=0.000$ ) at 6 months follow up compared to pre-diagnosis, the frequency of these two sexual activities significantly increased in the second half of the first post-treatment year (Intercourse:  $F(1,26)=32.877$ ,  $p=0.000$ ; Masturbation:  $F(1,26)=103.211$ ,  $p=0.000$ ). As Figure 7.2.5. indicates, a rather similar pattern was evident regarding frequency of sexual fantasies and ideal frequency of intercourse. Whilst no significant changes in these items were noted in the first half of the post-treatment year, a significant increase in frequency of sexual fantasies ( $F(1,25)=27.072$ ,  $p=0.000$ ) and ideal frequency of intercourse ( $F(1,25)=7.809$ ,  $p=0.010$ ) were noted in the second half of the post-treatment year. No changes in frequency of kissing and petting over time or at any assessment point were detected. As with 6 months follow up, examination of Table 7.2.3. and results from paired t-test point to significant discrepancies between means for the real and ideal frequency of intercourse at 12 months

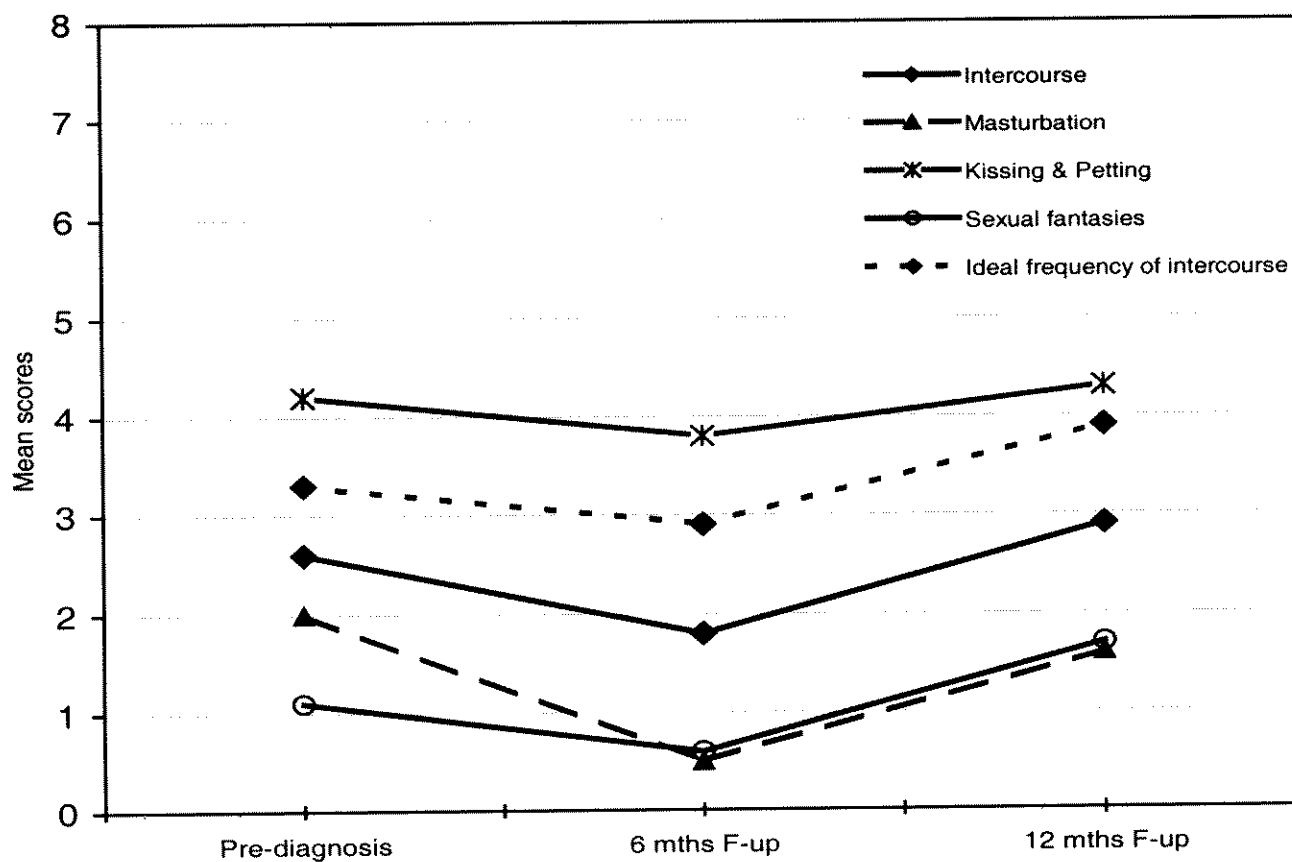
follow up ( $t=-3.891$ ,  $p=0.001$ ). This indicates that patients consistently desired more sexual encounters than they were currently experiencing at 12 months follow up (see Figure 7.2.5.).

Table 7.2.3. Means (and standard errors) of individual items of the Sexual Drive subscale

Items (max. score=8)	Pre-diagnosis	6 months F-up	12 months F-up
Frequency of Intercourse <sup>§</sup>	2.59 (0.22)	1.82 (0.25)	2.85 (0.24)
Frequency of Masturbation <sup>§</sup>	2.00 (0.28)	0.48 (0.17)	1.64 (0.17)
Frequency of Kissing & Petting	4.16 (0.48)	3.80 (0.58)	4.32 (0.56)
Frequency of Sexual fantasies <sup>§</sup>	1.12 (0.31)	0.62 (0.24)	1.69 (0.25)
Ideal Frequency of Intercourse <sup>§</sup>	3.27 (0.25)	2.89 (0.42)	3.85 (0.31)

Note: (0) = not at all, (1) = less than 1x /month, (2) = 1-2x /month, (3) = 1x /week, (4) = 2-3 x /week, (5) = 4-6x /week, (6) = 1 x /day, (7) = 2-3 x /day, (8) = more than 4 x /day  
<sup>§</sup> = significant quadratic trend

Figure 7.2.5. Mean scores for individual items of the Sexual Drive subscale

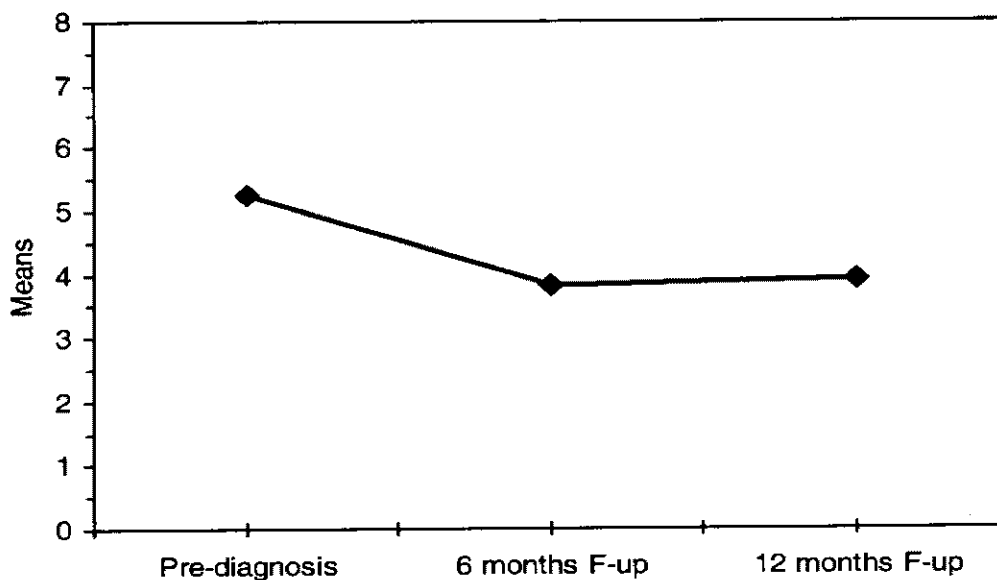


As noted in the 6 months follow up findings, 4 cancer patients (10%) who were sexually active pre-diagnosis did not **resume sexual intercourse following their treatment**, despite having a sexual partner. None of these women resumed sexual activity within the first 12 months post-treatment. Inspection of their global evaluation of sexual life scores at 12 months follow up revealed that all four patients reported that their sexual life had been “highly inadequate” or “could not be worse”. Consistent with these reports are their very poor drive and satisfaction outcomes, despite above average quality of life reported by three (of the four) patients. As stated earlier, three of these women had undergone surgery only, one received adjuvant brachytherapy. The woman who received the combined treatment, continued to report significant adverse vaginal changes such as a substantial degree of vaginal stenosis, lack of sexual excitement, reduced vaginal lubrication, dyspareunia as well as a late onset of lymphoedema. Despite the development of vaginal stenosis and reported sexual inactivity, this patient had not been given a vaginal dilator. Of the remaining three patients who had undergone surgery alone, two did not report any adverse vaginal changes or other treatment side effects, whilst one patient reported reduced genital sensations, reduced lubrication and a lack of sexual excitement. Inspection of other outcome measures revealed that one woman was dissatisfied with her relationship and another suffered from clinical levels of anxiety. According to the 6 months follow up data, two partners of surgically treated patients and one couple believed in the contagiousness of the patient’s illness/treatment. However, by 12 months follow up, only one couple reported believing in the possibility of “catching” the illness. In addition, inspection of these three patients’ responses at 12 months follow up revealed that two women did not want to discuss post-treatment changes in sexual functioning with their doctor (compared to all three women at 6 months follow up).

Results for the 3 x 1 ANOVA for **global evaluation of sexual functioning** (i.e. GSSI index), indicated significant changes over time ( $F(2,48)=4.682$ ,  $p=0.014$ ). Examination of the contrast matrix and Table 7.2.1. revealed that this effect was

due to a significant decline in satisfaction with sexual life in general at 6 months follow up compared to baseline ( $F(1,24)=8.909$ ,  $p=0.006$ ), which did not improve by 12 months follow up ( $F(1,24)=0.022$ ,  $p=0.884$ ). The levels of overall satisfaction with sexual life at 12 months follow up were significantly lower compared to baseline levels ( $F(1,24)=6.244$ ,  $p=0.020$ ) (see Figure 7.2.6.). According to the anchors of the scale, patients' baseline (i.e. pre-diagnosis) reports of having "above average" sexual life declined to "adequate" levels at both follow up assessments.

Figure 7.2.6. *Changes in global evaluation of sexual life (i.e. GSSI) of cancer patients over time*



At 12 months follow up, cancer patients were also asked to indicate on a scale from 0 (not at all) to 5 (extremely), **how much their sexual functioning had changed since their treatment and whether this change was for the better or the worse**. Five cancer patients (15%) indicated *no changes* in post-treatment sexual functioning and 2 (6%) patients indicated a change *for the better*. Of the remaining 27 (79%) cancer patients for whom sexual life had *deteriorated*, 16 (59%) women reported slight to moderate changes and 11 (41%) women indicated that their sexual life worsened "much", "very much" or "extremely".

## 7.2.4 Post-treatment changes in sexual functioning

(measured by SFAGIS)

The Sexual Functioning after Gynaecological Illness Scale (SFAGIS) was used to assess vaginal changes such as vaginal stenosis, reduced lubrication and sensations and to identify those that had resolved within the first post-treatment year. Further, it was of interest whether women's preferences regarding the provision of information related to the potential impact of gynaecological cancer and its treatment on sexual functioning had changed since the 6 months follow up.

As Table 7.2.4. indicates, varying degrees of **vaginal stenosis** were reported predominantly within the first 6 months post-treatment, with only a slightly higher percentage of patients reporting smaller/tighter vagina at 12 months post-treatment. Overall, approximately a third of cancer patients reported some degree of vaginal stenosis at both assessments.

Table 7.2.4. *Cancer patients' reports of the incidence and degree of vaginal stenosis at 6 and 12 months post-treatment*

<i>"After my treatment my vagina:"</i>	<i>6 months follow up (n=45)</i>	<i>12 months follow up (n=36)</i>
<i>Became completely closed</i>	1 (2.2%)	1 (2.8%)
<i>Became smaller or tighter</i>	13 (28.9%)	11 (30.6%)
<i>Perhaps changed in size – I am not sure</i>	14 (31.3%)	12 (33.3%)
<i>Became larger or looser</i>	2 (4.4%)	0 (0.0%)
<i>Does not seem to have changed in size</i>	15 (33.3%)	12 (33.3%)

An assessment of changes in **vaginal lubrication** during sexual relations revealed a further reduction of lubrication in the second half of the post-treatment year (see Table 7.2.5.). A number of patients did not complete this item as they did not have a sexual partner (i.e. 6 months F-up: 17.1%, 12 months F-up: 20.6%). Only 15% of cancer patients reported having a "normally wet" vagina at 12 months follow up, compared to 27% at 6 months follow up. The majority of the remaining women indicated that their vagina was a "little" dry



at 12 months follow up (34%). It is of interest that a notably higher percentage of women reported having a completely dry vagina at 12 months follow up (24%) compared to 6 months follow up (7%).

Table 7.2.5. *Cancer patients' reports of the incidence and degree of reduced vaginal lubrication during coitus at 6 and 12 months post-treatment*

<b>"When I have had sexual relations after my treatment my vagina was:"</b>	<b>6 months follow up (n=41)</b>	<b>12 months follow up (n=34)</b>
Completely dry	3 (7.3%)	8 (23.5%)
I don't know if my vagina was dry or wet	6 (14.6%)	3 (8.8%)
A little dry	14 (34.1%)	11 (32.4%)
Normally wet	11 (26.8%)	5 (14.7%)
This does not concern me because I do not have a partner	7 (17.1%)	7 (20.6%)

An assessment of **genital sensations** during sexual arousal at 6 and 12 months follow up revealed no major differences between the two assessments (see Table 7.2.6.). Over half of the cancer group reported some degree of reduction in genital sensations at 12 months follow up, with the majority of these patients reporting moderate changes.

Table 7.2.6. *Cancer patients' reports of the incidence and degree of genital sensations at 6 and 12 months post-treatment*

<b>"Since the end of my treatment I have had reduced sensations in my genitals:"</b>	<b>6 months follow up (n=41)</b>	<b>12 months follow up (n=34)</b>
Not at all	17 (41.5%)	15 (44.1%)
A little bit	11 (26.8%)	7 (20.6%)
Somewhat	6 (14.6%)	7 (20.6%)
Quite a bit	4 (9.8%)	3 (8.8%)
A lot	3 (7.3%)	2 (5.9%)

Examination of Table 7.2.7. indicates a higher percentage of moderate problems with **sexual excitement** at 12 months follow up compared to 6 months follow up. Only 10 (29%) cancer patients reported having normal sexual excitement at 12 months follow up. A lower percentage of women reported feeling no sexual excitement at 12 months than at 6 months follow up.

Table 7.2.7. *Cancer patients' reports of degree of sexual excitement at 6 and 12 months post-treatment*

<b>"Since the end of my treatment, I have felt:"</b>	<b>6 months follow up (n=42)</b>	<b>12 months follow up (n=34)</b>
No sexual excitement or "turn on"	9 (21.9%)	6 (17.6%)
Little sexual excitement	5 (11.9%)	6 (17.6%)
Some sexual excitement but less than before treatment	12 (28.6%)	12 (35.3%)
Normally sexually excited	16 (38.1%)	10 (29.4%)

At both assessments, just over half of the cancer patients reported that ***the topic of post-treatment changes in sexual functioning was addressed*** at some stage during consultations (6 months F-up: 53%, 12 months F-up: 56%). For detailed information on when these discussions took place see Table 7.2.8. It is important to note that at both assessments nearly half of cancer patients reported not discussing post-treatment sexual functioning or were unsure whether such discussions had taken place.

Table 7.2.8. *When sexual issues were discussed during consultations*

<b>"My doctor talked about my sex life:"</b>	<b>6 months follow up (n=24)</b>	<b>12 months follow up (n=19)</b>
Before treatment	6 (25%)	7 (36.8%)
During treatment	2 (8 %)	2 (10.5%)
End of treatment	6 (25%)	7 (36.8%)
Before & after treatment	10 (42%)	2 (10.5%)
Before, during & after treatment	0 (0.0%)	1 (5.3%)

*Note: Numbers (percentages) in this Table are based on reports of only those patients who reported to receive information regarding sexual matters at some stage during their consultations*

At both assessments, the majority of cancer patients indicated that they would ***like to discuss relevant aspects of sexual life with their doctor***, with most patients wanting such discussions to occur with their partner present (6 months F-up: 81%, 12 months F-up: 88%). A very small percentage of cancer patients preferred their doctor to speak separately to both of them about possible changes in post-treatment sexual life and one cancer patient wanted her doctor to speak only to her partner (see Table 7.2.9.).

Table 7.2.9. *Patients' preferences for discussing sexual issues during consultations*

<b>"If I had a choice, I would like my doctor:"</b>	<b>6 months follow up (n=43)</b>	<b>12 months follow up (n=35)</b>
<i>Not to speak about sexual matters</i>	11 (25.6%)	11 (31.4%)
<i>To speak about sexual matters</i>	32 (74.4%)	24 (68.6%)
<b>" If I had a partner, I would like my doctor:"</b>	<b>(n=41)</b>	<b>(n=24)</b>
<i>To speak to my partner only</i>	4 (9.8%)	1 (4.2%)
<i>To speak to both of us but not together</i>	4 (9.8%)	2 (8.3%)
<i>To speak to both of us together</i>	33 (80.5%)	21 (87.5%)

When asked **from whom** would they like **to receive sexual information** (see Table 7.2.10.), most of the patients reported having no preference, being comfortable with either a male or a female health care worker (6 months F-up: 48%, 12 months F-up: 41%) or another female such as doctor, nurse, social worker or psychologist (6 months F-up: 37%, 12 months F-up: 41%).

Table 7.2.10. *Cancer patients' preferences regarding from whom to receive information about potential post-treatment sexual changes*

<b>"If I had a choice I would like to receive sexual information from:"</b>	<b>6 months follow up (n=27)</b>	<b>12 months follow up (n=27)</b>
<i>A female health care worker (e.g. doctor, nurse, psychologist, social worker)</i>	10 (37.0%)	11 (40.7%)
<i>A female doctor only</i>	4 (14.8%)	5 (18.6%)
<i>A male health care worker (e.g. doctor, nurse, psychologist, social worker)</i>	0 (0.0%)	0 (0.0%)
<i>Either a male or a female healthcare worker</i>	13 (48.2%)	11 (40.7%)

*Note: Only responses of patients who indicated that they would like to receive information about sexual matters are included*

Women were also asked **when** they would like **to receive information about the possible impact of cancer and its treatment on sexual functioning**. At 12 months follow up a somewhat lower percentage of patients (24%) did not want any information concerning their post-treatment sexual life compared to 6 months follow up (34%). As evident from Table 7.2.11., women nominated various times for such discussions to occur. As at 6 months follow up, the two most common preferences for such discussions were: at the patient's request

should queries arise (6 months F-up: 22%, 12 months F-up: 29%) and prior to the first treatment (6 months F-up: 32%, 12 months F-up: 27%). A comparatively higher percentage of patients, at 12 months (15%) compared to 6 months follow up (0%), indicated that they would like to discuss sexual matters at several consultations.

Table 7.2.11. *Cancer patients' preferences for time periods regarding discussions of post-treatment sexual issues during consultations*

<b><i>"I would like to receive information about sexual expectations following treatment:"</i></b>	<b><i>6 months follow up (n=41)</i></b>	<b><i>12 months follow up (n=34)</i></b>
<i>Not at all</i>	14 (34%)	8 (23.5%)
<i>Prior to the 1<sup>st</sup> treatment</i>	13 (32%)	9 (26.5%)
<i>Immediately following the 1<sup>st</sup> treatment</i>	1 (2%)	1 (2.9%)
<i>During the 1<sup>st</sup> follow up consultation</i>	4 (1%)	1 (2.9%)
<i>On my request when queries arise</i>	9 (22%)	10 (29.4%)
<i>All of the above</i>	0 (0%)	5 (14.6%)

Frequency of common myths and misconceptions such as ***patients' and partners' beliefs indicating a risk of "catching" the illness*** from their partner were also explored. At both follow up assessments, the vast majority of patients (6 months F-up: 95%, 12 months F-up: 94%) understood that their partner could not be physically harmed in any way by their illness or its treatment. However, two patients consistently reported misconceptions about the contagiousness of cancer, although the type of responses varied at each assessment (see Table 7.2.12.). Of the 4 cancer patients who at 6 months follow up reported that their partner believed in the contagiousness of cancer or that the patient's treatment (e.g. radiotherapy) could harm them, 2 patients (5.8%) continued to report partners' beliefs in such myths at 12 months follow up (see Table 7.2.13.).

Table 7.2.12. *Prevalence of misconceptions and myths among cancer patients regarding contagiousness of their illness or its treatment*

<b>"Because of my illness, I believe a partner"</b>	<b>6 months follow up</b> (n=43)	<b>12 months follow up</b> (n=34)
Could "catch" my illness even if we did not have sexual relations	0 (0.0%)	1 (2.9%)
Could become sick or hurt if we had sexual relations	1 (2.3%)	1 (2.9%)
Could not be harmed provided we did not have sexual relations	1 (2.3%)	0 (0.0%)
Could not be harmed if we had sexual relations	41 (95.3%)	32 (94.1%)

Table 7.2.13. *Cancer patients' reports of misconceptions and myths among partners regarding contagiousness of the patient's illness or its treatment*

<b>"My partner"</b>	<b>6 months follow up</b> (n=43)	<b>12 months follow up</b> (n=34)
This does not concern me because I do not have a partner	7 (15.9%)	4 (11.8%)
Is afraid that he/she will "catch" my illness	2 (4.5%)	1 (2.9%)
Is afraid that my treatment (such as radiotherapy) will harm him/her	2 (4.5%)	0 (0.0%)
Does not know very much about my illness and its treatment	0 (0.0%)	1 (2.9%)
Knows that neither my illness nor its treatment can harm him/her	33 (75.0%)	28 (82.4%)

At 12 months follow up, cancer patients were asked ***whether and when they had received a vaginal dilator***. If they had, ***did they receive instructions for its use and did they used this rehabilitation tool***. Interestingly, of the 21 cancer patients who had undergone adjuvant radiotherapy and completed the second follow up, only 2 women reported being given a vaginal dilator within the first post-treatment year (see Table 7.2.14.); one just after her radiation treatment and the other more than three months following the end of her treatment. Although both women reported being given adequate instructions for its use (see Table 7.2.15.), one woman used the dilator less often than was advised and the other did not use it at all (see table 7.2.16).

Table 7.2.14. Cancer patients' reports of receiving a vaginal dilator

<i>"I received vaginal dilator:"</i>	<b>6 months follow up</b> (n=21)	<b>12 months follow up</b> (n=21)
<i>Not at all</i>	40 (95.2%)	32 (90.4%)
<i>Just after my radiation treatment</i>	1 (4.8%)	0 (0.0%)
<i>One month after the end of my treatment</i>	0 (0.0%)	1 (4.8%)
<i>Two to three months after the end of my treatment</i>	0 (0.0%)	0 (0.0%)
<i>More than three months after the end of my treatment</i>	0 (0.0%)	1 (4.8%)

Table 7.2.15. Cancer patients' reports of receiving instructions on how to use a vaginal dilator

<i>"I was given sufficient explanation on the use of a vaginal dilator:"</i>	<b>6 months follow up</b> (n=39)	<b>12 months follow up</b> (n=34)
<i>Yes</i>	1 (2.6%)	2 (5.9%)
<i>No</i>	0 (0.0%)	0 (0.0%)
<i>Not applicable</i>	38 (97.4%)	32 (94.1%)

Table 7.2.16. Cancer patients' reports on the frequency of use of a vaginal dilator

<i>"I use a vaginal dilator:"</i>	<b>6 months follow up</b> (n=41)	<b>12 months follow up</b> (n=34)
<i>Not at all because it was not given or prescribed to me</i>	39 (96.6%)	31 (94.2%)
<i>Not at all though it was given or prescribed to me</i>	0 (0.0%)	1 (2.9%)
<i>Less often than recommended</i>	1 (2.4%)	1 (2.9%)
<i>As often I was told to use it</i>	0 (0.0%)	0 (0.0%)
<i>More often than I was told to use it</i>	0 (0.0%)	0 (0.0%)

### **7.2.5 Long-term treatment side effects**

As Table 7.2.17. indicates, a significant number of side effects reported at 6 months follow up resolved within the second half of the post-treatment year, including bladder problems, nerve damage, reduced lubrication and dyspareunia. The incidence of bowel problems and lymphoedema remained relatively stable over time whilst more cancer patients reported shortened

vagina, skin damage and reduced lubrication at 12 months follow up compared to 6 months follow up.

Table 7.2.17. *A comparison of the incidence of side effects at 6 and 12 months post-treatment*

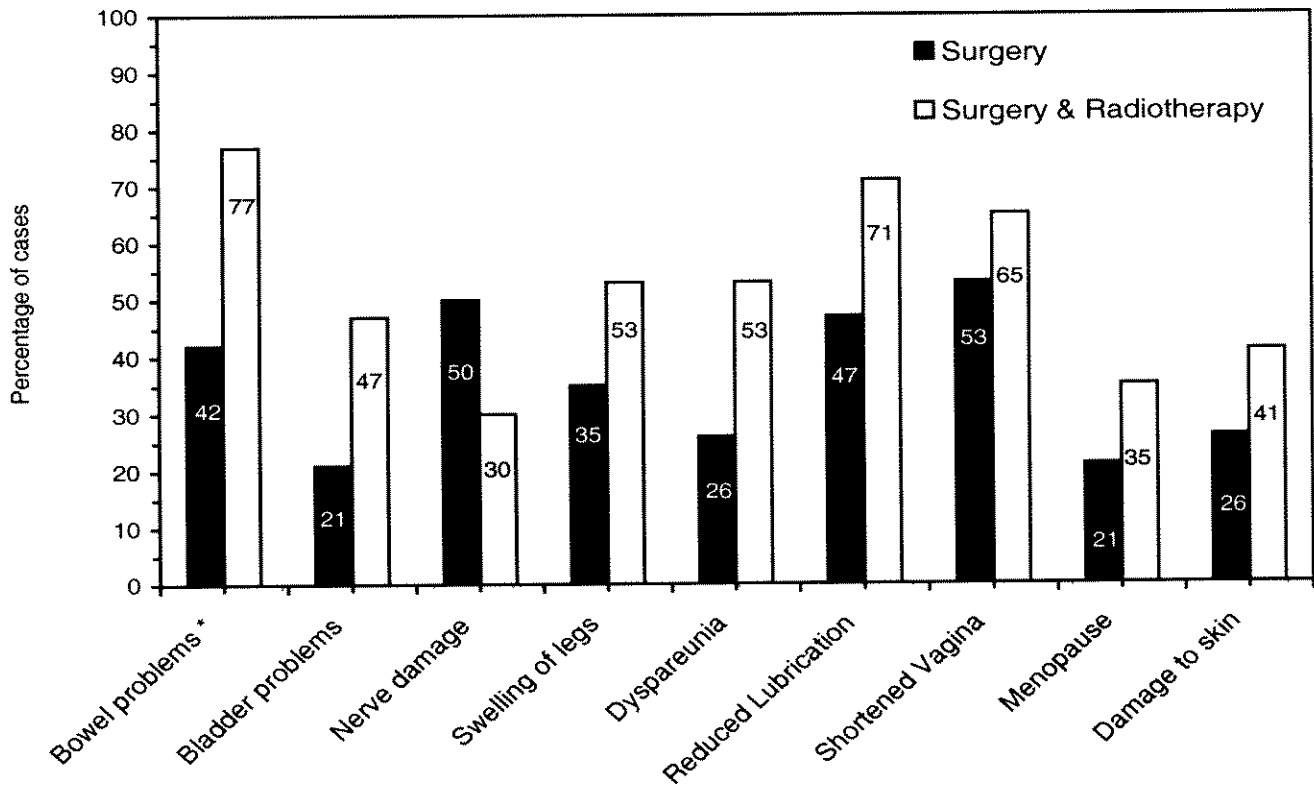
	6 months follow up	12 months follow up
<i>Bowel problems</i>	25 (54.3%)	21 (58.3%)
<i>Bladder problems</i>	21 (45.7%)	12 (33.3%)
<i>Nerve damage</i>	24 (52.2%)	15 (40.5%)
<i>Lymphoedema</i>	16 (34.8%)	16 (43.2%)
<i>Dyspareunia</i>	13 (68.4%)	14 (38.9%)
<i>Reduced lubrication</i>	20 (44.1%)	21 (58.3%)
<i>Shortened vagina</i>	21 (50.0%)	21 (58.3%)
<i>Onset of menopause</i>	18 (48.6%)	10 (27.9%)
<i>Skin damage</i>	10 (23.3%)	12 (33.3%)

The next step was to evaluate whether the incidence of side effects varied depending on the combination of treatment. As can be seen from Figure 7.2.7., a consistently greater percentage of irradiated cancer patients experienced various post-treatment side effects compared to patients treated with surgery alone. At twelve months follow up, irradiated patients reported significantly higher instances of bowel problems compared to patients with surgery only (Fisher's exact test (1-sided),  $p=0.039$ ). Similar trends were detected in frequencies of bladder problems (Fisher's exact test (1-sided),  $p=0.097$ ) and dyspareunia (Fisher's exact test (1-sided),  $p=0.098$ ).

No significant differences between the two treatment subgroups were detected regarding side effects of shortened vagina ( $p=0.347$ ), nerve damage or numbness in the pelvic area ( $p=0.140$ ), the onset of menopause ( $p=0.281$ ), reduced lubrication ( $p=0.142$ ), skin damage ( $p=0.278$ ) or lymphoedema ( $p=0.222$ ). Of the patients who had undergone pelvic lymph node dissection, 13 reported suffering from lymphoedema at 6 and 12 months follow ups (39% and 46% respectively). It is, however, important to note that the lack of significant

findings in these variables may have been due to insufficient power (see Figure 7.2.7.).

Figure 7.2.7. Percentages of long-term side effects experienced by cancer patients treated with surgery alone versus surgery and radiotherapy at 12 months post-treatment



As with 6 months follow up, patients were given the option to include any **additional side effects** not listed in the questionnaire. Only four cancer patients (11%) reported additional side effects, further supporting the comprehensiveness of the developed inventory. These included abdominal pain, reduced muscle tone, “hardening of one side of incision” (all consistent with undergoing the surgical procedure) and “feeling invaded and vulnerable”.

Figures 7.2.8. and 7.2.9. compare the incidence of short-term (at 6 months post-treatment) and long-term (at 12 months follow up) side effects for individual treatment groups, i.e. surgery alone and surgery plus radiotherapy. Overall, the percentages of side effects in the combined treatment group were higher than in



the “surgery alone” group. In the “surgery alone” group, the incidence of the majority of side effects reported at 6 months follow up remained at a similar level (e.g. bowel problems, lymphoedema, reduced lubrication) or declined by 12 months post-treatment (e.g. bladder problems, nerve damage). Damage to skin, shortened vagina and dyspareunia were the only side effects in this subgroup to considerably increase over time. In contrast, most of the reported side effects in the group with combined treatments became chronic (e.g. bowel problems, nerve damage, dyspareunia, shortened vagina) or the incidence of certain side effects increased by 12 months follow up, suggesting a delayed onset of these side effects (e.g. lymphoedema). Bladder problems and onset of menopause were the only two side effects in the combined treatment group to considerably decrease over time.

Figure 7.2.8. Percentages of side effects reported by cancer patients who had undergone **surgery alone** at 6 and 12 months post-treatment

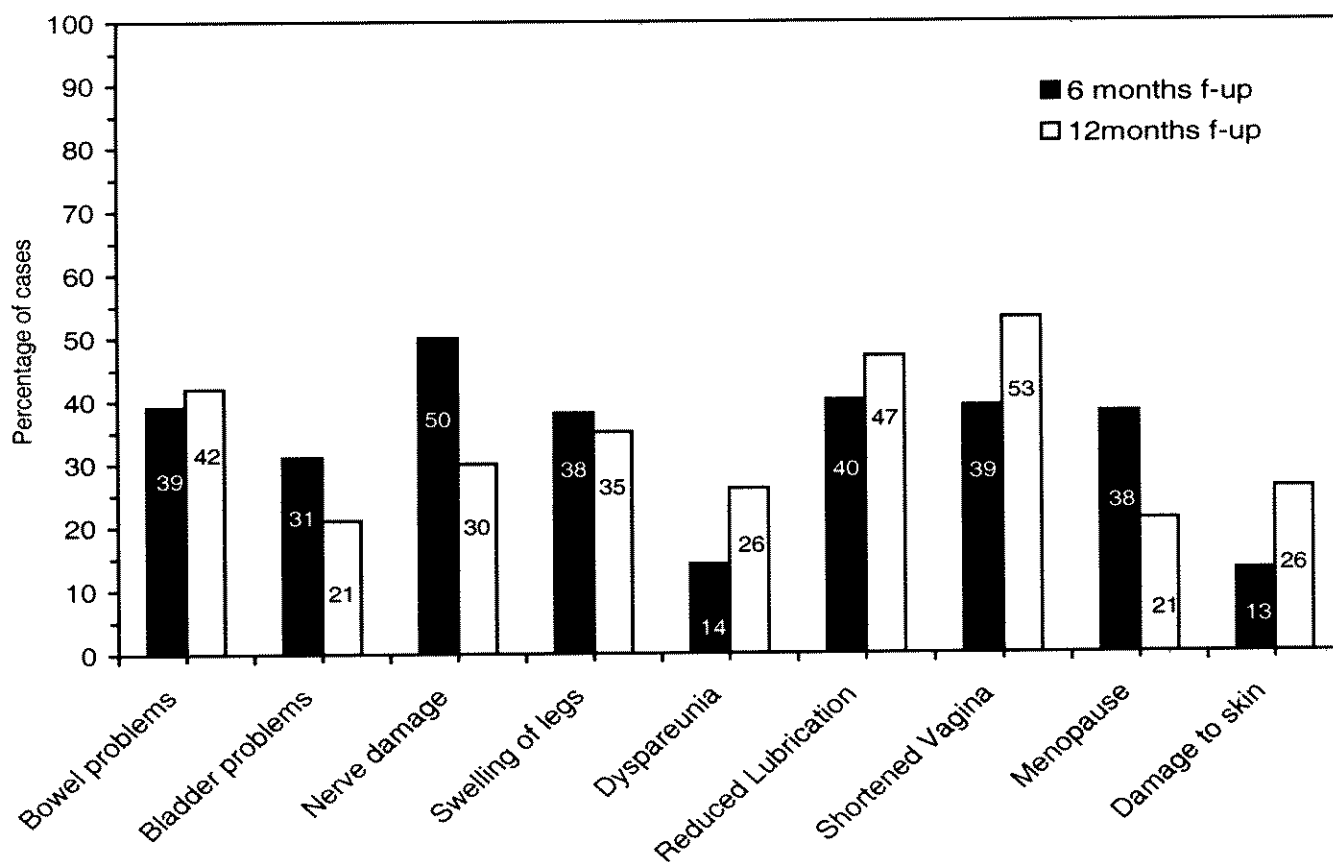
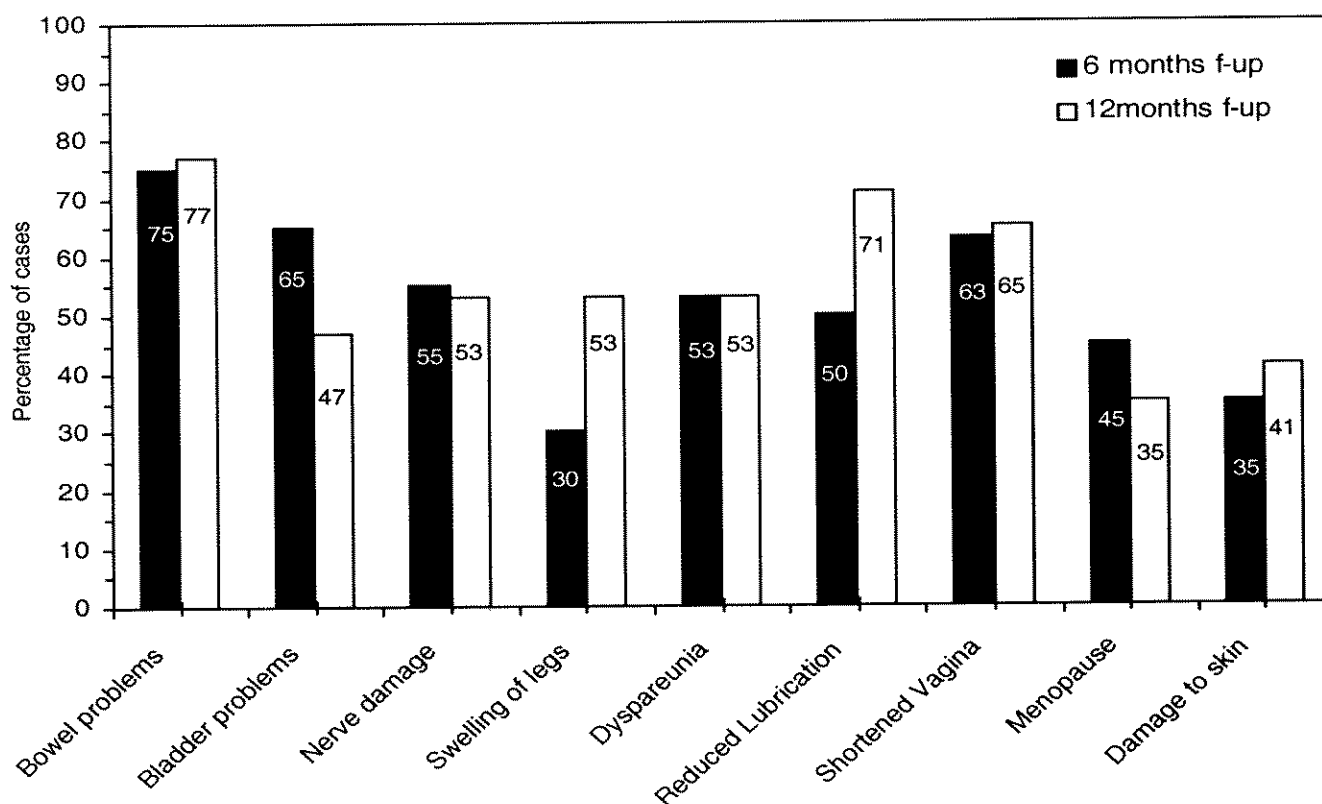


Figure 7.2.9. Percentages of side effects reported by cancer patients who had undergone **surgery with adjuvant radiotherapy** at 6 and 12 months post-treatment



### 7.2.6 Main issues pertinent to specific treatment modalities

At both follow ups, cancer patients were asked to rate how much each treatment impacted on each of the six identified issues (i.e. femininity/womanhood, physical appearance, sexual functioning, infertility, feeling prepared for the treatment and feeling confident nothing would go wrong during treatment). This was to assess whether patients' perceptions of various treatments impacting on these issues had changed over time or remained stable. Table 7.2.18. describes patients' responses regarding various issues related to various treatment modalities at both assessments. For each issue, the effect of surgery will be described first followed by an analysis of findings pertinent to specific radiation treatments.

At 12 months follow up, over half (59.4%) of cancer patients reported that their *femininity* was “somewhat” or “very much” reduced as a result of their surgery, which was higher than at 6 months follow up (42.2%). Similarly, more than half of cancer patients (59.3%) reported surgery-related moderate or significant changes in *physical appearance* at 12 months follow up, which was comparable to 6 months follow up findings (55.9%). A comparable percentage of cancer patients undergoing hysterectomy reported changes in *sexual functioning* over time. At both assessments, the majority of cancer patients reported that surgery “very much” affected their *fertility* (see Table 7.2.18.). It is important to note that all women who reported no impact of surgery on their fertility were peri- or post-menopausal prior to their treatment. The majority of patients reported being *prepared for the effect of surgery* and its side effects at both follow up assessments. The percentage of patients who indicated “not being prepared at all” for their surgery slightly decreased over time. In contrast, the percentage of patients who reported not *feeling confident that anything could go wrong during surgery* had risen over time (see Table 7.2.18.).

#### *The impact of radiation treatments*

Over time, changes regarding *femininity* as a consequence of brachytherapy were noted, with 70% of women reporting moderate to severe deterioration of femininity at 12 months follow up compared to only 35% at 6 months follow up (see Table 7.2.19.). In contrast, perception of external radiotherapy remained relatively stable within the first post-treatment year. Comparisons among treatments revealed that brachytherapy was perceived as the treatment most responsible for inducing a reduction in the sense of feeling feminine.

An opposite pattern was noted regarding changes in *physical appearance*. The detrimental effects of external radiotherapy on physical appearance intensified over time, with 42% women reporting moderate to severe changes at 12 months follow up compared to only 22% at 6 months follow up. However, perception of brachytherapy remained relatively stable over time (approximately 20%).

Treatment comparisons at 12 months follow up indicated that surgery was perceived by the majority of women as having the most severe impact on physical appearance compared to the two radiation treatments.

Regarding the impact of various treatments on *sexual functioning*, the perception of external radiotherapy slightly improved over time, with 70% patients reporting detrimental impact at 6 months follow up compared to only 50% at 12 months follow up. The impact of brachytherapy on sexual functioning was comparable at both follow ups, with 55% of women reporting a change at 6 months and 66% at 12 month post-treatment. A comparison of all treatments at 12 months follow up indicated that the most significant impact was perceived as being from i) surgery and ii) brachytherapy.

At 6 months follow up, the majority of cancer patients (88%) identified surgery as making them infertile, compared to half of the patients who identified radiation treatment. Over time, external radiotherapy was perceived as more prominent in causing infertility whilst brachytherapy was perceived as less prominent. Interestingly, at 12 months follow up, some women indicated that treatments and their side effects made them “somewhat” infertile.

A third of women indicated *not being prepared for external radiation treatment* and its side effects at both follow ups. The percentage of women who reported not being prepared for brachytherapy at 6 months follow up (18%) increased at one year post-treatment (33%). At 12 months follow up, patients reported feeling more prepared for surgical treatment (15%) than for either radiation treatment (33%).

At 12 months follow up, over a quarter of patients indicated that they were *not confident that nothing could go wrong during surgery*, whereas none of the patients reported this observation regarding either radiation treatment. At 6 months follow up nearly two thirds of patients (60%) reported being strongly and 10% moderately confident concerning brachytherapy procedure, whilst only 11%

reported strong and 89% moderate confidence in brachytherapy at 12 months follow up.

Table 7.2.19. *The impact of various cancer treatments on common issues reported by cancer patients at 6 and 12 months follow ups*

	Post-treatment assessments	Surgery (%)			External Radiation (%)			Brachytherapy (%)		
		No	Somewhat	Much	No	Somewhat	Much	No	Somewhat	Much
<i>Reduced Femininity</i>	6 months	58	40	2	58	33	8	64	27	9
	12 months	41	50	9	56	44	0	30	40	30
<i>Changed Physical Appearance</i>	6 months	44	33	23	58	25	17	80	10	10
	12 months	41	46	13	78	22	0	78	22	0
<i>Sexual Functioning affected</i>	6 months	38	43	19	30	40	30	44	22	33
	12 months	42	42	16	50	37	13	33	33	33
<i>The treatment &amp; its side effects made me infertile</i>	6 months	12	0	88	45	0	55	43	0	57
	12 months	23	7	71	25	12	63	57	14	29
<i>Prepared for the treatment &amp; its side effects</i>	6 months	23	41	36	33	33	33	18	46	36
	12 months	15	42	42	33	33	33	33	33	33
<i>Confident nothing could go wrong during the treatment</i>	6 months	16	36	48	27	36	36	30	10	60
	12 months	27	62	12	0	67	33	0	89	11

Note: Due to unequal sample sizes at 6 and 12 months follow ups, only percentages will be reported

### 7.2.7 Psychological responses pertinent to specific treatment modalities

Psychological responses elicited by each treatment at 12 months follow up were analysed using the newly developed measure described in the Method section and reported in the 6 months follow up Result section. A total score for each of the three factors generated by this measure (i.e. distress, disempowerment, degradation) was obtained by summing up variable scores that loaded on each factor at each follow up. Descriptive statistics for all three factors at 6 and 12 months follow up are shown in Table 7.2.20.

Changes in the three factors pertinent to *the impact of surgery* over time were computed using paired samples t-test. There was a trend of higher levels of

degradation related to surgery at 12 months follow up compared to 6 months post-treatment, although this effect just failed to reach a significance ( $t=-1.967$ ,  $p=0.058$ ). No differences over time were detected in patients' feeling distressed ( $t=-1.368$ ,  $p=0.181$ ) or disempowered ( $t=-0.443$ ,  $p=0.661$ ) related to their surgical experience (i.e. hysterectomy).

