

**THE BENEFITS OF HEALTH CARE BEYOND HEALTH: AN  
EXPLORATION OF NON-HEALTH OUTCOMES OF HEALTH  
CARE**

M. R. Haas

**A thesis submitted in fulfilment of requirements**

**for the degree of Doctor of Philosophy**

**Department of Public Health and Community Medicine**

**Faculty of Medicine**

**University of Sydney**

**May 2002**

## **Preface**

The sources of written information used in this thesis are the publicly available databases MEDLINE, CINAHL, PSYCHINFO and ECONLIT. Ethics approval for the research described and reported in Chapter 5 was obtained from the Central Sydney Area Health Service Ethics Review Committee and for that described and reported in Chapter 6 from the University of Sydney Human Ethics Committee. All research participants received written information sheets regarding the objectives and process of research and signed consent forms were received from all participants. I declare that the entire thesis is original work carried out by me, Marion Ruth Haas. None of the work carried out for this thesis has been submitted for any other degree.

## Summary

Recent interest in identifying and measuring health outcomes represents an advance in our understanding of how health care for individuals should be evaluated. However, the concept of health outcomes has mainly focussed on improvements in health status. Non-health outcomes of health care may also be important to patients. In this thesis, four tasks were undertaken with the aim of identifying non-health outcomes and establishing the extent of their relevance and importance to patients. First, the illness experience literature was reviewed to identify potential non-health outcomes. Seven categories of non-health outcomes were identified: information, being treated with dignity, being able to trust the health care provider, having distress recognised and supported, participating in decision making, legitimisation and reassurance. Second, to gain an in-depth understanding of these concepts, topic-specific literature was reviewed and synthesised. Third, in order to confirm how relevant and important the concepts were to patients, a qualitative study was conducted with each of two different groups of health service users. Broadly, patients considered that all the non-health concepts were relevant, although the extent to which they were important varied. Fourth, to test the relative importance of the seven concepts, a Stated Preference Discrete Choice experiment in the context of general practice was conducted. This study showed that most people thought their GP demonstrated behaviour likely to result in the production of non-health outcomes. The results showed that although all the non-health outcomes were, to some extent, preferred by respondents, trust was most important, followed by legitimisation and recognition of and support for emotional distress. Once again, these results point to the importance of context in the evaluation of health care from the patient's perspective. While still being perceived as positive aspects of health care, the provision of information and acting autonomously or participating in decisions about their health care were the non-health outcomes considered least important by patients.

## **Acknowledgments**

Peter Sainsbury provided support, guidance and encouragement as my supervisor for the entire period of the PhD. His thoughtfulness, professionalism, friendship and sense of humour are much appreciated. Gavin Mooney provided supervisory support for much of the time I spent researching and writing the thesis. Jane Hall, as well as being a valued colleague and friend, stepped into the breach to act as a