Table 7.2.20. *Descriptive statistics for surgery-related psychological responses of cancer patients at 6 and 12 months follow up*

		<b>Factor 1</b> <b>Distress</b> (max. score = 90)	<b>Factor 2</b> <b>Disempowerment</b> (max. score = 60)	<b>Factor 3</b> <b>Degradation</b> (max. score = 30)
<b>6 months F-up</b> (n=39)	<i>Mean</i>	38.39	19.65	4.12
	<i>Std. Deviation</i>	20.95	13.50	5.09
	<i>Range</i>	0.00 - 85.60	0.00 - 57.60	0.00 - 19.80
<b>12 months F-up</b> (n=35)	<i>Mean</i>	43.24	21.73	6.55
	<i>Std. Deviation</i>	22.57	15.71	6.55
	<i>Range</i>	0.50 - 110.50	0.00 - 64.50	0.00 - 21.70

Psychological responses of patients who had undergone *combined treatment modalities* were compared qualitatively, based on the identified factor structure from "surgical outcomes". Examination of Table 7.2.21. indicates that at 12 months follow up, cancer patients reported greater distress, disempowerment and to a lesser degree degradation with individual treatments, the greater the number of cancer treatments these patients received (i.e. combined surgery and both radiation treatments). This is in contrast to the 6 months follow up findings, where patients reported the opposite effect.

Table 7.2.21. *The mean scores (and standard deviations) for the factor structure of psychological responses of cancer patients related to specific treatment modalities at 6 and 12 months follow up*

Treatment groups	Post-treatment Assessments	DISTRESS related to			DISEMPOWERMENT related to			DEGRADATION related to		
		SR	ER	BR	SR	ER	BR	SR	ER	BR
<b>SR alone</b>	<i>6 months</i> (n=24)	<b>43.4</b> (21.4)			<b>20.4</b> (14.1)			<b>4.5</b> (5.8)		
	<i>12 months</i> (n=19)	<b>46.4</b> (19.6)			<b>21.5</b> (14.1)			<b>8.0</b> (7.4)		
<b>SR &amp; BR</b>	<i>6 months</i> (n=6)	<b>32.7</b> (19.7)		<b>38.9</b> (20.2)	<b>18.0</b> (10.6)		<b>25.1</b> (15.1)	<b>3.6</b> (3.1)		<b>13.2</b> (7.8)
	<i>12 months</i> (n=5)	<b>37.9</b> (36.3)		<b>40.0</b> (27.9)	<b>19.2</b> (25.5)		<b>27.1</b> (20.6)	<b>3.7</b> (3.8)		<b>12.2</b> (10.9)
<b>SR &amp; ER</b>	<i>6 months</i> (n=8)	<b>34.7</b> (16.9)	<b>36.4</b> (19.2)		<b>22.0</b> (16.2)	<b>29.8</b> (18.9)		<b>3.8</b> (3.9)	<b>10.1</b> (10.0)	
	<i>12 months</i> (n=7)	<b>38.7</b> (24.4)	<b>42.4</b> (22.4)		<b>22.0</b> (17.6)	<b>28.9</b> (19.6)		<b>4.9</b> (4.2)	<b>9.1</b> (9.9)	
<b>SR &amp; ER &amp; BR</b>	<i>6 months</i> (n=4)	<b>24.8</b> (24.8)	<b>24.7</b> (20.8)	<b>25.0</b> (18.8)	<b>13.6</b> (10.4)	<b>17.3</b> (12.2)	<b>16.9</b> (11.4)	<b>3.4</b> (6.9)	<b>8.2</b> (9.6)	<b>6.9</b> (7.7)
	<i>12 months</i> (n=3)	<b>42.7</b> (17.2)	<b>40.1</b> (15.6)	<b>45.4</b> (4.6)	<b>26.8</b> (4.2)	<b>29.6</b> (3.9)	<b>31.8</b> (10.8)	<b>5.2</b> (8.3)	<b>11.3</b> (9.7)	<b>11.1</b> (5.9)

Note: SR = Surgery, ER = External Radiotherapy, BR = Brachytherapy (i.e. internal radiotherapy)  
Maximum scores: Factor 1 = 90, Factor 2 = 60, Factor 3 = 30.

In all combined treatment groups, both radiation treatments were associated with more disempowerment and degradation compared to a surgical treatment at both assessments. However, it should be noted that any interpretation of the above tendencies should be made with caution due to the very small sample sizes.

At 6 months follow up, participants who received combined treatment modalities surprisingly appeared to rate each individual treatment as less distressing than those receiving surgery alone. Indeed, the more treatments that patients experienced, they reported finding each treatment relatively less distressing. Levels of reported distress associated with each treatment appeared to increase over time, particularly for patients who had received all three treatments. By

twelve months' follow up, the pattern of finding the multiple treatments to be less distressing was no longer evident (see Table 7.2.21.).

For disempowerment, a similar pattern emerged. That is, patients receiving all three treatments appeared to rate each individual treatment as relatively less disempowering than patients receiving either surgery alone or surgery with either brachytherapy or external beam radiation. However, over the ensuing twelve months, patients receiving all three interventions appeared to report their experiences of treatments as more disempowering. Indeed, at the 12 months follow up, these patients reported levels of disempowerment at least as high as the other groups, and in some instances higher.

In general, patients did not report surgery as being highly degrading, although there was a trend in three of the four treatment groups for reported levels of degradation to increase over time. Both brachytherapy and external beam radiation appeared to be related to higher levels of degradation than surgery. As with the other emotional responses, at the six month follow up there was a tendency for patients having all three treatments to rate the treatments as less degrading in comparison to patients having two, combined treatments or surgery alone. However, this pattern was no longer evidenced at twelve months follow up where the patients who had received all treatments again reported higher levels of degradation (see table 7.2.21.).

### **7.2.8 Changes in psychological functioning**

Results for the 3 x 1 repeated measures ANOVA for **anxiety levels** revealed no main effect for time ( $F(2,72)=0.200$ ,  $p=0.819$ ). As evident from Figure 7.2.10. and Table 7.2.22., cancer patients reported comparable, elevated, levels of anxiety (~ 6) across all three assessments. As with baseline analyses, patients' scores were categorised into non-clinical levels (0-7) and clinical levels (8-21). Approximately a third of cancer patients reported having suffered from **clinical anxiety** levels immediately post-surgery (30%), at 6 months post-treatment (33%) and at 12 months follow up (32%) (see Figure 7.2.11.).



Table 7.2.22. Group means (and standard errors) of the psychological status variables

Subscale	Post-treatment	6 months Follow up	12 months Follow up
<b>Anxiety</b>	5.73 (0.60)	5.76 (0.67)	6.05 (0.66)
<b>Depression</b> §	4.89 (0.55)	2.76 (0.34)	3.43 (0.51)

\*Note: Baseline means reported above differ from those cited in the Chapter 6 due to different covariates  
 § = significant main effect for time

Figure 7.2.10. Changes in anxiety and depression levels over time

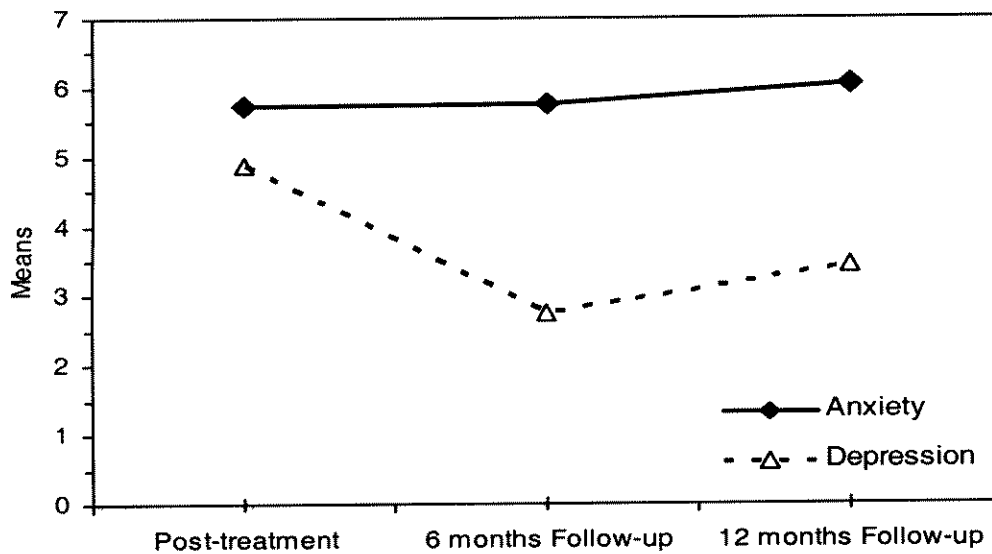
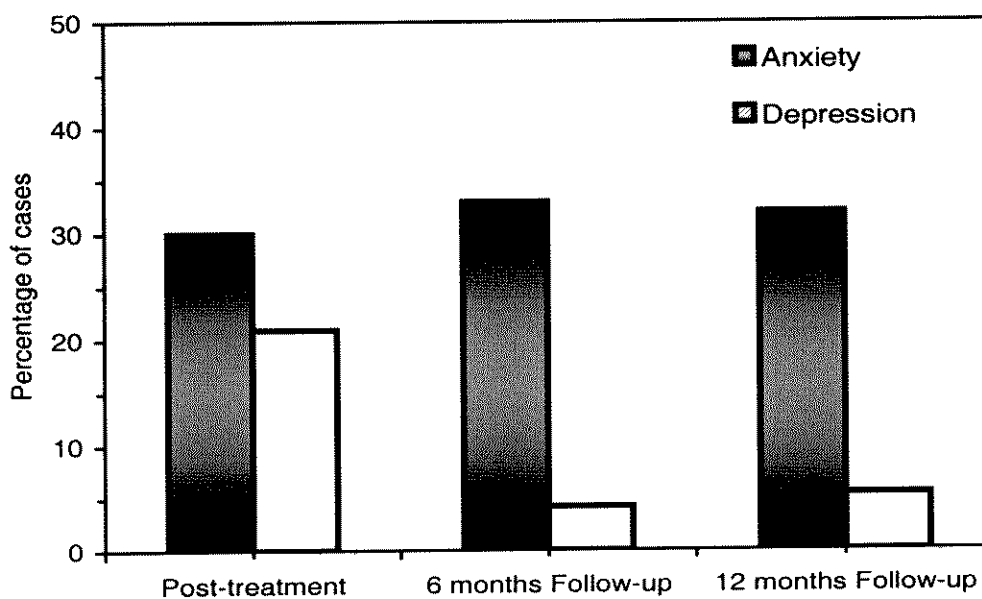


Figure 7.2.11. Changes in clinical levels of anxiety and depression over time



A rather different pattern emerged in *levels of depression*, as the 3 x 1 repeated measures ANOVA revealed significant differences in mood in the cancer group over time ( $F(2, 72)=8.982, p=0.000$ ). Examination of Table 7.2.22. and Figure 7.2.10. indicates that the main effect observed was due to a significant improvement of mood at 6 months follow up compared to post-surgery ( $F(1,36)=16.484, p=0.000$ ), with the levels of depression remaining low at 12 months follow up ( $F(1,36)=4.431, p=0.128$ ). Subsequently, the depression levels at 12 months post-treatment were significantly lower compared to immediately post-surgery ( $F(1,36)=6.431, p=0.016$ ). The relatively low mean depression scores in this sample indicate that the majority of patients were not *clinically depressed* during the first 12 months following their treatment. As Figure 7.2.11. indicates, a higher proportion of cancer patients (20.8%) reported clinical depression levels post-surgery than at 6 months follow up (4.2%) or 12 months follow up (5.4%).

### **7.2.9 Changes in mental adjustment styles of cancer patients**

As stated previously, the fighting spirit and fatalism subscales were not included in the analyses due to their low internal consistency based on the current sample. The repeated measures 3 x 1 ANOVA revealed a significant changes over time in the "anxious preoccupation" adjustment style ( $F(1,46)=5.882, p=0.019$ ). Examination of Table 7.2.23. indicates that this effect was due to patients being less anxiously preoccupied with their disease/treatment at 6 months follow up compared to baseline. The adjustment styles of hopelessness/helplessness ( $F(1,47)=0.377, p=0.542$ ) and cognitive avoidance ( $F(1,46)=0.06, p=0.808$ ) were comparable at both assessments.

Table 7.2.23. *Group means (and standard errors) of the mental adjustment styles of cancer patients*

<b>Subscale</b> (maximum score)	<b>Immediately</b> <b>Post-surgery</b>	<b>6 months</b> <b>Follow up</b>	<b>12 months</b> <b>Follow up</b>
<b>Hopelessness/Helplessness</b> (max. score = 32)	11.19 (3.82)	10.97 (3.97)	12.22 (4.02)
<b>Anxious preoccupation</b> (max. score = 32)	17.97 (4.78)	16.76 (5.10)	17.94 (4.68)
<b>Cognitive avoidance</b> (max. score = 16)	10.54 (3.31)	10.69 (2.97)	11.14 (2.43)

*Note: Group means of the Fighting spirit and Fatalism subscales are not included due to low internal consistency based on the current sample (n=36)*

### **7.2.10 Changes in Quality of Life of cancer patients**

Considering the deteriorating levels of sexual satisfaction during the first post-treatment year, it was important to investigate whether similar changes occurred regarding cancer patients' quality of life. Within subjects comparisons of total scores of these 5 subscales were analysed using repeated measures 3 x 1 ANOVA.

**Physical wellbeing** of cancer patients was found to significantly improve within the first 12 months post-treatment ( $F(2,72)=6.984, p=0.002$ ). As Table 7.2.24. and Figure 7.2.12. indicate, physical wellbeing substantially improved during the first 6 months post-treatment ( $F(1,36)=7.244, p=0.011$ ) and remained stable in the second half of the first post-treatment year ( $F(1,36)=0.196, p=0.661$ ). Patients' levels of physical wellbeing at 12 months follow up were significantly higher compared to their pre-treatment levels ( $F(1,36)=8.706, p=0.006$ ).

Figure 7.2.12. Changes in the five **Quality of Life dimensions** of cancer patients over time

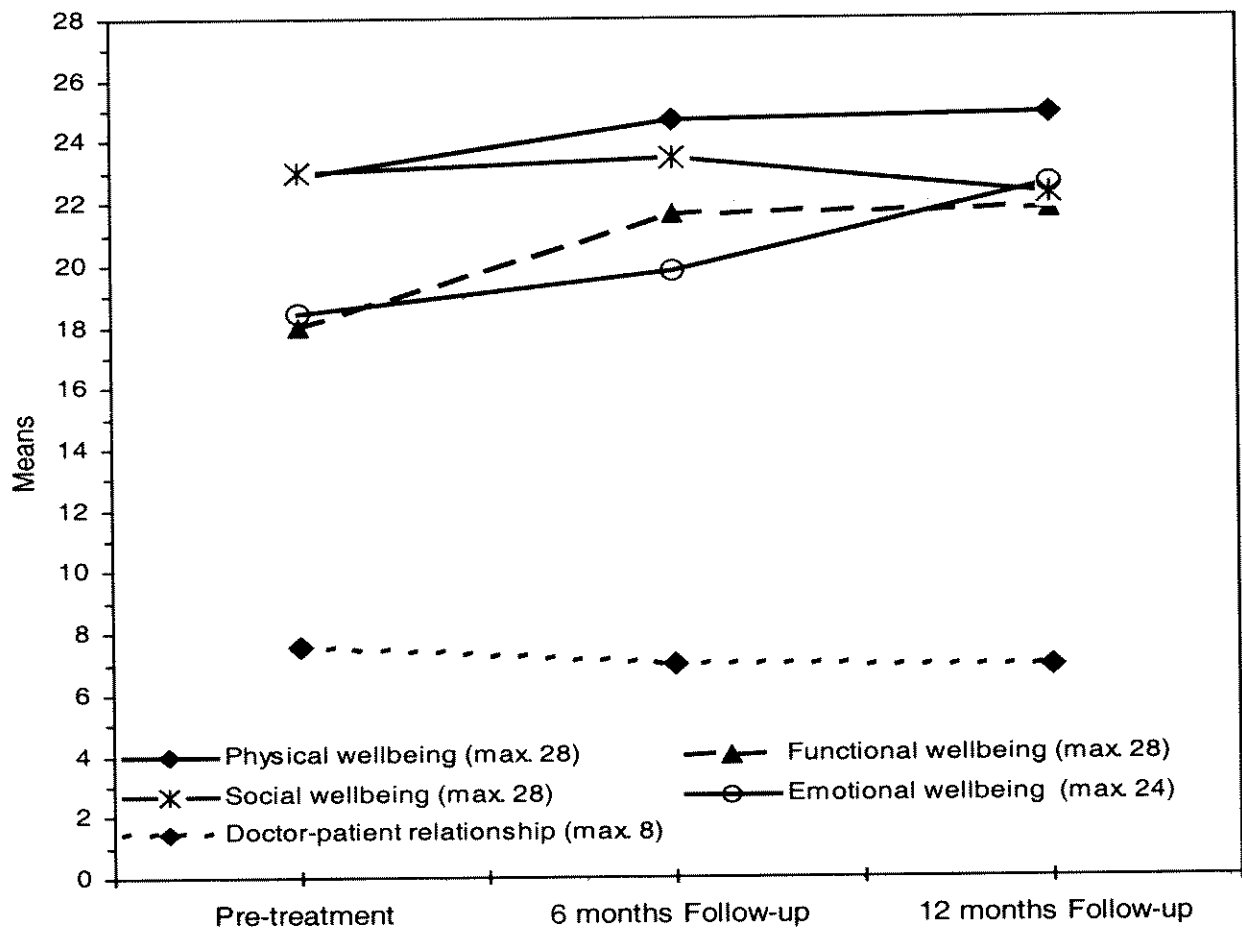


Table 7.2.24. Means (and standard errors) of Quality of Life dimensions of cancer patients

<b>Subscale (maximum score)</b>	<b>Pre-treatment</b>	<b>6 months Follow up</b>	<b>12 months Follow up</b>
<b>Physical wellbeing<sup>§</sup> (28)</b>	22.87 (0.56)	24.70 (0.45)	24.87 (0.48)
<b>Functional wellbeing<sup>§</sup> (28)</b>	17.97 (0.86)	21.62 (0.75)	21.73 (0.69)
<b>Social wellbeing (28)</b>	22.97 (0.62)	23.41 (0.80)	22.27 (0.85)
<b>Emotional wellbeing<sup>§</sup> (24)</b>	18.41 (0.63)	19.81 (0.68)	22.57 (0.69)
<b>Dr-patient relationship (8)</b>	7.57 (0.11)	6.97 (0.26)	6.87 (0.32)
<b>Total Quality of Life (120)</b>	89.45 (2.35)	98.48 (1.93)	96.14 (2.27)
<b>Cancer-related wellbeing<sup>§</sup> (56)</b>	36.38 (0.96)	40.21 (1.03)	42.56 (1.24)

\*Note: Baseline means reported above differ from those cited in the Chapter 6 due to different covariates  
 Higher means indicate better outcomes  
 § = significant main effect for time

Similarly, an assessment of **functional wellbeing** revealed significant main effect for time across the three assessment points ( $F(2,72)=9.213$ ,  $p=0.000$ ). The examination of means in Figure 7.2.12. and Table 7.2.24. indicates that these results were again due to a notable functional improvement at 6 months follow up compared to pre-treatment ( $F(1,36)=10.796$ ,  $p=0.002$ ), which remained high in the second half of the post-treatment year ( $F(1,36)=0.015$ ,  $p=0.904$ ). Functional levels at 12 months follow up were significantly higher than pre-treatment levels ( $F(1,36)=14.839$ ,  $p=0.000$ ).

Over the three assessments, significant changes were also detected for the **emotional wellbeing** subscale ( $F(2,72)=19.255$ ,  $p=0.000$ ). Examination of means in Figure 7.2.12. and Table 7.2.24. indicates that the significant time effect was again due to considerable improvements in emotional wellbeing between pre-treatment and 6 months follow up ( $F(1,36)=4.437$ ,  $p=0.042$ ), with further improvement detected at 12 months post-treatment ( $F(1,36)=18.649$ ,  $p=0.000$ ). Subsequently, emotional wellbeing of cancer patients at 12 months follow up significantly improved compared to pre-treatment levels ( $F(1,32)=31.826$ ,  $p=0.000$ ).

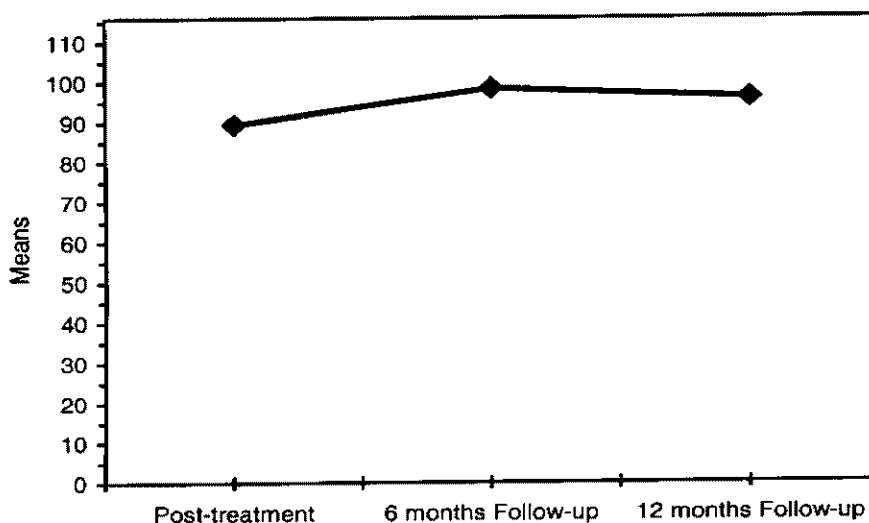
In contrast to emotional wellbeing, no main effect in levels of **social wellbeing** over time was detected ( $F(2,72)=1.177$ ,  $p=0.314$ ). As Figure 7.2.12. and Table 7.2.24. indicate, the cancer patients' already good pre-treatment levels of social wellbeing remained at the same level at 6 months follow up ( $F(1,36)=0.427$ ,  $p=0.518$ ) and at 12 months follow up ( $F(1,36)=2.376$ ,  $p=0.132$ ). No change in social wellbeing between pre-treatment and at 12 months post-treatment was found ( $F(1,36)=0.712$ ,  $p=0.404$ ).

The repeated measures 3 x 1 ANOVA for satisfaction with **doctor-patient relationship** revealed main effect of time across the three assessment points ( $F(2,72)=4.431$ ,  $p=0.015$ ). Examination of Figure 7.2.12. and Table 7.2.24. indicates that cancer patients' satisfaction significantly declined at 6 months

post-treatment compared to pre-treatment levels ( $F(1,36)=5.967$ ,  $p=0.020$ ), whilst levels of satisfaction at 6 months and 12 months post-treatment were comparable ( $F(1,36)=0.253$ ,  $p=0.618$ ). At 12 months follow up, cancer patients were significantly less satisfied with doctor-patient relationship than at pre-treatment ( $F(1,36)=5.587$ ,  $p=0.024$ ). It is important to note, however, that patients reported very high overall satisfaction with their treating doctor across all three assessments (see Figure 7.2.12.).

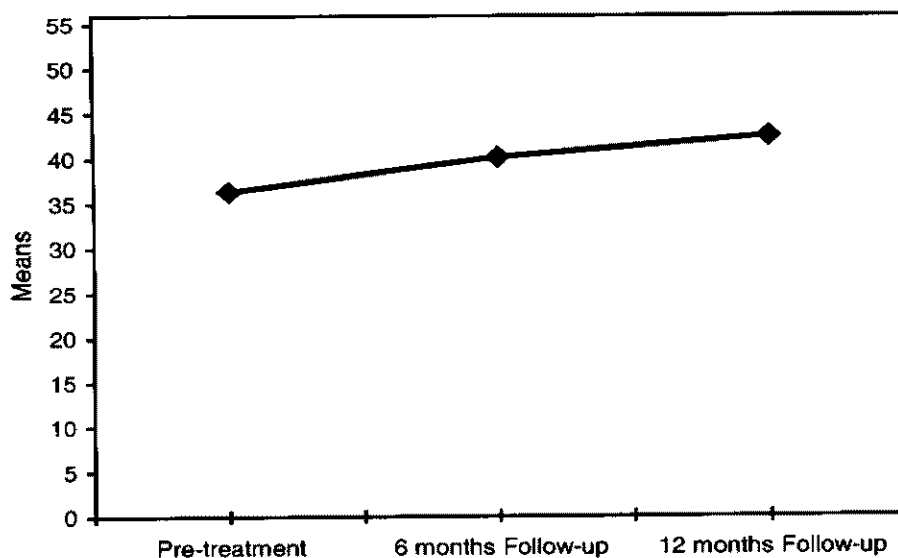
As stated previously, the total scores of the above five quality of life subscales were summed up and analysed to investigate any significant changes in the **overall quality of life** of cancer patients. A repeated measures 3 x 1 ANOVA significant differences over time ( $F(2,56)=10.482$ ,  $p=0.000$ ), cancer patients' quality of life significantly improving in the first 6 months post-treatment ( $F(2,115)=7.723$ ,  $p=0.001$ ) and remaining unchanged at 12 months follow up ( $F(1,28)=2.218$ ,  $p=0.148$ ). Considering the maximum score of 116, cancer patients were located in the upper quartile of possible scores for the first 12 months post-treatment and according to the anchors of the scale, their quality of life was "a little bit" impaired during the first post-treatment year (see Table 7.2.24. and Figure 7.2.13.).

Figure 7.2.13. *Changes in overall quality of life of cancer patients over time*



Over the three assessments, significant changes were also detected for **cancer-related wellbeing** subscale ( $F(2,66)=15.047, p=0.000$ ). Examination of means in Figure 7.2.14. and Table 7.2.24. indicates that the significant time effect was due to considerable improvements in cancer-related wellbeing between pre-treatment and 6 months follow up ( $F(1,33)=11.692, p=0.002$ ), with a trend of further improvement detected between 6 and 12 months post-treatment ( $F(1,33)=4.066, p=0.052$ ). Subsequently, cancer-related wellbeing of cancer patients at 12 months follow up significantly improved compared to pre-treatment levels ( $F(1,33)=30.208, p=0.000$ ).

Figure 7.2.14. *Changes in cancer-related wellbeing of cancer patients over time*



## **7.3 Results III: Prognostic variables for psycho-sexual adjustment and quality of life following early stage cervical and endometrial cancer**

### **7.3.1 Introduction**

Results from the previous section indicated that cancer patients' sexual and relationship outcomes were adversely affected at 6 months follow up, whilst by 12 months post-treatment, sexual drive (i.e. frequencies of various overt sexual behaviours) returned approximately to pre-treatment levels of functioning. This was in contrast to the levels of satisfaction with their sexual relationship which declined by 6 months post-treatment, remaining at significantly lower levels at 12 months follow up compared to pre-diagnosis. An opposite pattern of adjustment was revealed in cancer patients' post-treatment quality of life, with significant improvements in quality of life at 6 months follow up and its levels remaining high at one year post-treatment. Another interesting but alarming finding was the fact that approximately a third of the cancer patients remained clinically anxious across all three assessments. Despite these changes, the majority of women reported relatively minor changes in sexual functioning. Nonetheless, a small proportion reported considerably greater impairments. It is these women for whom additional resources may be required. However, it is necessary to determine in advance whether these women can be identified as "at risk" for more severe problems. Hence the main aims of this set of analyses were:

- 1) to aid identification of patients "at risk" of poor outcomes who might be in need of intervention
- 2) to advance our understanding on the mechanism underlying psychological and physiological processes of post-treatment sexual adjustment



- 3) to provide suggestions as to the timing and context of interventions in order to maximize their effectiveness

### **7.3.2 Preliminary analyses**

The participants for this section are those 50 cancer patients who completed the 6 months follow up. The sample characteristics can be found in Chapter V, section 5.2. The size of the sexually active cancer sample (n=36) constrained the number of variables, which could be tested for sexual satisfaction and relationship satisfaction. Therefore, the power analysis is rather limited given the number of different measurements, which may have influenced the course and outcome of treatment. It was felt most appropriate, therefore, to use a predominantly empirical basis for determining which variables should be entered into the analysis.

Since the three variables that significantly changed over time were satisfaction with relationship, sexual satisfaction and overall quality of life, it is these scores which have been entered into the analysis as the dependent variables. In addition, it was of clinical interest to investigate factors contributing to the persistently elevated levels of anxiety reported by a third of the cancer sample. Since the most prominent changes in satisfaction and quality of life variables occurred within the first 6 months post-treatment and since a higher number of sexually active cancer patients completed 6 months follow up, the regression analyses were conducted using 6 months follow up data. Those variables with the highest association or any of particular theoretical significance have been entered into the analyses as detailed below.

The four significant and clinically important results from the Results section 7.2. were deterioration in sexual satisfaction and relationship satisfaction, improvement in quality of life and elevated levels of anxiety. Therefore, the aim was to predict outcomes on these four indices and to examine whether a relationship existed among these outcomes. Pre-treatment (or pre-diagnosis) levels of other variables were correlated with the scores on post-treatment levels

of these four variables in order to empirically derive the variables which were to be entered into the analysis. This is due to the power limitations which exist for multiple regressions for a small sample of patients, allowing only 6-7 variables to be entered into the analysis to maintain reasonable case to variable ratio. A backwards step-wise multiple regression was performed since our aim was to determine the predictive model for the chosen variables.

### **7.3.3 Results**

Table 7.3.1. displays the correlation matrix for each variable and the dependent variables of sexual satisfaction, relationship satisfaction and anxiety scores at 6 months follow up. No demographic variables significantly correlated with the four investigated post-treatment outcomes, neither did post-treatment vaginal changes (e.g. shortened vagina, reduced lubrication) or other side effects (e.g. bowel/bladder problems, dyspareunia, lymphoedema). Variables significantly correlating with the selected outcomes were entered into the backwards step-wise multiple regression analyses.

As can be seen from Table 7.3.1., significant positive correlations were observed between post-treatment *sexual satisfaction* and baseline sexual satisfaction as measured by the Sexual satisfaction subscale of the Derogatis Sexual Functioning Inventory (DSFI); emotional wellbeing, gynaecological cancer-related wellbeing and an overall index of quality of life, all measured by the Functional Analysis of Cancer Treatment inventory; Relationship satisfaction assessed by Buunk's Relationship Satisfaction Interaction Scale, and anxiety levels measured by the Hospital Anxiety and Depression Scales (HADS).

For *relationship satisfaction* at 6 months post-treatment, significant correlations with the following baseline variables were identified: relationship satisfaction, sexual satisfaction, anxiety and depression levels assessed by the Hospital Anxiety and Depression Scales (HADS) and the adjustment style of hopelessness/helplessness measured by the Mini-Mental Adjustment to Cancer Scale (Mini-MAC). Since the baseline scores of all five quality of life subscales

were significantly correlated with post-treatment relationship satisfaction, it was decided to enter only the "overall quality of life" variable into the analysis, as this score combines outcomes of the five subscales (see Table 7.3.1.).

The *overall quality of life* at 6 months follow up was significantly correlated with the following baseline levels: all five dimensions of quality of life, sexual satisfaction, anxiety, and adjustment style of hopelessness/helplessness.

Post-treatment levels of *anxiety* were significantly correlated with pre-treatment levels of 1) emotional wellbeing, 2) doctor-patient communication, 3) total quality of life, 4) anxiety, 5) adjustment style of hopelessness/helplessness and 6) adjustment style of anxious pre-occupation as measured by the Mini-Mental Adjustment to Cancer Scale.

Table 7.3.1. *Correlation matrix for baseline measures of sexual satisfaction, relationship satisfaction, quality of life and anxiety scores of cancer patients at 6 months follow up.*

Subscales (number of items)	Sexual Satisfaction (T2)	Relationship Satisfaction (T2)	Quality of Life (T2)	Anxiety (T2)
T1: Physical wellbeing (7)	0.044	0.014	0.025	-0.213
T1: Functional wellbeing (7)	0.244	<b>-0.372*</b>	<b>0.332*</b>	-0.269
T1: Social wellbeing (7)	0.292	<b>-0.399*</b>	<b>0.371*</b>	-0.160
T1: Emotional wellbeing (6)	<b>0.373*</b>	<b>-0.375*</b>	<b>0.579**</b>	<b>-0.508**</b>
T1: Dr-patient relationship (2)	0.170	-0.177	<b>0.466**</b>	<b>-0.414**</b>
T1: Total Quality of Life (29)	<b>0.399*</b>	<b>-0.399*</b>	<b>0.558**</b>	<b>-0.485**</b>
T1: Cancer-related wellbeing (14)	<b>0.455**</b>	<b>-0.377*</b>	0.284	-0.246
T1: Sexual satisfaction (10)	<b>0.563**</b>	<b>0.777**</b>	<b>0.367*</b>	-0.295
T1: Relationship satisfaction (8)	<b>-0.393*</b>	<b>-0.454**</b>	-0.301	0.282
T1: Anxiety (7)	<b>-0.480**</b>	<b>0.537**</b>	<b>-0.401**</b>	<b>-0.548**</b>
T1: Depression (7)	-0.314	<b>0.356*</b>	-0.287	0.188
T1: Hopelessness/helplessness (8)	-0.247	<b>0.370*</b>	<b>-0.433**</b>	<b>0.367*</b>
T1: Anxious preoccupation (7)	-0.209	0.299	-0.265	<b>0.358*</b>

\* =  $p < 0.05$  (2-tailed), \*\* =  $p < 0.01$  (2-tailed)

T1 = Baseline assessment, T2 = 6 months follow up assessment

### 7.3.3.1 Prediction of sexual satisfaction at 6 months follow up

A backwards step-wise multiple regression involving the prediction of sexual satisfaction at 6 months post-treatment was performed. Baseline (i.e. pre-diagnosis) sexual satisfaction and baseline anxiety levels (assessed within 2 weeks post-surgery) were the only two variables significantly predicting levels of sexual satisfaction at 6 months post-treatment. They accounted for 41% of the variance. Statistical equations and levels of significance for the multiple regression reported here can be found in Table 7.3.2.

Table 7.3.2. Multiple regression tables for backwards step-wise hierarchical regression to predict levels of sexual satisfaction at 6 months follow up

#### Model Summary

Final Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	df1	df2	Sig. F Change
4	.676	.456	.419	2.2380	1	30	.616

Predictors: (Constant), T1:Anxiety, T1:Sexual satisfaction  
T1 = Baseline assessment

#### ANOVA

Final Model		Sum of Squares	df	Mean Square	F	Sig.
4	Regression	121.964	2	60.982	12.175	.000
	Residual	145.255	29	5.009		
	Total	267.219	31			

Predictors: (Constant), T1:Anxiety, T1:Sexual satisfaction  
Dependent Variable: T2: Sexual satisfaction  
T1 = Baseline assessment, T2 = 6 months follow up assessment

#### Coefficients

Final Model		Unstandardised Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error			
4	T1: (Constant)	4.237	1.771		2.392	.023
	T1: Sexual satisfaction	.568	.180	.452	3.165	.004
	T1: Anxiety	-.334	.122	-.390	-2.729	.011

a Dependent Variable: T2: Sexual satisfaction  
T1 = Baseline assessment, T2 = 6 months follow up assessment

### 7.3.3.2 Prediction of relationship satisfaction at 6 months follow up

A backwards step-wise multiple regression involving the prediction of relationship satisfaction at 6 months post-treatment was performed. Relationship satisfaction at 6 months post-treatment was predicted by baseline (i.e. pre-diagnosis) sexual and relationship satisfaction, baseline (i.e. pre-treatment) quality of life and baseline anxiety levels (assessed within 2 weeks post-surgery). Taken together, predictors accounted for 70% of the variance. Statistical equations and levels of significance for the multiple regression reported here can be found in Table 7.3.3.

Table 7.3.3. Multiple regression tables for backwards step-wise hierarchical regression to predict levels of relationship satisfaction at 6 months follow up

#### Model Summary

Final Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	df1	df2	Sig. F Change
3	.858	.735	.695	3.0430	1	27	.832

Predictors: (Constant), T1:Sexual satisfaction, T1:Anxiety, T1:Relationship satisfaction, T1:Total quality of life  
T1 = Baseline assessment

#### ANOVA

Final Model		Sum of Squares	df	Mean Square	F	Sig.
3	Regression	669.437	4	167.359	18.074	.000
	Residual	240.756	26	9.260		
	Total	910.194	30			

Predictors: (Constant), T1:Sexual satisfaction, T1:Anxiety, T1:Relationship satisfaction, T1:Total quality of life  
Dependent Variable: T2: Relationship satisfaction  
T1 = Baseline assessment, T2 = 6 months follow up assessment

#### Coefficients

Final Model		Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.
		B	Std. Error			
3	(Constant)	-11.914	6.597		-1.806	.083
	T1: Sexual satisfaction	-.757	.314	-.323	-2.415	.023
	T1: Relationship satisfaction	.850	.152	.772	5.586	.000
	T1: Total quality of life	.202	.068	.482	2.971	.006
	T1: Anxiety	.456	.215	.288	2.119	.044

a Dependent Variable: T2:Relationship satisfaction  
T1 = Baseline assessment, T2 = 6 months follow up assessment

### 7.3.3.3 Predictors of Quality of Life at 6 months follow up

In order to investigate the predictors of quality of life at 6 months follow up, a backwards step-wise multiple regression was performed. Baseline (i.e. pre-treatment) quality of life was identified as the only predictor of post-treatment quality of life at 6 months follow up, accounting for 28% of the variance. Statistical equations and levels of significance for the multiple regression reported here can be found in Table 7.3.4.

Table 7.3.4. Multiple regression tables for backwards step-wise hierarchical regression to predict levels of Quality of Life at 6 months follow up

#### Model Summary

Final Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	df1	df2	Sig. F Change
4	.552	.305	.283	8.5418	1	33	.221

d Predictors: (Constant), T1: Total quality of life  
T1 = Baseline assessment

#### ANOVA

Final Model		Sum of Squares	df	Mean Square	F	Sig.
4	Regression	1023.445	1	1023.445	14.027	.001
	Residual	2334.791	32	72.962		
	Total	3358.235	33			

Predictors: (Constant), T1: Total quality of life  
Dependent Variable: T2: Total quality of life  
T1 = Baseline assessment, T2 = 6 months follow up assessment

#### Coefficients

Final Model		Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.
		B	Std. Error			
4	(Constant)	63.922	9.371		6.821	.000
	T1: Total quality of life	.400	.107	.552	3.745	.001

Dependent Variable: T2: Total quality of life  
T1 = Baseline assessment, T2 = 6 months follow up assessment

### 7.3.3.4 Predictors of anxiety levels at 6 months follow up

A backwards step-wise multiple regression equation was used to predict outcome for anxiety at 6 months post-treatment. Anxiety levels of cancer patients reported at 6 months follow up were predicted by baseline anxiety (assessed within 2 weeks post-treatment) and baseline (i.e. pre-treatment) satisfaction with doctor-patient relationship. Both predictors accounted for 35% of the variance. Table 7.3.5. reports statistical equations and levels of significance for the multiple regression reported here.

Table 7.3.5. Multiple regression tables for backwards step-wise hierarchical regression to predict levels of anxiety at 6 months follow up

#### Model Summary

Final Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	df1	df2	Sig. F Change
4	.614	.377	.349	3.2627	1	46	.241

Predictors: (Constant), T1: Doctor-patient relationship, T1: Anxiety  
T1 = Baseline assessment

#### ANOVA

Final Model		Sum of Squares	df	Mean Square	F	Sig.
4	Regression	289.943	2	144.972	13.618	.000
	Residual	479.036	45	10.645		
	Total	768.979	47			

Predictors: (Constant), T1: Doctor-patient relationship, T1: Anxiety  
Dependent Variable: T2: Anxiety levels  
T1 = Baseline assessment, T2 = 6 months follow up assessment

#### Coefficients

Final Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
4	(Constant)	15.348	5.751		2.669	.011
	T1: Anxiety	.498	.129	.471	3.858	.000
	T1: Doctor-patient relationship	-1.704	.725	-.287	-2.350	.023

a Dependent Variable: T2: Anxiety levels  
T1 = Baseline assessment, T2 = 6 months follow up assessment

### **7.3.4 Summary of results**

Although relationship satisfaction and some aspects of quality of life were related to sexual satisfaction at 6 months follow up, only initial levels of sexual satisfaction and anxiety contributed independently to *sexual satisfaction* at 6 months follow up. Although relationship satisfaction did not predict sexual satisfaction, sexual satisfaction did contribute to *relationship satisfaction* at 6 months follow up. In addition, initial levels of relationship satisfaction and anxiety, both added to the variance in relationship satisfaction. This suggests that while poor relationship does not necessarily lead to poor sexual adjustment, anxious patients with poor pre-morbid sexual functioning are likely to experience sexual problems in the long-term. Those anxious patients with poor sexual and relationship functioning are likely to continue to experience relationship problems. Anxiety was predictive for both relationship and sexual functioning at 6 months follow up. Apart from baseline anxiety, the only significant predictor of anxiety at 6 months post-treatment was doctor-patient relationship. This suggests that doctors are likely to have an important role in minimising chronically heightened levels of anxiety following gynaecological cancer. In contrast, quality of life appeared to be largely independent of sexual and relationship functioning. That is, as in the longitudinal study where quality of life improved whilst sexual satisfaction declined compared to baseline, sexual functioning does not appear to be sufficient to affect the overall quality of life.



### 8. DISCUSSION

Content: *Overview of findings*

- Physical Outcomes*
- Hormonal changes
  - Vaginal changes
  - Side effects & the use of Dilators
- Psychological outcomes*
- Anxiety & Depression
  - Relationship Satisfaction
  - Mental Adjustment styles
- Sexual Outcomes*
- Sexual Drive/Overt sexual behaviours
  - Sexual satisfaction
  - Global satisfaction with sexual life
- Quality of Life Outcomes*
- Physical/Functional/Social/  
Emotional wellbeing &  
Doctor-patient relationship
  - Overall Quality of Life
- Informational needs*

## 8.1 Overview of findings

The current longitudinal findings suggest that treatment for early stage endometrial and cervical cancer does not result in major sexual and quality of life sequelae, despite many chronic adverse treatment side effects and a temporary decline in sexual drive. Although at 12 months follow up sexual and relationship satisfaction declined, these were not clinically impaired. Sexual satisfaction was predicted by patients' anxiety levels, which remained elevated throughout the study. Anxiety was in turn predicted by baseline levels of satisfaction with the doctor-patient relationship. Sexual functioning did not appear to have an independent effect on overall quality of life. Interestingly, the type of cancer treatment (i.e. surgery alone versus surgery plus radiotherapy) was not found to influence sexual or quality of life outcomes. Lack of group differences in sexual functioning at 6 months follow up suggested either successful adjustment of cancer patients to their diagnosis and treatment, or unexpectedly poor adjustment of benign and pre-invasive patients. The latter interpretation could be explained by i) an adverse physical and psychological impact of hysterectomy for patients in the benign group, and ii) the threat of developing a cancerous condition for patients in the pre-invasive group. The qualitative findings from Phase 1b supported the latter conclusion, indicating a long-term adverse impact of the diagnosis of pre-invasive cervical abnormalities on the psychological wellbeing of patients. Quantitative findings (Stage 2) further verified the usefulness of including pre-invasive patients as a second control group to control for the psychological impact of the threat of cancer.

The obtained findings will be compared primarily with results from five major longitudinal studies conducted to date with patients treated for early stage gynaecological cancer (Andersen *et al.*, 1989a; Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991; Kylstra *et al.*, 1999; Grumann *et al.*, 2001). Retrospective studies will be introduced only where considered relevant and helpful to elucidate the point being made. Considering the wealth of information reported in the result section, the discussion has been summarised into five main areas

of research outcomes: 1) Physical (hormonal changes, vaginal changes, side effects), 2) Psychological (depression, anxiety, relationship satisfaction), 3) Sexual (drive/overt sexual behaviours, sexual satisfaction, global satisfaction with sexual life), 4) Quality of life and 5) Informational needs. The discussion will begin with the evaluation of physical and psychological outcomes, which will allow these factors to be considered when documenting the obtained sexual and quality of life outcomes.

## **8.2 Physical outcomes**

### **8.2.1 Hormonal changes**

Women experiencing menopausal symptoms/status whether as a result of natural aging or surgery, radiotherapy or chemotherapy, have detectable hormonal deficiencies, particularly of oestrogen/progesterone and testosterone. These hormonal change can lead to vaginal atrophy, decreased vaginal lubrication, and a decreased libido/drive (Andersen *et al.*, 1989a). Since 60% of cancer patients and 42% of benign patient categorised themselves as peri- or post-menopausal at the beginning of our study, it would be remiss to ignore the possible confounding effect of hormonal changes, together with the use of HRT, on post-treatment sexual outcomes. By 6 months follow up, the peri- or post-menopausal status increased to 74% in the cancer group and to 66% in the benign group. By one year post-treatment, 81% of the participants in the cancer group described their stage of life as peri- or post-menopausal. However, it has to be noted that such an increase in percentages in cancer patients at 12 months follow up may have been due to the high attrition rate at the second follow up, rather than reflecting true changes in menopausal status.

In terms of HRT use, 11% of cancer patients and 28% of benign patients indicated its use at baseline, 23% of cancer patients and 48% of benign patients at 6 months follow up, with 23% of cancer patients still using HRT at 12 months follow up.

Although many patients in both groups (64% of cancer patients, 40% of benign patients) had undergone BSO, HRT treatment appropriate to ameliorate some ensuing surgically-induced menopausal symptoms was contra-indicated for those cancer patients with an oestrogen-sensitive tumour. Hence, increased usage of HRT by patients in the benign group was not surprising since more patients were eligible to receive HRT where such replacement was deemed appropriate. Further, cancer patients who received adjuvant radiotherapy (42%) were rendered less receptive to HRT due to radiation induced side effects that preclude the normalisation of vaginal lubrication and genital vasocongestion (Pitkin & van Voorhis, 1971; Flay & Matthews, 1995). This may have been a further contributing factor in lower HRT usage by cancer patients compared to benign patients.

### **8.2.2 Vaginal changes**

It was considered important to document perceived changes in vaginal anatomy and functioning as a consequence of various cancer treatments which are known to disrupt, and compromise, post-treatment sexual functioning (Bergmark *et al.*, 1999). The incidence of changes pertinent to specific treatment modalities have been reviewed previously (see 1.2.2.3). As expected, the current data indicated a higher incidence/degree of vaginal changes in the cancer group than in the benign group. More specifically, cancer patients reported a higher incidence of vaginal stenosis and a trend of reduced genital sensations compared to benign patients at 6 months follow up. A rather inconsistent picture emerged with respect to changes in vaginal lubrication. When the degree of vaginal dryness was assessed within the SFAGIS inventory, linking it to times of sexual activity, no group differences were detected. However, within the "side effects" inventory significantly more cancer patients than benign patients reported having a "dry vagina" as a result of their treatment. Differentiation between vaginal wetness during sexual arousal and as a normal state may account for this inconsistency. The fact that no group differences in levels of dyspareunia were evident between the benign and cancer groups at 6 months follow up further support this interpretation.

The comparison of 6 and 12 months follow up findings for cancer patients revealed that the majority of vaginal changes remained relatively stable over time, indicating a potentially chronic condition. In the first post-treatment year, approximately a third of cancer patients reported continuous vaginal stenosis and dyspareunia, and about half the patients reported being aware of reduced genital sensations and a shortened vagina. The incidence of vaginal dryness, related to sexual activity, increased over time in the cancer group from 41% to 56%, with a notably higher percentage of women reporting complete vaginal dryness at 12 months follow up (24%) compared to 6 months follow up (7%). As predicted, cancer patients treated with adjuvant radiotherapy reported a high incidence of side effects, these increasing over time with some of the side effects becoming chronic (e.g. reduced lubrication). In contrast, the overall incidence of side effects reported by patients treated with surgery alone remained stable, or declined, within the first post-treatment year.

The current dyspareunia findings are consistent with results from Schover *et al.* (1989) and Grumann *et al.* (2001), but are higher than those reported by Andersen *et al.* (1989a). For most vaginal abnormalities (i.e. reduced lubrication, lessened sensations and inelasticity/stenosis and shortened vagina) higher rates were noted than those reported by other studies (Bergmark *et al.*, 1999, Kylstra *et al.*, 1999; Andersen *et al.*, 1989a). This may indicate poorer outcomes for cancer patients in the current study.

Several factors account for these discrepancies. Firstly, the differences in the study design, and assessment periods in particular, need to be considered. For instance, Bergmark *et al.* (1999) assessed patients at 5 years post-treatment compared to the current assessments at 6 and 12 months follow ups. Some side effects may diminish over time and/or patients may learn to adjust to their vaginal changes, eventually no longer perceiving them as significant. Secondly, higher rates of vaginal changes reported within the current study could be attributed to elevated levels of anxiety of both benign and cancer patients. It

would appear from our findings that not all patients undergoing radical hysterectomy sensed the shortening of their vagina (37% did not). As noted within the literature review (see Chapter I, section 1.2.2.1), radical hysterectomy is the surgical treatment of choice for cervical cancer, which invariably includes removal of the cervix and approximately one-third of the proximal vagina, together with the removal of the uterus and other selected tissues. Vaginal shortening may also develop as a result of the formation of upper vaginal adhesions following radiation treatment. Interestingly, 7 (18%) benign patients reported experiencing the effect of a shortened vagina although the surgical procedure they had received (i.e. TAH) usually includes the removal of only a small amount of vaginal tissue sufficient to seal the vaginal vault after the removal of the uterus. The reporting of a shortened vagina in these instances may indicate a considerable psychological component influencing the perception of post-treatment vaginal changes for some patients. This explanation may thus account for a higher percentage of reports of a shortened vagina in the current study compared to those of Bergmark *et al.* (1999) and Schover *et al.* (1989).

Thirdly, less specific methods of operationalisation of variables assessing vaginal changes in the current study may also have contributed to the reported higher rates of adverse outcomes compared to previous studies. For instance, Kylstra *et al.* (1999) in their longitudinal study with early stage gynaecological patients reported an increase in problems involving frequencies of lubrication (from 4% to 8%) and genital insensitivity (from 4% to 8%) at 6 and 12 months follow ups. These percentages, however, reflected the number of patients reporting vaginal problems “regularly” or “always”. In contrast, our findings assessed the degree rather than the chronicity of post-treatment vaginal changes as in the Kylstra *et al.* (1999) study. Whilst in our study, minor reduction in vaginal lubrication remained stable over time (“little dry”, 34% at 6 months and 32% at 12 months follow up), the incidence of a complete lack of lubrication (“completely dry”) increased over time from 7% at 6 months to 24% at 12 months post-treatment. Hence the different focus of the assessment of vaginal changes between studies may account for discrepant findings. Further, our

findings of cancer patients reporting dyspareunia at 6 and 12 months post-treatment (33% and 40% respectively) are higher than those reported by Andersen *et al.* (1989a). However, Andersen *et al.*'s (1989a) results refer to the diagnosis of a sexual dysfunction based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-III, American Psychiatric Association, 1980). Behavioural disruptions, as well as significant distress as a result of that disruption, were required for the diagnosis of a sexual dysfunction. Since the current study focused on the behavioural component only, higher rates of dyspareunia noted in the current study compared to the Anderson *et al.* (1989a) are in the expected direction.

Finally, no baseline assessment of pre-treatment vaginal variables was conducted. It is possible that the elevated incidence of vaginal problems in the current study at both follow ups were already present prior to the treatment, although this seems unlikely.

Our findings of the incidence of dyspareunia at 6 and 12 months follow up (33% and 40%) are comparable to the dyspareunia results of Schover *et al.* (1989) and Grumann *et al.* (2001). Schover *et al.* (1989) reported frequencies of painful penetration at 6 and 12 months post-treatment as 28% and 21% respectively and pain during "deep thrusting" as 39% and 45% respectively. In the study by Grumann *et al.* (2001), 45% of patients reported a mild or severe dyspareunia at 4 months follow up and 39% at 8 months follow up.

In summary, a considerable proportion (a third to a half) of cancer patients participating in this study suffered from a number of adverse vaginal changes as a result of their treatment. Except for dyspareunia, the incidence of vaginal changes reported in this study indicates poorer outcomes compared to previous studies conducted in this area. These discrepancies seem to be due to a poorer psychological status of cancer patients, different times of measurement and the use of less specific methods of operationalisation of variables assessing vaginal changes in the current study.

### **8.2.3 Dilators**

Although vaginal dryness and narrowing/stenosis are common side effects of external and internal radiation treatments, severe vaginal narrowing may be, to some degree, preventable. In order to maximise vaginal patency, it is recommended that a patient uses a vaginal dilator together with topical oestrogen creams, or engages in sexual intercourse 3-4 times a week (Robinson *et al.*, 1999). In this way the effect of scarring can be lessened and adhesions minimised, thus assisting the vagina to gain and maintain maximum flexibility (Robinson, *et al.*, 1999). Vaginal patency is important not only for a more comfortable physical engagement in sexual intercourse, but also to enable adequate pelvic examinations in order to monitor any recurring changes in vaginal tissue (Pitkin & van Voorhis, 1971).

Drawing on information given by patients in the qualitative study (Phase 1a) and previous research findings (Schover *et al.*, 1989; Robinson *et al.*, 1999), we expected a minimal usage of vaginal dilators among those patients for whom this device is highly recommended in order to ameliorate the physiological effects of radiotherapy. Of the 23 radiotherapy patients who completed the follow up questionnaires, 18 women were sexually active. However, only two irradiated patients reported being given a vaginal dilator, one immediately post-radiation and one 2-3 months following the radiation treatment. Of these, one patient reported using the dilator less than recommended and the second patient reported not using it at all. These findings are alarming considering a third of cancer patients reported some degree of vaginal stenosis at both assessments and one woman who was not given a vaginal dilator to use, reported that her vagina was completely closed at 6 and 12 months post-treatment. Investigation as to whether the 18 patients who reported being sexually active maintained their vaginal patency by engaging in regular sexual intercourse, revealed the mean post-treatment frequency of intercourse was 1-2 times per month ( $SD=1.2$ ), with only one woman reporting having intercourse 2-3 times per week. This is considerably below the recommended frequency of 3-4 times a week for maintaining vaginal patency following radiation treatment.



Such findings further support our results from the qualitative study (Phase 1a) identifying a gap in post-radiotherapy rehabilitation regarding the provision and use of vaginal dilators. Since only two patients in the current study were given a vaginal dilator to use, no reliable conclusions can be drawn regarding compliance with their use. Comparison with other studies regarding reasons for non-compliance is also deemed unfeasible.

#### **8.2.4 Other side effects**

Overall, the cancer group was expected to report an higher incidence of side effects compared to benign patients, due to the further damage caused by adjuvant radiation to the skin, nerve pathways and bowel. Bladder problems were not predicted to significantly differ between the two patient groups, since bladder problems were presumed to be primarily caused by surgical procedures. Only those patients who had undergone pelvic lymph node dissection were predicted to report incidences of lymphoedema, in some cases as a delayed onset side effect.

As predicted, a higher percentage of cancer patients reported the occurrence of various side effects compared to benign patients. However, since benign patients reported a higher incidence of skin problems and cancer patients reported a higher incidence of bladder problems; these results were not in the expected direction. No differences between the benign and cancer groups in the occurrence of bowel problems and nerve damage were noted at 6 months follow up. Over a third of cancer patients (39%) who had undergone pelvic lymph node dissection suffered from lymphoedema at 6 months follow up, which increased to 46% at one year post-treatment. Similarly, a slight increase was noted in the incidences of skin problems from 6 months follow up to 12 months follow up (23% and 33% respectively). Whilst just over half the cancer patients reported the occurrences of bowel problems at both follow ups, the incidence of bladder

problems (44% vs. 33%) and nerve damage (52% vs. 41%) decreased from 6 to 12 months post-treatment.

Butler-Manuel, Summerville, Ford, Riley, Chan *et al.* (1998) used standardised questionnaires to assess bladder and bowel functioning in patients who had undergone a radical hysterectomy and bilateral pelvic lymph node dissection 8 to 25 months prior to the study (mean time=16.3 months). As in the current study, almost half of their patients received adjuvant radiotherapy. The incidence of urinary incontinence was found to increase from 7.9% pre-operatively to 31.6% following the surgery. Bowel problems increased from 36.8% pre-operatively to 60.5% post-operatively, with diarrhoea increasing considerably (from 2.6% to 18.4%) compared to only a slight increase in constipation (from 34.2% to 42.1%). Butler-Manuel *et al.*'s (1998) findings are comparable to those reported by the current cancer patients at 12 months follow up, with more than half the current sample reporting bowel problems (58%) and a third reporting bladder problems (33%).

The reported levels of skin damage in the pelvic area was significantly higher in the benign group (61%) than the cancer group (23%). This was counter-intuitive since the cancer group included some patients who received internal and external radiotherapy as well as a hysterectomy. One would have expected scarring as a result of hysterectomy to be comparable in both groups. However, those patients receiving adjuvant radiotherapy would have been expected to report further skin damage due to burning and residual skin sensitivity in the irradiated areas. Although skin discolouration at the site of administration of the radiation beam does gradually fade, the area can remain sensitive to sunlight, soaps, perfume and irritation from some fabrics for considerable lengths of time. The fact that patients in the cancer group reported damage to the skin less often than patients in the benign group at 6 months follow up, may be attributable to the predominance of more compelling issues related to their disease, rendering skin damage less prominent and not worthy of comment. Whereas, without more

important existential issues to take prominence in their lives, the benign patients may have focussed more attention on the side effects they had.

## **8.3 The impact of specific treatment modalities**

### ***8.3.1 Main issues pertinent to specific treatment modalities***

A novel aspect of the current study was the employment of newly developed measures to investigate differences in levels of impact of specific treatment modalities on changes in femininity, physical appearance, sexual functioning and fertility within the first post-treatment year. The preparedness for, and confidence in, individual treatment procedures was also assessed. The obtained data indicated that psychological and physical components have differing weights within various issues and treatment modalities.

Brachytherapy was seen to have a considerable impact on the cancer patients' sense of *femininity*, since 70% of patients considered brachytherapy to have reduced their femininity at 12 months follow up, compared to 35% at 6 months follow up. This is somewhat understandable considering brachytherapy is an invasive attack on the vagina and whereas the physical impact may be short lived, the psychological trauma of such a violation can have a profound effect that exacerbates over time. In contrast, only a minimal exacerbation was evident regarding external beam radiotherapy (41% at 6 months, 44% at 12 months) and regarding surgery (42% at 6 months, 59% at 12 months). A greater proportion of cancer patients (40%) than benign patients (23%) reported that their femininity was adversely affected by surgery. Since both cancer and benign patients had undergone a hysterectomy, the greater degree of lessening of femininity in cancer patients may be attributable to the psychological component of the threat of cancer. The threat of cancer as a destabilising factor for femininity is further supported by the fact that 18% of patients treated with LLETZ for pre-invasive cervical abnormalities also reported a lessening of femininity in the absence of invasive treatment. It can be inferred that the

psychological threat of cancer and violation of the genitalia may be key components impacting on the sense of femininity.

Notably more cancer patients reported a lessening of femininity as a result of brachytherapy (6 months: 35%; 12 months: 70%) compared to the percentage of patients reporting brachytherapy-related changes in **physical appearance** (6 months: 20%, 12 months: 22%), further supporting a delayed psychological rather than physical impact of the treatment. Over half of the cancer patients (59%) reported that surgery disrupted their sense of femininity at 12 months follow up, with the same percentage also reporting disruptions to their physical appearance as a result of surgery. Further, surgery was seen to affect physical appearance to a greater degree (59%) than either radiation treatment (or both 22%) at 12 months follow up. These data indicate an acute and prolonged adverse effect of gynaecological surgery on physical appearance, above that of radiation treatments.

The extent to which the patients reported their **sexual functioning** was affected bore little relationship to the severity of their treatment modality at 12 months follow up, with approximately half of all patients reporting sexual disruption. It was, however, very interesting to note that 50% of patients in the pre-invasive group also reported disruption to their sexual functioning. The surgical treatment (LLETZ) is a minimally invasive procedure, hence an alternative explanation for the reported disruption to sexual functioning needs to be sought. It is possible that the implication that CIN has a component of HPV (a sexually transmitted disease) may have curtailed sexual activity for these patients. The sense of mistrust in their body as they cannot personally detect or monitor their condition, as noted in the current qualitative study (Phase 1b), may also have made a sexual activity more circumspect. Of further interest is the 44% of pre-invasive patients who reported an adverse effect on their **fertility** levels. This is of concern, since the majority of pre-invasive patients reported being prepared for treatment and feeling confident that nothing could go wrong with the treatment. One is therefore lead to question whether the preparedness for treatment and

contained adequate discussion regarding the realistic likelihood of infertility and/or the psychological components inherent in the threat of cancer for these patients.

The psychological aspects of ***preparedness for, and confidence in, the treatment*** may also be applicable for other treatment modalities. Whereas practical procedural preparations may have been high as shown across all modalities, the psychological effects of these treatments may not have been as adequately covered, contributing to a lessening of femininity and an impact on sexual functioning and issues of fertility long term. High levels of disruption to sexual functioning could be ameliorated by sensitive sexual education and open discussion facilitated by health care professionals. Issues of lessening of fertility could also benefit from in-depth discussions and reassurance, particularly with pre-invasive patients.

### ***8.3.2 Psychological responses pertinent to specific treatment modalities***

As the current qualitative study (Phase 1a) and the literature review (see section 1.6.3) indicated, various cancer treatments and their side effects lead to significant disruptions in the physical and psychological wellbeing of patients, long after the active treatment had been completed. The stressful nature of brachytherapy in particular has been reported in a number of studies (Velji & Fitch, 2001; Karlsson & Andersen, 1985; Andersen *et al.*, 1984). Since to our knowledge no empirical data exists regarding the understanding of the main psychological responses pertinent to various treatment modalities for gynaecological cancer, the current data represent a novel insight into this unexplored area of cancer research. However, due to the small sample sizes, limiting the use of statistical analyses, the interpretation of the obtained results can be considered largely speculative and hypothesis generating, rather than conclusive and hypothesis testing.

At 6 months follow up, cancer patients reported higher levels of distress related to **surgery** than benign patients. Since the physical extent of the surgical procedure for both groups would have been similar, it is likely that psychological factors contributed to the higher levels of distress in cancer patients. For cancer patients, surgery is sudden, urgent and imperative as a life saving treatment, thus causing the prospect of surgery and its outcome to assume great importance. In contrast, for benign patients, the decision to undergo surgery follows a history of long-standing debilitating symptoms and less invasive procedures, and hence is not usually urgent or imperative. Consequently, the basis of predominating levels of distress pertinent to surgery may have differed for each patient group, with cancer patients having the added stress of surgery being the first crucial treatment in the fight to save their lives. The psychological implications of the surgery for cancer patients may, therefore, have rendered them more vulnerable to distress associated with this procedure post-surgery to 6 months follow up than would be the case for benign patients.

Interesting findings were noted in the cancer patients undergoing **adjuvant therapies**, particularly with patients receiving all three treatment modalities (i.e. surgery, external beam radiation and brachytherapy). At 6 months follow up these patients rated each individual treatment as less distressing, less disempowering and less degrading than those patients receiving surgery alone or a combination of two treatment modalities. Although carcinomas requiring multiple treatments are often deemed more aggressive than those amenable to surgery alone, it would appear that receiving extra treatments allowed the patient to continue to feel pro-active in their fight against cancer, possibly mediating subsequent distress from the actual treatment procedure. Interestingly, by 12 months post-treatment, patients who received combined treatment modalities reported their experiences of treatment as more distressing, disempowering and degrading than at 6 months post-treatment. Indeed, their levels of psychological responses at 12 months post-treatment

closely resembled, and in some instances exceeded, levels reported by other treatment groups.

There are a number of possible explanations for these findings. As the current qualitative data (Phase 1a) indicated, it is at this later stage, when physical healing is complete, that women begin the process of integrating their experiences on a psychological level. Since the length of active treatment for patients who receive multiple adjuvant therapies is prolonged and associated with higher incidences of side effects, some of which may be delayed, it is likely that the process of psychological adjustment to the experience of invasive treatments was delayed compared to patients who had undergone a single treatment or two treatment modalities.

Overall, these findings suggest that the increase in negative psychological responses at 12 months follow up is underpinned by both psychological and physical impact of these procedures. Consequently, health care professionals need to address the psychological component of treatment procedures when preparing patients for these procedures and post-treatment sequelae. Notwithstanding their potential significance, these findings need to be interpreted with caution due to the very small number of patients in the combined treatment groups. Clearly, further exploration of the obtained trends, using large sample sizes, is warranted.

## **8.4 Psychological outcomes**

An assessment of anxiety and depression was included in the current study as possible confounding variables which were believed to influence patients' responses regarding the primary outcome variables (i.e. sexual and quality of life outcomes). It was expected that levels of anxiety and depression would decrease over time in all patient groups, although this decline would be less prominent for the cancer group. Depression findings were consistent with our expectations and those of other literature, showing improvement of mood by 6

months follow up which remained stable for the second half of the first post-treatment year. However, the pattern of anxiety findings was rather surprising, indicating elevated levels of anxiety throughout the study, with a third of cancer patients reporting clinical levels of anxiety. Further, anxiety was identified as one of two significant predictors of sexual satisfaction (the other being baseline sexual satisfaction levels), which in turn was the only sexual variable that declined over time. It was therefore considered important to evaluate anxiety results more comprehensively.

As reported in the Results section, the majority of patients in the current study were not clinically depressed at any assessment point. Nevertheless, although benign patients' levels of **depression** significantly declined by 6 months follow up, they remained above those of cancer patients. This is consistent with previous studies showing elevated levels of depression prior to hysterectomy, which post-hysterectomy, remain higher than the background population (e.g. Gath *et al.*, 1982a; Ryan, Dennerstein & Peperell, 1989). By 6 months follow up, the mood of cancer and benign patients improved more than that of pre-invasive patients, although this difference did not reach significance. However, this result may have been due to the "flooring" effect since only a very small number of pre-invasive patients indicated experiencing any depressive symptoms at baseline (7.3%) and 6 months follow up (2.9%). The current longitudinal results for cancer patients indicated improvements in mood at 6 months follow up. These remained stable at 12 months post-treatment, with only 4-5% of patients reporting clinical levels of depression at either follow up assessment. Psychological symptoms of distress have been commonly shown to normalise by 12 months following cancer diagnosis, as patients integrate their illness into their lives. However, as Gotheridge & Dresner (2002) conclude, a significant minority of cancer patients continues to suffer from long-standing depressive symptoms. Overall, depressed mood was not identified as a major problem for cancer patients in the current study and thus was not considered as a significant confounder in the evaluation of the obtained sexual and quality of life outcomes.



In contrast to our expectation, ***anxiety levels of cancer patients*** did not improve over time but remained elevated during the first post-treatment year, with approximately a third of patients exhibiting clinical levels of anxiety across all three assessments (HADS score >8). These results indicate that a considerable subgroup of early stage cervical and endometrial cancer patients experience elevated levels of anxiety long after their treatment has been completed. Backwards stepwise regression analysis identified only two main predictors of elevated anxiety in cancer patients at 6 months follow up: baseline levels of anxiety (i.e. post-surgery) and baseline satisfaction with the doctor-patient relationship (i.e. pre-treatment). Interestingly, baseline adjustment styles of anxious pre-occupation and hopelessness-helplessness, although highly correlated with the 6 months follow up anxiety levels, did not contribute independently to the variance in anxiety.

The finding of doctor-patient relationship predicting post-treatment anxiety is an important one as it provides a possible explanation for the continuous elevation of anxiety in 30% of the cancer sample. More importantly, it highlights an opportunity for doctors to reduce patients' levels of distress. Cancer patients who reported high levels of satisfaction with the doctor-patient relationship prior to the treatment became less anxious at 6 months follow up. This points to the quality and effectiveness of early contact between health care professionals and patients as being important in reducing post-treatment anxiety, which in turn influences sexual satisfaction outcomes. Whether the doctor-patient relationship continues to be equally important in ameliorating the anxiety is unclear. Intuitively, it would be expected not to play much of a role since doctor-patient contact is minimal during follow up. However, the quality of the contact may be the significant factor at these times. The open invitation to contact the doctor, should there be a need, may be sufficient in itself to reduce patients' anxiety.

Ong, Visser, Lammes & de Haes (2000) found that one of the main predictors of patients' quality of life and satisfaction was the affective quality of the consultation. This is consistent with our qualitative findings (Phase 1b) where doctors' communication style and empathetic manner were identified as the most important mediating factors of patients' psychological adjustment. Following treatment and a subsequent lessening of contact with health professionals, the reassurance provided by health care professionals may recede whilst the realisation that the cancerous condition may not be irrevocably relieved, remains. Patients commonly report that the overwhelming challenge of diagnosis and treatment takes all their internal resources. Paradoxically, it is when treatment finishes and they no longer feel they are engaging in "curative" treatments that the full impact of their condition is acutely felt. This may contribute to the consistently elevated levels of anxiety documented at 6 and 12 months follow up. Indeed, our qualitative findings (Phase 1a) pointed to a greater need to discuss the experience of having cancer, its treatment and side effects, some 6 to 12 months post-treatment, after the initial physical healing is complete. Such findings were also noted in the qualitative study by Bradley, Pitts, Redman & Calvert (1999) investigating the experience of long-term follow up for women with early stage endometrial cancer. They found that recurrence anxiety, identified as the main element of follow up, was alleviated only by medical reassurance, which was judged worthwhile only if provided by a gynaecological consultant. The authors conclude that women who have a continual need for follow up in the absence of any active clinical disease attend for psychological purposes (as a coping resource rather than a medical resource) (Bradley *et al.*, 1999). This, in turn, is consistent with studies that found interventions enhancing adjustment to cancer most effective when they are not presented immediately after diagnosis, but rather several months post-treatment, when patients are more inclined to deal with emotional rather than existential issues (Klee *et al.*, 2000b, Edgar *et al.*, 1992).

### Comparisons with other studies

Fifteen studies investigated rates and treatment of psychological disorders occurring in women with gynaecological cancer (also see Thompson & Shear, 1998). Whilst all these studies assessed depression, only nine measured levels of anxiety in gynaecological cancer populations (Cain *et al.*, 1983; Cain, Kohorn, Quinlan, Latimer & Schwartz, 1986; Andersen *et al.*, 1989b; Corney *et al.*, 1992; Cull *et al.*, 1993; Paraskevaidis, Kitchener & Walker, 1993; Hilliard, 1994; Grumann *et al.*, 2001; Schover *et al.*, 1989). A summary of their findings is presented in Table 8.1. Overall, post-treatment rates of anxiety in cancer patients were found to be significantly higher than those in the general population.

Table 8.1. *Studies measuring anxiety levels in women with gynaecological cancer as identified in the review by Thompson & Shear (1998) supplemented by additional studies identified by the Ph.D. candidate*

<b>Study</b>	<b>Subjects</b>	<b>Design/ Assessments</b>	<b>Method of Measurement</b>	<b>Results</b>
Cain <i>et al.</i> (1983)	- stage I-IV gyn. cancer patients (n=60) - female controls - community sample	Cross-sectional study: within 1 month of diagnosis	Hamilton Anxiety Scale  State Trait Anxiety Inventory (STAI) (>6 significant)	Mild to moderate levels of anxiety in cancer patients (mean=12)  Cancer patients reported significantly more symptoms than community sample and significantly less than the clinically depressed patients
Cain <i>et al.</i> (1986)	- gyn. cancer patients (n=72)	Intervention study:  group therapy (8 sessions) vs. individual therapy vs. no therapy	Hamilton Anxiety Scale  State Trait Anxiety Inventory (STAI)	Both therapy groups reported less anxiety than no treatment group at 6 months  Anxiety significantly lower for individual therapy at post-treatment testing only

<b>Study</b>	<b>Subjects</b>	<b>Design/ Assessments</b>	<b>Method of Measurement</b>	<b>Results</b>
Andersen <i>et al.</i> (1989)	- stage I & II gyn. cancer patients (n=65) - benign patients (n=22) - healthy controls (n=60)	Longitudinal study: pre-treatment vs. 4-, 8- & 12-months post-treatment	Profile of Mood States (POMS)	Cancer & benign patients significantly more anxious pre-treatment compared to the healthy controls  No significant differences among groups at 4-, 8- or 12-months follow up  Improvements from pre-treatment to 4 months follow up but no further improvements thereafter
Schover <i>et al.</i> (1989)	- stage I-II cervical cancer patients (n=63)	Longitudinal study: Pre-treatment (retrospective) vs. 6 and 12 months follow ups	Brief Symptom Inventory (BSI)	A significant decline in anxiety at 6 months follow up  By 12 months follow up, further decline in anxiety, with additional decline in levels of depression
Corney <i>et al.</i> (1992)	- vulvar & cervical cancer patients (n=105)	Retrospective study: 6 months to 5 years post-treatment	Hospital Anxiety and Depression Scale (HADS)	41% "probable" or "definite" cases of anxiety (>8)
Cull <i>et al.</i> (1993)	- cervical cancer patients (n=83) - general population	Cross-sectional study: A mean of 2 years post-treatment	State Trait Anxiety Inventory (STAI)	Higher anxiety than general female population  Higher psychological distress than published data quoted for disease free cancer patients
Paraskevaidis & Kitchener (1993)	- gyn. cancer patients (n=117)		Hospital Anxiety and Depression Scale (HADS) - used only for 25 months follow up	High rates of anxiety post-surgery  21% of patients clinically anxious at 25 months post-treatment (>7)
Hilliard (1994)	- gyn. cancer patients (n=17)		Structured Clinical Interview for DSM-IV (SCID)	65% of patients had significant symptoms of Post-traumatic Stress Disorder (PTSD)
Grumann <i>et al.</i> (2001)	a) stage 1b cervical cancer patients (n=20) b) benign patients (n=18) c) healthy controls (n=20)	Longitudinal controlled study Pre-treatment (retrospective) vs. 4- & 8- months post-treatment	Derogatis Sexual Functioning Inventory (DSFI): Affect subscale	Cancer patients' affect scores were consistently below those reported by the benign group (as well as healthy controls) although no statistical group differences were detected

As evident from Table 8.1., only two studies used the HADS scale for the assessment of post-treatment levels of anxiety and depression (Paraskevaidis *et al.*, 1993; Corney *et al.*, 1992). Studies using other measures have produced inconsistent results, with persistent distress reported in some studies and improvements over time reported in others (Schover *et al.*, 1989; Andersen *et al.*, 1989b; Grumann *et al.*, 2001). However, studies using HADS reported results consistent with our findings, showing persistent distress in gynaecological cancer patients over time. For instance, Paraskevaidis *et al.* (1993) investigated the effect of doctor-patient communication on the mental health of women with gynaecological cancer (n=117; cited in Thomson & Shear, 1998). They identified 21% of cancer patients as clinically anxious (score >7) at 25 months post-treatment. In a retrospective study by Corney *et al.* (1992), psychological distress in gynaecological patients was assessed between 6 months and 5 years post-surgery. It was found that 41% of patients suffered from “probable” or “definite” cases of anxiety (score >8). Interestingly, these outcomes were not associated with age, the type of operation, or the time between the interview and the operation. More importantly, two-thirds of patients who were sexually active prior to the operation indicated ongoing sexual problems and the presence of these problems was found to be significantly associated with the women’s levels of anxiety. These findings are consistent with the current longitudinal results of long-term heightened anxiety among cancer patients and its significant impact on post-treatment sexual functioning.

As predicted, the psychological wellbeing of **benign patients** significantly improved over time with recovery from surgery, although their anxiety and depression levels were consistently above those of cancer and pre-invasive patients. Such results indicate higher levels of residual distress in benign patients compared to the other patient groups. This may be accounted for by long-standing debilitating symptoms such as anaemia (with consequent fatigue), or chronic pelvic pain experienced by benign patients that adversely affect both

their physical and psychological health (e.g. anxiety and depression). The reported lessening of psychological distress in benign patients over time was expected, since undergoing a hysterectomy would alleviate some of these symptoms and thus lead to improvements in psychological wellbeing (also see Bachmann, 1990). In our study, distress levels, while decreasing over time, were still higher than those of the other patient groups, suggesting that the debilitating nature of this condition has a more lasting influence on patients' post-treatment health than previously thought. Emotional lability, characteristic of women undergoing natural menopause (Robertson, 1996), may have contributed to the relatively high levels of residual psychological distress.

Although total anxiety scores of *pre-invasive patients* at 6 months follow up were significantly lower than those of benign patients, they were comparable to those of cancer patients. This finding may be accounted for by the slightly increased risk of cancer associated with the pre-invasive condition, despite the minimally invasive treatments, lack of symptoms and immediate risk associated with this condition. In the qualitative study (Phase 1b), the majority of asymptomatic patients with a pre-invasive condition reported that they felt betrayed by their body which had failed to warn them of potentially dangerous changes. The detrimental impact of "the cancer threat" on psychological wellbeing of pre-invasive patients was further demonstrated by the lack of group differences in levels of *clinical* anxiety at 6 months follow up. The presence of elevated levels of anxiety within the pre-invasive group at this time may be accounted for by patients' reactions to the increased frequency of investigatory practices such as Pap smear tests, serving as a reminder of their increased vulnerability to cancer. Significant anxiety was associated with the experience of an abnormal Pap smear and its treatment in the study by Nugent *et al.* (1993). Irrespective of the procedure or diagnosis, women identified uncertainty as a primary concern (i.e. uncertainty about the meaning of an abnormal Pap result as well as about cancer and infertility) (Lauver *et al.*, 1999). Psychosocial distress is especially linked with concerns relating to cancer occurrence, the

possibility that the disease and its treatment may affect sexual functioning and fertility, as well as the possibility of transmitting the disease to the partner(s) (Kavanagh & Broom, 1997; Campion *et al.*, 1988; Reed *et al.*, 1999). Uncertainty regarding the threat of cancer occurrence and reproductive concerns, were also identified as the most prominent factors influencing psychosexual adjustment and quality of life in our qualitative study (Phase 1b). This area deserves further research in its own right.

Overall, no clinically significant levels of depression were observed and therefore mood levels were not considered a significant confounder of sexual and quality of life outcomes in this study. The current findings, however, indicated that approximately a third of patients, regardless of their gynaecological condition, remain clinically anxious at 6 months follow up, with no improvement detected in the cancer group at one year post-treatment. The current quantitative findings regarding elevated post-treatment levels of anxiety pointed to the importance of a satisfying doctor-patient relationship from the time of diagnosis/treatment, whilst qualitative findings (Phase 1a) pointed to the importance of continued psychological care long after physical healing is complete. The current quantitative findings of pre-invasive patients complement our qualitative findings (Phase 1b) regarding the length of time required to allay patients' concerns that persist after the repair of cervical tissue and the recommencement of a normal life. There is a danger, therefore, that the impact of this "minor" condition with "minimal" treatment may be underestimated by health care professionals. These findings demonstrate that patients with or without evidence of cancer, experience a degree of psychological distress at various stages of their recovery. Accordingly, there is a need for continuous dialogue between health care professionals and their patients to maximise post-treatment adjustment and ensure optimal care.

## 8.5 Relationship satisfaction

As with psychological functioning, assessment of relationship satisfaction was included to control for its potential confounding effect on sexual functioning and quality of life outcomes. Based on previous findings, we assumed that relationship satisfaction would remain stable over time. Interestingly, our data revealed comparable deterioration in satisfaction with intimate relationships in all three patient groups, suggesting an adverse impact of gynaecological conditions on relationship satisfaction. Despite this decline, all patients reported relatively high levels of satisfaction throughout the study. Since the majority of previous longitudinal studies emphasised the stability of patients' relationship satisfaction (Grumann *et al.*, 2001, Andersen *et al.*, 1989b; Weijmar Schultz *et al.*, 1991), factors that predicted such an uncommon outcome found in the current study were explored. Post-treatment relationship satisfaction was predicted by a number of baseline factors including pre-diagnosis relationship satisfaction, pre-diagnosis sexual satisfaction, post-treatment anxiety levels and pre-treatment overall quality of life. Such findings reinforce the fact that many domains in the person's life influence relationship satisfaction.

At each assessment, patients' evaluation of their relationship was superior to that of Buunk's (1987) comparison group of healthy, married women. One explanation for such superior findings is that patients may have initially overestimated their levels of relationship satisfaction since baseline assessment took place 4-7 days post-surgery and women were asked to reflect back on their pre-diagnosis functioning. It is recognised that at the time of diagnosis and treatment partners commonly rally to support their ill partner. The elevated baseline satisfaction levels then declined to more typical levels as the situation returned to normal (i.e. at 6 and 12 months post-treatment). Alternatively there may be cultural differences in levels of relationship satisfaction typically reported, and Buunk's (1987) American sample may not be readily comparable with an Australian sample. This is more likely since Grumann *et al.* (2001), who also used Buunk's scale to assess marital relationship with Australian patients



treated for early stage cervical cancer, also reported slightly superior satisfaction levels to those of Buunk's comparison sample. Further, the cancer and benign groups in Grumann's sample displayed as positive an evaluation of their relationship as did healthy women. Consequently, it appears most likely that the decline seen in this study does represent a true decline in relationship satisfaction in response to the diagnosis and treatment of gynaecological diseases.

## **8.6 Sexual outcomes**

### ***8.6.1 Sexual drive***

It was hypothesised that sexual drive in cancer patients would have significantly declined by six months post-treatment compared to pre-diagnosis levels, with lowered levels of drive remaining stable between 6 and 12 months follow up. In contrast, benign patients were expected to report no change or a slight improvement in their sexual drive at 6 months follow up. Pre-invasive patients were expected to experience a slight decline in sexual drive at 6 months follow up.

A trend of deteriorating levels of frequency of *overt sexual behaviours* (i.e. *sexual drive*) was detected in all groups at 6 months post-treatment. These reductions were largely due to significant declines in the frequency of intercourse and masturbation. Post-hoc comparisons of pre- and post-treatment sexual drive levels, whilst controlling for age and psychological status, showed significant differences only within the pre-invasive group. Longitudinal findings in the cancer group revealed that by 12 months follow up frequency of the assessed sexual behaviours returned to pre-diagnosis levels, indicating only a temporary impact of the cancer diagnosis and its treatment, since sexual drive was subsequently restored within the first post-treatment year.

### *Clinical significance of findings*

In order to assess whether the decline in sexual drive at 6 months follow up (as measured by Derogatis Sexual Functioning Inventory: Drive subscale) was clinically significant, the obtained levels of sexual drive were evaluated against Derogatis & Melisaratos's sample of women diagnosed with sexual dysfunctions and healthy female controls (Derogatis & Melisaratos, 1979). The obtained levels of sexual drive, ranging from 13.0 (SE=1.5) to 15.5 (SE=1.03) at baseline and from 9.4 (SE=1.7) to 12.3 (SE=1.1) at 6 months follow up, were below the means reported for female volunteers with no sexual dysfunction (mean=16.5, SD=6.7) (Derogatis & Melisaratos, 1979). Such low drive levels may be explained by a notably older sample of cancer and benign patients in the current study (mean<sub>cancer</sub>=50.9, SD=11.6; mean<sub>benign</sub>=47.6, SD=8.3), compared to that of Derogatis & Melisaratos (mean=32.3, SD=9.0). It is important to note, however, that the DSFI Drive subtest does not discriminate between females with and without sexual dysfunctions.

Although to our knowledge no other prospective study in this area utilized total scores of the DSFI Drive subscale, other longitudinal studies do assess changes in frequencies of sexual behaviours such as intercourse and/or masturbation, these forming a part of the Drive subscale. For instance, cancer patients and healthy controls in the Kylstra *et al.*'s (1999) study, who were of comparable age to our patients (mean<sub>cancer</sub>=45.5, SD=13.0; mean<sub>controls</sub>=42.0, SD=9.3), reported engaging in sexual contact approximately once a week at baseline. Baseline intercourse frequency in the study by Andersen *et al.* (1989a) was twice per week (mean<sub>age</sub>=42, range=25-65). The cancer group in the Schover *et al.* (1989) study, which was notably younger than the current sample (mean<sub>age</sub>=38, SD=9), reported a baseline frequency of intercourse as twice per week and for masturbation once per month. These findings suggest that the obtained baseline frequencies of the cancer group (i.e. intercourse: once a week, masturbation: once to twice a month), although lower than the scores noted in the original Derogatis & Melisaratos (1979) sample, are within the range of sexual behaviour

frequencies commonly reported by gynaecological cancer patients of similar age.

As the current literature review indicated, only three longitudinal studies in this area used benign patients as a control group (Andersen *et al.*, 1989a; Weijmar Schultz *et al.*, 1991; Grumann *et al.*, 2001). However, no data as to the specific frequencies of intercourse were provided in the studies by Grumann *et al.* (2001) or Weijmar Schultz *et al.* (1991). Baseline frequency of intercourse in the Andersen *et al.*'s (1989a) sample was twice per week (mean<sub>age</sub>=39, range<sub>age</sub>=22-59), compared to once a week, reported by the current benign group. Such discrepancy in frequencies is anticipated since Andersen *et al.*'s sample was notably younger than our benign patients. In contrast, benign patients in a large prospective study by Rhodes *et al.* (1999) reported the mean pre-treatment sexual activity of 2.3 times per month (n=1299; age range: 35-49), which was significantly lower than the frequency reported in the current study. Such discrepancies in findings reinforce the complex interplay of factors that mediate women's sexual functioning. Nonetheless, since the obtained frequencies of intercourse were located between those found in two longitudinal studies, they were considered characteristic of the gynaecologically benign patient population.

As mentioned previously no longitudinal study in this area included pre-invasive patients as a control group. In a cross-sectional study by Reed *et al.* (1999), pre-invasive patients (n=169) reported a medium baseline frequency of intercourse between 2 and 6 times per week. This is comparable to the current study, where the *medium* frequency of intercourse for pre-invasive patients was between 2 and 3 times a week. The mean age of Reed *et al.*'s sample (33 years old) was comparable to the current sample (30 years old). The current findings are also comparable to the baseline *mean* sexual frequencies of pre-invasive patients in the Campion *et al.* (1988) study (mean = once a week).

In summary, although short-term post-treatment outcomes indicate a gradual decline of sexual behaviours, the level of functioning in the current sample did not indicate clinical impairment in sexual drive. Further, the baseline levels of sexual drive reported in the current study seem to reflect the levels characteristic of the targeted population of gynaecological patients.

#### *Lack of group differences*

At 6 months follow up, the sexual drive of women who had undergone treatment for gynaecological cancer was comparable to the sexual drive of women treated for benign and pre-invasive gynaecological conditions. It was considered important to evaluate whether such a lack of group differences was due to the successful post-treatment adjustment of cancer patients or to poor outcomes of patients in the control groups. Findings from the most recent studies support the view that women with early stage gynaecological cancer are not especially prone to severe sexual problems and seem to cope well with the impact cancer and its treatment has on their sexual lives (Leenhouts *et al.*, 2002). Longitudinal studies that included patients with benign gynaecological conditions in their design, point to adverse psycho-sexual sequelae of surgery for both benign and malignant conditions (Kylstra *et al.*, 1999; Andersen *et al.*, 1989a, Weijmar Schultz *et al.*, 1991).

From a physiological perspective, a hysterectomy has traditionally been perceived as having no adverse effects on sexual functioning, suggesting that post-treatment adverse sexual reactions were primarily psychogenic in nature. However, current levels of knowledge of the physiology of female sexuality suggest the possibility that sexual response following genital surgery may be, at least partially, determined by physiological variables (Weijmar Schultz *et al.*, 1991). For instance, changes in sexual hormonal levels as a direct result of oophorectomy have been shown to impact on sexual functioning and drive in particular (Helstrom, 1994; Nathorst-Boos *et al.*, 1992; Dennerstein & Burrows, 1982). During sexual arousal reductions in vasocongestion in the pelvic area may occur due to damage to circulatory pathways, and the "tenting effect" may

be limited by the inelasticity of vaginal scarring and loss of sensation. In addition, interference with the site of greatest sensitivity for stimulating orgasm in women may result in a considerable lessening, and possible cessation, of orgasmic ability. Weijmar Schultz *et al.* (1991) found a post-operative decrease in orgasmic capacity, desire and arousal levels among their patients treated for benign gynaecological conditions. Similarly, in Andersen *et al.*'s (1989a) sample, benign patients reported multiple, severe sexual disruptions following their hysterectomy. However, while this explains poorer functioning in the benign group, it is notable that similar declines were also observed in the pre-invasive group.

#### *Comparisons of the current findings with other studies*

Existing longitudinal studies show variability in the level of sexual activities/desire and its changes over time. The pattern of current findings is congruent with results found by Andersen *et al.* (1989a), which showed a decline in sexual activity at 4 months follow up with the levels normalising by 8 months post-treatment. An opposite trend was found in the study by Schover *et al.* (1989), with sexual desire and sexual activity remaining at initial levels at 6 months follow up, but declining significantly by one year post-treatment. This late-appearing sexual drive morbidity was attributed to the debilitating long-term side effects of radiotherapy. At 6 months follow up sexual desire and/or frequency of sexual contact of irradiated women was comparable to that of women treated with hysterectomy alone. However, by one year post-treatment, irradiated patients reported significantly lower levels of sexual desire, underlined by an increase in the incidence of dyspareunia (Schover *et al.*, 1989). Although in the current study, irradiated women reported a significantly higher incidence of dyspareunia compared to women treated with surgery alone, no significant treatment group differences in sexual drive levels were detected. However, Schover's "radiotherapy" subgroup consisted of a high percentage of women who received "radiation alone" (38%) and only a comparably small number of patients who received surgery plus radiotherapy (19%). In the current study, the radiotherapy sample comprised solely of women treated with a combination of

surgery and radiotherapy. The differing clinical characteristics of the radiation samples may thus contribute to the discrepancy in results.

Contrary to the current findings, two Dutch longitudinal studies found stable frequencies of sexual contact within 12 and 24 months post-treatment (Kylstra *et al.*, 1999; Weijmar Schultz *et al.*, 1991). This discrepancy could be explained by a much younger group of cancer patients involved in the study by Weijmar Schultz *et al.* (1991; mean age=39, range 18-64), associated with an overall higher level of motivation to engage in post-treatment sexual activity compared to the current study. Further, in both Dutch studies, the first assessment took place at a time when levels of sexual activity and desire may have already been adversely affected by the news of the cancer diagnosis and its pending treatments (i.e. following diagnosis but prior to the treatment). In contrast, the baseline measurement in the current study assessed pre-diagnosis levels of sexual functioning retrospectively. Such methodological discrepancies may have a bearing on the difference in sexual drive findings of the studies. Another explanation for the discrepancy between current findings and those of Weijmar Schultz *et al.* (1991) and Kylstra *et al.* (1999) is the fact that in neither of the latter studies was psychological functioning of patients assessed and controlled for in their analyses. Considering the known influence of psychological distress on sexual functioning and sexual satisfaction and the strong impact of these psychological variables on sexual outcomes found in the current study, such an omission may have produced a rather different pattern of data.

A small group of cancer patients in the current study (11%) did not resume sexual intercourse by 12 months follow up. This proportion of patients is consistent with previous longitudinal research showing that a certain percentage of patients treated for gynaecological cancer either do not resume sexual activity following their treatment, or their sexual relations cease within the first year post-treatment (Schover *et al.*, 1989, Andersen *et al.*, 1989a). In a study by Schover *et al.* (1989), 5% of their patients were celibate pre-operatively, however, within

the first post-operative year the percentage rose to 15%. Similarly, Butler-Manuel *et al.* (1998), in their retrospective study (mean time since surgery was 16 months), also reported that 15% of cervical cancer patients treated with radical hysterectomy and bilateral pelvic nodes dissection did not resume a sexual life post-treatment.

Of the four cancer patients in the current study who did not resume sexual activity post-treatment, only one was treated with adjuvant radiotherapy. This patient stated she subsequently suffered adverse vaginal changes/side effects that prevented her engaging in sexual intercourse. The remaining three patients had undergone surgery alone and reported no incapacitating vaginal changes or treatment side effects following their treatment. Inspection of their data indicated that myths of the contagiousness of the patient's condition may have contributed to these patients not resuming a satisfactory sexual relationship. Regrettably, neither Schover *et al.* (1989) nor Butler-Manuel *et al.* (1998) specified the underlining reasons for the cessation of sexual activity in their study. Myths about cancer and sexuality are still relatively prevalent, including fears that cancer is contagious through sexual activity, that resuming sexual intercourse will trigger a recurrence of cancer or that a sexual partner can be exposed to radiation within a previously irradiated vagina (Schover & Jensen, 1988). Although only a minority of patients may believe these myths, those who do give them credence often needlessly discontinue their sexual activity as a result (Schover & Jensen, 1988).

Although no other prospective studies used pre-invasive cancer patients as a control group, qualitative findings from the Phase 1b study indicated a significant long-lasting impact on psychological functioning as a result of this minor physical condition. Such an impact may in turn influence levels of sexual drive. Indeed pre-invasive patients reported a significant decline in their sexual drive levels from pre-diagnosis to 6 months follow up. As the physical impact of the LLETZ procedure for pre-invasive patients is minimal and only of short-term duration (4

weeks healing period of sexual abstinence), the reported decline in sexual drive was assumed to have a psychological basis.

In the first study which directly focused on sexual functioning and pre-invasive cancer, Campion *et al.* (1988) compared women diagnosed with CIN and HPV infection and women diagnosed with a sexually transmitted disease with no presence of CIN. As in the present study, women diagnosed with CIN and HPV reported reduced sexual interest/drive, arousal, orgasm, and frequency of intercourse following their treatment. In addition, a significant increase in negative feelings towards intercourse and the sexual partner associated with the abnormal Pap smear was found in patients treated for CIN and HPV. A high percentage of sexual impairment after therapy (over & above that of diagnosis) was also reported by Filiberti *et al.* (1993). At 3 month follow up, women who had had a positive Pap smear showed significant impairments in sexual interest/drive, mood, daily activities and sleep patterns as well as elevations in worries about cancer (Lerman *et al.*, 1991). McDonald *et al.* (1989) found that prior to colposcopy the predominant concern was fear of cancer (100%). This is consistent with findings from our qualitative study (Phase 1b) indicating that cancer fears and reproductive concerns were the two major concerns pre- and post-colposcopy. Whilst pre-colposcopy, fears of cancer occurrence predominated (76%), post-treatment the main focus shifted to fears about a future ability to conceive and carry a child (62%). Nevertheless, 43% of women reported cancer fears as predominant concern following their treatment. A shift in predominating concerns from pre- to post-colposcopy and surgical treatment was also noted in the study by McDonald *et al.* (1989). However, in their study the predominating pre-colposcopy concerns of cancer shifted post-treatment to the loss of attractiveness and sexual dysfunction (61% and 47% respectively). The differences in post-treatment main concerns between the current study and McDonald *et al.*'s (1989) study are somewhat expected since McDonald's sample was younger (mean age 27 years) compared to our sample (mean age=34). Whilst women in their 20's are commonly characterised by focus on body image and sexual adequacy, women in their 30's focus more on fertility



issues and questions related to parenthood (Schain *et al.*, 1986). Alternatively, such discrepancy in post-treatment main concerns may reflect the nature of, and reassurance from, information provided by health care professionals regarding the minimal impact of the disease and its treatment on fertility, in those studies.

In summary, the results of the present study indicate that although levels of sexual drive in the cancer group declined at 6 months follow up, similar patterns were observed in both control groups. Hence, this result was not specific to those women with gynaecological cancer. It is, however, important to note that none of the declines were clinically significant. The results of the long-term follow up suggest that sexual drive, unlike sexual satisfaction (reported in the next section), returns to baseline levels by 12 months follow up in cancer group. These findings further reinforce the notion that to evaluate patients' overall sexual functioning solely on the basis of a physiologically driven measure, such as frequency of sexual activities, is highly limiting and potentially inaccurate.

### **8.6.2 Sexual satisfaction**

It was hypothesised that the sexual satisfaction of cancer patients would remain stable over time, despite a predicted reduction in sexual drive and the occurrence of post-treatment vaginal changes, hormonal changes and side effects. It was expected that baseline (i.e. pre-diagnosis) high levels of relationship satisfaction, adequate levels of sexual satisfaction and satisfaction with intimate aspects of relating, would counteract the detrimental impact of post-treatment side effects, vaginal changes and hormonal changes, thus resulting in no changes in sexual satisfaction over time. Sexual satisfaction for benign patients was expected to improve over time with the reduction of debilitating gynaecological symptoms and subsequent lessening of psychological distress associated with the condition. Sexual satisfaction for pre-invasive patients was expected to decline slightly over time, due mainly to the psychological impact of a perceived threat of developing cancer and a more circumspect approach to sexual activities. Despite these predicted changes in levels of satisfaction over time, levels of sexual satisfaction in all three groups

were expected to converge by the 6 month follow up, as the expected changes would counteract initial differences at baseline.

Our hypothesis was supported at 6 months follow up, showing comparable levels of sexual satisfaction among all patient groups. However, since satisfaction scores in the cancer and pre-invasive groups suggested a tendency of continuous decline, the lack of significant findings may have been due to insufficient power. Interestingly, the benign group showed no change in sexual satisfaction over time. A significant decline in sexual satisfaction was detected within the longitudinal (12 months follow up) data analyses of cancer patients. As expected, at 6 months follow up, sexual satisfaction of cancer patients appeared to be best predicted by baseline sexual satisfaction. Importantly, baseline anxiety levels (measured 1-3 weeks post-surgery) were the only other predictor of post-treatment sexual satisfaction outcomes at 6 months follow up. Interestingly, physical variables such as post-treatment vaginal changes and side effects did not seem to carry any predictive relevance.

#### *Clinical significance of findings*

In order to assess whether the decline in sexual satisfaction at 6 months follow up was clinically significant, the obtained levels of sexual functioning were evaluated against standard subscale scores for women with sexual dysfunctions and those for healthy female controls (Derogatis & Melisaratos, 1979). The two independent DSFI subscales measuring satisfaction and fulfilment related to various sexual behaviours (i.e. Satisfaction subscale) and a global evaluation of sexual life (GSSI index) yielded comparable patterns of results, thus validating the accuracy of the current satisfaction findings. Outcomes of both satisfaction subscales showed an adverse impact of the gynaecological conditions/treatments on patients' sexual satisfaction, although this decline failed to reach statistical significance at 6 months follow up, whilst controlling for the effect of age and psychological status. However, the decline in satisfaction became evident in the longitudinal analyses for the cancer group, reaching significance at 6 months follow up and remaining at low levels at 12 months follow up.

The mean group scores for *sexual satisfaction* in the current sample ranged from 6.65 (SE=0.5) to 8.1 (SE=0.8) at baseline (i.e. pre-diagnosis) and from 6.6 (SE=0.5) to 7.3 (SE=0.8) at 6 months follow up. Considering the mean scores of the DSFI Satisfaction subscale for women with and without sexual dysfunction are 4.2 (SD=2.2) and 8.9 (SD=1.1) respectively (Derogatis & Melisaratos, 1979), sexual satisfaction levels in our sample did not suggest clinical impairment at either assessment. Similarly, the obtained 6 months follow up GSSI group means, ranging from 4.4 (SE=0.6) to 5.2 (SE=0.4), were comparable to the means of female non-patient controls (mean=4.8, SD=2.2) and above levels reported by women with sexual dysfunction (mean=2.3, SD=2.2) (Derogatis & Melisaratos, 1979). In summary, the overall evaluation of sexual life reported by the current patient groups was in the “adequate” (4) to “above average” (5) range throughout the study and thus above levels characteristic for women with sexual dysfunctions. The absence of group differences in the current sample further supports the notion of overall favourable sexual satisfaction outcomes of cancer patients at 6 months follow up.

#### *Comparisons of the current findings with other studies*

The lack of a significant effect of time for sexual satisfaction at 6 months follow up would suggest comparability of the current results with other prospective studies reporting stable sexual satisfaction over time (Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991, Kylstra *et al.*, 1999, Grumann *et al.*, 2001). However, a significant decline in sexual satisfaction was detected within the longitudinal (12 months follow up) data analyses of cancer patients (see Results section 7.2.3). It needs to be noted that the sample size was not sufficient to control for covariates in the longitudinal analyses. Therefore, the significant findings obtained in this study need to be considered with caution, given the relationship between sexual satisfaction and anxiety evident in the current sample. Nonetheless, power was sufficient to detect large and clinically meaningful differences both in groups and over time.

Whilst the deterioration of sexual satisfaction during the first post-treatment year was also found in the study by Andersen *et al.* (1989a), other longitudinal studies report stable satisfaction with sexual life over time (Grumann *et al.*, 2001; Kylstra *et al.*, 1999; Schover *et al.*, 1989; Weijmar Schultz *et al.*, 1991). In order to explain these inconsistencies, a number of points will be considered.

Firstly, the discrepancy in satisfaction findings between this and other studies may have been due to methodological differences. In studies reporting stable sexual satisfaction over time, the initial assessment frequently reflects sexual satisfaction prior to the patient's treatment, which is known to be affected by the cancer diagnosis and its symptoms. Indeed, Andersen (1993) recognises the time of diagnosis as the first point of psychological and behavioural morbidity. She and her colleagues have noted that indicators of cervical and endometrial cancer such as post-menopausal bleeding were concurrent with a loss of sexual desire, low arousal and/or dyspareunia (Andersen, Lachenbruch, Anderson & deProse, 1986). Further, within the baseline, benign and cancer patients in the current study reported that their sexual functioning "somewhat" deteriorated following their diagnosis ( $\text{mean}_{Ca}=3.3$ ,  $\text{SD}_{Ca}=1.8$ ;  $\text{mean}_{Be}=3.2$ ,  $\text{SD}_{Be}=1.6$ ), whilst pre-invasive patients reported "little" disruption to their sexual life ( $\text{mean}_{PI}=1.9$ ,  $\text{SD}_{PI}=1.2$ ). Considering that patients in this study were approached following their treatment and therefore their baseline assessment of sexual functioning would have been retrospective in any case, it was considered preferable to inquire about their usual pre-diagnosis levels of sexual functioning rather than their pre-treatment levels. The current baseline findings therefore reflect perceptions of sexual satisfaction prior to the diagnosis and/or symptoms identified as relating to the gynaecological condition. This may at least partially explain the comparably higher levels of sexual satisfaction reported by cancer patients (i.e. "above average") in this sample compared to other studies.

The possibility of cancer patients overestimating their pre-diagnosis levels of sexual functioning at the time of completing the baseline questionnaire (1-3 weeks post-surgery), needs to be considered. The reported baseline levels of

sexual satisfaction (“above average”) corresponds with those reported by healthy controls in the Grumann *et al.* (2001). Since her study was also conducted at one of the Sydney centres participating in the current study, challenges the notion of overestimation. Based on these points we may conclude that the current findings seem to reflect a genuine trend of deteriorating sexual satisfaction levels from pre-diagnosis to post-treatment, which was not detected in other studies due to differing times of baseline assessment (Weijmar Schultz *et al.*, 1991; Kylstra *et al.*, 1999; Grumann *et al.*, 2001). In the only other longitudinal study to compare pre-diagnosis levels of sexual satisfaction (although using a single item measure) with those at 6 and 12 months follow up, overall sexual satisfaction remained at a “moderate” level throughout the study (Schover *et al.*, 1989).

It is interesting that in the majority of prospective studies reporting stable sexual satisfaction, relationship satisfaction has also been stable. In this respect, Weijmar Schultz *et al.*'s (1991) conclusions are particularly relevant, proposing that sexual satisfaction is not compromised by the patients' adverse sexual functioning outcomes *per se* but rather involves other factors such as emotional intimacy between partners. If in times of crisis, engagement in sexual activities satisfies the woman's greater need for intimacy, she may assess her sexual interaction with her partner as satisfactory, in spite of persisting vaginal changes and other treatment side effects (Weijmar Schultz *et al.*, 1991). The importance of intimacy and non-sexual affection was also highlighted in our qualitative findings (Phase 1a), where satisfactory sexual expressions for many cancer patients equated more with the expression of intimate aspects (sensuality, sharing of vulnerabilities, reassurance) than with coital aspects of their sexual relationship. This is in contrast to the traditionally held view that the frequency of sexual intercourse is a key indicator of satisfactory sexual functioning (Derogatis *et al.*, 1988). Initially, the decline in sexual satisfaction at 6 months follow up appeared underlined by a corresponding deterioration in sexual drive levels (i.e. frequencies of sexual activities). However, sexual satisfaction remained low at

12 months follow up despite the fact that sexual drive levels returned to those at pre-diagnosis, thus indicating the initial notion was not valid.

If we adopt Weijmar Schultz *et al.*'s (1991) line of thought supported by the current qualitative findings, then perhaps the decline in sexual satisfaction may be explained by the continuous deterioration of relationship satisfaction, commonly accompanied by a lessening of closeness and emotional intimacy between partners. This view is supported by the gradual increase in levels of dissatisfaction with a sexual partner from 5% at baseline to 22% at 6 months follow up, with approximately a third of patients consistently reporting poor communication with their partners about sexual matters. However, the current quantitative findings suggest that where sexual satisfaction is initially low, poor relationship satisfaction continues to deteriorate over time, particularly amongst anxious patients. More importantly, poor initial levels of relationship satisfaction did not account for poor sexual satisfaction, whilst high rates of anxiety did. Since baseline anxiety contributed independently towards the variance of both sexual satisfaction and relationship satisfaction, this latter interpretation seems the more likely. Taken together, these data indicate that the reported decline in sexual satisfaction levels seems to be underpinned by psychological aspects rather than solely related to the quantitative aspects of sexual relating or physiological changes pertinent to the cancer and its treatment.

The role of cultural differences with regard to discrepancies in the current sexual satisfaction outcomes compared to other studies was also considered. The work of Weijmar Schultz *et al.* (1991) and Kylstra *et al.* (1999) carried out within the Dutch community may reflect a cultural difference in attitudes regarding sexual matters. Generally speaking, the socio-sexual baseline norms within the Dutch population appear to display a greater ease with the discussion of sexual issues. This would indicate a possible broader base of sexual awareness and education, thus influencing many aspects of understanding and adjustment to medical conditions having a strong sexual component, such as gynaecological

conditions. This in turn may well impact on the reported findings of sexual outcomes for patients in these communities.

Similarly to Kylstra *et al.* (1999) and Weijmar Schultz *et al.* (1991), stable general sexual satisfaction was reported by Grumann *et al.* (2001). Grumann *et al.* (2001), using the DSFI GSSI index (also used in the current study) assessed longitudinal sexual outcomes of Australian cervical cancer patients recruited from one of the cancer centres participating in the current study. The difference in outcomes between Grumann *et al.*'s (2001) study and the current study may be explained by a number of methodological differences including: a) time of the initial assessment (i.e. prior to treatment vs. post-treatment), b) assessment periods compared (0-,4-,8-months post-treatment vs. 0-,6-,12-months post-treatment), and c) clinical and demographic characteristics of the cancer sample (type of treatment: surgery alone vs. combined treatment modalities; mean age: 38 vs. 51). The possibility of insufficient power in Grumann *et al.*'s (2001) sample (n=20) to detect changes in sexual satisfaction of cancer patients over time also needs to be considered, given that their results indicated a slight trend of deterioration in satisfaction levels over time (T1=5.7, T2=5.5 and T3=5.3). Whilst in the predicted direction, the effect size (0.19) of Grumann's findings was small, indicating insufficient power for detecting mean score differences. Therefore, it is not surprising that Grumann *et al.* (2001) failed to find a significant effect. The power analysis in the current study pointed to a medium effect size at 6 months follow up (0.5) and a large effect size at 12 months follow up (0.7), suggesting an increased likelihood of detecting differences where these actually occurred. A sample of 21 cancer patients would have been required to detect the results, which the current study satisfied. Therefore, it seems likely that the current findings reflect a true decline in sexual satisfaction in cancer patients over time.

### *Exploration of factors/mechanisms underlying the reported decline in sexual satisfaction*

The current 12 month follow up findings implied that whilst cancer patients engaged in sexual activities at the same frequency as at baseline, their satisfaction with their sexual life significantly deteriorated. It was of interest to explore the underlying mechanisms of patients' motivation to engage in sexual encounters and their possible link to the reported decline in sexual satisfaction. Wilmoth (2001) identified "a new sexual self" that emerges following treatment for cancer, as the core concept pivotal to successful post-treatment adjustment in women treated for breast cancer (also see Wyatt & Friedman, 1996). "The long road back to self" was the statement used by Lamb & Sheldon (1994) to describe a process of rebuilding in a group of American women with endometrial cancer. Findings from a qualitative study by Zagwaard (2000) indicated that such a process of rebuilding a sexual life was significantly influenced by the experience of the first post-treatment intercourse. According to the current 6 months follow up findings, more than half (58%) of the cancer patients indicated that their first post-treatment sexual encounter was unsatisfactory and 67% reported poor communication about sexual matters with their partners. Perhaps the establishment of a new sexual self and sexual life was prolonged due to the couples' inadequate communication about ways of improving sexual interaction, thus resulting in a reduction of sexual satisfaction post-treatment.

Carenza, Stentella, Albanese, & Etiope (1982) found that many patients with cervical cancer continue to have regular sexual contact although feeling little sexual interest. In their qualitative study, van de Wiel *et al.* (1988) investigated factors underlying the reduction in sexual motivation in patients with cervical cancer. They found that sexual interaction was valued significantly less by cancer patients than by women from a non-patient control group. This finding was explained by a considerable deprecation of themselves as a sexual partner, which was noted among patients with cervical cancer (van de Wiel *et al.*, 1988). It was also noted that these patients were likely to conform to the expectations



of their partners and society's prevailing socio-sexual norms, irrespective of the cost to themselves. The authors attributed this behaviour, to a large extent, to a fear of losing one's partner by non-compliance. This behaviour may also have served to indicate to the patient that no irrevocable changes had occurred (Carenza *et al.*, 1982). Interestingly, in their study, no post-treatment changes in overall sexual behaviour, complaints or dissatisfaction with partners, were noted (van de Wiel *et al.*, 1988).

In the current study sexual satisfaction levels declined over time. It is possible that since the majority of areas of patients' quality of life (e.g. physical, functional, social and emotional wellbeing) returned to, and in many cases exceeded, pre-treatment levels, patients may have anticipated parallel recovery in their sexual functioning. Weijmar Schultz *et al.* (1991) comments that the level to which a patient may evaluate her sexual satisfaction depends upon her ability to reconcile her idealised expectations with those expectations she can realistically achieve. The information the patient and her partner is given regarding possible side effects, sexual capabilities and limitation they can expect post treatment, plays an important role in the way the couple recommences their sexual life and the sexual satisfaction the patient gains from that. Hence the role of the treating doctor in exploring these aspects with the patient and her partner, including positive reinforcement of appropriate current sexual techniques, becomes a crucial factor in promoting a realistic basis for sexual satisfaction, as evidenced by the patients in this study. Where this information is not understood or is inadequate for the patient's needs, the level of sexual satisfaction may indeed be seen as declining. This may have been the case in the current study where only 53% of patients recalled having a discussion regarding sexual matters during consultations with their oncologists.

In summary, the current findings point to a unique pattern of data regarding changes in sexual satisfaction over time identified as a result of employing a methodology different from that used in previous studies. In view of the current findings, it is concluded that cancer patients experience a gradual decline in

sexual satisfaction from their pre-diagnosis levels within the first post-treatment year, although the decline does not reach the clinical range. This deterioration in sexual satisfaction in cancer patients seems to be underpinned by psychological issues (e.g. mental health, relationship satisfaction, patients' idealistic versus realistic expectations of post-treatment changes), rather than physiological factors (e.g. vaginal and hormonal changes). Frequency of intercourse has long been regarded as the primary, if not the only, means of assessing sexual functioning. However, it is becoming increasingly recognised, and our data support the view, that the role of both physical and emotional intimacy warrants consideration as essential indicators within a healthy sexual life. This is also evidenced by socio-sexual studies that indicate that the wish for intimacy is considered the most important motivation for women to engage in sexual contact (Jayne, 1981).

## **8.7 Quality of Life**

We hypothesised that the quality of life of cancer and benign patients at six months follow up would have improved compared to pre-treatment levels, whilst the pre-invasive group would maintain high levels of quality of life. This hypothesis was supported, with cancer and benign patients reporting significant improvements post-treatment. Quality of life remained high in the pre-invasive group, however a trend of lower quality of life scores in the pre-invasive group compared to cancer group was noted at 6 months follow up. These outcomes were underpinned by significant improvements in physical, functional and emotional wellbeing of cancer and benign patients, whilst the physical and functional wellbeing of pre-invasive patient showed a slight deterioration. At both assessments cancer patients reported significantly higher levels of social wellbeing and support compared to the two control groups. A comparison of 6 and 12 months follow up findings revealed no further changes in levels of physical, functional and social wellbeing, or in levels of satisfaction with doctor-patients relationship, however a significant improvement in emotional wellbeing was detected. Pre-treatment overall quality of life of cancer patients was

identified as the sole predictor for their overall wellbeing at 6 months post-treatment.

#### *Clinical significance of findings*

Based on their empirical findings, Cella *et al.* (2002) suggest that, whilst a small increase in the total FACT score (i.e. 1-3 points) is sufficient to conclude there is an improvement in the patients' overall quality of life, to draw a conclusion regarding patients' deterioration in quality of life requires a larger degree of change (> 4 points). In the current study the change scores of cancer and benign patients were 11 and 14 points respectively indicating that the improvements in overall quality of life of these patients reflect true changes. In contrast, the minimal degree of deterioration in quality of life of pre-invasive patients (2 points) does not allow for clinically meaningful conclusions to be drawn regarding deterioration in the overall quality of life of these patients. Nevertheless, it should be noted that the FACT inventory is a specific measure designed to assess outcomes of cancer patients with considerable focus on physical and functional wellbeing, and thus may not be sensitive to changes associated with less severe gynaecological conditions such as pre-invasive cervical abnormalities. In the light of this latter point the decline in pre-invasive patients' quality of life at 6 months follow up might indeed reflect a true deterioration.

#### *Comparisons of the current findings with other studies*

Only three longitudinal studies assessing sexual outcomes of gynaecological cancer patients included assessment of various domains of quality of life in their design (Andersen *et al.*, 1989b; Schover *et al.*, 1989; Grumann *et al.*, 2001). More importantly, to our knowledge, no longitudinal study to date assessing sexual outcomes of early stage gynaecological cancer patients, used standardised measure of quality of life, which comprehensively captured its multi-dimensional nature.

Andersen *et al.* (1989b) devised a new 34-item inventory, based on the Katz Adjustment Scales (Katz & Lyerly, 1963), to assess social adjustment and employment in early stage gynaecological patients, among other outcomes. No significant differential disruption of familial/social relationships, or activities among groups of cancer, benign and healthy patients/women, or across time was found. In view of their previous findings of significant disruptions in the area of cancer patients' sexual functioning, the authors conclude that there is a specificity, rather than globality, to disruptions occurring in quality of life. Our data indicating concurrent deterioration of sexual satisfaction and improvements in overall quality of life of cancer patients are consistent with this conclusion.

Assessment of the post-treatment quality of life of cancer patients in the study by Schover *et al.* (1989) was based on the patients' ability to resume daily activities in the following areas: care of the family, housework, quiet hobbies, active hobbies, socialising and job outside the home. By one year post-treatment quality of life had declined for the women who had undergone radiotherapy compared to women treated with hysterectomy alone. These findings were not supported by the current study as no differences in overall quality of life between cancer therapy subgroups were detected. However, the assessment of quality of life in the study by Schover *et al.* (1989) was mainly based on the functional and physical domains of quality of life, whilst neglecting emotional and social aspects of wellbeing. In contrast, the current study involved a comprehensive assessment of quality of life.

Grumann *et al.* (2001) assessed the post-treatment quality of life of stage 1B cervical cancer patients and benign patients, using only the physical wellbeing sub-scale of the FACT inventory. At 4 and 8 months follow ups, both groups of patients exhibited comparable levels of post-operative physical wellbeing (4 months follow up: CG: 22, BG: 23 and 8 months follow up: CG:21 and BG: 24). Cancer patients in the current study reported slightly higher physical wellbeing at both assessments (6 and 12 months follow up: 25) whilst the findings of the

current benign group was comparable to that of Grumann *et al.* (2001) (6 months follow up: 24).

Recently, Lutgendorf, Anderson, Ullrich, Johnsen, Buller *et al.* (2002) conducted a prospective study investigating quality of life and mood in women with early stage (n=65) and locally advanced gynaecological cancer (n=33). Sexual functioning was not assessed. Women were assessed pre-treatment and at 12 months post-treatment. As in the current study, all patients reported significant improvements in quality of life and mood during the first post-treatment year. These findings further support favourable post-treatment adjustment in the domain of quality of life of the current sample.

An interesting, and perhaps counter-intuitive, pattern of responses was noted in the longitudinal data. Cancer patients reported significant improvements in emotional wellbeing over time although their anxiety levels remained elevated. A clarification of this finding was obtained from studies of other chronic illnesses such as rheumatoid arthritis and multiple sclerosis, investigating the relationship between quality of life and psychopathology measures (Sharpe, Sensky, Brewin & Allard, 2001; Fruehwald, Loeffler-Stastka, Eher, Saletu & Baumhackl, 2001). These studies found a relationship between emotional wellbeing and depression rather than emotional wellbeing and anxiety. This explanation is consistent with the current cancer group findings reporting very low levels of depression at both follow up assessments.

Surprising as it may seem, there is little research regarding the quality of life/psycho-sexual outcomes of undergoing an hysterectomy for benign gynaecological conditions (Weber, Walters, Schover, Church & Piedmonte, 1999). This is despite the fact that hysterectomy is a common surgical treatment used to treat specific gynaecological conditions. As expected, quality of life of *benign patients* in the current study significantly improved following their surgery. This finding was also found in the prospective study by Carlson, Miller

& Fowler (1994), conducted with patients treated for non-malignant gynaecological conditions (n=418). Significant improvements in health-related quality of life was reported at 6 months follow up and sustained by 12 months follow up. The small, albeit non-significant, decrease in overall wellbeing of *pre-invasive patients* over time may indicate that this group remains affected long after their relatively minor condition had been detected and treated (where appropriate). As found in the qualitative study (Phase 1b, see Chapter IV), the need for continuous monitoring of the condition by frequent Pap smear tests represents a constant reminder of their "at risk" status of developing a malignant condition. Even if we assume that this patient group experienced no clinically meaningful change in quality of life over time, the fact that the pre-treatment quality of life scores of pre-invasive patients were comparable to cancer patients provides further indication of a considerable impact of this pre-invasive condition on the overall quality of life.

In summary, whilst the negative impact of the diagnosis and treatment of a pre-invasive gynaecological condition on women's quality of life represents a novel finding, the significant improvements in quality of life reported by patients with benign and malignant gynaecological conditions were in the expected direction. It was considered important to explore the underlying reasons for patients' reports of a high quality of life despite a decline in their sexual satisfaction. The phenomenon known as a response shift may serve to explain this outcome (Schwartz & Sprangers, 1999).

#### *The relevance of response shift*

Quality of life considerations are particularly important in the treatment of chronic conditions, such as are seen in the benign and cancer groups, which can often require long-term adherence to complex and potentially toxic treatment regimens (Wilson, 1999). Whenever there is a change in health status altering its state of equilibrium, most people are inclined to begin the process of response, reassessment, readjustment and coping. This process, termed "response shift", has been recently recognised within clinical and scientific

settings. Response shifts involve informative shifts in an individual's internal standards, values and priorities, and/or in the conceptualisation of quality of life, concurrent with changes in actual health status (Schwartz & Sprangers, 1999). These shifts may be described as a normal, adaptive psychological process for dealing with persistent physiological symptoms (whether such symptoms are explicable or inexplicable), leading to gradual improvements in general health perceptions and overall quality of life.

When patients are confronted with a threat to their lives, it is likely that their internal standards of quality of life, and sexual functioning in particular, undergo an alteration. For instance, following treatment, sexual problems could be viewed to be of minor importance to cancer patients in light of the existential issues they have had to face (Weijmar Schultz & van de Wiel, 2003). This may explain why cancer patients in this study experienced an improvement in quality of life despite their ongoing disruption to sexual functioning. Further, it may be that oncology patients have a "response bias" of viewing even small changes as positive and meaningful in light of tremendous physical and emotional costs and investment in treatment (Cella *et al.*, 2002). It can be hypothesised that the findings of the current study reflect the response shift phenomenon since despite some decline in sexual functioning and high rates of post-treatment symptoms, cancer patients reported high levels of overall quality of life, comparable to the control groups' outcomes. Presumably, these patients learnt to value what they had and worried about losing that, rather than emphasising changes or losses that had already occurred. As Anderson and Lutgendorf (2000) conclude: "Cancer survivorship exemplifies the strength of the human body and spirit with quality of life often enhanced by the experience of having survived a potentially fatal disease as well as toxic and painful treatment" (p. 24). The extent to which a cancer patient may be able to optimise their experience of confronting and surviving a cancerous condition and living with the consequences is dependent, to a large extent, on the attitude, communication and empathy of their partner and their treating gynae-oncologist, as evidenced in our study (also see Ong *et al.*, 2000).

## **8.8 Informational needs**

Communication within the doctor-patient relationship has been increasingly recognised as a major factor contributing to health outcomes (Greenfield, Kaplan & Ware, 1985; Kaplan, Greenfield & Ware, 1989). Poor physician communication has been found to lead to uncertainty and denial (Maguire & Faulkner, 1988), anxiety and depression (Fallowfield, Hall, Maguire & Baum, 1990), non-compliance (Pruyn, Rijckman, van Brunschot & van den Borne, 1985) and poorer psychological adjustment (Butow, Dunn, Tattersall & Jones, 1995; Rainey, 1985; Molleman, Krabbendam, Annyas, Koops, Sleijfer & Vermey, 1984). The current findings provide further support for the importance of the doctor-patient relationship and its influence on anxiety in gynaecological cancer patients, which in turn, was found to affect levels of sexual satisfaction.

In the current study, only 53% of cancer patients reported that sexual matters were discussed during medical consultations, with another 20% of patients being unsure whether they discussed sexual issues with their physicians. The picture was similar for benign patients with slightly more than half (55%) of patients stating that sexual issues were discussed with them by their doctors. Five percent (5%) of benign patients reported being unsure as to whether such discussions had taken place. Although it is possible that women prefer not to engage in discussions about sexual issues and, hence, under-report discussions about sexual matters, the majority of patients reported wanting more information regarding the effects of gynaecological cancer and its treatment on sexual functioning. Therefore, it seems unlikely that the large proportion of women who could not recall discussions about sexual functioning were simply failing to report such discussions. Presumably, had doctors discussed sexual functioning adequately on numerous occasions, patients would have reported these discussions.

Further, these patients participated in this study investigating sexual outcomes, which may have increased their awareness of sexual functioning and could have



prompted discussions about sexual matters, not only with their partners, but also their treating health care professionals. Consequently, the high proportion of cancer patients who reported that they were either unsure whether such discussions took place or that discussions did not take place, most likely reflects that these issues were not covered in sufficient depth in consultations. Taken together, in almost half of the cancer and benign sample, the topic of sexuality was not raised during consultations in sufficient depth for them to be recalled. This occurred despite the fact that the majority of patients in both groups indicated they wanted discussions concerning sexual matters to take place at various times during their consultations (from diagnosis to post-treatment and follow ups) and that they would have liked their partners to be involved in such discussions.

Nonetheless, the current findings reflect an improvement in the dissemination of information regarding sexual matters compared with those obtained in Vincent *et al.*'s study (1975), where 75% of the gynaecological oncology patients reported receiving no information regarding sexual adjustment before, during, or after their treatment. However, considering Vincent *et al.*'s (1975) study was conducted almost three decades ago, the changes are less than expected. For example in two recent studies, the majority of gynaecological cancer patients (92% and 90% respectively) reported having discussed issues of sexuality with their medical specialist and being satisfied with the information obtained (79% and 80%) (Kylstra *et al.*, 1999; Leenhouts *et al.*, 2001). Kylstra *et al.* (1999) and Leenhouts *et al.* (2001) both concluded that sexual matters are being more readily discussed within medical consultations now. However, it is important to note that these studies were conducted in the Netherlands, where sexuality tends to be more openly discussed and accepted. Studies from other countries, which are consistent with the current one, convey a more pessimistic picture, commonly reporting half of the patient sample not having discussions on sexual matters with their treating health care professionals (e.g. UK: Stead, Brown, Fallowfield & Selby, 2003; Corney *et al.* 1993; Canada: Bourgeois-Law & Lotocki, 1999; Australia: Poad & Arnold, 1994).

In our study, poor communication between health care professionals and patients regarding sexual matters was best exemplified by the alarmingly low number of patients aware of the existence of dilators as a rehabilitation tool following radiotherapy. Importantly, four of the cancer patients did not resume their post-treatment sexual life, three of whom believed that cancer is contagious. Of particular interest, these were the patients who indicated no interest in discussing sexual issues with their doctor. These findings are consistent with previous studies where myths and misinformation regarding cancer have been shown to adversely affect post-treatment sexual adjustment (Schover & Jensen, 1988; Krumm & Lamberti, 1993; Seibel *et al.*, 1980). However, these findings pose an additional problem in that those patients that endorse myths are the same patients who do not wish to discuss sexual issues. Although this group was a small group of women in the present study, they present a particular challenge for effective communication about sexual functioning in the context of gynaecological cancer.

Whilst health care professionals working in the area of gynae-oncology need to respect any patient's/couple's unwillingness to engage in discussions of a sexual nature, it is important to identify the basis for this reluctance. Several factors may contribute to an unwillingness to address sexual matters, some pertinent to the patients/couples, others to the health care professional. Embarrassment surrounding such an intimate topic is common in many older women/couples, evidenced by shyness in revealing the extent of their sexual knowledge and sexual techniques. Cultural, religious and social constraints may pose a barrier for some patients/couples. A presumption that discussing sexual matters is inappropriate in the context of treatment and adjustment following cancer may also prevail (Butler *et al.*, 1998). Although some of these factors have been identified in studies to date others are speculative and further research is needed to determine which of these are relevant. Irrespective of the patients' difficulties confronting sexual matters, the health care professional has

a duty of care to offer a comprehensive treatment regime that includes post-treatment psycho-sexual components.

For the majority of patients in the current study, however, a need for addressing sexual matters repeatedly throughout the entire illness, from diagnosis onwards, was reported. Zagwaard *et al.* (2000), in their qualitative study with gynaecological cancer patients, found that patients identified a need for information regarding sexual matters during three key time periods coinciding with specific events in the course of their illness: 1) *at diagnosis* and the beginning of treatment where information regarding the likely effects and side effects of the treatment on sexual issues was paramount, 2) *recovery and pending the first attempt at recommencing sexual intercourse*, when the main issues centred around the possibility of pain and/or bleeding occurring during and/or after sexual intercourse, 3) the period following the first post-treatment sexual encounter that marked *the beginning of reinstating their sexual life* where information on sexual techniques and aids such as dilators was requested. These periods are consistent with those identified by physicians and psychologists based on information gathered from their experiences working with women with various types of gynaecological cancer (Schover & Fife, 1985). Partners also expressed a need for specific information at particular times, with information regarding developing better communication skills and flexible sex roles being sought during early recovery and at the time of recommencement of sexual intercourse (van de Wiel, Weijmar Schultz, Wouda & Bouma, 1990b). Information relevant to the waiting period before recommencing sexual intercourse, the likelihood of coital bleeding and methods for resolution of sexual difficulties, were also frequently sought (van der Does & Duyvis, 1988).

The fact that the initial doctor-patient relationship predicted post-treatment anxiety levels, which subsequently predicted sexual adjustment, further supports the importance of an open and honest information exchange between doctor and patient. Possible changes in sexual functioning post-treatment appears to be an essential component for discussion, as is the use of a vaginal dilator to

ameliorate certain conditions where indicated. However, the current data indicate that Australian gynae-oncologists do not discuss sexual issues with their patients adequately, including the importance of using a dilator to promote vaginal patency. There is a danger that patients may interpret the lack of discussion concerning sexuality during consultations as indicative of the view that it is not appropriate to discuss sexual matters within the context of gynaecological cancer and its treatment. Further, previous research has identified that few patients would be prepared to instigate discussions about sexual issues with their treating physician, despite patients wanting additional information to be made available to them (Vincent *et al.*, 1975).

It is essential the health care professional has a competent knowledge of sexual matters related to post-treatment adjustment following gynaecological cancer (sexual techniques in particular), and the communication skills to discuss them comfortably at a level indicated by the patient/couple. Where skills are lacking the health care professional may find difficulty in putting the patient/couple at ease, gaining trust, relieving embarrassment to increase receptivity, being sensitive to cues, tailoring information to promoting questioning. It is important to note that the lack of discussion experienced by patients in this study could have been due to a lack of training of the health care professionals as to how best to approach and conduct these discussions. In recognition of this need for training, The NSW Cancer Council (2002) has produced an interactive teaching package "Talking about Sexuality, Body Image and Cancer: A teaching resource for health professionals", which is expected to facilitate discussion on the topic of sexuality and result in a more holistic treatment regime. Clearly, more research is needed to assess the direct impact of training strategies on the provision of care by health-care professionals when addressing the psycho-sexual adjustment of gynaecological cancer patients (Butler *et al.*, 1998).

### **9. OVERVIEW OF LIMITATIONS AND STRENGTHS OF THE PROJECT**

Whilst recognising the somewhat limited size of the sample and acknowledging that a significantly larger sample size would reflect the current findings more strongly, we do believe that the findings are a genuine reflection of the post-treatment psycho-sexual outcomes of patients treated for early stage cervical and endometrial cancer. The thoroughness of the concept and design of this study allow for this conclusion. An evaluation of limitations and strengths of this study will be discussed, followed by a summary of conclusions and clinical implications.

#### **9.1 Limitations of the study**

Any psychological research in the field of oncology requires a sensitive approach, this being most necessary in the area of psycho-sexual adjustment. Thus, necessary modifications to standard methodological norms had to be considered in order to balance empathetic concerns for patients who had recently undergone treatment for a life-threatening illness with scientific rigour and study objectives. Our study was no exception, with various adaptations needing to be implemented. We do not believe, however, that these adaptations essentially compromised the rigour of this study.

##### ***Sample size & response rate***

Although every effort was made to maximise adequate sample sizes in all patient groups, the voluntary nature of participation and right to withdraw from the study were stressed to every patient approached. Although most patients were initially enthusiastic about the study, the immediate post-treatment phase

is a stressful one and therefore a number of patients who initially agreed to take part failed to complete the assessments.

### *Cancer group*

A considered limitation of the present study was the sample size of this group. The number of cancer patients eligible to participate in the present study was smaller than anticipated ( $n=87$ ) with the uptake from those patients approached at a relatively low 61%. The process of data collection was hindered by a number of factors, including changes in staff members in three of the five participating hospitals and more importantly, the recent decline in incidences of early stage cervical cancer. With respect to the latter, notably fewer women were being treated for early stage cervical cancer in all participating centres compared to previous years. It appears that the establishment of the National Cervical Cancer Screening Program in Australia in 1991 had begun to prove effective by the time this study commenced. Indeed, the Australian Institute of Health and Welfare (1998) reported a 32% reduction of cervical cancer deaths in the seven years following the program's introduction. The success of the screening program suggests that more patients are now being diagnosed and treated earlier for pre-invasive conditions, which appears to have limited the occurrence of invasive cervical cancer.

The 61% recruitment rate in the cancer group is less than optimal and may affect the generalisability of the results and the power of the study. However, analyses of those who took part and decliners indicate no significant differences between groups, making this less likely. Further, it is suggested by Cohen (1992) that 21 participants should be sufficient to detect large effect sizes, however, both moderate and small effect sizes may be obscured. In the present study, this is likely to have been relevant to variables such as sexual drive and depression assessed within the 6 months prospective analyses, both revealing a trend of decline but failing to reach significance. With a larger sample these variables may have reached levels of statistical significance. It can be argued that moderate to small effect sizes would be of questionable clinical relevance.

Findings that are of both clinical and statistical significance are more compelling and the current sample size was sufficient to detect large and clinically meaningful changes.

A small sample size poses problems when examining changes over time in sexual outcome variables. As a consequence, the results of the longitudinal analyses and the prediction of outcomes need to be interpreted with caution. There is a possibility that contributing factors were obscured by the lack of power thus making the drawing of conclusions as to the processes at work, questionable. This in turn renders the interpretation of results more speculative and although the results may serve to generate hypotheses they do not allow for the drawing of definite conclusions. It should also be noted that the large number of statistical comparisons was not controlled for by adjusting the accepted level of significance. To have adjusted significance levels would have compounded problems of restricted power, and limitations to power were seen as a priority. However, as a result, it is possible that some of the findings reflect Type II error, and are related to chance. The use of multiple assessments of the same groups over time and the relative consistency of findings across assessment periods, reduces the chance of accepting a statistically significant result that is due only to chance.

Increasing the sample size would have increased the power of this study. The inclusion of patients with other gynaecological cancers, such as ovarian and vulvar cancers was considered and rejected since different types of gynaecological diseases and their stages entail psychological concomitants different to cervical and endometrial cancer. The additional difficulties inherent in both these cancerous conditions, such as genital mutilation with vulvar cancer, were believed to potentially significantly bias the results and patients with these conditions were therefore rejected as potential participants.

An option of expanding the sample size by including patients who had received "radiotherapy alone" was also considered and rejected. Since radiotherapy

alone is not a usual treatment for early stage cervical/endometrial cancers it was considered that including these patients would not have substantially increased numbers for participation. Of 87 eligible patients, only three women had undergone radiotherapy alone. These patients were not included in the final sample to maximise the purity of the research design.

Although the stringent inclusion criteria resulted in a lower sample size than the optimum level we would have liked, the power remains sufficient to allow the detection of large effect sizes. Moreover, the present sample size is above the median of previous prospective longitudinal studies in this area (n=61 in Schover *et al.*, 1989; n=47 in Andersen *et al.*, 1989a; n=21 in Weijmar Schultz *et al.*, 1991; n=58 in Kylstra *et al.*, 1999; n=20 in Grumann *et al.*, 2001).

#### *Benign patients*

Overall the recruitment of patients for the benign group was more limited than that for the cancer group. Two factors may have contributed to this situation: 1) recruitment was restricted to those patients undergoing a Total Abdominal Hysterectomy for their condition (excluding vaginal hysterectomy), and numbers of patients undergoing this treatment were low, 2) before patients could be approached to join the study, assessment of their suitability, and permission from their treating gynaecological surgeon was required. This permission unfortunately was not always forthcoming, which in turn led to a restricted number of potential candidates who could be approached to participate in this study.

The 6 months follow up attrition rate was also higher than expected. Furthermore, a significant number of benign patients noted in their 6 months follow up questionnaires that they were not interested in further participation. Based on Grumann *et al.*'s (2001) longitudinal study conducted in Australia in one of the centres participating in the current study, no further changes in levels of sexual functioning and quality of life from 6 to 12 months post-treatment were expected in the benign group. Being aware of our experience of attrition at



baseline and 6 months follow up, together with the reported declines from other studies, we elected not to include benign patients in a 12 months follow up assessment. We anticipated that the small sample of participants likely to comply with completing any further questionnaires at 12 months follow up could bias the results. Neither would a very small compliance rate at 12 months follow up have confirmed or refuted our hypothesis with any degree of reliability.

#### *Pre-invasive group*

Based on previous studies the recruitment of participants to this group was expected to be problematic and high attrition rates at follow up were expected (Conaglen *et al.*, 2001; Neilson & Jones, 1998). Every attempt was made to ensure adequate recruitment and a continuation of participation to allow for reliable data to be recorded. Therefore, in contrast to the other two patient groups, recruitment of participants for this pre-invasive group took place prior to treatment. The decision to approach patients to participate whilst they awaited their first consultation and colposcopy at the colposcopy clinic, was prompted by numerous reports of high rates of non-attendance at follow up appointments (Rajaram *et al.*, 1998; Stewart *et al.*, 1994; Marcus *et al.*, 1992). A larger sample of patients than those in either the cancer or benign groups was initially recruited to guard against an assumed rise in attrition rates. Unfortunately, the attrition rate exceeded the level at which generalisability for this group could be guaranteed. One factor contributing to this attrition may be the age of the participants, who were much younger than cancer and benign patients. Within this population life changes happen more rapidly and extraneous issues assume more importance. Many participants had moved residence between baseline assessment and follow up times, which impeded reminder telephone calls and letters being sent to maintain contact. Many patients also failed to attend follow up clinical appointments, again restricting contact. Further, patients who dropped out at follow ups may have been less affected and, therefore, not seen the relevance of the study.

### ***Comparability of patient groups***

Differing demographic characteristics between the pre-invasive group and the cancer/benign groups were evident. These differences, marked by the older age of cancer/benign patients, impaired the comparability of the groups, particularly since sexual practices can alter with age (Master & Johnson, 1980). However, the average pre-invasive population is young and this was reflected accordingly in the present sample of pre-invasive patients. Thus, from a clinical point of view, patient groups adequately represented the average age group of each assessed gynaecological condition. To compensate for the methodological problems in comparing sexual outcomes of differing age groups, age was controlled for in all analyses involving the three patient groups (i.e. 6 months prospective analyses). Further, the vast majority of the sample was of Anglo-Saxon origin. As a result, it is unclear as to how these results might generalise to other ethnic groups where the process of post-treatment sexual adjustment could differ significantly. It also needs to be noted that the current findings may not represent the experiences of women who received chemotherapy as their adjuvant treatment (a very small number of cancer patients received adjunct chemotherapy (n=8) in our study).

### ***Procedure***

Data concerning usual sexual functioning and relationship satisfaction was obtained retrospectively from cancer and benign patients, which may have resulted in an overestimation of previous functioning as a response to the current cancer diagnosis and treatment. Practical limitations rendered the retrospectivity of the baseline questionnaire in this study unavoidable. Usually patients are asked to arrive at hospital the day prior to their surgery. This day is used for medical tests/examination and preparation for the operation. From a psychological perspective, it was deemed inappropriate to interfere with this procedure by requesting permission to approach patients at this time. In fact, Kylstra *et al.* (1999), who conducted initial assessment pre-operatively, obtained a compliance rate of only 37%. The authors comment on patients' reports of feeling preoccupied with the trauma of recent diagnosis and pending surgery,

which lead to a very low baseline response rate. Based on these considerations, patients were approached between five and ten days post surgery. The effect of this part of the procedure was taken into account when discussing the results.

### ***A rehabilitative effect as a result of participation in the research project***

One could argue that any detailed assessment of sexual functioning has the ability to impact on the participants. The question then arises as to whether the group of patients repeatedly and comprehensively assessed about their psychosexual functioning is incompatible with the patient population that did not participate in the study. Weijmar Schultz *et al.* (1991) in their longitudinal study included a "testing" control group, which was assessed only once at 12 months post-treatment. No differences were observed between the cancer group which participated in all four assessments and the "testing" comparison group of cancer patients. Although no "testing" group was included in the current study, the indirect therapeutic effect of participation seems unlikely or negligible. This is particularly so, since presumably this effect would be exerted through increased communication about sexuality, which was not observed in this study.

### ***Questionnaires***

We were mindful of the participants' comments regarding the length of the questionnaires during the pilot phase of this study. The implication was that the willingness to complete questionnaires declined considerably as the length of the questionnaires increased. The physical and psychological trauma women experience so close to the diagnosis and treatment process was also considered when reviewing measures for inclusion. Since many of the cancer patients were seriously ill and traumatised post surgery when the baseline retrospective questionnaire was given, the number of items within that questionnaire was kept to a minimum. This may have restricted information to some extent, but non-compliance in completing the questionnaire was deemed a greater risk. Therefore, it was considered likely that a more comprehensive battery of questionnaires would have lead to higher refusal and drop out rates of potential participants, which in turn would have increased the risk of biased

results. The questionnaires we used did not include a measurement of sexual self-schema (Andersen & Cyranowski, 1994; Andersen *et al.*, 1997). However, we acknowledge the importance and the relevance of the sexual self-schema to our study and recommend including its measurement in future research in this area.

An assessment of sexual dysfunctions was also omitted from the test sets. Many factors contributed to this decision. To our knowledge no standardised measures are available to assess sexual dysfunctions. Although Andersen *et al.* (1989a) and Grumann *et al.* (2001) used self-constructed measures for their longitudinal studies assessing sexual dysfunctions based on DSM-IV (American Psychiatric Association, 1994), those measures have not been formally standardised or validated and did not appropriately reflect the aspects of sexuality targeted in the current study. The lack of readily available measures may be accounted for by recent shifts in the conceptualisation of women's sexual problems (Bancroft *et al.*, 2001). Traditionally research exploring sexual functioning and satisfaction has been primarily evaluated using physical components of sexual activity such as arousal, orgasm and frequency of sexual intercourse, as the primary indicators of sexual functioning, whilst overlooking the impact of qualitative factors in sexual relating. Recently this imbalance has begun to be addressed with the recognition and acceptance of emotional and intimacy components, together with the general state of mental health, as having a definite impact on women's satisfaction with their sexual relationships. The traditional, more physically orientated appraisal of sexual functioning may have distorted the evaluation of sexual dysfunction in women, overestimating the prevalence of sexual dysfunction. Indeed, based on their longitudinal findings Weijmar Schultz *et al.* (1991) concluded that sexual satisfaction is not limited to the experience of sexual arousal and orgasm, but also includes other factors such as intimacy between partners. Our qualitative and quantitative findings confirmed such conclusions, with patients focusing on the qualitative rather than quantitative aspects when discussing their sexual relations (i.e. issues of communication between partners, intimacy etc.) Consequently, the focus of the

current study centred on a comprehensive assessment of sexual satisfaction. Our results appear to validate our choice of measures since they pointed to the importance of including and emphasising psychological aspects of relating, as well as the physiological responses, regarding post-treatment sexual adjustment for cervical/endometrial cancer patients.

### ***Omission of partners***

We recognise the importance of comments from partners of patients with gynaecological cancers. Very few studies addressing the concerns of partners are available (Zagwaard *et al.*, 2000; Lalos *et al.*, 1995; van de Wiel *et al.*, 1990b; Weijmar Schultz *et al.*, 1986). The design of the qualitative study (Phase 1a) allowed for patients to invite their partners to be interviewed by the researcher. Although we did ask patients to approach their partners, the response rate of partners willing to be interviewed was extremely low (10%), with only two partners agreeing to participate. Although their comments were valuable they were not deemed representative of those partners not giving an interview and thus have been omitted. This lack of response serves to highlight the great need for future studies to devise appropriate strategies to encourage the partners of patients treated with gynaecological cancers to become more involved in research projects. On the basis of this experience in the qualitative study, limited funding and time constraints of this project, the decision was reached not to include partners in the second, quantitative phase.

Notwithstanding these limitations, the current study has many distinct strengths.

## **9.2 Strengths of the study**

### ***Theory & Design***

The impetus for the conceptualisation of the current study was based on the recognition of the important role of psychological and social factors, apart from physiological factors, in sexual adjustment of patients treated for early stage cervical/endometrial cancers. Inconsistencies among the existing findings in this

relatively new field have alluded to the complex interplay and dynamics operating among these factors.

The design of the study and operationalisation of relevant factors was based on a thorough literature review complimented by our qualitative studies. We deemed it crucial to include a qualitative aspect to our study to ensure a comprehensive coverage of all relevant factors/concerns of women treated for cervical/endometrial cancer and to use current idiom to discuss sexual issues, thereby limiting misunderstanding between patients and researchers/clinicians. Employing a qualitative study also allowed for the development of a theoretical explanatory model (see Figure 3.1), which facilitated the formulation of our empirical predictions. The subsequent quantitative phase revealed relevant prognostic information and significant trends in post-treatment adjustment in this population. In summary, we believe that the current comprehensive, methodologically rigorous study offers an important theoretical as well as clinical applications for findings, thus facilitating development of informed decisions regarding treatment options and continued care following treatment of early stage cervical and endometrial cancer.

### ***Comprehensiveness of the study***

Patients' functioning was assessed across a range of areas including *physiological* (e.g. stage and type of disease, treatment modalities, hormonal implications, relevance of physical impairments as a result of vaginal changes), *psychological* (e.g. psychological distress, relationship satisfaction, adjustment styles), and *doctor-patient relationship/communication and informational needs* (e.g. approachability of doctors, use of rehabilitation devices such as dilators).

Sexual functioning was explored in terms of sexual drive, overt sexual behaviours, satisfaction with various aspects of sexual relating (sexual satisfaction) and overall satisfaction with sexual life. The standardised scales adopted for use in the present study were validated and reliable inventories (e.g. Derogatis & Melisaratos, 1979; Cella *et al.*, 1993; Watson *et al.*, 1994). The

scales for the Derogatis Sexual Functioning Inventory (DSFI, Derogatis & Melisaratos, 1979) in particular were anticipated to produce valid data, since they are not only highly regarded instruments for the assessment of sexual functioning, but have also been reliably used in the research into sexual functioning of gynaecological cancer patients (e.g. Andersen *et al.*, 1986; Grumann *et al.*, 2001; Andersen & Hacker, 1983c). The many dimensions of quality of life, including physical, functional, social, emotional wellbeing and doctor-patient relationship, were assessed using a well-validated multi-dimensional cancer-specific measure (FACT). Standardised measures were supplemented by newly developed specific measures formulated from responses elicited from the preliminary qualitative study, providing opportunity for patients to record their perceived side effects and distress from individual treatment modalities.

#### ***A spectrum of gynaecological conditions studied***

An additional strength of this study was the extensive spectrum of gynaecological conditions explored. The psychological and physical impact of the cancer diagnosis and subsequent treatments for early stage cervical and endometrial cancer were compared to; ii) the psychological and physical outcomes of the surgery for benign gynaecological conditions, hysterectomy, and ii) the psychological impact of the diagnosis of pre-invasive cervical abnormalities and the associated uncertainty of being at an increased risk of developing cancer. To our knowledge this is the first prospective longitudinal study in this area to include patients with pre-invasive gynaecological condition as a control group. The fact that in many respects this control group seemed to have a poorer outcome than their prognosis would warrant, supports the importance of psychological factors and the use of this group as a valid control group.

#### ***Prospective, longitudinal controlled design***

We considered it necessary to conduct a longitudinal study to allow time for relevant physiological changes to develop, progress, stabilise, recede and

possibly disappear and the process of psycho-sexual adjustment to consolidate. Consequently each group was assessed by specific questionnaires at designated times. The current study controlled for psychological confounding factors such as marital satisfaction, psychological status, adjustment styles, socio-economical status, all of which have the potential to modify sexual functioning. The employment of two control groups allowed for isolation of the outcomes unique to the diagnosis of cancer and its various treatments.

### ***Multi-centre study & generalisability of data***

A multi-centre catchment area was employed to maximise the sample size and facilitate the generalisability of the obtained data. Five major Sydney hospitals agreed to participate in this study with most referring gynae-oncologists being actively involved. All five participating hospitals were the main referral centres for women from rural as well as metropolitan catchment areas. The lack of differences between decliners and participants at baseline and at 12 months follow up, the low drop-out rate of cancer participants at 6 months follow up and the range of socio-demographic experiences of patients from these five diverse catchment areas, all support the generalisability of the results to a group of early stage cervical and endometrial cancer patients undergoing treatment in Australia.



### 10. SUMMARY & CLINICAL IMPLICATIONS

With the increase in survival rates in patients diagnosed with and treated for cervical and endometrial cancer, comes the necessity to expand current understanding of adjustment and quality of life following treatment regimes. Sexual health has gained prominence over the last decade with research into sexual functioning following gynaecological cancer producing important, albeit often conflicting, data. Psycho-sexual research within an oncological setting is an extremely sensitive area for investigation fraught with methodological and ethical difficulties. Hence many studies are conceptually and methodologically imprecise. This has given rise to a diffuse picture of the nature and severity of adverse sexual sequelae in gynaecological cancer patients. This is further complicated by changes in the way female sexuality and sexual function/dysfunction are conceptualised. The role and importance of psychological factors is being validated as more research in this and associated areas, is conducted. Consequently there is recognition of the need for the enhancement of primarily physiological treatments with equally valuable psychological support strategies.

The aim of the present study was to provide a comprehensive picture of the psycho-sexual adjustment and quality of life of patients undergoing various treatments for early stage cervical and endometrial cancer. A thorough literature review complemented by two qualitative studies (Phase 1a & b) revealed that: 1) an adequate evaluation of sexual outcomes cannot be exclusively based on the frequency of sexual activities, but rather by assessing both quantitative and qualitative (intimate) aspects of sexual relating, 2) adverse sexual functioning sequelae may be influenced not only by physiological, but also psychological factors such as the adjustment styles of patients and levels of anxiety and

depression, 3) it is important to evaluate the quality of the doctor-patient relationship and the provision of comprehensive informational needs, as these exert a considerable influence on levels of post-treatment adjustment, particularly in the area of sexual and psychological functioning. Relationships between these factors, as well as the overall quality of life of cervical and endometrial cancer patients, were prospectively assessed in the second quantitative phase of the study. Based on the obtained findings, the following conclusions and clinical implications can be made:

- 1) Life areas, other than sexual functioning, are resilient to major disruption and rebound fairly quickly following treatment, particularly for cancer and benign patients. Overall, cancer patients are adjusting surprisingly well, considering that within 6 months they had been faced with the diagnosis of cancer, subsequently undergone radical surgery with some patients receiving adjuvant radiotherapy (and in few instances chemotherapy). Despite these upheavals, their outcomes are comparable to patients in control groups who did not have to face the combined effects of cancer, the threat of recurrence and invasive treatments.
- 2) The current longitudinal findings suggest that treatment for early stage cervical and endometrial cancer does not result in major, continuing sexual upheaval and sequelae. Despite many irrevocable adverse vaginal changes and treatment side effects, and a temporary decline in sexual drive and overt sexual behaviours, the only lasting decline is seen in sexual satisfaction. Moreover, sexual satisfaction was predicted by psychosocial factors rather than the physiological impact of cancer or its treatment. Such data validate the multi-factorial nature of post-treatment sexual adjustment. Consequently, evaluation of post-treatment sexual life by health care professionals needs to include assessment of quality of, and satisfaction with, sexual relations rather than focusing on coital activity *per se*.

- 3) At 6 months follow up, the main outcomes of patients were comparable across the three groups. Such lack of group differences has at least two possible explanations; 1) a successful adjustment of cancer patients to their diagnosis and treatment, or 2) an unexpectedly poor adjustment of benign and pre-invasive patients to their diagnosis and treatment, or 3) a combination of both. Good adjustment by cancer patients could be due to a response shift in cancer patients who have survived the immediate threat of cancer, while receiving intense attention from health care professionals and support persons; thus their post-treatment evaluation of quality of life and mood may reflect a greater appreciation of what they have. The poorer adjustment of patients in the control groups could be due to: i) a poorer level of physical and psychological wellbeing prior to surgery resulting in a protracted physical and psychological recovery rate in the benign group, and ii) the ongoing threat of the cancerous condition in the pre-invasive group. The qualitative findings from Phase 1b suggested that pre-invasive patients report a long-term adverse impact of the diagnosis of CIN on their psychological wellbeing. Where this is the case, there is a danger that the impact of this minor gynaecological condition will be underestimated by treating health care professionals and as a consequence relevant psychological support or intervention may not be offered.
- 4) Anxiety levels remained elevated in approximately a third of patients in all groups and these predicted poorer sexual and relationship functioning over time. Brief screening measures such as HADS could identify these women. It is important to elicit the nature of patients' concerns, which differ depending upon their condition, and give information in an optimistic but realistic manner to alleviate unnecessary anxiety where possible.
- 5) The present findings indicated that only half of cancer patients had discussions about sexual matters with their oncologists that were sufficiently meaningful to be recalled. The presence of myths and

misconceptions regarding contagiousness of cancer in a small but significant minority of patients was also noted. Of particular concern was the lack of discussions about dilators, such that women were either unaware of them, or their use and importance in the context of post-irradiation rehabilitation. More importantly, the doctor-patient relationship was found to be the principal determinant of patients' levels of long-term anxiety. It is important that discussions about sexuality occur on numerous occasions and be provided in a non-threatening and non-judgmental manner, within a supportive environment. Health care professionals need to address the topic of sexuality with their patients from diagnosis onwards, thus legitimising patients' concerns in this area, making it easier for them to raise issues concerning sexual functioning at other times, as they became more salient. It is therefore important that appropriate training is provided for health care professionals, to improve their skills in eliciting and managing such discussions of sexual matters with patients and partners. The publication of a booklet and workshop "Talking about Sexuality, Body Image and Cancer: A teaching resource for health professionals" by the New South Wales Cancer Council (2001) on this topic should prove of great value in the interim whilst more in-depth curriculums are developed to address training needs amongst health care professionals. Moreover, the recognition of the value of the continuous doctor-patient dialogue concerning psycho-sexual matters may be applicable across other chronic diseases requiring doctor-patient interaction, with the potential of improving the quality of life for many survivors.

A final point arising from this body of work is the value of combining a qualitative and quantitative approach within health research. In this study, the qualitative findings contributed significantly to the interpretation of quantitative results, allowing less speculative conclusions to be drawn.

In conclusion, the cancer patients in this study did experience deterioration in their sexual satisfaction over time. However, for the most part, sexual satisfaction was only mildly impaired, with few differences between the cancer group and other groups of women presenting with gynaecological conditions. Moreover, the deterioration in sexual satisfaction was an island of disruption in a scenario that otherwise represented a good adjustment for these women following cancer. Since anxiety immediately post-treatment was found to predict subsequent sexual functioning, and anxiety did not improve over time, it is possible to identify women at risk of developing chronic anxiety and sexual problems, thus enabling *early* intervention strategies to be implemented. Irrespective of the 'relatively good' outcomes, some areas of patient care emerged as needing more attention.

The doctor-patient relationship is of great importance, having the potential to impact very positively on the patient's anxiety level and ability to recommence a rewarding sexual life. More comprehensive discussions and reassurance concerning sexual techniques and the use of aids such as the dilator to enhance sexual experiences, are recommended. It would be remiss to be content with the 'relatively good' outcomes for patients treated for early stage cervical and endometrial cancer, when there is ample scope to facilitate even better outcomes, especially in the area of sexual satisfaction. For most people a rewarding sexual life constitutes sound sexual health and is a vital part of their existence. Sexual health is defined as:

*"the positive integration of somatic, emotional, intellectual, and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love"*

(WHO, 1975)

This study recognises the importance of the diverse components of sexual health. It is recommended that further research continues to address these components in an holistic manner.

## Reference List

- Abitbol, M. M., & Davenport, J. H. (1974a). The irradiated vagina. *Obstetrics & Gynecology*, 44(2), 249-256.
- Abitbol, M. M., & Davenport, J. H. (1974b). Sexual dysfunction after therapy for cervical carcinoma. *American Journal of Obstetrics & Gynecology*, 119(2), 181-189.
- Abramson, P. R. (1990). Sexual science: Emerging discipline or oxymoron? *Journal of Sex Research*, 27(2), 147-165.
- Adelusi, B. (1980). Coital function after radiotherapy for carcinoma of the cervix uteri. *British Journal of Obstetrics & Gynaecology*, 87(9), 821-823.
- Alexander, D. A., Naji, A. A., Pinion, S. B., Mollison, J., Kitchener, H. C., Parkin, D. E., Abramovich, D. R., & Russell, I. T. (1996). Randomised trial comparing hysterectomy with endometrial ablation for dysfunctional uterine bleeding: Psychiatric and psychosocial aspects. *British Medical Journal*, 312(7026), 280-284.
- Alvarez, R. D., Soong, S. J., Kinney, W. K., Reid, G. C., Schray, M. F., Podratz, K. C., Morley, G. W., & Shingleton, H. M. (1989). Identification of prognostic factors and risk groups in patients found to have nodal metastasis at the time of radical hysterectomy for early-stage squamous carcinoma of the cervix. *Gynecologic Oncology*, 35(2), 130-135.
- American Cancer Society. (2002). *Cancer reference information*: American Cancer Society.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington DC: American Psychiatric Association.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (DSM IV)* (4th ed.). Washington DC: American Psychiatric Association.
- Anastasi, A. (1988). *Psychological testing* (6th ed.). London: Collier Macmillan.
- Andersen, B. L. (1984). Psychological aspects of gynaecological cancer. In A. K. Broome (Ed.), *Psychology and gynaecological problems* (pp. 117-141). New York: Tavistock/Routledge.

- Andersen, B. L. (1986). *Women with cancer: Psychological perspectives*. New York: Springer.
- Andersen, B. L. (1993). Predicting sexual and psychologic morbidity and improving the quality of life for women with gynecologic cancer. *Cancer*, 71(4 Suppl), 1678-1690.
- Andersen, B. L. (1995). Quality of life for women with gynecologic cancer. *Current Opinion in Obstetrics & Gynecology*, 7(1), 69-76.
- Andersen, B. L. (1996). Stress and quality of life following cervical cancer. *Journal of the National Cancer Institute*, 21, 65-70.
- Andersen, B. L., Anderson, B., & DeProsse, C. (1989a). Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. *Journal of Consulting & Clinical Psychology*, 57(6), 683-691.
- Andersen, B. L., Anderson, B., & DeProsse, C. (1989b). Controlled prospective longitudinal study of women with cancer: II. Psychological outcomes. *Journal of Consulting & Clinical Psychology*, 57(6), 692-697.
- Andersen, B. L., Beck, G., Ouelette-Kobasa, S., Revenson, T. A., & Temoshok, L. (1989). Directions for a psychology research agenda in cancer. *Health Psychology*, 8(6), 753-760.
- Andersen, B. L., & Cyranowski, J. M. (1994). Women's sexual self-schema. *Journal of Personality & Social Psychology*, 67(6), 1079-1100.
- Andersen, B. L., & Hacker, N. F. (1983a). Psycho-sexualadjustment after vulvar surgery. *Obstetrics & Gynecology*, 62, 457-462.
- Andersen, B. L., & Hacker, N. F. (1983b). Psycho-sexualadjustment following pelvic excenteration. *Obstetrics & Gynecology*, 61, 331-338.
- Andersen, B. L., & Hacker, N. F. (1983c). Treatment for gynaecologic cancer: A review of the effects on female sexuality. *Health Psychology*, 2, 203-221.
- Andersen, B. L., & Hacker, N. F. (1983d). Psycho-sexualadjustment of gynecologic oncology patients: A proposed model for future investigation. *Gynecologic Oncology*, 15(2), 214-223.

- Andersen, B. L., & Jochimsen, P. R. (1985). Sexual functioning among breast cancer, gynecologic cancer, and healthy women. *Journal of Consulting & Clinical Psychology*, 53(1), 25-32.
- Andersen, B. L., Karlsson, J. A., Anderson, B., & Tewfik, H. H. (1984). Anxiety and cancer treatment: Response to stressful radiotherapy. *Health Psychology*, 3(6), 535-551.
- Andersen, B. L., Lachenbruch, P. A., Anderson, B., & deProsse, C. (1986). Sexual dysfunction and signs of gynecologic cancer. *Cancer*, 57(9), 1880-1886.
- Andersen, B. L., Turnquist, D., LaPolla, J., & Turner, D. (1988). Sexual functioning after treatment of *in situ* vulvar cancer: Preliminary report. *Obstetrics & Gynecology*, 71(1), 15-19.
- Andersen, B. L., & van der Does, J. (1994). Surviving gynecologic cancer and coping with sexual morbidity: An international problem. *International Journal of Gynecologic Cancer*, 4, 225-240.
- Andersen, B. L., Woods, X. A., & Copeland, L. J. (1997). Sexual self-schema and sexual morbidity among gynecologic cancer survivors. *Journal of Consulting & Clinical Psychology*, 65(2), 221-229.
- Anderson, B., & Lutgendorf, S. (2000). Quality of life as an outcome measure in gynecologic malignancies. *Current Opinion in Obstetrics & Gynecology*, 12(1), 21-26.
- Andreasson, B., Moth, I., Jensen, S. B., & Bock, J. E. (1986). Sexual function and somatopsychic reactions in vulvectomy-operated women and their partners. *Acta Obstetrica et Gynecologica Scandinavica*, 65, 7-10.
- Antoni, M. H., & Goodkin, K. (1988). Host moderator variables in the promotion of cervical neoplasia: I. Personality facets. *Journal of Psychosomatic Research*, 32(3), 327-338.
- Antoni, M. H., & Goodkin, K. (1989). Host moderator variables in the promotion of cervical neoplasia: II. Dimensions of life stress. *Journal of Psychosomatic Research*, 33(4), 457-467.



- Areskog-Wijma, B. (1987). The gynaecological examination: Women's experiences and preferences and the role of the gynaecologist. *Journal of Psychosomatic Obstetrics & Gynecology*, 6(1), 59-69.
- Auchincloss, S. (1991). Sexual dysfunction after cancer treatment. *Journal of Psychosocial Oncology*, 9(1), 23-42.
- Auchincloss, S. S. (1989). Sexual dysfunction in cancer patients: Issues in evaluation and treatment. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psycho-oncology: Psychological care of the patient with cancer*. New York: Oxford University Press.
- Auchincloss, S. S. (1995). After treatment. Psychosocial issues in gynecologic cancer survivorship. *Cancer*, 76(10 Suppl), 2117-2124.
- Aylard, P. R., Gooding, J. H., McKenna, P. J., & Snaith, R. P. (1987). A validation study of three anxiety and depression self-assessment scales. *Journal of Psychosomatic Research*, 31(2), 261-268.
- Bachmann, G. A. (1990). Psycho-sexual aspects of hysterectomy. *Women's Health Issues*, 1(1), 41-49.
- Baileff, A. (2000). Cervical screening: Patients' negative attitudes and experiences. *Nursing Standard*, 14(44), 35-37.
- Bailie, R., & Petrie, K. (1990). Women's attitudes to cervical smear testing. *New Zealand Medical Journal*, 103(892), 293-295.
- Bancroft, J., Graham, C. A., & McCord, C. (2001). Conceptualizing women's sexual problems. *Journal of Sex & Marital Therapy*, 27(2), 95-103.
- Bard, M., & Sutherland, A. M. (1952). Adaptation to radical mastectomy. *Cancer*, 8, 656-671.
- Bennetts, A., Irwig, L., Oldenburg, B., Simpson, J. M., Mock, P., Boyes, A., Adams, K., Weisberg, E., & Shelley, J. (1995). PEAPS-Q: A questionnaire to measure the psychosocial effects of having an abnormal pap smear. Psychosocial Effects of Abnormal Pap Smears Questionnaire. *Journal of Clinical Epidemiology*, 48(10), 1235-1243.

- Bensing, J. (1991). Doctor-patient communication and the quality of care. *Social Science & Medicine*, 32(11), 1301-1310.
- Bergmark, K., Avall-Lundqvist, E., Dickman, P. W., Henningsohn, L., & Steineck, G. (1999). Vaginal changes and sexuality in women with a history of cervical cancer. *New England Journal of Medicine*, 340(18), 1383-1389.
- Bertelsen, K. (1983). Sexual dysfunction after treatment of cervical cancer. *Danish Medical Bulletin*, 30, 31-34.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research*, 52(2), 69-77.
- Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. *Social Science & Medicine*, 16(14), 1329-1338.
- Bos, G. (1986). Sexuality of gynecological cancer patients: Quantity and quality. *Journal of Psychosomatic Obstetrics & Gynecology*, 5(3), 217-224.
- Bosch, F. X., Munoz, N., de Sanjose, S., Guerrerro, E., Ghaffari, A. M., Kaldor, J., Castellsague, X., Shah, K. V., & Gaffari, A. M. (1994). Importance of human papillomavirus endemicity in the incidence of cervical cancer: An extension of the hypothesis on sexual behavior. *Cancer Epidemiology, Biomarkers & Prevention*, 3(5), 375-379.
- Botelho, R. (2000). Hysterectomy and sexuality. Paper presented at the *Proceedings of the 1st Congress of the Federation of National European Menopause Societies*, Prague, Czech Republic.
- Bourgeois-Law, G., & Lotocki, R. (1999). Sexuality and gynaecological cancer: A needs assessment. *Canadian Journal of Human Sexuality*, 8(4), 231-240.
- Bradley, E. J., Pitts, M. K., Redman, C. W. E., & Calvert, E. (1999). The experience of long-term hospital follow up for women who have suffered early stage gynecological cancer: A qualitative interview study. *International Journal of Gynaecological Cancer*, 9(6), 491-496.
- Bransfield, D. D., Horiot, J.-C., & Nabid, A. (1984). Development of a scale for assessing sexual function after treatment for gynecologic cancer. *Journal of Psychosocial Oncology*, 2(1), 3-19.

- Brinton, L. A., & Fraumeni, J. F. (1986). Epidemiology of uterine cervical cancer. *Journal of Chronic Diseases*, 39(12), 1051-1065.
- Brinton, L. A., Hamman, R. F., Huggins, G. R., Lehman, H. F., Levine, R. S., Mallin, K., & Fraumeni, J. F. (1987). Sexual and reproductive risk factors for invasive squamous cell cervical cancer. *Journal of the National Cancer Institute*, 79(1), 23-30.
- Bruner, D. W., & Boyd, C. P. (1999). Assessing women's sexuality after cancer therapy: Checking assumptions with the focus group technique. *Cancer Nursing*, 22(6), 438-447.
- Bruner, D. W., Lanciano, R., Keegan, M., Corn, B., Martin, E., & Hanks, G. E. (1993). Vaginal stenosis and sexual function following intracavitary radiation for the treatment of cervical and endometrial carcinoma. *International Journal of Radiation Oncology, Biology, Physics*, 27(4), 825-830.
- Buddeberg, C., Wolf, C., Sieber, M., Riehl-Emde, A., Bergant, A., Steiner, R., Landolt-Ritter, C., & Richter, D. (1991). Coping strategies and course of disease of breast cancer patients. Results of a 3-year longitudinal study. *Psychotherapy & Psychosomatics*, 55(2-4), 151-157.
- Bullard, D. G., Causey, G. G., Newman, A. B., Orloff, R., Schanche, K., & Wallace, D. H. (1979). Sexual health care and cancer: A needs assessment. *Frontiers of Radiation Therapy & Oncology*, 14, 55-58.
- Butler, L., Banfield, V., Sveinson, T., & Allen, K. (1998). Conceptualizing sexual health in cancer care. *Western Journal of Nursing Research*, 20(6), 683-699.
- Butler-Manuel, S. A., Summerville, K., Ford, A., Riley, A., Chan, F., Monga, A., Sultan, A. H., Carter, P. G., Sherperd, J. H., & Barton, D. P. J. (1998). Subjective self-assessment of morbidity 8-25 months following radical hysterectomy for cervical cancer. *Journal of the Society for Gynecologic Investigation*, 5(1 Suppl), 79A.
- Butow, P. N., Dunn, S. M., Tattersall, M. H., & Jones, Q. J. (1995). Computer-based interaction analysis of the cancer consultation. *British Journal of Cancer*, 71(5), 1115-1121.
- Butow, P. N., Kazemi, J. N., Beeney, L. J., Griffin, A. M., Dunn, S. M., & Tattersall, M. H. (1996). When the diagnosis is cancer: Patient communication experiences and preferences. *Cancer*, 77(12), 2630-2637.

- Buunk, B. (1982). Strategies of jealousy: Styles of coping with extramarital involvement of the spouse. *Family Relations*, 31, 13-18.
- Buunk, B. (1987). Conditions that promote breakups as a consequence of extradyadic involvements. *Journal of Social & Clinical Psychology*, 5(3), 271-284.
- Buunk, B., & Bosman, J. (1986). Attitude similarity and attraction in marital relationships. *Journal of Social Psychology*, 126(1), 133-134.
- Buunk, B. P. (1990). Relational interaction satisfaction scale. In B. F. Touliatos & B. F. Perlmutter & M. A. Straus (Eds.), *Handbook of family measurement techniques* (pp. 106-107). London: Sage Publications.
- Buunk, B. P., Collins, R. L., Taylor, S. E., VanYperen, N. W., & Dakof, G. A. (1990). The affective consequences of social comparison: Either direction has its ups and downs. *Journal of Personality & Social Psychology*, 59(6), 1238-1249.
- Cain, E. N., Kohorn, E. I., Quinlan, D. M., Latimer, K., & Schwartz, P. E. (1986). Psychosocial benefits of a cancer support group. *Cancer*, 57(1), 183-189.
- Cain, E. N., Kohorn, E. I., Quinlan, D. M., Schwartz, P. E., Latimer, K., & Rogers, L. (1983). Psychosocial reactions to the diagnosis of gynecological cancer. *Obstetrics & Gynecology*, 62, 635-641.
- Cairney, J., & Wade, T. J. (2002). The influence of age on gender differences in depression: Further population-based evidence on the relationship between menopause and the sex difference in depression. *Social Psychiatry & Psychiatric Epidemiology*, 37(9), 401-408.
- Cairns, K. V., & Valentich, M. (1986). Vaginal reconstruction in gynecologic cancer: A feminist perspective. *Journal of Sex Research*, 22(3), 333-346.
- Campion, M. J., Brown, J. R., McCance, D. J., Atia, W., Edwards, R., Cuzick, J., & Singer, A. (1988). Psycho-sexualtrauma of an abnormal cervical smear. *British Journal of Obstetrics & Gynaecology*, 95(2), 175-181.
- Campion, M. J., & Reid, R. (1990). Screening for gynecologic cancer. *Obstetrics & Gynecology Clinics of North America*, 17(4), 695-727.

- Campion, M. J., Singer, A., Clarkson, P. K., & McCance, D. J. (1985). Increased risk of cervical neoplasia in consorts of men with penile condylomata acuminata. *Lancet*, 1(8435), 943-946.
- Capone, M. A., Good, R. S., Westie, K. S., & Jacobson, A. F. (1980). Psychosocial rehabilitation of gynecologic oncology patients. *Archives of Physical Medicine & Rehabilitation*, 61(3), 128-132.
- Carenza, L., Stentella, P., Albanese, M. G., & Etiope, S. (1982). Psychological and psychosomatic aspects of sexual life of women following radical hysterectomy for carcinoma of the cervix. In H. J. Prill & M. Stauber (Eds.), *Advances in psychosomatic obstetrics and gynecology*. Berlin: Springer.
- Carlson, K. J., Miller, B. A., & Fowler, F. J. (1994). The main women's health study: I. Outcomes of hysterectomy. *Obstetrics & Gynecology*, 83(4), 556-565.
- Carlsson, M., Strang, P., & Bjurström, C. (2000). Treatment modality affects long-term quality of life in gynaecological cancer. *Anticancer Research*, 20(1B), 563-568.
- Carlsson, M. E., & Strang, P. M. (1998). Educational support programme for gynaecological cancer patients and their families. *Acta Oncologica*, 37(3), 269-275.
- Cassileth, B. R., Volckmar, D., & Goodman, R. L. (1980). The effect of experience on radiation therapy patients' desire for information. *International Journal of Radiation Oncology, Biology, Physics*, 6(4), 493-496.
- Catania, J. A., Gibson, D. R., Chitwood, D. D., & Coates, T. J. (1990). Methodological problems in AIDS behavioral research: Influences on measurement error and participation bias in studies of sexual behavior. *Psychological Bulletin*, 108(3), 339-362.
- Cella, D., Hahn, E. A., & Dineen, K. (2002). Meaningful change in cancer-specific quality of life scores: Differences between improvement and worsening. *Quality of Life Research*, 11(3), 207-221.
- Cella, D., Ingham, J., & Portenoy, R. K. (1998). Research methods in psycho-oncology. In J. C. Holland (Ed.), *Psycho-oncology* (pp. 1135-1162). New York: Oxford University Press.
- Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., & Brannon, J. (1993). The Functional Assessment

of Cancer Therapy (FACT) scale: Development and validation of the general measure. *Journal of Clinical Oncology*, 11(3), 570-579.

- Chenitz, W. C., & Swanson, J. M. (1986). Qualitative research using grounded theory. In W. C. Chenitz & J. M. Swanson (Eds.), *From practice to grounded theory* (pp. 3-15). Menlo Park, CA: Addison-Wesley.
- Cochran, S. D., Hacker, N. F., Wellisch, D. K., & Berek, J. S. (1987). Sexual functioning after treatment for endometrial cancer. *Journal of Psychosocial Oncology*, 5(2), 47-61.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112(1), 155-159.
- Coker, A. L., Bond, S. M., Williams, A., Gerasimova, T., & Pirisi, L. (2002). Active and passive smoking, high-risk human papillomaviruses and cervical neoplasia. *Cancer Detection & Prevention*, 26(2), 121-128.
- Conaglen, H. M., Hughes, R., Conaglen, J. V., & Morgan, J. (2001). A prospective study of the psychological impact on patients of first diagnosis of human papillomavirus. *International Journal of STD & AIDS*, 12(10), 651-658.
- Conte, H. R. (1986). Multivariate assessment of sexual dysfunction. *Journal of Consulting & Clinical Psychology*, 54(2), 149-157.
- Corney, R. H., Crowther, M. E., Everett, H., Howells, A., & Shepherd, J. H. (1993). Psycho-sexual dysfunction in women with gynaecological cancer following radical pelvic surgery. *British Journal of Obstetrics & Gynaecology*, 100(1), 73-78.
- Corney, R. H., Everett, H., Howells, A., & Crowther, M. E. (1992). Psychosocial adjustment following major gynaecological surgery for carcinoma of the cervix and vulva. *Journal of Psychosomatic Research*, 36(6), 561-568.
- Crowther, M. E., Corney, R. H., & Shepherd, J. H. (1994). Psycho-sexual implications of gynaecological cancer. *British Medical Journal*, 308(6933), 869-870.
- Cull, A., Cowie, V. J., Farquharson, D. I., Livingstone, J. R., Smart, G. E., & Elton, R. A. (1993). Early stage cervical cancer: Psychosocial and sexual outcomes of treatment. *British Journal of Cancer*, 68(6), 1216-1220.

- Davidson, J. M., & Myers, L. S. (1988). Endocrine factors in sexual psychophysiology. In R. C. Rosen & G. Beck (Eds.), *Patterns of sexual arousal: Psychophysiological processes and clinical applications* (pp. 158-186). New York: Guilford Press.
- Decker, W., & Schwartzman, E. (1962). Sexual functioning following treatment for carcinoma of the cervix. *American Journal of Obstetrics & Gynecology*, 83, 401-405.
- Decruze, S. B., Guthrie, D., & Magnani, R. (1999). Prevention of vaginal stenosis in patients following vaginal brachytherapy. *Clinical Oncology*, 11(1), 46-48.
- Dennerstein, L., & Burrows, G. (1982). Hormone replacement therapy and sexuality in women. *Clinical Endocrinology and Metabolism*, 11, 661-679.
- Dennerstein, L., Wood, C., & Burrows, G. (1982). *Hysterectomy: How to deal with the physical and emotional aspects*. Melbourne: Oxford University Press.
- Derchain, S. F., Roteli-Martins, C. M., Syrjanen, K. J., de Abreu, H. J., Martinez, E. Z., & Alves, V. A. (1999). Association of oncogenic human papillomavirus DNA with high grade cervical intraepithelial neoplasia: The role of cigarette smoking. *Sexually Transmitted Infections*, 75(6), 406-408.
- Derogatis, L. R. (1975). *Derogatis sexual functioning inventory*. Maryland: Clinical Psychometric Research, Inc.
- Derogatis, L. R. (1986). The unique impact of breast and gynecologic cancers on body image and sexual identity in women: A reassessment. In V. J.M. (Ed.), *Body image, self-esteem and sexuality in cancer patients* (2nd ed., pp. 1-14). Basel: Karger.
- Derogatis, L. R. (1996). *DSFI: Derogatis Sexual Functioning Inventory: Preliminary Scoring Manual* (2nd ed.). Maryland: Clinical Psychometric Research Inc.
- Derogatis, L. R., Lopez, M. C., & Zinzeletta, E. M. (1988). Clinical applications of the DSFI in the assessment of sexual dysfunctions. In R. A. Brown & J. R. Field (Eds.), *Treatment of sexual problems in individual and couple therapy* (pp. 167-186). New York: PMA Publishing Corporation.
- Derogatis, L. R., & Melisaratos, N. (1979). The DSFI: A multidimensional measure of sexual functioning. *Journal of Sex & Marital Therapy*, 5(3), 244-281.

- Derogatis, L. R., Morrow, G. R., Fetting, J., Penman, D., Piasetsky, S., Schmale, A. M., Henrichs, M., & Carnicke, C. L., Jr. (1983). The prevalence of psychiatric disorders among cancer patients. *Journal of American Medical Association*, 249(6), 751-757.
- Eddy, D. M. (1990). Screening for cervical cancer. *Annals of Internal Medicine*, 113(3), 214-226.
- Eden, J. A. (1995). *Women's hormone problems*. Sydney: Royal Hospital for Women.
- Edgar, L., Rosberger, Z., & Nowlis, D. (1992). Coping with cancer during the first year after diagnosis. Assessment and intervention. *Cancer*, 69(3), 817-828.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(3), 215-229.
- Fallowfield, L., Jenkins, V., Farewell, V., Saul, J., Duffy, A., & Eves, R. (2002). Efficacy of a cancer research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet*, 359(9307), 650-656.
- Fallowfield, L. J., Hall, A., Maguire, G. P., & Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *British Medical Journal*, 301(6752), 575-580.
- Filiberti, A., Tamburini, M., Stefanon, B., Merola, M., Bandieramonte, G., Ventafridda, V., & De Palo, G. (1993). Psychological aspects of genital human papillomavirus infection: A preliminary report. *Journal of Psychosomatic Obstetrics & Gynecology*, 14(2), 145-152.
- Flay, L. D., & Matthews, J. H. (1995). The effects of radiotherapy and surgery on the sexual function of women treated for cervical cancer. *International Journal of Radiation Oncology, Biology, Physics*, 31(2), 399-404.
- Frank, E., Anderson, C., & Rubinstein, D. (1978). Frequency of sexual dysfunction in "normal" couples. *New England Journal of Medicine*, 299(3), 111-115.
- Fruehwald, S., Loeffler-Stastka, H., Eher, R., Saletu, B., & Baumhackl, U. (2001). Depression and quality of life in multiple sclerosis. *Acta Neurologica Scandinavica*, 104(5), 257-261.



- Gagnon, F. (1950). Contribution to the study of the etiology and prevention of cancer of the cervix of the uterus. *American Journal of Obstetrics and Gynaecology*, 60, 516-522.
- Gamel, C., Hengeveld, M., & Davis, B. (2000). Informational needs about the effects of gynaecological cancer on sexuality: A review of the literature. *Journal of Clinical Nursing*, 9(5), 678-688.
- Gath, D., Cooper, P., Bond, A., & Edmonds, G. (1982b). Hysterectomy and psychiatric disorder: II. Demographic psychiatric and physical factors in relation to psychiatric outcome. *British Journal of Psychiatry*, 140, 343-350.
- Gath, D., Cooper, P., & Day, A. (1982a). Hysterectomy and psychiatric disorder: I. Levels of psychiatric morbidity before and after hysterectomy. *British Journal of Psychiatry*, 140, 335-342.
- Gilbar, O., Steiner, M., & Atad, J. (1995). Adjustment of married couples and unmarried women to gynaecological cancer. *Psycho-Oncology*, 4, 203-211.
- Glasdam, S., Jensen, A. B., Madsen, E. L., & Rose, C. (1996). Anxiety and depression in cancer patients' spouse. *Psycho-Oncology*, 4, 203-211.
- Glasser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Goodkin, K., Antoni, M. H., & Blaney, P. H. (1986). Stress and hopelessness in the promotion of cervical intraepithelial neoplasia to invasive squamous cell carcinoma of the cervix. *Journal of Psychosomatic Research*, 30(1), 67-76.
- Goodwin, J. S., Hunt, W. C., Key, C. R., & Samet, J. M. (1987). The effect of marital status on stage, treatment, and survival of cancer patients. *Journal of American Medical Association*, 258, 3125-3129.
- Gotheridge, S. M., & Dresner, N. (2002). Psychological adjustment to gynecologic cancer. *Primary Care Update: Obstetrics & Gynaecology*, 9(2), 80-84.
- Gottesman, D., & Lewis, M. (1982). Differences in crisis reactions among cancer and surgery patients. *Journal of Consulting & Clinical Psychology*, 50, 381-388.
- Grassi, L., Rosti, G., Lasavia, A., & Marangola, M. (1993). Psychosocial variables associated with mental adjustment to cancer. *Psycho-Oncology*, 2(1), 11-20.

- Greenfield, S., Kaplan, S., & Ware, J. E., Jr. (1985). Expanding patient involvement in care. Effects on patient outcomes. *Annals of Internal Medicine*, 102(4), 520-528.
- Greer, S. (2000). Fighting spirit in patients with cancer [comment]. *Lancet*, 355(9206), 847-848.
- Greer, S., Moorey, S., Baruch, J. D., Watson, M., Robertson, B. M., Mason, A., Rowden, L., Law, M. G., & Bliss, J. M. (1992). Adjuvant psychological therapy for patients with cancer: A prospective randomised trial. *British Medical Journal*, 304(6828), 675-680.
- Greer, S., Moorey, S., & Watson, M. (1989). Patients' adjustment to cancer: The Mental Adjustment to Cancer (MAC) scale vs clinical ratings. *Journal of Psychosomatic Research*, 33(3), 373-377.
- Greer, S., Morris, T., & Pettingale, K. W. (1979). Psychological response to breast cancer: Effect on outcome. *Lancet*, 2(8146), 785-787.
- Greer, S., & Watson, M. (1987). Mental adjustment to cancer: Its measurement and prognostic importance. *Cancer Surveys*, 6(3), 439-453.
- Gress, L. (1978). Human sexuality and aging. In M. Underwood-Barnard & B. J. Clancy & K. E. Krantz (Eds.), *Human sexuality for health professionals* (pp. 222-234). Toronto: W.B. Saunders Company.
- Grumann, M. (1998). *Sexual function after radical hysterectomy for early stage cancer of the cervix: Do psychosocial factors influence the outcome?* (Dissertation). Phillips-University, Marburg/Lahn, Germany.
- Grumann, M., Robertson, R., Hacker, N. F., & Sommer, G. (2001). Sexual functioning in patients following radical hysterectomy for stage IB cancer of the cervix. *International Journal of Gynecological Cancer*, 11(5), 372-380.
- Guba, E. G., & Lincoln, Y. S. (1992). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches* (2nd ed.). San Francisco: Jossey-Bass Publishers.

- Gutl, P., Greimel, E. R., Roth, R., & Winter, R. (2002). Women's sexual behavior, body image and satisfaction with surgical outcomes after hysterectomy: A comparison of vaginal and abdominal surgery. *Journal of Psychosomatic Obstetrics & Gynaecology*, 23(1), 51-59.
- Gynaecological Oncology Study Group. (1995). *Gynaecological oncology: Clinical practice guidelines*. Sydney.
- Hacker, N. F. (1986). Principles of cancer therapy. In N. F. Hacker & J. G. Moore (Eds.), *Essentials of Obstetrics and Gynecology* (pp. 457-465). Sydney: W.B. Saunders Company.
- Hacker, N. F., & Moore, J. G. (1998). *Essentials of obstetrics and gynecology* (3rd ed.). Toronto: WB. Saunders Company.
- Haes, J. C. J. M., & van Knippenberg, F. C. E. (1985). The quality of life of cancer patients: A review of the literature. *Social Science & Medicine*, 20, 809-817.
- Hamberger, A. D., Unal, A., Gershenson, D. M., & Fletcher, G. H. (1983). Analysis of the severe complications of irradiation of carcinoma of the cervix: Whole pelvis irradiation and intracavitary radium. *International Journal of Radiation Oncology, Biology, Physics*, 9(3), 367-371.
- Hann, D. M., Oxman, T. E., Ahles, T. A., Furstenberg, C. T., & Stukes, T. A. (1995). Social support adequacy and depression in older patients with metastatic cancer. *Psycho-Oncology*, 4, 213-221.
- Harris, R., Good, R. S., & Pollack, L. (1982). Sexual behavior of gynecologic cancer patients. *Archives of Sexual Behavior*, 11(6), 503-510.
- Hatch, K. D. (1994). Cervical cancer. In J. S. Berek & N. F. Hacker (Eds.), *Practical Gynecologic Oncology* (2nd ed., pp. 243-283). Baltimore: Williams & Wilkins.
- Helstrom, L. (1994). Sexuality after hysterectomy: a model based on quantitative and qualitative analysis of 104 women before and after subtotal hysterectomy. *Journal of Psychosomatic Obstetrics & Gynecology*, 15(4), 219-229.
- Helstrom, L., Lundberg, P. O., Sorbom, D., & Backstrom, T. (1993). Sexuality after hysterectomy: A factor analysis of women's sexual lives before and after subtotal hysterectomy. *Obstetrics & Gynecology*, 81(3), 357-362.

- Henwood, K. L., & Pidgeon, N. F. (1993). *Qualitative research and psychological theorizing*. Hammersley, Martyn.
- Herrmann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale (HADS): A review of validation data and clinical results. *Journal of Psychosomatic Research*, 42(1), 17-41.
- Hilliard, C. L. (1994). Psychological trauma responses in cervical, endometrial, and ovarian oncology patients: Post-traumatic stress disorder as a moderating condition. *Dissertation Abstracts International: Section B: the Sciences & Engineering*, 54(8-B), 4391.
- Ho, G. Y., Bierman, R., Beardsley, L., Chang, C. J., & Burk, R. D. (1998). Natural history of cervicovaginal papillomavirus infection in young women. *New England Journal of Medicine*, 338(7), 423-428.
- Holland, J., & Watson, M. (1995). Psycho-oncology. *Psycho-Oncology*, 4(4), frontpage.
- Homesley, H. D. (1995). Management of vulvar cancer. *Cancer*, 76, 2159-2170.
- Horden, A. (1999). Sexuality in palliative care: Addressing a taboo subject. In S. Aranda & M. O'Connor (Eds.), *Palliative care nursing: A guide to practice*. Australia: Ausmed Publications.
- Horowitz, M. (1979). Psychological responses to serious life events. In V. Hamilton & D. M. Warburton (Eds.), *Human stress and cognition*. Chichester: Wiley.
- Horton, B. (1991). Sexual outcomes arising from the diagnosis and treatment of cervical cancer and cervical intraepithelial neoplasia: A review of the literature. *Sexual & Marital Therapy*, 6(1), 29-39.
- Howell, D. C. (1997). *Statistical methods for psychology* (4th ed.). Boston: Duxbury Press.
- Ibbotson, T., Maguire, P., Selby, P., Priestman, T., & Wallace, L. (1994). Screening for anxiety and depression in cancer patients: The effects of disease and treatment. *European Journal of Cancer*, 1, 37-40.
- Inoue, T., Chihara, T., & Morita, K. (1986). Post-operative extended-field irradiation in patients with pelvic and/or common iliac metastases from cervical carcinoma stages 1b to 1Ib. *Gynecologic Oncology*, 25, 234-243.

- Iwamoto, R. (1997). Radiation therapy. In S. E. Otto (Ed.), *Oncology Nursing* (3rd ed.). USA: Mosby-Year Book, Inc.
- Jamison, R. N., Burish, T. G., & Wallston, K. A. (1987). Psychogenic factors in predicting survival of breast cancer patients. *Journal of Clinical Oncology*, 5(5), 768-772.
- Jayne, C. (1981). A two-dimensional model of female sexual response. *Journal of Sex & Marital Therapy*, 7(1), 3-30.
- Jenkins, B. (1988). Patients' reports of sexual changes after treatment for gynecological cancer. *Oncology Nursing Forum*, 15(3), 349-354.
- Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: Results from a large study in UK cancer centres. *British Journal of Cancer*, 84(1), 48-51.
- Johnston, M., & Vogele, C. (1993). Benefits of psychological preparation for surgery: A meta-analysis. *Annals of Behavioral Medicine*, 15, 245-256.
- Jones, R. (1995). Why do qualitative research? *British Medical Journal*, 311(6996), 2.
- Jones, W. B., Shingleton, H. M., Russell, A., Chmiel, J. S., Fremgen, A. M., Clive, R. E., Zuber-Ocwieja, K. E., & Winchester, D. P. (1995). Patterns of care for invasive cervical cancer. Results of a national survey of 1984 and 1990. *Cancer*, 76(10 Suppl), 1934-1947.
- Juraskova, I., Butow, P., Robertson, R., Sharpe, L., McLeod, C., & Hacker, N. (2003). Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psycho-Oncology*, 12(3), 267-279.
- Kagan, A. R., Nussbaum, H., Gilbert, H., Chan, P. Y., Rao, A., Saltz, A., Tawa, K., & Wollins, M. (1979). A new staging system for irradiation injuries following treatment for cancer of the cervix uteri. *Gynecologic Oncology*, 7(2), 166-175.
- Kaplan, H. S. (1970). *The new sex therapy: Active treatment of sexual dysfunctions*. New York/Montreal: Brunner/Mazel Book Center.
- Kaplan, H. S. (1975). *The illustrated manual of sex therapy*. New York: Souvenir Press.

- Kaplan, S. H., Greenfield, S., & Ware Jr, J. E. (1989). Impact of the doctor-patient relationship on the outcomes of chronic disease. In M. Steward & D. Roter (Eds.), *Communicating with medical patients* (pp. 228-245). Newbury Park: Sage Publications.
- Karlsson, J. A., & Andersen, B. L. (1985). Radiation therapy and psychological distress in gynecologic oncology patients: Outcomes and recommendations for enhancing adjustment. *Journal of Psychosomatic Obstetrics & Gynaecology*, 5(4), 283-294.
- Katz, M. M., & Lyerly, S. B. (1963). Methods for measuring adjustment and social behavior in the community: I. Rationale, description, discriminative validity and scale development. *Psychological Reports*, 13(2), 503-535.
- Kavanagh, A. M., & Broom, D. H. (1997). Women's understanding of abnormal cervical smear test results: A qualitative interview study. *British Medical Journal*, 314(7091), 1388-1391.
- Kavanagh, A. M., & Broom, D. H. (1998). Embodied risk: My body, myself? *Social Science & Medicine*, 46(3), 437-444.
- Khanna, N., & Phillips, M. D. (2001). Adherence to care plan in women with abnormal Papanicolaou smears: A review of barriers and interventions. *Journal of the American Board of Family Practice*, 14(2), 123-130.
- Khastgir, G., & Studd, J. (1998). Hysterectomy, ovarian failure, and depression. *Menopause*, 5(2), 113-122.
- Khastgir, G., Studd, J., & Catalan, J. (1999). Is there a hormonal basis to hysterectomy-related depression? *British Journal of Obstetrics & Gynaecology*, 106(7), 620-622.
- Kinney, W. K., Alvarez, R. D., Reid, G. C., Schray, M. F., Soong, S. J., Morley, G. W., Podratz, K. C., & Shingleton, H. M. (1989). Value of adjuvant whole-pelvis irradiation after Wertheim hysterectomy for early-stage squamous carcinoma of the cervix with pelvic nodal metastasis: A matched-control study. *Gynecologic Oncology*, 34, 258-262.
- Kjerulff, K. H., Langenberg, P. W., Rhodes, J. C., Harvey, L. A., Guzinski, G. M., & Stolley, P. D. (2000). Effectiveness of hysterectomy. *Obstetrics & Gynecology*, 95(3), 319-326.

- Klee, M., Thranov, I., & Machin, D. (2000a). Life after radiotherapy: The psychological and social effects experienced by women treated for advanced stages of cervical cancer. *Gynecologic Oncology*, 76(1), 5-13.
- Klee, M., Thranov, I., & Machin, D. (2000b). The patients' perspective on physical symptoms after radiotherapy for cervical cancer. *Gynecologic Oncology*, 76(1), 14-23.
- Kraft, M. E. (1999). The relationship between the repressive coping style and breast cancer incidence. *Dissertation Abstracts International: Section B: the Sciences & Engineering*, 59(9-B), 5154.
- Krumm, S., & Lamberti, J. (1993). Changes in sexual behavior following radiation therapy for cervical cancer. *Journal of Psychosomatic Obstetrics & Gynaecology*, 14(1), 51-63.
- Kylstra, W. A., Leenhouts, G. H., Everaerd, W., Panneman, M. J., Hahn, D. E., Weijmar Schultz, W. C., Van de Wiel, H. B., & Heintz, A. P. (1999). Sexual outcomes following treatment for early stage gynecological cancer: A Prospective multicenter study. *International Journal of Gynecologic Cancer*, 9, 387-395.
- Lalinec-Michaud, M., & Engelsmann, F. (1985). Anxiety, fears and depression related to hysterectomy. *Canadian Journal of Psychiatry*, 30(1), 44-47.
- Lalos, A., Jacobsson, L., Lalos, O., & Stendahl, U. (1995). Experiences of the male partner in cervical and endometrial cancer: A prospective interview study. *Journal of Psychosomatic Obstetrics & Gynecology*, 16(3), 153-165.
- Lamb, M. A. (1990). Psycho-sexual issues: The woman with gynecologic cancer. *Seminars in Oncology Nursing*, 6(3), 237-243.
- Lamb, M. A. (1996). Sexuality and sexual functioning. In R. McCorkle & M. Grant & M. Frank-Stromborg & S. B. Baird (Eds.), *Cancer Nursing: A comprehensive textbook* (2nd ed.). Philadelphia: W.B. Saunders.
- Lamb, M. A., & Sheldon, T. A. (1994). The sexual adaptation of women treated for endometrial cancer. *Cancer Practice*, 2(2), 103-113.
- Lamberti, J. (1979). Sexual adjustment after radiation therapy for cervical carcinoma. *Medical Aspects of Human Sexuality*, March, 87-88.

- Lambley, P. (1993). The role of psychological processes in the aetiology and treatment of cervical cancer: A biopsychological perspective. *British Journal of Medical Psychology*, 66(Pt 1), 43-60.
- Lampic, C., Wennberg, A., Schill, J. E., Glimelius, B., Brodin, O., & Sjoden, P. O. (1994). Coping, psychosocial well-being and anxiety in cancer patients at follow up visits. *Acta Oncologica*, 33(8), 887-894.
- Lasnik, E., & Tatra, G. (1986). [Sex behavior following primary radiotherapy of cervix cancer]. *Geburtshilfe und Frauenheilkunde*, 46(11), 813-816.
- Lauver, D. R., Kruse, K., & Baggot, A. (1999). Women's uncertainties, coping, and moods regarding abnormal papanicolaou results. *Journal of Womens Health & Gender Based Medicine*, 8(8), 1103-1112.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Pub. Co.
- Leenhouts, G. H., Kylstra, W. A., Everaerd, W., Hahn, D. E., Schultz, W. C., van de Wiel, H. B., & Heintz, A. P. (2002). Sexual outcomes following treatment for early-stage gynecological cancer: A prospective and cross-sectional multi-center study. *Journal of Psychosomatic Obstetrics & Gynecology*, 23(2), 123-132.
- Lerman, C., Miller, S. M., Scarborough, R., Hanjani, P., Nolte, S., & Smith, D. (1991). Adverse psychologic consequences of positive cytologic cervical screening. *American Journal of Obstetrics & Gynecology*, 165(3), 658-662.
- Lesko, L. M., Massie, M. J., & Holland, J. (1993). Oncology. In A. Stoudemore & B. Fogel (Eds.), *Psychiatric care of the medical patient* (pp. 566). New York: Oxford University Press.
- Levy, S. M., Herberman, R. B., Maluish, A. M., Schlien, B., & Lippman, M. (1985). Prognostic risk assessment in primary breast cancer by behavioral and immunological parameters. *Health Psychology*, 4(2), 99-113.
- Levy, S. M., Lee, J., Bagley, C., & Lippman, M. (1988). Survival hazards analysis in first recurrent breast cancer patients: Seven-year follow up. *Psychosomatic Medicine*, 50(5), 520-528.
- Li, C., Samsioe, G., & Iosif, C. (1999). Quality of life in endometrial cancer survivors. *Maturitas*, 31, 227-236.



- Lichtman, R. R., & Taylor, S. E. (1986). Close relationships and the female cancer patient. In B. L. Andersen (Ed.), *Women with cancer: Psychological perspectives* (pp. 233-256). New York: Springer.
- Lilley, L. L. (1987). Human need fulfillment alteration in the client with uterine cancer. The registered nurses' perception versus the clients' perception. *Cancer Nursing*, 10(6), 327-337.
- Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine*, 47(10), 1485-1494.
- Love, A. W., Kissane, D. W., Bloch, S., & Clarke, D. M. (2002). Diagnostic efficiency of the Hospital Anxiety and Depression Scale in women with early stage breast cancer. *Australian & New Zealand Journal of Psychiatry*, 36(2), 246-250.
- Lutgendorf, S. K., Anderson, B., Rothrock, N., Buller, R. E., Sood, A. K., & Sorosky, J. I. (2000). Quality of life and mood in women receiving extensive chemotherapy for gynecologic cancer. *Cancer*, 89(6), 1402-1411.
- Lutgendorf, S. K., Anderson, B., Ullrich, P., Johnsen, E. L., Buller, R. E., Sood, A. K., Sorosky, J. I., & Ritchie, J. (2002). Quality of life and mood in women with gynecologic cancer: A one year prospective study. *Cancer*, 94(1), 131-140.
- Mackay, E. V., Beischer, N. A., Pepperell, R. J., & Wood, C. (1990). Menopause and climateric. In E. V. Mackay & R. J. Beischer & R. J. Pepperell & C. Wood (Eds.), *Illustrated textbook of gynaecology* (pp. 97-109). Sydney Philadelphia London Toronto: W.B. Saunders.
- MacLeod, C. A., Fowler, A., Duval, P., & et al. (1999). Adjuvant high-dose rate brachytherapy with or without external beam radiotherapy post-hysterectomy for endometrial cancer. *International Journal of Gynaecological Cancer*, 9, 247-255.
- Maguire, P., & Faulkner, A. (1988). Communicate with cancer patients: 1. Handling bad news and difficult questions. *British Medical Journal*, 297(6653), 907-909.
- Marcus, A. C., Crane, L. A., Kaplan, C. P., Reading, A. E., Savage, E., Gunning, J., Bernstein, G., & Berek, J. S. (1992). Improving adherence to screening follow up among women with abnormal Pap smears: Results from a large clinic-based trial of three intervention strategies. *Medical Care*, 30(3), 216-230.

- Masters, W. H., & Johnson, J. E. (1966). *Human sexual response*. Massachusetts: Little, Brown & Company.
- Masters, W. H., & Johnson, V. E. (1980). *Human sexual response* (3rd ed.). Toronto: Bantam.
- Matthews, A. K., Aikens, J. E., Helmrich, S. P., Anderson, D. D., Herbst, A. L., & Waggoner, S. E. (1999). Sexual functioning and mood among long-term survivors of clear-cell adenocarcinoma of the vagina or cervix. *Journal of Psychosocial Oncology*, 17(3-4), 27-45.
- McCance, K. L., & Huether, S. E. (1998). *Pathophysiology: The biologic basis for disease in adults and children* (3rd ed.). St. Louis: Mosby.
- McCormick, J. S. (1989). Cervical smears: A questionable practice? *Lancet*, 2(8656), 207-209.
- McDonald, T. W., Neutens, J. J., Fischer, L. M., & Jessee, D. (1989). Impact of cervical intraepithelial neoplasia diagnosis and treatment on self-esteem and body image. *Gynecologic Oncology*, 34(3), 345-349.
- McNair, D. M., Lorr, M., & L.F., D. (1971). *Profile of Mood States*. San Diego, CA: Educational and Industrial Testing Service.
- Molleman, E., Krabbendam, P. J., Annyas, A. A., Koops, H. S., Sleijfer, D. T., & Vermey, A. (1984). The significance of the doctor-patient relationship in coping with cancer. *Social Science & Medicine*, 18(6), 475-480.
- Moore, J. G. (1986). Benign diseases of the uterus. In N. F. Hacker & J. G. Moore (Eds.), *Essentials of Obstetrics and Gynecology*. Sydney: WB Saunders Company.
- Moorey, S., & Greer, S. (1989). *Psychological therapy for patients with cancer: A new approach*. Oxford: Heinman Medical Books.
- Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B., & Bliss, J. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *British Journal of Psychiatry*, 158, 255-259.

- Morris, T., Pettingale, K., & Haybittle, J. (1992). Psychological response to cancer diagnosis and disease outcome in patients with breast cancer and lymphoma. *Psycho-Oncology*, 1(2), 105-114.
- Moth, I., Andreasson, B., Jensen, S. B., & Bock, J. E. (1983). Sexual function and somatopsychic reactions after vulvectomy. *Danish Medical Bulletin*, 30(2 Suppl), 27-30.
- Munro, A. J., Biruls, R., Griffin, A. V., Thomas, H., & Vallis, K. A. (1989). Distress associated with radiotherapy for malignant disease: A quantitative analysis based on patients perceptions. *British Journal of Cancer*, 60(3), 370-374.
- Nail, L. (1993). Coping with intracavitary radiation treatment for gynecologic cancer. *Cancer Practice*, 1, 218-224.
- Nathorst-Boos, J., & von Schoultz, B. (1992). Psychological reactions and sexual life after hysterectomy with and without oophorectomy. *Gynecologic & Obstetric Investigation*, 34(2), 97-101.
- Nathorst-Boos, J., von Schoultz, B., & Carlstrom, K. (1993). Elective ovarian removal and estrogen replacement therapy: Effects on sexual life, psychological well-being and androgen status. *Journal of Psychosomatic Obstetrics & Gynecology*, 14(4), 283-293.
- National Cervical Screening Program. (1997). *Pap smear test results: A guide for women with an abnormal Pap smear test* (2nd ed.). Canberra: Department of Health and Family Services.
- National Health and Medical Research Council. (2002). *National statement on ethical conduct in research involving humans*. Australia.
- Neilson, A., & Jones, R. K. (1998). Women's lay knowledge of cervical cancer/cervical screening: Accounting for non-attendance at cervical screening clinics. *Journal of Advanced Nursing*, 28(3), 571-575.
- Nelson, J. H., Jr., Averette, H. E., & Richart, R. M. (1989). Cervical intraepithelial neoplasia (dysplasia and carcinoma *in situ*) and early invasive cervical carcinoma. *Cancer Journal for Clinicians*, 39(3), 157-178.
- NSW Cancer Council. (2002). *Talking about sexuality, body image and cancer: A teaching resource for health professionals*. Sydney: NSW Cancer Council.

- NSW Cervical Screening Program. (2001). *Cervical cancer screening in NSW: Annual statistical report 2000*. Sydney: NSW Cervical Screening Program & Pap Test Register.
- Nugent, L. S., Tamlyn-Leaman, K., Isa, N., Reardon, E., & Crumley, J. (1993). *Anxiety and the colposcopy experience*. *Clinical Nursing Research*, 2(3), 267-277.
- Nunns, D., Williamson, K., Swaney, L., & Davy, M. (2000). The morbidity of surgery and adjuvant radiotherapy in the management of endometrial carcinoma. *International Journal of Gynecological Cancer*, 10(3), 233-238.
- Ong, L. M. L., Visser, M. R. M., Lammes, F. B., & de Haes, J. C. J. M. (2000). Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Education & Counseling*, 41(2), 145-156.
- Osborne, R. H., Elsworth, G. R., Kissane, D. W., Burke, S. A., & Hopper, J. L. (1999). The Mental Adjustment to Cancer (MAC) Scale: Replication and refinement in 632 breast cancer patients. *Psychological Medicine*, 29(6), 1335-1345.
- Paavonen, J. (1999). Sexual dysfunction associated with treatment of cervical cancer. *Sexually Transmitted Infections*, 75(6), 375-376.
- Palmblad, J. E. (1987). Stress-related modulation of immunity: A review of human studies. *Cancer Detection & Prevention*, 1(Suppl), 57-64.
- Palmer, A. G., Tucker, S., Warren, R., & Adams, M. (1993). Understanding women's responses to treatment for cervical intraepithelial neoplasia. *British Journal of Clinical Psychology*, 32(1), 101-112.
- Paraskevaïdis, E., Kitchener, H. C., & Walker, L. G. (1993). Doctor-patient communication and subsequent mental health in women with gynaecological cancer. *Psycho-Oncology*, 2, 195-200.
- Parham, G. P., & Hicks, M. L. (1995). Gynecologic cancer among the socioeconomically disadvantaged. *Cancer*, 76(10 Suppl), 2176-2180.
- Pitkin, R. M., & van Voorhis, L. W. (1971). Post-irradiation vaginitis. An evaluation of prophylaxis with topical estrogen. *Radiology*, 99(2), 417-421.

- Poad, D., & Arnold, E. P. (1994). Sexual function after pelvic surgery in women. *Australian & New Zealand Journal of Obstetrics & Gynaecology*, 34(4), 471-474.
- Pope, C., & Mays, N. (1995). Qualitative research: Reaching the parts other methods cannot reach: An introduction to qualitative methods in health and health care services research. *British Medical Journal*, 311(6996), 42-45.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: analysing qualitative data. *British Medical Journal*, 320(7227), 114-116.
- Posner, T., & Vessey, M. (1988). *Prevention of cervical cancer: The patient's view*. London: Kings Fund Publishing Office.
- Pruyn, J. F., Rijckman, R. M., van Brunschot, C. J., & van den Borne, H. W. (1985). Cancer patients' personality characteristics, physician-patient communication and adoption of the Moerman diet. *Social Science & Medicine*, 20(8), 841-847.
- Rainey, L. C. (1985). Effects of preparatory patient education for radiation oncology patients. *Cancer*, 56(5), 1056-1061.
- Rajaram, S. S. (1998). Non-adherence to follow up treatment of an abnormal Pap smear: A case study. *Cancer Nursing*, 21(5), 342-348.
- Read, J. (1999). ABC of sexual health: Sexual problems associated with infertility, pregnancy, and ageing. *British Medical Journal*, 318(7183), 587-589.
- Reed, B. D., Ruffin, M. T., Gorenflo, D. W., & Zazove, P. (1999). The psychosexual impact of human papillomavirus cervical infections. *The Journal of Family Practice*, 48(2), 110-116.
- Reid, R., & Campion, M. J. (1989). HPV-associated lesions of the cervix: Biology and colposcopic features. *Clinical Obstetrics & Gynecology*, 32(1), 157-179.
- Rhodes, J. C., Kjerulff, K. H., Langenberg, P. W., & Guzinski, G. M. (1999). Hysterectomy and sexual functioning. *Journal of American Medical Association*, 282(20), 1934-1941.
- Roberts, C. S., Rossetti, K., Cone, D., & Cavanagh, D. (1992). Psychosocial impact of gynecologic cancer: A descriptive study. *Journal of Psychosocial Oncology*, 10, 99-109.

- Robertson, R. (1996). Sexuality and the menopause. In B. Wren & L. E. Nachtigall (Eds.), *Clinical management of the menopause* (pp. 41-48). Sydney: McGraw Hill.
- Robinson, J. W. (1998). Sexuality and cancer: Breaking the silence. *Australian Family Physician*, 27(1&2), 45-47.
- Robinson, J. W., Faris, P. D., & Scott, C. B. (1999). Psycho-educational group increases vaginal dilation for younger women and reduces sexual fears for women of all ages with gynecological carcinoma treated with radiotherapy. *International Journal of Radiation Oncology, Biology, Physics*, 44(3), 497-506.
- Rodrigue, J. R., & Park, T. L. (1996). General and illness-specific adjustment to cancer: Relationship to marital status and marital quality. *Journal of Psychosomatic Research*, 40(1), 29-36.
- Ryan, M. M., Dennerstein, L., & Pepperell, R. (1989). Psychological aspects of hysterectomy: A prospective study. *British Journal of Psychiatry*, 154, 516-522.
- Schain, W. S. (1986). Sexual functioning, self esteem and cancer care. In J. M. Vaeth (Ed.), *Body image, self-esteem, and sexuality in cancer patients* (2nd ed., pp. 15-23). Basel: Karger.
- Schiffman, M. H. (1992). Recent progress in defining the epidemiology of human papillomavirus infection and cervical neoplasia. *Journal of the National Cancer Institute*, 84(6), 394-398.
- Schiffman, M. H., Bauer, H. M., Hoover, R. N., Glass, A. G., Cadell, D. M., Rush, B. B., Scott, D. R., Sherman, M. E., Kurman, R. J., & Wacholder, S. (1993). Epidemiologic evidence showing that human papillomavirus infection causes most cervical intraepithelial neoplasia. *Journal of the National Cancer Institute*, 85(12), 958-964.
- Schipper, H., Clinch, J., McMurray, A., & Levitt, M. (1984). Measuring the quality of life of cancer patients: The Functional Living Index-Cancer: development and validation. *Journal of Clinical Oncology*, 2(5), 472-483.
- Schnoll, R. A., Harlow, L. L., Brandt, U., & Stolbach, L. L. (1998). Using two factor structures of the Mental Adjustment to Cancer (MAC) scale for assessing adaptation to breast cancer. *Psycho-Oncology*, 7(5), 424-435.

- Schofield, P., Butow, P., Thompson, J., Tattersall, M., Beeney, L., & Dunn, S. (in press). Psychological responses to patients receiving a diagnosis of cancer. *Annals of Oncology*.
- Schover, L. R. (1990). Sexual problems in chronic illness. In S. R. Leiblum & R. C. Rosen (Eds.), *Principles and practice of sex therapy* (2nd ed., pp. 319-351). New York: Guilford Press.
- Schover, L. R., & Fife, M. (1985). Sexual counseling of patients undergoing radical surgery for pelvic or genital cancer. *Journal of Psychosocial Oncology*, 3(3), 21-41.
- Schover, L. R., Fife, M., & Gershenson, D. M. (1989). Sexual dysfunction and treatment for early stage cervical cancer. *Cancer*, 63(1), 204-212.
- Schover, L. R., & Jensen, S. B. (1988). *Sexuality and chronic illness: A comprehensive approach*. New York London: The Guilford Press.
- Schwartz, C. E., Daltroy, L. H., Brandt, U., Friedman, R., & Stolbach, L. (1992). A psychometric analysis of the Mental Adjustment to Cancer scale. *Psychological Medicine*, 22(1), 203-210.
- Schwartz, C. E., & Sprangers, M. A. (1999). Methodological approaches for assessing response shift in longitudinal health-related quality-of-life research. *Social Science & Medicine*, 48(11), 1531-1548.
- Segnan, N., Senore, C., Giordano, L., Ponti, A., & Ronco, G. (1998). Promoting participation in a population screening program for breast and cervical cancer: A randomized trial of different invitation strategies. *Tumori*, 84(3), 348-353.
- Seibel, M. M., Freeman, M. G., & Graves, W. L. (1980). Carcinoma of the cervix and sexual function. *Obstetrics & Gynecology*, 55(4), 484-487.
- Seibel, M. M., Freeman, M. G., & Graves, W. L. (1982). Sexual function after surgical and radiation therapy for cervical carcinoma. *Southern Medical Association Journal*, 75(10), 1195-1197.
- Sharpe, L., Sensky, T., Brewin, C. R., & Allard, S. (2001). Characteristics of handicap for patients with recent onset rheumatoid arthritis: The validity of the Disease Repercussion Profile. *Rheumatology*, 40(10), 1169-1174.

- Sharts-Hopko, N. C. (2001). Hysterectomy for nonmalignant conditions. *American Journal of Nursing*, 101(9), 32-40.
- Shell, J. A., & Smith, C. K. (1994). Sexuality and the older person with cancer. *Oncology Nursing Forum*, 21(3), 553-558.
- Sherwin, B. B., & Gelfand, M. M. (1987). The role of androgen in the maintenance of sexual functioning in oophorectomized women. *Psychosomatic Medicine*, 49(4), 397-409.
- Slattery, M. L., Overall, J. C., Jr., Abbott, T. M., French, T. K., Robison, L. M., & Gardner, J. (1989). Sexual activity, contraception, genital infections, and cervical cancer: Support for a sexually transmitted disease hypothesis. *American Journal of Epidemiology*, 130(2), 248-258.
- Smith, J., & Bigrigg, A. (1994). *Hysterectomy and alternative operations*. London: Headway, Holder & Stoughton.
- Somerset, M., & Peters, T. J. (1998). Intervening to reduce anxiety for women with mild dyskaryosis: Do we know what works and why? *Journal of Advanced Nursing*, 28(3), 563-570.
- Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-28.
- Speroff, L., Glass, R. H., & Kase, N. G. (1994). Menopause and post-menopausal hormone therapy. In L. Speroff & R. H. Glass & N. G. Kase (Eds.), *Clinical Gynecologic Endocrinology and Infertility* (5th ed., pp. 583-649). Baltimore, Maryland: Williams & Wilkins.
- Spiegel, D. (1991). *Can psychotherapy prolong cancer survival? Current concepts in psycho-oncology*. New York: Memorial Sloan Kettering Cancer Centre.
- Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, 48(11), 1507-1515.
- Stead, M. L. (2003). Sexual dysfunction after treatment for gynaecologic and breast malignancies. *Current Opinion in Obstetrics & Gynecology*, 15(1), 57-61.



- Stead, M. L., Brown, J. M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*, 88(5), 666-671.
- Stead, M. L., Fallowfield, L., Brown, J. M., & Selby, P. (2001). Communication about sexual problems and sexual concerns in ovarian cancer: Qualitative study. *British Medical Journal*, 323(7317), 836-837.
- Stewart, D. E., Buchegger, P. M., Lickrish, G. M., & Sierra, S. (1994). The effect of educational brochures on follow up compliance in women with abnormal Papanicolaou smears. *Obstetrics & Gynecology*, 83(4), 583-585.
- Stone, K. M., Zaidi, A., Rosero-Bixby, L., Oberle, M. W., Reynolds, G., Larsen, S., Nahmias, A. J., Lee, F. K., Schachter, J., & Guinan, M. E. (1995). Sexual behavior, sexually transmitted diseases, and risk of cervical cancer. *Epidemiology*, 6(4), 409-414.
- Straham, R., & Gerbasi, K. C. (1972). Short homogeneous versions of the Marlowe-Crowe Social Desirability Scale. *Journal of Clinical Psychology*, 28, 191-193.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park: CA: Sage.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks CA: Sage.
- Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics* (3rd ed.). New York: HarperCollins College Publishers.
- Tamburini, M., Filiberti, A., Ventafridda, V., Bianchi, F., & Volterrani, F. (1984). Emotional status, sexuality and quality of life in patients treated for carcinoma of the uterine cervix. *The Cervix and the Lower Female Genital Tract*, 2, 261-268.
- Taylor, J. F., Rosen, R. C., & Leiblum, S. R. (1994). Self-report assessment of female sexual function: Psychometric evaluation of the Brief Index of Sexual Functioning for Women. *Archives of Sexual Behavior*, 23(6), 627-643.
- Thomas, G. M. (1994). Radiation therapy. In N. F. Hacker & J. S. Berek (Eds.), *Practical Gynecologic Oncology* (2nd ed., pp. 35-73). New York: Williams & Wilkins.

- Thomas, G. M. (1994). Radiation therapy. In N. F. Hacker & J. S. Berek (Eds.), *Practical Gynecologic Oncology* (2nd ed., pp. 35-73). New York: Williams & Wilkins.
- Thompson, D. S., & Shear, M. K. (1998). Psychiatric disorders and gynecological oncology: A review of the literature. *General Hospital Psychiatry*, 20(4), 241-247.
- Thranov, I., & Klee, M. (1994). Sexuality among gynecologic cancer patients: A cross-sectional study. *Gynecologic Oncology*, 52(1), 14-19.
- Topping, A. (1996). Sexuality and breast cancer. In S. Denton (Ed.), *Breast Cancer Nursing*. London: Chapman & Hall.
- Touliatos, J., Perlmutter, B. F., & Straus, M. A. (1990). *Handbook of family measurement techniques*. London: Sage Publications.
- Tracey, E. A., & Supramaniam, R. (2002). *Cancer in New South Wales: Incidence and mortality 2000, featuring projections to 2010 for selected sites*. Sydney: The Cancer Council NSW.
- Tucker, J. B. (1999). Modification of attitudes to influence survival from breast cancer [comment]. *Lancet*, 354, 1320.
- Uno, T., Itami, J., Aruga, M., Kotaka, K., Fujimoto, H., Sato, T., Minoura, S., & Ito, H. (1998). High dose rate brachytherapy for carcinoma of the cervix: Risk factors for late rectal complications. *International Journal of Radiation Oncology, Biology, Physics*, 40(3), 615-621.
- van de Weil, H. B., Weijmar Schultz, W. C., Wouda, J., & Bouma, J. (1990c). Sexual functioning of partners of gynaecological oncology patients: A pilot study on involvement, support, sexuality and relationship. *Sexual and Marital Therapy*, 5, 123-130.
- van de Wiel, H. B., Weijmar Schultz, W. C., Hallensleben, A., Thurkow, F. G., & Bouma, J. (1988). Sexual functioning following treatment of cervical carcinoma. *European Journal of Gynaecological Oncology*, 9(4), 275-281.
- van de Wiel, H. B., Weijmar Schultz, W. C., Hallensleben, A., Thurkow, F. G., Bouma, J., & Verhoeven, A. C. (1990a). Sexual functioning of women treated for cancer of the vulva. *Sexual & Marital Therapy*, 5(1), 73-82.

- van de Wiel, H. B., Weijmar Schultz, W. C., Wouda, J., & Bouma, J. (1990b). Sexual functioning of partners of gynaecological oncology patients: A pilot study on involvement, support, sexuality and relationship. *Sexual & Marital Therapy*, 5(2), 123-130.
- van der Does, J. V. S., & Duyvis, D. J. (1988). Psychosocial adjustment of spouses of cervical carcinoma patients. *Journal of Psychosomatic Obstetrics & Gynaecology*, 10, 163-171.
- Vanyperen, N. W., & Buunk, B. P. (1991). Sex-role attitudes, social comparison, and satisfaction with relationships. *Social Psychology Quarterly*, 54(2), 169-180.
- Vasicka, A., Popovich, N. R., & Brausch, C. C. (1958). Post-radiation course of patients with cervical carcinoma: A clinical study of psychic, sexual and physical well-being of sixteen patients. *Obstetrics & Gynecology*, 11(4), 403-414.
- Velji, K., & Fitch, M. (2001). The experience of women receiving brachytherapy for gynecologic cancer. *Oncology Nursing Forum*, 28(4), 743-751.
- Vincent, C. E., Vincent, B., Greiss, F. C., & Linton, E. B. (1975). Some marital-sexual concomitants of carcinoma of the cervix. *Southern Medical Association Journal*, 68(5), 552-558.
- Vinod, S. K., MacLeod, C. A., Dalrymple, C., Elliott, P., Atkinson, K., Carter, J., & Firth, I. (2000). Surgery and post-operative radiotherapy for early stage cervical cancer. *Australian & New Zealand Journal of Obstetrics & Gynaecology*, 40(1), 66-69.
- von Eschenbach, A. C., & Schover, L. R. (1984). The role of sexual rehabilitation in the treatment of patients with cancer. *Cancer*, 54(11 Suppl), 2662-2667.
- Vuorento, T., Maaenpaae, J., & Huhtaniemi, I. (1992). Follow up of ovarian endocrine function in premenopausal women after hysterectomy by daily measurements of salivary progesterone. *Clinical Endocrinology*, 36, 51-53.
- Walling, M., Andersen, B. L., & Johnson, S. R. (1990). Hormonal replacement therapy for postmenopausal women: A review of sexual outcomes and related gynecologic effects. *Archives of Sexual Behavior*, 19(2), 119-137.
- Wang, C. J., Leung, S. W., Chen, H. C., Sun, L. M., Fang, F. M., Huang, E. Y., Hsiung, C. Y., & Changchien, C. C. (1998). The correlation of acute toxicity and late rectal injury in radiotherapy for cervical carcinoma: Evidence suggestive of consequential effect (CQLE). *International Journal of Radiation Oncology*, 40(1), 85-91.

- Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., & Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer: The MAC scale. *Psychological Medicine*, 18(1), 203-209.
- Watson, M., Haviland, J. S., Greer, S., Davidson, J., & Bliss, J. M. (1999). Influence of psychological response on survival in breast cancer: A population-based cohort study. *Lancet*, 354(9187), 1331-1336.
- Watson, M., Law, M., dos Santos, M., Greer, S., Baruch, J., & Bliss, J. (1994). The Mini-MAC: Further development of the Mental Adjustment to Cancer scale. *Journal of Psychosocial Oncology*, 12(3), 33-46.
- Weber, A. M., Walters, M. D., Schover, L. R., Church, J. M., & Piedmonte, M. R. (1999). Functional outcomes and satisfaction after abdominal hysterectomy. *American Journal of Obstetrics & Gynecology*, 181(3), 530-535.
- Weijmar Schultz, W. C., Bransfield, D. D., van de Weil, H. B., & Bouma, J. (1992). Sexual outcome following female genital cancer treatment: A critical review of methods of investigation and results. *Sexual & Marital Therapy*, 7(1), 29-64.
- Weijmar Schultz, W. C., & van de Weil, H. B. (1991). *Sexual functioning after gynaecological cancer treatment* (Dissertation). Groningen State University, The Netherlands.
- Weijmar Schultz, W. C. M., & van de Wiel, H. B. M. (2003). Sexuality, intimacy, and gynecological cancer. *Journal of Sex & Marital Therapy*, 29(Suppl1), 121-128.
- Weijmar Schultz, W. C. M., van de Wiel, H. B. M., & Bouma, J. (1991). Psychosexual functioning after treatment for cancer of the cervix: A comparative and longitudinal study. *International Journal of Gynecologic Cancer*, 1, 37-46.
- Weijmar Schultz, W. C. M., van de Wiel, H. B. M., Hahn, D. E. E., & van Driel, M. F. (1992). Sexuality and cancer in women: An integrative model of sexual function in women after treatment for cancer. *Annual Review of Sex Research*, 3, 151-200.
- Weisman, A. D., & Worden, J. W. (1976-77). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 7, 1-15.
- Wellard, S., & Joyce, T. (1998). Cancer & Sexuality: A neglected issue? In G. Poulton (Ed.), *Nursing the person with cancer*. Australia: Ausmed Publications.

- Williams, J. B., Spitzer, R. L., Linzer, M., Kroenke, K., Hahn, S. R., deGruy, F. V., & Lazev, A. (1995). Gender differences in depression in primary care. *American Journal of Obstetrics & Gynecology*, 173(2), 654-659.
- Wilmoth, M. C. (2001). The aftermath of breast cancer: An altered sexual self. *Cancer Nursing*, 24(4), 278-286.
- Wilmoth, M. C., & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 29(4), 413-421.
- Wilson, I. B. (1999). Clinical understanding and clinical implications of response shift. *Social Science & Medicine*, 48(11), 1577-1588.
- World Health Organisation (WHO). (1975). *Education and treatment in human sexuality: The training of health professionals*. Geneva, Switzerland: WHO.
- Wortman, C. B. (1984). Social support and the cancer patient: Conceptual and methodological issues. *Cancer*, 53(Suppl), 2339-2362.
- Wright, J., Jones, G., Whelan, T., & Lukka, H. (1994). Patient preference for high or low dose rate brachytherapy in carcinoma of the cervix. *Radiotherapy & Oncology*, 33(3), 187-194.
- Wright, V. C., Davies, E., & Riopelle, M. A. (1983). Laser surgery for cervical intraepithelial neoplasia: Principles and results. *American Journal of Obstetrics & Gynecology*, 145(2), 181-184.
- Wyatt, G. R. N., & Friedman, L. M. A. (1996). Long-term female cancer survivors: Quality of life issues and clinical implications. *Cancer Nursing*, 19(1), 1-7.
- Yeo, B. K., & Perera, I. (1995). Sexuality of women with carcinoma of the cervix. *Annals of the Academy of Medicine*, 24(5), 676-678.
- Zagwaard, M. I., Gamel, C. J., Dugris, D. J., & Logmans, A. (2000). [The experience of sexuality and information received in women with cervical cancer and their partners]. *Verpleegkunde*, 15(1), 18-27.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.

# Appendix

Please note that only questionnaire sets administered to the cancer group are include in the Appendix. Although the general format of letters/questionnaires administered to the control groups remained the same, certain modifications applied: i) the term "cancer" was replaced with the term "gynaecological conditions" and ii) cancer-specific measures/items were omitted or modified (also see Table 5.6).

- I. *Ethics approval letters*
- II. *Introductory letter (Baseline)*
- III. *Informational sheet & Consent form*
- IV. *Baseline Questionnaire*
  - Index: Demographic sheet.....pages 2-4
  - Functional Analysis of Cancer Treatment (FACT) scale.....5-6
  - FACT– CX (cervical cancer subscale).....7
  - Relationship Satisfaction Scale.....8
  - Derogatis Sexual Functioning Inventory (DSFI): Satisfaction subscale..8
  - DSFI: Global Sexual Satisfaction Index.....9
  - DSFI: Drive subscale.....9
  - Hospital Anxiety and Depression Scale (HADS).....10
  - Mini-Mental Adjustment to Cancer (MAC) scale .....11-13
- V. *Introductory letter (6 months follow up)*
- VI. *Follow up Questionnaire (6 months follow-up)*
  - Index: Demographic sheet.....pages 2-3
  - Functional Analysis of Cancer Treatment (FACT) scale.....4-5
  - FACT– CX (cervical cancer subscale).....6
  - Relationship Satisfaction Scale.....7
  - Derogatis Sexual Functioning Inventory (DSFI): Satisfaction subscale..7
  - DSFI: Global Sexual Satisfaction Index.....8
  - DSFI: Drive subscale.....8
  - Sexual Functioning After Gynaecological Cancer Scale (SFAGIS)...9-10
  - Treatment-specific measure assessing side-effects.....11-12
  - Treatment specific measure assessing main issues.....13
  - Treatment-specific measure assessing psychological responses...14-17
  - Hospital Anxiety and Depression Scale (HADS).....10
  - Mini-Mental Adjustment to Cancer (MAC) scale .....11-13
- VI. *Introductory letter (12 months follow up)*
- VII. *Final follow up Questionnaire (12 months follow up)*
  - Index: see 6 months follow up Questionnaire
- VIII. *Letter of thanks*
- IX. *Correlational matrixes*



## HUMAN ETHICS COMMITTEE

The University of Sydney  
Room L4.14 Main Quad A14  
Sydney 2006

Tel: (02) 9351.4811 Fax: (02) 9351.6786 E-mail: [gail@reschois.usyd.edu.au](mailto:gail@reschois.usyd.edu.au)

Dr P N Butow  
Medical Psychology Unit  
Department of Medicine  
D06

8 February 1999

Dear Dr Butow

Your recent application *Sexual outcomes of treatment for cervical and endometrial cancer* was considered by the Ethics Manager on 8 February 1999, and in doing so acknowledges your final approval from the South Eastern Sydney Area Health Service Research Ethics Committee - Eastern Section and the Central Sydney Area Health Service Ethics Review Committee.

Your right to proceed under their authority has been noted.

The University insurers together with Risk Management has agreed that this notification will satisfy the requirements in order for the University to assume liability for the research.

Yours sincerely,

**Ms G Briody**  
*Manager of Ethics & Biosafety Administration*

# Northern Sydney Health Service

better health: from the Harbour to the Hawke

ROYAL NORTH SHORE HOSPITAL  
ST LEONARDS NSW AUSTRALIA

September 9, 1999

RESEARCH OFFICE

Level 4, Vindin House

Telephone: (02) 9926 8106

Facsimile: (02) 9926 6179

email: pemartin@doh.health.nsw.gov.au

Dr Phyllis Butow  
Executive Director, Medical Psychology Unit  
Department of Psychological Medicine and Medicine  
University of Sydney, NSW 2006

Dear Dr Butow,

**Re: Protocol 9907-114M - P Butow, I Juraskova, R Robertson  
Sexual outcomes of treatment for cervical and endometrial cancer**

Thank you for your letter of 3 September 1999 providing clarification on patient recruitment as requested by the Human Research Ethics Committee at its meeting on Wednesday, 18<sup>th</sup> August 1999.

I am pleased to inform you that your protocol on the above study has been approved. The approved versions of the Patient Information Sheets (Cancer and Control Groups) and Consent Form are dated 06 August 1999.

In order to comply with the *Guidelines for Good Clinical Research Practice (GCRP) in Australia*, and in line with RNSH HREC policy, may I remind you that it is the Chief Investigator's responsibility to ensure that:

1. A report is provided to the HREC at the completion of the study.
2. The HREC is notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. This includes notifying the HREC of any changes to the staff involved with the protocol.
3. All major/serious adverse events in your patients are reported to the HREC within 15 working days.
4. The HREC is notified of the outcome of all submissions of this protocol to other Ethics Committees.

HREC approval is valid for three (3) years from the date of the approval letter. Investigators are requested to submit a progress report annually.

Investigators are required to ensure that the usual Infection Control Policies and Procedures for Royal North Shore Hospital and Community Health Service apply.

Yours sincerely,



**Professor Sharon McKinley**  
Chair  
Human Research Ethics Committee







# SOUTH WESTERN SYDNEY AREA HEALTH SERVICE

## Research Ethics Committee

Locked Bag 7017, LIVERPOOL BC, NSW, 1871

Phone: 02 9828 5727

Facsimile: 02 9828 5962

September 19, 2000

Assoc Professor Phyllis Butow  
Medical Psychology Unit  
Blackburn Building (DO6)  
The University of Sydney  
Australia 2006

Dear Associate Professor Butow,

**Project No: 00/079 – Sexual Outcomes following Treatment for Cervical and Endometrial Cancer**

Thank you for your correspondence dated 13<sup>th</sup> September, 2000 with regard to the above project.

As the Patient Information Sheet and the Partner Information Sheet have been amended as requested, formal approval is hereby granted for this study to proceed as a Category A Project.

Ethics clearance is granted for periods of up to twelve months. This project will be due for renewal on the 31<sup>st</sup> August, 2001, and you must provide a Progress Report (attached) or final report by this date. If no report is supplied, ethics clearance for this project may be cancelled.

Your attention is drawn to the attached document *Guidelines for Investigators* which sets out not only the principles under which research should be conducted, but also the conditions under which Ethics approval is granted by the Committee. Also enclosed for your information, is a copy of the document *Guidelines for Responsible Practice in Research and Dealing with Problems of Research Misconduct*.

Please note that the Committee must be notified **IMMEDIATELY** of any untoward or unexpected complications or side effects arising during the project or of any ethical or medico-legal problems that may arise. Also, any changes to the original protocol must be submitted to the Committee for approval.

Would you please quote the above project number in all future correspondence relating to this project.

Yours sincerely,

EMERITUS PROFESSOR A. LYKKE,  
Chairperson,  
SWSAHS Research Ethics Committee.

for: Mr. I. Southwell,  
Chief Executive Officer.

- Category A: Projects with limited risk potential, including quality assurance surveys.  
Category B: Projects with significant patient risks.  
Category C: Drug trials (international/national) sponsored by drug companies and already covered for risk evaluation and monitoring of adverse reactions.



# **LIVERPOOL HEALTH SERVICE**

*A Unit of The South Western Sydney Area Health Service*

## **Division of Women's and Child Health Education and Research Committee**

*Division Of Women's and Child Health  
Caroline Chisholm Centre*

*Telephone: (02) 9828 5680  
Facsimile: (02) 9828 5672*

August 4, 2000

A/Prof Phyllis Butow,  
The Medical Psychology Research Unit,  
Blackburn Building (DO6),  
The University of Sydney,  
NSW. 2006.  
e-mail: medpsych@mail.usyd.edu.au

Dear A/Prof Butow,

Thank you for your research proposal: 'Sexual Outcomes following Treatment for Cervical and Endometrial Cancer.' The Division of Women's and Child Health Education and Research Committee on Monday, July 24, 2000 reviewed your proposal.

On behalf of the Committee, I congratulate you on your proposal and the Committee has approved that your project be implemented. Where appropriate, please forward your proposal to the South Western Sydney Area Health Service Ethics Committee. The Committee noted that Dr Gregory Gard, Liverpool Health Service was included as one of the Chief Investigators and will be the contact person at Liverpool Health Service.

I would like to take this opportunity on behalf of the Committee to wish you all the best for your research project and we look forward to reading the report of your findings. Let me encourage you also to share this information with wider audiences.

Yours sincerely,

**Richard Gilfillan** (Committee Secretary)  
for Professor Felix Wong  
Committee Chairman and Medical Director

---

*Mailing Address: Locked Bag 7103, Liverpool. BC NSW 1871*

# WESTERN SYDNEY AREA HEALTH SERVICE

## HUMAN RESEARCH ETHICS COMMITTEE

Research Office, Clinical Sciences,  
Westmead Hospital NSW 2145  
Australia

Telephone: 02 9845 8183  
Facsimile: 02 9845 8302

In reply please quote:

HS/TG HREC99/8/4.9(869)

**Committee Secretariat:**

**Professor Stephen Leeder**  
Chairman  
Professor of Public Health &  
Community Medicine

**Dr Howard Smith**  
Secretary  
Medical Graduate -  
Endocrinologist

**Committee Members:**

**Mr Leonard Burney**  
Layman

**Dr Michael Cole**  
Neonatal Pediatrician

**Ms Deirdre D'Souza**  
Clinical Trials Pharmacist

**Dr Peter Ellis**  
Forensic Pathologist

**Ms Vivien Lane**  
Nursing Professional  
Development Unit - Research

**Ms Jillian Gwynne Lewis**  
Patient Representative

**Father Laurence McNamara**  
Minister of Religion

**Professor Sydney Nade**  
Professor of Orthopaedics

**Mr John Watts**  
Lawyer

**Miss Freda Whitlam AM**  
Laywoman

3 February, 2000

Ms Ilona Juraskova  
Medical Psychology Unit  
Dept of Medicine  
University of Sydney  
NSW 2006

Dear Ms Juraskova

Research Proposal: 'Sexual Outcomes of Treatment for Cervical and Endometrial Cancer'

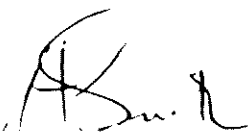
The Western Sydney Area Health Service Human Research Ethics Committee has no record of receiving your letter dated 22 November 1999. Thank you for your reply which provides satisfactory answers to the questions raised by the Committee. Approval for your proposal can now be given.

Please note that approval of this research proposal applies to the ethical content of the trial and individual arrangements should be negotiated with heads of departments in those situations where the use of their resources is involved (eg nursing etc). The Committee requests you notify them of the commencement date of the study or the date which subjects are recruited. In accordance with the NH&MRC Statement on Human Experimentation 'Supplementary Note 1', the Committee requires you to provide a brief report on progress at the end of each 12 month period..

In all future correspondence concerning this study, please quote your approval number: **HREC99/8/4.9(869)**.

The Committee wishes you well with your project.

Yours sincerely



Dr Howard Smith  
Secretary  
Western Sydney Area Health Service  
Human Research Ethics Committee

# SOUTH EASTERN SYDNEY AREA HEALTH SERVICE

## RESEARCH ETHICS COMMITTEE - Eastern Section

Room G71, EBB  
Cnr High & Avoca Strs  
Randwick NSW 2031  
Tel: 9382 3583  
Fax: 9382 2813

18 November, 1998

Dr P. Butow  
Department of Medical Psychology  
Royal Prince Alfred Hospital  
CAMPERDOWN NSW 2050

Dear Dr Butow

**Re: Sexual Outcomes of Treatment for Cervical and Endometrial Cancer. Ref: 98/165.**

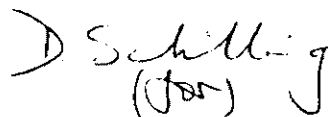
The Research Ethics Committee at its meeting of 17 November, 1998 considered the Executive Approval given on 27 October, 1998 for the following changes for the above study, and this decision was ratified.

- \* **Clarification of Recruitment.**
- \* **Clarification of Interview Procedure by offering the subject a choice of venue for the interview.**
- \* **Consent Forms E1 and C1.**
- \* **Clarification of the number of questionnaires and when they will be distributed.**

In accordance with National Health and Medical Research Council Guidelines, the Committee requires you to furnish it with a progress report each twelve months and on completion of the study.

The Committee wish you well with the continuation of your study.

Yours sincerely



Kim Breheny  
Research Ethics Co-ordinator

Telephone: (02) 9515 6766  
Facsimile: (02) 9515 7176  
Reference: X96-0214  
6.4/AUG98



CENTRAL SYDNEY AREA  
HEALTH SERVICE

19 August 1998

Dr P Butow  
Executive Director  
Medical Psychology Unit  
Level 10, Building 82  
Royal Prince Alfred Hospital

Dear Dr Butow,

Re: Protocol No X96-0214 - "Sexual outcomes of treatment for cervical and endometrial cancer"

The Ethics Review Committee, at its meeting of 12 August 1998, considered your undated correspondence (received on 30 June 1998) concerning an amendment to the above study, and recommended approval to proceed.

Yours sincerely,

Lesley Townsend  
Secretary  
Ethics Review Committee

HERC\COR98-08 (p71)



RPA



University of Sydney



CRGH

CSAHS

Queen Elizabeth II Centre  
59 Missenden Road

Camperdown NSW 2050

Telephone: (02) 9515 9600

Facsimile: (02) 9515 9611

Incorporating

- Royal Prince Alfred Hospital
- Concord Repatriation General Hospital
- Canterbury Hospital
- United Dental Hospital

- Balmain Hospital
- Division of Population
- Rozelle Hospital
- Division of General Practice



# The Medical Psychology Research Unit

The University of Sydney  
*In collaboration with*  
Royal North Shore Hospital and  
Royal Prince Alfred Hospital

Telephone 61 2 9515 6580  
Facsimile 61 2 9515 5697  
Email medpsych@mail.usyd.edu.au

---

## RESEARCH INTO PSYCHO-ONCOLOGICAL ASPECTS OF PATIENT'S NEEDS

Dear

You are invited to take part in a research project investigating the effects of different treatments for women with gynaecological cancer. The aim of the project is to assess the general effect of various treatments used, but more specifically the effect on sexual functioning. We fully understand that this may involve intrusion into an area that is very personal and sensitive, especially at such a difficult time during your treatment. However, it is important to get feedback from people who have a personal experience of these treatments.

The project will follow the physical, emotional and sexual changes that take place during the first 12 months following treatment. This will be done by a series of questionnaires, post-operatively, at 6 and 12 months after that. We hope that this information will help us to better prepare women for these treatments and to identify what assistance is needed during recovery.

Participation in the project is entirely voluntary, it will not affect the quality of treatment or care that you receive from your doctor. You can withdraw from the study at any time. Support from this department will be available to you, should you require it. Any information you give will remain strictly confidential. More in-depth information about the project is available to help you decide whether or not to participate.

Thank you for considering this invitation. If you have any questions, please contact me at any time on 9515 5698.

We wish you a speedy recovery

Kind regards,

Ilona Juraskova  
(Research Co-ordinator)

---

Postal address: Medical Psychology Unit, Blackburn Building (DO6), University of Sydney, Australia 2006

A/Prof Phyllis Butow  
Executive Director  
Ph: 9515 6580

Prof Martin Tattersall  
Director  
Ph: 9351 3675



## **MEDICAL PSYCHOLOGY RESEARCH UNIT**

**The University of Sydney**  
DEPARTMENTS OF PSYCHOLOGICAL MEDICINE  
AND MEDICINE, SYDNEY, NSW, 2006, AUSTRALIA

### **PARTICIPANT INFORMATION STATEMENT**

#### **The impact of treatment for gynaecological cancer** **on Sexuality and Quality of Life**

You are invited to participate in a study investigating the impact of early stage cervical and endometrial cancer on quality of life. We hope to learn about the general impact of various treatments used, but more importantly about their impact on sexual health. It is important to get feedback from people who have a personal experience of these treatments, so that health professionals can gain a better understanding of the repercussions following treatment. This will allow health professionals to offer most appropriate treatment and care to women with gynaecological cancer.

You are offered the opportunity to participate in this study since you have been diagnosed and treated for early stage cervical or endometrial cancer. Should you decide to participate, you will be asked to fill in three sets of questionnaires, one immediately post-surgery and the other two at 6 and 12 months post-treatment. Each questionnaire takes about half an hour to complete. The questionnaire asks you about your physical, psychological and sexual wellbeing. Enclosed is a consent form, a questionnaire, and a reply paid envelope. Please return your completed questionnaire in the envelope provided.

We recognize that some people may find certain questions embarrassing or disturbing, or that they raise new issues. Should this inadvertently happen, a clinical psychologist will be available to help you, should you require their services. You may find it helpful to review and record your experiences, however, we cannot guarantee any benefit from participation. Many women find it satisfying to know that their experiences will benefit other women in the future who undergo treatments for similar gynaecological conditions.

Any information about you that is obtained in connection with this study will remain confidential and will be disclosed only with your written permission. Where results of the study are required to be published or disclosed as a completed academic document, it will be impossible to identify individual participants. You will be given a code number so your name does not appear on the computer database. The data from this study will be stored in a locked filing cabinet to which only the research staff has access. Computer files will be password protected. The data will be kept for seven years, and then disposed of by shredding or erasure.

Participation in the study is voluntary: you are not obliged to participate, and if you do, you can withdraw from the study at any time by phoning the research co-ordinator Ilona Juraskova on 9515 5698. Whatever your decision, it will not affect any medical treatment you are currently receiving or may receive in the future. Neither will it affect the relationship with your health professionals, since they will not be informed of your participation (or any subsequent withdrawal). If you have any questions at any time, please contact Ilona Juraskova or Associate Professor Phyllis Butow (ph. 9515 7097). You will be given a copy of this form to keep.



**MEDICAL PSYCHOLOGY RESEARCH UNIT**  
The University of Sydney

**PARTICIPANT CONSENT FORM**

**The impact of treatment for gynaecological conditions**  
**on sexuality and quality of life**

You are making a decision whether or not to participate in the aforementioned research project. Your signature indicates that you have read and understood the information provided and have decided to participate.

\_\_\_\_\_  
Signature of subject

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Please PRINT name

\_\_\_\_\_  
Please PRINT name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Relationship of witness

\_\_\_\_\_  
Signature(s) of investigators

\_\_\_\_\_  
Please PRINT name

**REVOCATION OF CONSENT**

I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT make any difference to my medical care or my relationship with the hospital or my medical attendants.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Please PRINT name

The section for Revocation of Consent should be forwarded to MS. Ilona Juraskova, Medical Psychology Research Unit, Blackburn bld. D06., University of Sydney, 2006.





# MEDICAL PSYCHOLOGY RESEARCH UNIT

The University of Sydney  
DEPARTMENTS OF PSYCHOLOGICAL MEDICINE  
AND MEDICINE, SYDNEY, NSW, 2006, AUSTRALIA

## THE IMPACT OF TREATMENT FOR GYNAECOLOGICAL CANCER ON SEXUALITY AND QUALITY OF LIFE (Baseline)

### What is this questionnaire about?

This questionnaire is part of a large project investigating the effects of different treatments for cervical and endometrial cancer on quality of life, and particularly on sexual functioning. We hope that this information will help us to better prepare women for these treatments and assist them in adjusting once the treatment is over.

### Instructions:

If you have more than one intimate relationship, please select the most important one, and answer the questions with that person in mind. Most questions require you to tick a box which best sums up your opinion or situation. There are no right or wrong answers. We want to ensure that patients get the best care possible, so please say how things really are for you.

Everything you say will be kept in total confidence by the researchers.  
None of the people treating you will see your answers.

Please return your completed questionnaire in the reply paid envelope provided.  
If you have any questions or concerns please phone Ms. Ilona Juraskova  
(research co-ordinator) on 9515 5698.

Please put in the date you complete the questionnaires at the bottom of this page.

Thank you for your help with this research

Date: \_\_\_\_\_

Study ID # \_\_\_\_\_

### SECTION A: Some information about yourself

The first section of this questionnaire asks some general background questions. They will not be used for identification. The information will help us to identify which issues are important to particular groups (e.g. younger versus older women).

1. What is your age? ..... years
2. What is your religion denomination/ spiritual belief? .....
  - Is your religion important in your life?     Yes     No
3. What is your occupation (if retired, past occupation)? .....
  - Do you work at present?     Yes     No
4. What is the highest education qualification you have obtained?
  - Year 10 or below
  - Year 12 - HSC (leaving)
  - TAFE certificate/diploma, Business College
  - University degree
  - Higher degree (postgraduate)
5. What is your parent's country of birth?
  - Mother's .....    Father's .....
6. Do you speak a language other than English at home?
  - No, only English
  - Yes I speak .....
7. What is your present marital status?
  - Never married
  - Married or de facto
  - Widowed
  - Separated but not divorced
  - Divorced
  - Other (please specify .....
8. Do you have a regular sexual partner?
  - Yes
  - No

9. Do you have children?

- a, Yes
- b, No

If yes, what are their ages: girls \_\_\_\_\_ boys \_\_\_\_\_

10. At what stage of your "change of life" are you?

- a, Pre - menopausal
- b, During menopause
- c, Post - menopausal

11. How often do you have a drink containing alcohol?

- a, Never
- b, Monthly or less
- c, 2-4 times a month
- d, 2-3 times a week
- e, 4 or more times a week

How many cigarettes a day do you smoke?

- a, I don't smoke
- b, 10 or less
- c, 11-20
- d, 21-25
- e, 26 or more

12. Are you currently taking any of the following medications:

- Hormone Replacement Therapy (HRT)  a, No  b, Yes

If yes, for how long have you taken HRT:

- a, 0-7 days
- b, 1-4 weeks
- c, 1-6 months
- d, 6-12 month
- e, 12+ months

Antidepressants (e.g. Prozac, Zoloft)

- a, No
- b, Yes

If yes, for how long have you taken antidepressants:

- a, 0-7 days
- b, 1-4 weeks
- c, 1-6 months
- d, 6-12 months
- e, 12+ months

Sedatives (e.g. Rotipnol, Normison)

- a, No
- b, Yes

If yes, for how long have you taken sedatives:

- a, 0-7 days
- b, 1-4 weeks
- c, 1-6 months
- d, 6-12 months
- e, 12+ months

13. Have you ever been in hospital for any psychiatric disorder (e.g. schizophrenia)?

- a, No
- b, Yes

14. Did you experience any other major life events (e.g. divorce, job changes etc.) in the past 12 months? Please list:

---



---



---

**SECTION B:**

Below is a list of statements that other people with your illness have said are important. By **ticking one box per line**, please indicate how true each statement has been for you during the **MONTH PRIOR TO THE SURGERY**.

**PHYSICAL WELL-BEING**

- |   | <i>Not at all</i>        | <i>A little bit</i>      | <i>Somewhat</i>          | <i>Quite a bit</i>       | <i>Very much</i>         |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. I have a lack of energy.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I have nausea.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Because of my physical condition, I have trouble meeting the needs of my family. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I have pain.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am bothered by side effects of treatments.                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I feel sick.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I am forced to spend time in bed.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8. Looking at the above seven questions, how much would you say your **PHYSICAL WELL-BEING** affects your quality of life?

- |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|

**SOCIAL/FAMILY WELL-BEING**

- |   | <i>Not at all</i>            | <i>A little bit</i>         | <i>Somewhat</i>          | <i>Quite a bit</i>       | <i>Very much</i>         |
|---|------------------------------|-----------------------------|--------------------------|--------------------------|--------------------------|
| 9. I feel distant from my friends.  | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I get emotional support from my family.   | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. I get support from friends and neighbors.   | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. My family has accepted the illness.   | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Family communication about my illness is poor.  | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. I feel close to my partner (or the person who is my main support)                         | <input type="checkbox"/>     | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Have you been sexually active during last year?<br>If YES I'm satisfied with my sex life. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

16. Looking at the above seven questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

- |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|

**RELATIONSHIP WITH DOCTOR**

17. I have confidence in my doctor(s).

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

*Not at all*   *A little bit*   *Somewhat*   *Quite a bit*   *Very much*

18. My doctor is available to answer my questions.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

19. Looking at the above two questions, how much would you say your **RELATIONSHIP WITH DOCTOR** affects your quality of life?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

**EMOTIONAL WELL-BEING**

20. I feel sad.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

*Not at all*   *A little bit*   *Somewhat*   *Quite a bit*   *Very much*

21. I am proud of how I am coping with my illness.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

22. I am losing hope in the fight against my illness.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

23. I feel nervous.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

24. I worry about dying.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

25. I worry that my condition will get worse.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

26. Looking at the above six questions, how much would you say your **EMOTIONAL WELL-BEING** affects your quality of life?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

**FUNCTIONAL WELL-BEING**

27. I am able to work (include work at home).

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

*Not at all*   *A little bit*   *Somewhat*   *Quite a bit*   *Very much*

28. My work (include work at home) is fulfilling.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

29. I am able to enjoy life.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

30. I have accepted my illness.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

31. I am sleeping well.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

32. I am enjoying the things I usually do for fun.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

33. I am content with the quality of my life right now.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

34. Looking at the above seven questions, how much would you say your **FUNCTIONAL WELL-BEING** affects your quality of life?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

**ADDITIONAL CONCERNS**

- |   | <i>Not at all</i>        | <i>A little bit</i>      | <i>Somewhat</i>          | <i>Quite a bit</i>       | <i>Very much</i>         |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 35. I am bothered by discharge or bleeding from my vagina.        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. I am bothered by odour coming from my vagina                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. I am afraid to have sex.                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 38. I feel sexually attractive.                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 39. My vagina feels too narrow or short.                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 40. I have concerns about my ability to have children.            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 41. I am afraid the treatment may harm my body.                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 42. I am interested in having sex.                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 43. I like the appearance of my body.                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 44. I am bothered by bowel problems (e.g. constipation)           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 45. I have a good appetite.                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 46. I have trouble controlling my urine.                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 47. I have burning or discomfort when I urinate.                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 48. This cancer and its treatment have caused a financial burden. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 49. I am able to eat the foods that I like.                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

50. Looking at the above fifteen questions, how much would you say these **ADDITIONAL CONCERNS** affect your quality of life?

- |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|

Below you find a list of statements about the relationship between you and your partner. Please tick a box that best describes your relationship **TYPICALLY** (that is before you had symptoms/were diagnosed with cancer).

- |  | <i>Never</i>             | <i>Rarely</i>            | <i>Sometimes</i>         | <i>Often</i>             | <i>Very often</i>        |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. I feel happy when I am with my partner.       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. We have quarrels.                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Things go well between us.                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I regret being involved in this relationship. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. My partner irritates me.                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I consider leaving my partner.                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I enjoy the company of my partner.            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I feel our relationship will not last.        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Below are some statements about sexual satisfaction. Please indicate whether each statement is true of your **TYPICAL** (that is before you had symptoms/were diagnosed with cancer) sexual functioning by ticking either true or false for each item.

- |  | <i>True</i>              | <i>False</i>             |
|--|--------------------------|--------------------------|
| 1. Usually I am satisfied with my sexual partner.                                  | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I feel I do not have sex frequently enough.                                     | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. There is not enough variety in my sex life.                                     | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Usually after sex I feel relaxed and fulfilled.                                 | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Usually sex does not last long enough.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am not very interested in sex.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Usually I have a satisfying orgasm with sex.                                    | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Foreplay before intercourse is usually very arousing for me.                    | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Often I worry about my sexual performance.                                      | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Usually my partner and I have good communication about sex.                    | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Who usually instigates sexual encounters?<br>(e.g. myself / my partner / both) | <input type="checkbox"/> | <input type="checkbox"/> |

Below is a rating scale on which we would like you to record your personal evaluation of how satisfying your sexual relationship was **TYPICALLY** (that is before you had symptoms/were diagnosed with cancer). By ticking the box indicate which statement best describes your present sexual relationship.

- (8) Could not be better
- (7) Excellent
- (6) Good
- (5) Above average
- (4) Adequate
- (3) Somewhat inadequate
- (2) Poor
- (1) Highly inadequate
- (0) Could not be worse

Below we would like you to indicate the frequency with which you **TYPICALLY** (that is before you had symptoms/were diagnosed with cancer) engaged in certain sexual activities. Please indicate how often you experienced each of the sexual activities below by ticking the box that is closest to your personal frequency.

	Not at all	Less than once a month	1-2 times a month	Once a week	2-3 times per week	4-6 times per week	Once a day	2-3 times per day	4+ times per day
INTERCOURSE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MASTURBATION	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
KISSING & PETTING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SEXUAL FANTASIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT WOULD BE YOUR IDEAL FREQUENCY OF SEXUAL INTERCOURSE?

- Not at all
- A little bit
- Somewhat
- Much
- Very Much
- Extremely

Since you first had symptoms (related to the gynaecological condition), how much has your sexual functioning changed? Please indicate, by ticking a box.

- Not at all
- A little bit
- Somewhat
- Much
- Very Much
- Extremely

If changed, was the change for better  or for worse  ?

Please, read each item and tick the box next to the reply which comes closest to how you have been feeling in the **PAST WEEK**. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or "wound up":
  - Most of the time
  - A lot of time
  - From time to time, occasionally
  - Not at all
2. I still enjoy the things I used to enjoy:
  - Definitely as much
  - Not quite so much
  - Only a little
  - Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen:
  - Very definitely & quite badly
  - Yes, but not too badly
  - A little but it doesn't worry me
  - Not at all
4. I can laugh and see the funny side of things:
  - As much as I always could
  - Not quite so much now
  - Definitely not so much now
  - Not at all
5. Worrying thoughts go through my mind:
  - A great deal of the time
  - A lot of time
  - From time to time but not too often
  - Only occasionally
6. I feel cheerful:
  - Not at all
  - Not often
  - Sometimes
  - Most of the time
7. I can sit at ease and feel relaxed:
  - Definitely
  - Usually
  - Not often
  - Not at all
8. I feel as if I am slowed down:
  - Nearly all the time
  - Very often
  - Sometimes
  - Not at all

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

10. I have lost interest in my appearance:

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

11. I feel restless, as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

12. I look forward with enjoyment to things:

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

13. I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very much
- Not at all

14. I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

A number of statements are given below which describe people's reactions to having cancer. Please tick the appropriate box, indicating how far it applies to you **AT PRESENT**.

- |  | Definitely does not apply to me | Does not apply to me     | Applies to me            | Definitely applies to me |
|--|---------------------------------|--------------------------|--------------------------|--------------------------|
| 1. I felt like giving up.                                  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I am upset about having cancer.                         | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I am determined to beat this disease.                   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I make a positive effort not to think about my illness. | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- |   | Definitely does not apply to me | Does not apply to me     | Applies to me            | Definitely applies to me |
|---|---------------------------------|--------------------------|--------------------------|--------------------------|
| 5. I've had a good life, what's left is a bonus.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I feel that life is hopeless.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. It is a devastating feeling.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I see my illness as a challenge  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Not thinking about it helps me cope.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I've put myself in the hands of God.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. I feel completely at loss about what to do.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. I suffer great anxiety about it.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. I try to fight the illness.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. I deliberately push all thoughts of cancer out of my mind.                                  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Since my cancer diagnosis I now realize how precious life is and I'm making the best of it. | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. I can't handle it.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. I'm a little frightened.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. I am very optimistic.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. I distract myself when my thoughts about my illness come to my head                         | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. I count my blessings.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. I feel there is nothing I can do to help myself.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. I worry about the cancer returning or getting worse.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. At the moment I take one day at a time.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. I think it is the end of the world.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. I feel very angry about what has happened to me.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- |  | <i>Definitely<br/>does not<br/>apply to me</i> | <i>Does not<br/>apply<br/>to me</i> | <i>Applies<br/>to me</i> | <i>Definitely<br/>applies<br/>to me</i> |
|--|--|-------------------------------------|--------------------------|---|
| 26. I can't cope.  | <input type="checkbox"/>                       | <input type="checkbox"/>            | <input type="checkbox"/> | <input type="checkbox"/>                |
| 27. I have difficulty in believing that this has happened to me. | <input type="checkbox"/>                       | <input type="checkbox"/>            | <input type="checkbox"/> | <input type="checkbox"/>                |
| 28. I am not very hopeful about the future.                      | <input type="checkbox"/>                       | <input type="checkbox"/>            | <input type="checkbox"/> | <input type="checkbox"/>                |
| 29. I am apprehensive.   | <input type="checkbox"/>                       | <input type="checkbox"/>            | <input type="checkbox"/> | <input type="checkbox"/>                |

---

*Please write any comments about your experience (both positive and negative) which have not been covered by the questionnaire (if you run out of space, please continue on the back of this page):*



# The Medical Psychology Research Unit

The University of Sydney  
*In collaboration with*  
Royal North Shore Hospital and  
Royal Prince Alfred Hospital

Telephone 61 2 9515 6580  
Fascimile 61 2 9515 5697  
Email medpsych@mail.usyd.edu.au

---

## RESEARCH INTO PSYCHO-ONCOLOGICAL ASPECTS OF PATIENT'S NEEDS

---

Dear

Thank you for your valuable contribution to the research project investigating the quality of life of women following treatment for gynaecological conditions. Your responses obtained from the previous questionnaire provided us with essential feedback and comments.

We are at the stage of investigating if there is a *short-term impact* of this condition on quality of life and sexual functioning. Enclosed is the second set of questionnaires, similar to the one you completed previously. The obtained information will help health professionals to better understand the effects of this experience on various aspects of women's wellbeing and to identify their short-term and long-term needs. Our ultimate goal is to improve the health care of women undergoing similar treatments in the future.

Please return the completed questionnaire in the reply paid envelope provided. We would like to reassure you that your feedback is important and relevant to us even if you do not experience any treatment-related difficulties. Your information is kept in the strictest confidence. We are grateful for the time you have dedicated to this project. If you have any questions, please do not hesitate to contact me at any time on 9515 5698.

Yours sincerely,

Ilona Juraskova  
(Research Co-ordinator)

---

Postal address: Medical Psychology Unit, Blackburn Building (DO6), University of Sydney, Australia 2006

A/Prof. Phyllis Butow  
Executive Director  
Ph: 9515 6580

Prof Martin Tattersall  
Director  
Ph: 9351 3675





# MEDICAL PSYCHOLOGY RESEARCH UNIT

The University of Sydney  
DEPARTMENTS OF PSYCHOLOGICAL MEDICINE  
AND MEDICINE, SYDNEY, NSW, 2006, AUSTRALIA

## THE IMPACT OF TREATMENT FOR GYNAECOLOGICAL CANCER ON SEXUALITY AND QUALITY OF LIFE (6 months Follow up)

### What is this questionnaire about?

This questionnaire is similar to the one you completed previously (immediately following the surgery). It is part of a large project investigating the effects of different treatments for gynaecological conditions on quality of life, and particularly on sexual functioning. We hope that this information will help us to better prepare women for these treatments and assist them to adjust once the treatment is over. This questionnaire will allow us to monitor any short-term changes that may have taken place during the recovery period.

### Instructions:

If you have more than one intimate relationship, please select the most important one, and answer the questions with that person in mind. Most questions require you to tick a box which best sums up your opinion or situation. There are no right or wrong answers. We want to ensure that patients get the best care possible, so please say how things really are for you.

**Everything you say will be kept in total confidence by the researchers.  
None of the people treating you will see your answers.**

Please return your completed questionnaire in the reply paid envelope provided. If you have any questions or concerns please phone Ms. Iliana Juraskova (research co-ordinator) on 9515 5698. Please put in the date you complete the questionnaires at the bottom of this page.

**Thank you for your help with this research.**

### SECTION A: Some information about yourself

The first section of this questionnaire asks some general background questions to determine what has changed for you since you last completed our questionnaire.

1. What is your occupation (if retired, past occupation)? .....

Do you work at present ?

- Yes
- No

2. What is your present marital status?

- Never married
- Married or de facto
- Widowed
- Separated but not divorced
- Divorced
- Other (please specify .....

3. Do you have a regular sexual partner?

- Yes
- No

Have you changed your sexual partner since last completing this questionnaire?

- Yes
- No

4. At what stage of your "change of life" are you?

- Pre - menopausal
- During menopause
- Post - menopausal

5. Over the past 6 months, how often have you had a drink containing alcohol?

- Never
- Monthly or less
- 2-4 times a month
- 2-3 times a week
- 4 or more times a week

How many cigarettes do you smoke a day?

- I don't smoke
- 10 or less
- 11-20
- 21-25
- 26 or more

Date: \_\_\_\_\_

Study ID # \_\_\_\_\_

**SECTION B:**

Below is a list of statements that other people with your illness have said are important. By ticking one box per line, please indicate how true each statement has been for you during the **LAST MONTH**.

6. Are you currently taking any of the following medications:

Hormone Replacement Therapy (HRT)  No  Yes

If yes, for how long have you taken HRT:

- <sub>a</sub> 0-7 days
- <sub>b</sub> 1-4 weeks
- <sub>c</sub> 1-6 months
- <sub>d</sub> 6-12 month
- <sub>e</sub> 12+ months

Antidepressants (e.g. Prozac, Zolof)  No  Yes

If yes, for how long have you taken antidepressants:

- <sub>a</sub> 0-7 days
- <sub>b</sub> 1-4 weeks
- <sub>c</sub> 1-6 months
- <sub>d</sub> 6-12 months
- <sub>e</sub> 12+ months

Sedatives (e.g. Rohypnol, Normison)  No  Yes

If yes, for how long have you taken sedatives:

- <sub>a</sub> 0-7 days
- <sub>b</sub> 1-4 weeks
- <sub>c</sub> 1-6 months
- <sub>d</sub> 6-12 months
- <sub>e</sub> 12+ months

7. Within the last six months, have you been in hospital for any psychiatric disorder (e.g. schizophrenia)?

No  Yes

**PHYSICAL WELL-BEING**

- |   | Not at all               | A little bit             | Somewhat                 | Quite a bit              | Very much                |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. I have a lack of energy.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I have nausea.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Because of my physical condition, I have trouble meeting the needs of my family. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I have pain.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am bothered by side effects of treatments.                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I feel sick.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I am forced to spend time in bed.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8. Looking at the above seven questions, how much would you say your **PHYSICAL WELL-BEING** affects your quality of life?

**SOCIAL/FAMILY WELL-BEING**

- |  | Not at all               | A little bit             | Somewhat                 | Quite a bit              | Very much                |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 9. I feel distant from my friends.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I get emotional support from my family.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. I get support from friends and neighbours.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. My family has accepted the illness.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Family communication about my illness is poor.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. I feel close to my partner (or the person who is my main support)  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Have you been sexually active during last 6 months? <input type="checkbox"/> Yes <input type="checkbox"/> No |                          |                          |                          |                          |                          |
| If YES I'm satisfied with my sex life.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

16. Looking at the above seven questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

**RELATIONSHIP WITH DOCTOR**

17. I have confidence in my doctor(s).  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
18. My doctor is available to answer my questions.
19. Looking at the above two questions, how much would you say your **RELATIONSHIP WITH DOCTOR** affects your quality of life?

**EMOTIONAL WELL-BEING**

20. I feel sad.  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
21. I am proud of how I am coping with my illness.
22. I am losing hope in the fight against my illness.
23. I feel nervous.
24. I worry about dying.
25. I worry that my condition will get worse.
26. Looking at the above six questions, how much would you say your **EMOTIONAL WELL-BEING** affects your quality of life?

**FUNCTIONAL WELL-BEING**

27. I am able to work (include work at home).  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
28. My work (include work at home) is fulfilling.
29. I am able to enjoy life.
30. I have accepted my illness.
31. I am sleeping well.
32. I am enjoying the things I usually do for fun.
33. I am content with the quality of my life right now.
34. Looking at the above seven questions, how much would you say your **FUNCTIONAL WELL-BEING** affects your quality of life?

**ADDITIONAL CONCERNS**

35. I am bothered by discharge or bleeding from my vagina.  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
36. I am bothered by odour coming from my vagina.
37. I am afraid to have sex.
38. I feel sexually attractive.
39. My vagina feels too narrow or short.
40. The treatment affected my ability to have children.
41. I am afraid the treatment harmed my body.
42. I am interested in having sex.
43. I like the appearance of my body.
44. I am bothered by bowel problems (e.g. diarrhoea).
45. I have a good appetite.
46. I have trouble controlling my urine.
47. I have burning or discomfort when I urinate.
48. This cancer and its treatment have caused a financial burden.
49. I am able to eat the foods that I like.
50. Looking at the above fifteen questions, how much would you say these **ADDITIONAL CONCERNS** affect your quality of life?

Below you find a list of statements about the relationship between you and your partner. Make your evaluation by ticking one answer that best describes your **CURRENT** satisfaction with your relationship.

	Never	Rarely	Sometimes	Often	Very often
1. I feel happy when I am with my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. We have quarrels.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Things go well between us.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I regret being involved in this relationship.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My partner irritates me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I consider leaving my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I enjoy the company of my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel our relationship will not last.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Below are some statements about sexual satisfaction. Please indicate whether each statement is true or false for each item. **your CURRENT (i.e. POST-TREATMENT) sexual functioning** by ticking either true or false for each item.

	True	False
1. I am satisfied with my sexual partner.	<input type="checkbox"/>	<input type="checkbox"/>
2. I feel I do not have sex frequently enough.	<input type="checkbox"/>	<input type="checkbox"/>
3. There is not enough variety in my sex life.	<input type="checkbox"/>	<input type="checkbox"/>
4. After sex I feel relaxed and fulfilled.	<input type="checkbox"/>	<input type="checkbox"/>
5. Sex does not last long enough.	<input type="checkbox"/>	<input type="checkbox"/>
6. I am not very interested in sex.	<input type="checkbox"/>	<input type="checkbox"/>
7. I have a satisfying orgasm with sex.	<input type="checkbox"/>	<input type="checkbox"/>
8. Foreplay before intercourse is very arousing for me.	<input type="checkbox"/>	<input type="checkbox"/>
9. Often I worry about my sexual performance.	<input type="checkbox"/>	<input type="checkbox"/>
10. My partner and I have good communication about sex.	<input type="checkbox"/>	<input type="checkbox"/>
11. The first post-treatment sexual encounter was satisfying.	<input type="checkbox"/>	<input type="checkbox"/>
12. Who instigated the first post-treatment sexual encounter?	<input type="checkbox"/>	<input type="checkbox"/>

Below is a rating scale on which we would like you to record your personal evaluation of how satisfying your sexual relationship is at **PRESENT** (i.e. following treatment). By ticking the box indicate which statement best describes your present sexual relationship.

- (8) Could not be better
- (7) Excellent
- (6) Good
- (5) Above average
- (4) Adequate
- (3) Somewhat inadequate
- (2) Poor
- (1) Highly inadequate
- (0) Could not be worse

Below we would like you to indicate the frequency with which you **CURRENTLY** engage in certain sexual activities. Please indicate how often you experience each of the sexual activities below by ticking the category that is closest to your personal frequency.

	Not at all	Less than once a month	1-2 times a month	Once a week	2-3 times per week	4-6 times per week	Once a day	2-3 times per day	4+ times per day
INTERCOURSE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MASTURBATION	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
KISSING & PETTING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SEXUAL FANTASIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT WOULD BE YOUR IDEAL FREQUENCY OF SEXUAL INTERCOURSE?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

OVERALL, by ticking a box indicate how much has the treatment affected your sexual functioning?

Not at all	A little bit	Somewhat	Much	Very Much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If changed, was this for better  or for worse ?

Please tick one response for each of the questions below:

1. After my treatment my vagina
  - became completely closed
  - became smaller or tighter
  - perhaps changed in size – I am not sure
  - became larger or looser
  - does not seem to have changed size compared to before treatment
2. When I have had sexual relations after my treatment my vagina was
  - this does not concern me because I do not have a partner
  - completely dry
  - I do not know if my vagina was dry or wet
  - a little dry
  - normally wet
3. Since the end of my treatment, I have had reduced sensations in my genitals
  - not at all
  - a little bit
  - somewhat
  - quite a bit
  - a lot
4. Since the end of my treatment, I have felt
  - no sexual excitement or "turn on"
  - a little sexual excitement
  - some sexual excitement but less than before treatment
  - normally sexually excited
5. My doctor talked about my sex life (you can tick more than one box)
  - not at all
  - I do not remember if he/she talked about it
  - before my treatment
  - during my treatment
  - after the end of my treatment
6. If I had a choice, I would like my doctor
  - not to speak to me about sexual matters
  - to speak to me about sexual matters

If I had a partner, I would like my doctor

  - to speak to my partner about sexual matters
  - to speak to my partner and to myself about sexual matters, but not together
  - to speak to both my partner and myself together about sexual matters

7. If I had a choice, I would like to receive sexual information from
  - nobody – I do not want any information
  - a female health care worker (doctor, nurse, social worker, psychologist)
  - a female doctor only
  - a male health care worker (doctor, nurse, social worker, psychologist)
  - either a male or a female health care worker

8. I would like to receive information about sexual expectations following treatment
  - not at all
  - prior to the first treatment
  - immediately following the first treatment
  - during my first follow-up consultation
  - on my request when queries arise
  - all of the above

9. Because of my illness, I believe a partner
  - could "catch" my illness even if we did not have sexual relations
  - could become sick or hurt if we had sexual relations
  - could not be harmed provided we did not have sexual relations
  - could not be harmed if we had sexual relations

10. My partner
  - this does not concern me because I do not have a partner
  - is afraid that he/she will "catch" my illness
  - is afraid that my treatment (such as radiotherapy) will harm him/her
  - does not know very much about my illness and its treatment
  - knows that neither my illness nor its treatment can harm him/her

11. I received a vaginal dilator
  - not at all
  - just after my radiation treatment
  - one month after the end of my treatment
  - two to three months after the end of my treatment
  - more than three months after the end of my treatment

I was given sufficient explanation on the use of a dilator:

- Yes
- No
- Not applicable

12. I use a vaginal dilator
  - not at all because it was not given or prescribed to me
  - not at all even though it was given or prescribed to me
  - less often than recommended
  - as often as I was told to use it
  - more often than I was told to use it

Below is a list of common side effects experienced by women who had been treated for conditions similar to yours. By ticking the appropriate box, please indicate which side effect you believe resulted from which particular treatment.

**Have you experienced the following side effects after your cancer treatment?**

- **Bowel problems (e.g. diarrhoea, constipation):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Shortened vagina:**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Bladder problems (eg. loss of bladder control, burning when passing urine):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Nerve damage/Numbness (in the pelvic area):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Onset of menopause:**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know

**Have you experienced the following side effects after your cancer treatment?**

- **Dry vagina:**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Lymphoedema (seen as swelling of the legs):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Painful intercourse (dyspareunia):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Damage to skin (scarring or burns in the pelvic area):**  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know
  
- **Did you experience any side effects not listed above? (please specify):** \_\_\_\_\_  
 No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A. Surgery  B. External Radiotherapy  C. Brachytherapy  D. Other: \_\_\_\_\_  E. I don't know

Please, tick the appropriate box indicating how long it has been since you had each of the following treatments:

◆ I had surgery (e.g. radical hysterectomy, total abdominal hysterectomy):

- not applicable (I did not have surgery)
- less than a month ago
- 1 - 6 months ago
- 6-12 months ago

◆ I had external beam radiation treatment:

- not applicable (I did not have external radiotherapy)
- less than a month ago
- 1 - 6 months ago
- 6-12 months ago

◆ I had internal (cesium) radiation treatment (brachytherapy):

- not applicable (I did not have brachytherapy)
- less than a month ago
- 1 - 6 months ago
- 6-12 months ago

Listed below are common issues experienced by women who had been treated for conditions similar to yours. By circling one number per column please indicate the extent to which each statement is true for you in relation to particular treatment. Please ignore any treatment you did not receive.

	Surgery	External Beam Radiotherapy	Internal (Cesium) Radiotherapy
Example: The treatment and its effects side were invasive	Not at all 0 A little bit 1 Somewhat 2 Quite a bit 3 Very much 4	Not at all 0 A little bit 1 Somewhat 2 Quite a bit 3 Very much 4	Not at all 0 A little bit 1 Somewhat 2 Quite a bit 3 Very much 4
The treatment and its side effects have reduced my femininity / womanhood	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have changed my physical appearance	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
I was prepared for the treatment and its side effects	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
I felt confident that nothing would go wrong during the treatment	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have affected my sexual functioning	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have made me infertile	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4

Below is a list of words that describe feelings experienced by women who have been treated for conditions similar to yours. By putting a slash through the line for each treatment please indicate the degree to which each emotion best describes your feelings related to each treatment. Ignore lines for any treatment you did NOT receive.

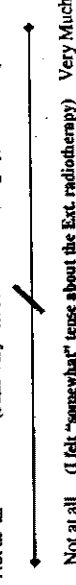
**Example:**

I felt tense

Surgery:



External radiotherapy:



Brachytherapy:



I felt embarrassed

Surgery:



External radiotherapy:



Brachytherapy:



I felt relieved

Surgery:



External radiotherapy:



Brachytherapy:



I felt depressed

Surgery:



External radiotherapy:



Brachytherapy:



*I felt anxious/worried*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt informed*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt degraded*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt angry*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt accepting*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt revolted*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt in control*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt isolated*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much



Please, read each item and tick the box next to the reply which comes closest to how you have been feeling in the PAST WEEK. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or "wound up":
- Most of the time
  - A lot of time
  - From time to time, occasionally
  - Not at all

2. I still enjoy the things I used to enjoy:
- Definitely as much
  - Not quite so much
  - Only a little
  - Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely & quite badly
  - Yes, but not too badly
  - A little but it doesn't worry me
  - Not at all

4. I can laugh and see the funny side of things:
- As much as I always could
  - Not quite so much now
  - Definitely not so much now
  - Not at all

5. Worrying thoughts go through my mind:
- A great deal of the time
  - A lot of time
  - From time to time but not too often
  - Only occasionally

6. I feel cheerful:
- Not at all
  - Not often
  - Sometimes
  - Most of the time

7. I can sit at ease and feel relaxed:
- Definitely
  - Usually
  - Not often
  - Not at all

8. I feel as if I am slowed down:
- Nearly all the time
  - Very often
  - Sometimes
  - Not at all

I felt scared

Surgery:  Not at all  Very Much

External radiotherapy:  Not at all  Very Much

Brachytherapy:  Not at all  Very Much

I felt numb

Surgery:  Not at all  Very Much

External radiotherapy:  Not at all  Very Much

Brachytherapy:  Not at all  Very Much

I felt shocked

Surgery:  Not at all  Very Much

External radiotherapy:  Not at all  Very Much

Brachytherapy:  Not at all  Very Much

I felt frustrated

Surgery:  Not at all  Very Much

External radiotherapy:  Not at all  Very Much

Brachytherapy:  Not at all  Very Much

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- Not at all  
 Occasionally  
 Quite often  
 Very often

10. I have lost interest in my appearance:

- Definitely  
 I don't take so much care as I should  
 I may not take quite as much care  
 I take just as much care as ever

11. I feel restless, as if I have to be on the move:

- Very much indeed  
 Quite a lot  
 Not very much  
 Not at all

12. I look forward with enjoyment to things:

- As much as I ever did  
 Rather less than I used to  
 Definitely less than I used to  
 Hardly at all

13. I get sudden feelings of panic:

- Very often indeed  
 Quite often  
 Not very much  
 Not at all

14. I can enjoy a good book or radio or TV programme:

- Often  
 Sometimes  
 Not often  
 Very seldom

A number of statements are given below which describe people's reactions to having cancer. Please tick the appropriate box, indicating how far it applies to you **AT PRESENT**.

- |  | <i>Definitely does not apply to me</i> | <i>Does not apply to me</i> | <i>Applies to me</i>     | <i>Definitely applies to me</i> |
|--|--|-----------------------------|--------------------------|---------------------------------|
| 1. I felt like giving up.                                  | <input type="checkbox"/>               | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/>        |
| 2. I am upset about having cancer.                         | <input type="checkbox"/>               | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/>        |
| 3. I am determined to beat this disease.                   | <input type="checkbox"/>               | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/>        |
| 4. I make a positive effort not to think about my illness. | <input type="checkbox"/>               | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/>        |

*Definitely does not apply to me*

*Applies to me*

*Does not apply to me*

*Definitely applies to me*

5. I've had a good life; what's left is a bonus.

6. I feel that life is hopeless.

7. It is a devastating feeling.

8. I see my illness as a challenge.

9. Not thinking about it helps me cope.

10. I've put myself in the hands of God.

11. I feel completely at a loss about what to do.

12. I suffer great anxiety about it.

13. I try to fight the illness.

14. I deliberately push all thoughts of cancer out of my mind.

15. Since my cancer diagnosis I now realize how precious life is and I'm making the best of it.

16. I can't handle it.

17. I am a little frightened.

18. I am very optimistic.

19. I distract myself when my thoughts about my illness come to my head

20. I count my blessings.

21. I feel there is nothing I can do to help myself.

22. I worry about the cancer returning or getting worse.

23. At the moment I take one day at a time.

24. I think it is the end of the world.

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
25. I feel very angry about what has happened to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I can't cope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I have difficulty in believing that this has happened to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I am not very hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I am apprehensive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please write any comments about your experience (both positive and negative) which have not been covered by the questionnaire (if you run out of space, please continue on the back of this page):*

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
5. I've had a good life; what's left is a bonus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel that life is hopeless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. It is a devastating feeling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I see my illness as a challenge.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Not thinking about it helps me cope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I've put myself in the hands of God.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel completely at a loss about what to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I suffer great anxiety about it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I try to fight the illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I deliberately push all thoughts of cancer out of my mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Since my cancer diagnosis I now realize how precious life is and I'm making the best of it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I can't handle it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am a little frightened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am very optimistic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I distract myself when my thoughts about my illness come to my head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I count my blessings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I feel there is nothing I can do to help myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I worry about the cancer returning or getting worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. At the moment I take one day at a time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I think it is the end of the world.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# The Medical Psychology Research Unit

The University of Sydney  
*In collaboration with*  
Royal North Shore Hospital and  
Royal Prince Alfred Hospital

Telephone 61 2 9515 6580  
Facsimile 61 2 9515 5697  
Email medpsych@mail.usyd.edu.au

---

## RESEARCH INTO PSYCHO-ONCOLOGICAL ASPECTS OF PATIENT'S NEEDS

Dear

Thank you for your valuable contribution to the research project investigating the quality of life of women following treatment for gynaecological conditions. Your responses obtained from previous questionnaires provided us with essential feedback and comments.

We are at the stage of investigating if there is a *long-term impact* of this condition on quality of life and sexual functioning. Enclosed is the last set of questionnaires, similar to the ones you completed previously. The obtained information will help health professionals to better understand the effects of this experience on various aspects of women's wellbeing and to identify their short-term and long-term needs. Our ultimate goal is to improve the health care of women undergoing similar treatments in the future.

Please return the completed questionnaire in the reply paid envelope provided. We would like to reassure you that your feedback is important and relevant to us even if you do not experience any treatment-related difficulties. Your information is kept in the strictest confidence. We are grateful for the time you have dedicated to this project. If you have any questions, please do not hesitate to contact me at any time on 9515 5698.

Yours sincerely,

Ilona Juraskova  
(Research Co-ordinator)

---

Postal address: Medical Psychology Unit, Blackburn Building (DO6), University of Sydney, Australia 2006

A/Prof. Phyllis Butow  
Executive Director  
Ph: 9515 6580

Prof Martin Tattersall  
Director  
Ph: 9351 3675



# MEDICAL PSYCHOLOGY RESEARCH UNIT

The University of Sydney  
DEPARTMENTS OF PSYCHOLOGICAL MEDICINE  
AND MEDICINE, SYDNEY, NSW, 2006, AUSTRALIA

## THE IMPACT OF TREATMENT FOR GYNAECOLOGICAL CANCER ON SEXUALITY AND QUALITY OF LIFE (12 months Follow up)

### What is this questionnaire about?

This questionnaire is similar to the ones you completed previously (immediately following the surgery and at 6 months post-treatment). It is part of a large project investigating the effects of different treatments for gynaecological conditions on quality of life, and particularly on sexual functioning. We hope that this information will help us to better prepare women for these treatments and to assist them in adjusting once the treatment is over. The current questionnaire will allow us to monitor any long-term changes that may have taken place during the recovery period.

### Instructions:

If you have more than one intimate relationship, please select the most important one, and answer the questions with that person in mind. Most questions require you to tick a box which best sums up your opinion or situation. There are no right or wrong answers. We want to ensure that patients get the best care possible, so please say how things really are for you.

Everything you say will be kept in total confidence by the researchers.  
None of the people treating you will see your answers.

Please return your completed questionnaire in the reply paid envelope provided. If you have any questions or concerns please phone Ms. Ilona Juraskova (research co-ordinator) on 9515 5698. Please put in the date you complete the questionnaires at the bottom of this page.

**Thank you for your help with this research.**

Date: \_\_\_\_\_

Study ID # \_\_\_\_\_

### SECTION A: Some information about yourself

The first section of this questionnaire asks some general background questions to determine what has changed for you since you last completed our questionnaire.

1. What is your occupation (if retired, past occupation)? .....

Do you work at present?

- 1, Yes
- 2, No

2. What is your present marital status?

- 1, Never married
- 2, Married or de facto
- 3, Widowed
- 4, Separated but not divorced
- 5, Divorced
- 6, Other (please specify .....

3. Do you have a regular sexual partner?

- 1, Yes
- 2, No

Have you changed your sexual partner since last completing this questionnaire?

- 1, Yes
- 2, No

4. At what stage of your "change of life" are you?

- 1, Pre - menopausal
- 2, During menopause
- 3, Post - menopausal

5. Over the past 6 months, how often have you had a drink containing alcohol?

- 1, Never
- 2, Monthly or less
- 3, 2-4 times a month
- 4, 2-3 times a week
- 5, 4 or more times a week

How many cigarettes a day do you smoke?

- 1, I don't smoke
- 2, 10 or less
- 3, 11-20
- 4, 21-25
- 5, 26 or more

**SECTION B:**

Below is a list of statements that other people with your illness have said are important. By ticking one box per line, please indicate how true each statement has been for you during the **LAST MONTH**.

6. Are you currently taking any of the following medications:

Hormone Replacement Therapy (HRT)  No  Yes

If yes, for how long have you taken HRT:

- a 0-7 days
- b 1-4 weeks
- c 1-6 months
- d 6-12 months
- e 12+ months

Antidepressants (e.g. Prozac, Zoloft)  No  Yes

If yes, for how long have you taken antidepressants:

- a 0-7 days
- b 1-4 weeks
- c 1-6 months
- d 6-12 months
- e 12+ months

Sedatives (e.g. Rohypnol, Normison)  No  Yes

If yes, for how long have you taken sedatives:

- a 0-7 days
- b 1-4 weeks
- c 1-6 months
- d 6-12 months
- e 12+ months

7. Within the last six months, have you been in hospital for any psychiatric disorder (e.g. schizophrenia)?

- No
- Yes

**PHYSICAL WELL-BEING**

Not at all  A little bit  Somewhat  Quite a bit  Very much

1. I have a lack of energy.
2. I have nausea.
3. Because of my physical condition, I have trouble meeting the needs of my family.
4. I have pain.
5. I am bothered by side effects of treatments.
6. I feel sick.
7. I am forced to spend time in bed.
8. Looking at the above seven questions, how much would you say your **PHYSICAL WELL-BEING** affects your quality of life?

**SOCIAL/FAMILY WELL-BEING**

Not at all  A little bit  Somewhat  Quite a bit  Very much

9. I feel distant from my friends.
10. I get emotional support from my family.
11. I get support from friends and neighbours.
12. My family has accepted the illness.
13. Family communication about my illness is poor.
14. I feel close to my partner (or the person who is my main support)
15. Have you been sexually active during last 6 months?  Yes  No  
If YES I'm satisfied with my sex life.
16. Looking at the above seven questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

**RELATIONSHIP WITH DOCTOR**

17. I have confidence in my doctor(s).  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
18. My doctor is available to answer my questions.
19. Looking at the above two questions, how much would you say your **RELATIONSHIP WITH DOCTOR** affects your quality of life?

**EMOTIONAL WELL-BEING**

20. I feel sad.  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
21. I am proud of how I am coping with my illness.
22. I am losing hope in the fight against my illness.
23. I feel nervous.
24. I worry about dying.
25. I worry that my condition will get worse.
26. Looking at the above six questions, how much would you say your **EMOTIONAL WELL-BEING** affects your quality of life?

**FUNCTIONAL WELL-BEING**

27. I am able to work (include work at home).  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
28. My work (include work at home) is fulfilling.
29. I am able to enjoy life.
30. I have accepted my illness.
31. I am sleeping well.
32. I am enjoying the things I usually do for fun.
33. I am content with the quality of my life right now.
34. Looking at the above seven questions, how much would you say your **FUNCTIONAL WELL-BEING** affects your quality of life?

**ADDITIONAL CONCERNS**

35. I am bothered by discharge or bleeding from my vagina.  
 Not at all  A little bit  Somewhat  Quite a bit  Very much
36. I am bothered by odour coming from my vagina.
37. I am afraid to have sex.
38. I feel sexually attractive.
39. My vagina feels too narrow or short.
40. The treatment affected my ability to have children.
41. I am afraid the treatment harmed my body.
42. I am interested in having sex.
43. I like the appearance of my body.
44. I am bothered by bowel problems (e.g. diarrhoea).
45. I have a good appetite.
46. I have trouble controlling my urine.
47. I have burning or discomfort when I urinate.
48. This cancer and its treatment have caused a financial burden.
49. I am able to eat the foods that I like.
50. Looking at the above fifteen questions, how much would you say these **ADDITIONAL CONCERNS** affect your quality of life?

Below you find a list of statements about the relationship between you and your partner. Make your evaluation by ticking one answer that best describes your **CURRENT** satisfaction with your relationship.

- |  | Never                    | Rarely                   | Sometimes                | Often                    | Very often               |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. I feel happy when I am with my partner.       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. We have quarrels.                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Things go well between us.                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I regret being involved in this relationship. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. My partner irritates me.                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I consider leaving my partner.                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I enjoy the company of my partner.            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I feel our relationship will not last.        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Below are some statements about sexual satisfaction. Please indicate whether each statement is true of your **CURRENT** (i.e. **POST-TREATMENT**) sexual functioning by ticking either true or false for each item.

- |   | True                     | False                    |
|---|--------------------------|--------------------------|
| 1. I am satisfied with my sexual partner.                           | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I feel I do not have sex frequently enough.                      | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. There is not enough variety in my sex life.                      | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. After sex I feel relaxed and fulfilled.                          | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Sex does not last long enough.                                   | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am not very interested in sex.                                 | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I have a satisfying orgasm with sex.                             | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Foreplay before intercourse is very arousing for me.             | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Often I worry about my sexual performance.                       | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. My partner and I have good communication about sex.             | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. The <b>post-treatment</b> sexual encounters are satisfying.     | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Who usually instigates <b>post-treatment</b> sexual encounters? | <input type="checkbox"/> | <input type="checkbox"/> |

Below is a rating scale on which we would like you to record your personal evaluation of how satisfying your sexual relationship is at **PRESENT**. By ticking the box indicate which statement best describes your present sexual relationship.

- (8) Could not be better
- (7) Excellent
- (6) Good
- (5) Above average
- (4) Adequate
- (3) Somewhat inadequate
- (2) Poor
- (1) Highly inadequate
- (0) Could not be worse

Below we would like you to indicate the frequency with which you **CURRENTLY** engage in certain sexual activities. Please indicate how often you experience each of the sexual activities below by ticking the category that is closest to your personal frequency.

- |                   | Now or all               | Less than once a month   | 1-2 times a month        | Once a week              | 2-3 times per week       | 4-6 times per week       | Once a day               | 2-3 times per day        | 4+ times per day         |
|-------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| INTERCOURSE       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| MASTURBATION      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| KISSING & PETTING | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| SEXUAL FANTASIES  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

WHAT WOULD BE YOUR IDEAL FREQUENCY OF SEXUAL INTERCOURSE?

- |                          |                          |                          |                          |                          |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|

**OVERALL**, by ticking a box indicate how much has the treatment affected your sexual functioning?

- |                                     |                                       |                                   |                               |                                    |                                    |
|-------------------------------------|---------------------------------------|-----------------------------------|-------------------------------|------------------------------------|------------------------------------|
| Not at all <input type="checkbox"/> | A little bit <input type="checkbox"/> | Somewhat <input type="checkbox"/> | Much <input type="checkbox"/> | Very Much <input type="checkbox"/> | Extremely <input type="checkbox"/> |
|-------------------------------------|---------------------------------------|-----------------------------------|-------------------------------|------------------------------------|------------------------------------|

If changed, was this for better  or for worse  ?



Please tick one response for each of the questions below:

1. After my treatment my vagina
- became completely closed
  - became smaller or tighter
  - perhaps changed in size - I am not sure
  - became larger or looser
  - does not seem to have changed size compared to before treatment
2. When I have had sexual relations after my treatment my vagina was
- this does not concern me because I do not have a partner
  - completely dry
  - I do not know if my vagina was dry or wet
  - a little dry
  - normally wet
3. Since the end of my treatment, I have had reduced sensations in my genitals
- not at all
  - a little bit
  - somewhat
  - quite a bit
  - a lot
4. Since the end of my treatment, I have felt
- no sexual excitement or "turn on"
  - a little sexual excitement
  - some sexual excitement but less than before treatment
  - normally sexually excited
5. My doctor talked about my sex life (you can tick more than one box)
- not at all
  - I do not remember if he/she talked about it
  - before my treatment
  - during my treatment
  - after the end of my treatment
6. If I had a choice, I would like my doctor
- not to speak to me about sexual matters
  - to speak to me about sexual matters
- If I had a partner, I would like my doctor
- to speak to my partner about sexual matters
  - to speak to my partner and to myself about sexual matters, but not together
  - to speak to both my partner and myself together about sexual matters

7. If I had a choice, I would like to receive sexual information from
- nobody - I do not want any information
  - a female health care worker (doctor, nurse, social worker, psychologist)
  - a female doctor only
  - a male health care worker (doctor, nurse, social worker, psychologist)
  - either a male or a female health care worker

8. I would like to receive information about sexual expectations following treatment
- not at all
  - prior to the first treatment
  - immediately following the first treatment
  - during my first follow-up consultation
  - on my request when queries arise
  - all of the above

9. Because of my illness, I believe a partner
- could "catch" my illness even if we did not have sexual relations
  - could become sick or hurt if we had sexual relations
  - could not be harmed provided we did not have sexual relations
  - could not be harmed if we had sexual relations

10. My partner
- this does not concern me because I do not have a partner
  - is afraid that he/she will "catch" my illness
  - is afraid that my treatment (such as radiotherapy) will harm him/her
  - does not know very much about my illness and its treatment
  - knows that neither my illness nor its treatment can harm him/her

11. I received a vaginal dilator
- not at all
  - just after my radiation treatment
  - one month after the end of my treatment
  - two to three months after the end of my treatment
  - more than three months after the end of my treatment

I was given sufficient explanation on the use of a dilator:

- Yes
- No
- Not applicable

12. I use a vaginal dilator
- not at all because it was not given or prescribed to me
  - not at all even though it was given or prescribed to me
  - less often than recommended
  - as often as I was told to use it
  - more often than I was told to use it

Below is a list of common side effects experienced by women who had been treated for conditions similar to yours. By ticking the appropriate box, please indicate which side effect you believe resulted from which particular treatment.

Have you experienced the following side effects after your cancer treatment?

- Bowel problems (e.g. diarrhoea, constipation):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Shortened vagina:  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Bladder problems (eg. loss of bladder control, burning when passing urine):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Nerve damage/Numbness (in the pelvic area):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Onset of menopause:  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know

Have you experienced the following side effects after your cancer treatment?

- Dry vagina:  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Lymphoedema (seen as swelling of the legs):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Painful intercourse (dyspareunia):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Damage to skin (scarring or burns in the pelvic area):  No  Yes  
 If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know
- Did you experience any side effects not listed above? (please specify): \_\_\_\_\_  
 No  Yes

If yes, which treatment (if any) do you think was predominantly responsible for this side effect?  
 A Surgery  B External Radiotherapy  C Brachytherapy  D Other: \_\_\_\_\_  E I don't know

Please, tick the appropriate box indicating how long it has been since you had each of the following treatments:

◆ I had surgery (e.g. radical hysterectomy, total abdominal hysterectomy):

- not applicable (I did not have surgery)  
 6-12 months ago  
 12-18 months ago  
 18+ months ago

◆ I had external beam radiation treatment:

- not applicable (I did not have external radiotherapy)  
 6-12 months ago  
 12-18 months ago  
 18+ months ago

◆ I had internal (cesium) radiation treatment (brachytherapy):

- not applicable (I did not have brachytherapy)  
 6-12 months ago  
 12-18 months ago  
 18+ months ago

Listed below are common issues experienced by women who had been treated for conditions similar to yours. By circling one number per column please indicate the extent to which each statement is true for you in relation to particular treatment. Please ignore any treatment you did not receive.

	Surgery	External Beam Radiotherapy	Internal (Cesium) Radiotherapy
Example: The treatment and its effects side were invasive	Not at all A little bit Somewhat Quite a bit Very much 0 1 2 3 4 ②	Not at all A little bit Somewhat Quite a bit Very much 0 1 2 3 4 ①	Not at all A little bit Somewhat Quite a bit Very much 0 1 2 3 4 ①
The treatment and its side effects have reduced my femininity / womanhood	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have changed my physical appearance	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
I was prepared for the treatment and its side effects	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
I felt confident that nothing would go wrong during the treatment	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have affected my sexual functioning	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
The treatment and its side effects have made me infertile	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4

Below is a list of words that describe feelings experienced by women who have been treated for conditions similar to yours. By putting a slash through the line for each treatment please indicate the degree to which each emotion best describes your feelings related to each treatment. Ignore lines for any treatment you did NOT receive.

### Example:

<u>I felt tense</u>	Surgery:	External radiotherapy:	Brachytherapy:
	Not at all ————— Very Much (I felt very "tense" about the Surgery)	Not at all ————— Very Much (I felt "somewhat" tense about the Ext. radiotherapy)	Not at all ————— Very Much (I did not have any Brachytherapy -> leave blank)

### I felt embarrassed

Surgery:	Not at all ————— Very Much
External radiotherapy:	Not at all ————— Very Much
Brachytherapy:	Not at all ————— Very Much

### I felt relieved

Surgery:	Not at all ————— Very Much
External radiotherapy:	Not at all ————— Very Much
Brachytherapy:	Not at all ————— Very Much

### I felt depressed

Surgery:	Not at all ————— Very Much
External radiotherapy:	Not at all ————— Very Much
Brachytherapy:	Not at all ————— Very Much

*I felt anxious/worried*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt informed*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt degraded*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt angry*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt accepting*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt revolted*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt in control*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

*I felt isolated*

Surgery: Not at all ————— Very Much

External radiotherapy: Not at all ————— Very Much

Brachytherapy: Not at all ————— Very Much

Please, read each item and tick the box next to the reply which comes closest to how you have been feeling in the PAST WEEK. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or "wound up":
- Most of the time  
 A lot of time  
 From time to time, occasionally  
 Not at all

2. I still enjoy the things I used to enjoy:
- Definitely as much  
 Not quite so much  
 Only a little  
 Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely & quite badly  
 Yes, but not too badly  
 A little but it doesn't worry me  
 Not at all













4. I can laugh and see the funny side of things:
- As much as I always could  
 Not quite so much now  
 Definitely not so much now  
 Not at all

5. Worrying thoughts go through my mind:
- A great deal of the time  
 A lot of time  
 From time to time but not too often  
 Only occasionally

6. I feel cheerful:
- Not at all  
 Not often  
 Sometimes  
 Most of the time

7. I can sit at ease and feel relaxed:
- Definitely  
 Usually  
 Not often  
 Not at all

8. I feel as if I am slowed down:
- Nearly all the time  
 Very often  
 Sometimes  
 Not at all

<b><u>I felt scared</u></b>	
Surgery:	Not at all  Very Much
External radiotherapy:	Not at all  Very Much
Brachytherapy:	Not at all  Very Much
<b><u>I felt numb</u></b>	
Surgery:	Not at all  Very Much
External radiotherapy:	Not at all  Very Much
Brachytherapy:	Not at all  Very Much
<b><u>I felt shocked</u></b>	
Surgery:	Not at all  Very Much
External radiotherapy:	Not at all  Very Much
Brachytherapy:	Not at all  Very Much
<b><u>I felt frustrated</u></b>	
Surgery:	Not at all  Very Much
External radiotherapy:	Not at all  Very Much
Brachytherapy:	Not at all  Very Much



	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
25. I feel very angry about what has happened to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I can't cope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I have difficulty in believing that this has happened to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I am not very hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I am apprehensive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

*Please write any comments about your experience (both positive and negative) which have not been covered by the questionnaire (if you run out of space, please continue on the back of this page):*



# The Medical Psychology Research Unit

The University of Sydney  
*In collaboration with*  
Royal North Shore Hospital and  
Royal Prince Alfred Hospital

Telephone 61 2 9515 6580  
Facsimile 61 2 9515 5697  
Email medpsych@mail.usyd.edu.au

---

## RESEARCH INTO PSYCHO-ONCOLOGICAL ASPECTS OF PATIENT'S NEEDS

Dear

Thank you for returning your final questionnaire. Your support and co-operation is greatly appreciated. We will send you a brief summary of our findings when all the information has been finalised and interpreted. The services of our department are available to you, should you feel the need to take advantage of them. Feel free to contact me at any time on 9515 5698.

Thank you again for sharing your experiences with us.

Yours sincerely,

Ilona Juraskova  
(Research co-ordinator)

---

Postal address: Medical Psychology Unit, Blackburn Building (DO6), University of Sydney, Australia 2006

A/Prof. Phyllis Butow  
Executive Director  
Ph: 9515 6580

Prof Martin Tattersall  
Director  
Ph: 9351 3675



CORRELATIONAL MATRIX: Demographic characteristics and Baseline outcome variables (i.e. DSRI, FACT scales)

	AGE	MARITAL status	EDUCATION	OCCUPATION	CHILDREN	Base: PHYSICAL wellbeing	Base: FUNCTIONAL wellbeing	Base: SOCIAL wellbeing	Base: EMOTIONAL wellbeing	Base: Dr-Patient Rship.	Base: TOTAL Oot. score	Base: Ca wellbeing	Base: RSHIP SATISFACTION	Base: SEX SATISFACTION	Base: SEX DRIVE	Base: GSSI
AGE	1.000	-.259**	-.164*	-.024	.522**	-.111	-.154**	.103	.351**	.330**	.064	-.135	-.179**	-.134	-.495**	-.126
Pearson Correlation																
Sig. (2-tailed)		.000	.022	.745	.000	.124	.032	.151	.000	.061	.360	.061	.029	.064	.000	.108
N	197	197	188	188	197	195	195	195	195	195	189	195	150	168	175	165
MARITAL status		1.000	.093	-.114	-.328**	.180**	-.110	-.182**	-.102	.027	-.017	.147**	.157	.053	.160*	.009
Pearson Correlation																
Sig. (2-tailed)		.000	.197	.121	.000	.012	.126	.007	.012	.027	.822	.041	.054	.492	.035	.904
N	197	197	195	188	197	195	195	195	195	195	189	195	150	175	165	165
EDUCATION			1.000	-.462**	-.354**	-.034	.046	-.120	-.086	.022	-.078	.065	.024	.019	.166*	.028
Pearson Correlation																
Sig. (2-tailed)		.093	.000	.000	.000	.642	.523	.088	.237	.002	.286	.776	.811	.029	.720	.720
N	195	195	195	188	195	193	193	193	193	193	187	193	148	166	173	163
OCCUPATION			-.462**	1.000	.233**	.019	-.045	.039	.023	.091	.019	-.209**	.075	-.083	-.159*	-.109
Pearson Correlation																
Sig. (2-tailed)		.121	.000	.000	.001	.795	.539	.596	.372	.298	.004	.372	.298	.040	.175	.175
N	188	188	188	188	188	186	186	186	186	186	181	186	142	160	167	157
CHILDREN			-.354**	.233**	1.000	-.107	-.216**	.065	.086	.234**	-.040	-.210**	.021	.003	-.353*	-.009
Pearson Correlation																
Sig. (2-tailed)		.000	.000	.001	.000	.137	.002	.235	.234	.001	.586	.003	.800	.969	.000	.906
N	197	197	195	188	197	195	195	195	195	195	189	195	150	175	165	165
Base: PHYSICAL wellbeing			-.034	.019	-.107	1.000	.574**	.239**	.223**	.129	.720**	.437**	-.037	.206**	.014	.124
Pearson Correlation																
Sig. (2-tailed)		.012	.642	.795	.137	.073	.000	.002	.002	.073	.000	.000	.650	.007	.855	.112
N	195	195	193	186	195	195	195	195	195	195	189	195	150	168	175	165
Base: FUNCTIONAL wellbeing			.046	.019	-.216**	.574**	1.000	.346**	.308**	.139	.804**	.529**	-.221**	.244**	.179*	.231**
Pearson Correlation																
Sig. (2-tailed)		.126	.523	.539	.002	.000	.000	.000	.000	.052	.000	.000	.007	.001	.018	.003
N	195	195	193	186	195	195	195	195	195	195	189	195	150	175	165	165
Base: SOCIAL wellbeing			-.120	.039	.085	.239**	.346**	1.000	.272**	.302**	.671**	.253**	-.462**	.312**	.126	.383**
Pearson Correlation																
Sig. (2-tailed)		.007	.098	.596	.235	.001	.000	.000	.000	.000	.000	.000	.000	.027	.095	.000
N	195	195	193	186	195	195	195	195	195	195	189	195	150	175	165	165
Base: EMOTIONAL wellbeing			-.086	.023	.086	.223**	.308**	.272**	1.000	.145*	.601**	.424**	-.336**	.170*	.188*	.086
Pearson Correlation																
Sig. (2-tailed)		.156	.193	.750	.234	.002	.000	.000	.000	.044	.000	.000	.000	.027	.013	.272
N	195	195	193	186	195	195	195	195	195	195	189	195	150	168	175	165
Base: Dr-Patient Rship			-.221**	.091	.234**	.129	.139	.302**	.145*	1.000	.358**	.578**	-.051	.027	-.204**	-.062
Pearson Correlation																
Sig. (2-tailed)		.027	.002	.217	.001	.073	.052	.195	.044	.195	.189	.189	.150	.188	.007	.430
N	195	195	193	186	195	195	195	195	195	195	189	195	150	175	165	165
Base: TOTAL Oot. score			-.078	.019	-.040	.720**	.804**	.671**	.601**	.358**	1.000	.578**	-.360**	.326**	.048	.284**
Pearson Correlation																
Sig. (2-tailed)		.822	.286	.800	.586	.000	.000	.000	.000	.000	.000	.000	.000	.000	.535	.000
N	189	189	187	181	189	189	189	189	189	189	189	147	150	146	146	143
Base: Ca wellbeing			.065	-.208**	-.210**	.437**	.529**	.253**	.424**	.086	.579**	1.000	-.172*	.316*	.196**	.259*
Pearson Correlation																
Sig. (2-tailed)		.041	.366	.004	.003	.000	.000	.000	.000	.232	.000	.000	.036	.000	.009	.001
N	195	195	193	186	195	195	195	195	195	195	189	195	150	168	175	165
Base: RSHIP SATISFACTION			-.024	.075	.021	-.037	-.221**	-.462**	-.336**	-.051	-.360**	-.172*	1.000	-.360**	-.126	-.419**
Pearson Correlation																
Sig. (2-tailed)		.054	.776	.372	.800	.650	.007	.000	.000	.532	.000	.036	.000	.000	.131	.000
N	150	150	148	142	150	150	150	150	150	150	147	150	150	146	146	143
Base: SEX SATISFACTION			.019	-.083	.003	.206**	.244**	.312**	.170**	.027	.725	.316**	1.000	1.000	.350**	.632**
Pearson Correlation																
Sig. (2-tailed)		.084	.811	.298	.969	.007	.001	.000	.027	.725	.000	.000	.000	.000	.000	.000
N	168	168	166	160	168	168	168	168	168	168	166	168	146	168	163	164
Base: SEX DRIVE			.166*	-.159*	-.353**	.014	.179*	.126	.188*	-.204**	.048	.196**	-.126	.350**	1.000	.397**
Pearson Correlation																
Sig. (2-tailed)		.035	.029	.040	.000	.855	.018	.009	.013	.007	.131	.000	.000	.000	.000	.000
N	175	175	173	173	175	175	175	175	175	175	171	175	146	163	175	162
Base: GSSI			.028	-.109	-.009	.124	.231**	.383**	.086	-.062	.284**	.259**	-.419**	.632**	.397**	1.000
Pearson Correlation																
Sig. (2-tailed)		.904	.720	.175	.906	.112	.003	.000	.272	.430	.001	.001	.000	.000	.000	.000
N	165	165	163	157	165	165	165	165	165	165	163	165	143	164	162	165

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**CORRELATIONAL MATRIX: Demographic variables and Outcome variables' change scores (Baseline vs. 6 months follow up)**

	AGE	OCCUPATION	EDUCATION	MARITAL status	CHILDREN	MENOPAUSAL status	PHYSICAL QoL change scores	FUNCTIONAL QoL change scores	SOCIAL QoL change scores	EMOTIONAL QoL change scores	Dr-Pr/ship changed scores	Total QoL changed scores	change scores sex satisfaction	SEX drive change scores	GSSI change scores
AGE	1.000	-.024	-.024	-.024	-.024	-.024	.105	-.013	-.111	-.210*	-.132	-.036	.100	.129	-.186
Pearson Correlation							.252	.889	.224	.021	.149	.708	.352	.201	.089
Sig. (2-tailed)															
N	197	188	188	197	197	197	121	121	121	121	121	110	88	100	85
OCCUPATION	-.024	1.000	-.462**	-.114	.233**	.094	.041	.152	.082	.031	.176	.138	.077	.169	.143
Pearson Correlation							.662	.102	.323	.742	.058	.155	.484	.099	.200
Sig. (2-tailed)															
N	188	188	188	188	188	188	117	117	117	117	117	107	85	97	82
EDUCATION	-.164*	-.462**	1.000	.093	-.354**	-.205**	-.078	-.134	-.006	.102	.124	-.081	-.012	-.059	.064
Pearson Correlation							.395	.145	.946	.266	.176	.402	.912	.561	.562
Sig. (2-tailed)															
N	195	188	195	195	195	195	120	120	120	120	120	109	87	99	84
MARITAL status	-.259**	-.114	.093	1.000	-.328**	-.155*	-.093	-.066	.308**	-.026	.070	.056	-.025	-.267**	.025
Pearson Correlation							.313	.469	.001	.773	.447	.559	.816	.007	.817
Sig. (2-tailed)															
N	197	188	195	197	197	192	121	121	121	121	121	110	88	100	85
CHILDREN	.522**	.233**	-.354**	-.328**	1.000	.401**	.147	.223*	.014	.005	-.162	.181	.065	.244*	-.135
Pearson Correlation							.108	.014	.882	.957	.076	.059	.547	.217	.217
Sig. (2-tailed)															
N	197	188	195	197	197	192	121	121	121	121	121	110	88	100	85
MENOPAUSAL status	.719**	.084	-.205**	-.155*	.401**	1.000	-.018	-.082	-.123	-.152	-.039	-.065	.041	.214*	-.158
Pearson Correlation							.843	.374	.181	.089	.671	.503	.710	.034	.152
Sig. (2-tailed)															
N	192	183	190	192	192	192	119	119	119	119	119	108	86	98	83
PHYSICAL QoL change scores	.252	.662	.395	.313	.108	.843	1.000	.464**	.221*	.159	.060	.700**	-.049	-.044	.074
Pearson Correlation															
Sig. (2-tailed)															
N	121	117	120	120	121	119	121	121	121	121	121	110	88	99	85
FUNCTIONAL QoL change scores	-.013	.152	-.134	-.066	.223*	-.082	.464**	1.000	.260**	.105	-.139	.754**	-.123	.051	-.002
Pearson Correlation															
Sig. (2-tailed)															
N	889	102	.145	.469	.014	.374	.000	.004	.004	.250	.128	.000	.254	.616	.983
SOCIAL QoL change scores	-.111	.092	-.006	.308**	.014	-.123	.221*	.260**	1.000	.179*	.180*	.592**	-.108	-.108	-.001
Pearson Correlation															
Sig. (2-tailed)															
N	224	323	.946	.001	.882	.181	.015	.004	.050	.048	.048	.000	.316	.286	.996
EMOTIONAL QoL change scores	-.210*	-.031	.102	.266	.773	.099	.082	.250	.179*	1.000	.156	.508**	-.037	-.246*	-.052
Pearson Correlation															
Sig. (2-tailed)															
N	121	117	120	121	121	119	121	121	121	121	121	110	88	99	85
Dr-Pr/ship changed scores	-.132	.176	.124	.070	-.162	-.039	.060	.139	.180*	.156	1.000	.265**	.032	.048	.045
Pearson Correlation															
Sig. (2-tailed)															
N	.149	.068	.176	.447	.076	.671	.511	.128	.048	.088	.088	.005	.770	.639	.684
Total QoL change scores	-.036	.138	-.081	.056	.181	-.065	.700**	.754**	.592**	.508**	.265**	1.000	-.066	-.066	-.041
Pearson Correlation															
Sig. (2-tailed)															
N	.708	.155	.402	.559	.059	.503	.000	.000	.000	.000	.005	.110	.386	.533	.719
change scores sex satisfaction	.100	.077	-.012	-.025	.065	.041	-.049	-.123	-.108	-.037	.032	-.096	1.000	-.485**	-.258*
Pearson Correlation															
Sig. (2-tailed)															
N	.352	.484	.912	.816	.547	.710	.648	.254	.316	.730	.770	.386	.000	.000	.020
SEX drive change scores	.129	.169	-.059	-.267**	.244*	.214*	-.044	.051	-.108	-.246*	.048	-.066	-.485**	1.000	.329**
Pearson Correlation															
Sig. (2-tailed)															
N	.201	.089	.561	.007	.015	.034	.666	.616	.286	.014	.639	.533	.000	.000	.002
GSSI change scores	-.186	.143	.064	.025	-.135	-.158	.074	-.002	-.001	-.052	.045	-.041	-.258*	-.329**	1.000
Pearson Correlation															
Sig. (2-tailed)															
N	.089	.200	.562	.817	.217	.152	.499	.963	.684	.719	.684	.719	.020	.002	.002
	.85	.82	.84	.85	.85	.83	.85	.85	.85	.85	.85	.80	.81	.85	.85

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

CORRELATIONAL MATRIX for Baseline variables and dependent variables of Sexual satisfaction/Relationship/Anxiety & Quality of Life at 6 months Follow up

Variable	Age	Sex	Marital Status	Education	Occupation	Income	Health	Relationship	Sexual Satisfaction	Relationship Satisfaction	Sexual Anxiety	Quality of Life	Sexual Satisfaction	Relationship Satisfaction	Sexual Anxiety	Quality of Life
Age	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Sex	0.31	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Marital Status	0.18	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Education	0.08	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Occupation	0.05	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Income	0.02	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Health	0.01	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Relationship	0.45	0.31	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Sexual Satisfaction	0.38	0.28	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Relationship Satisfaction	0.35	0.25	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Sexual Anxiety	0.15	0.10	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Quality of Life	0.12	0.08	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00

\* Correlation is significant at the 0.05 level (2-tailed).

UNIVERSITY OF SYDNEY LIBRARY



000000609516030

RARE BOOKS LIB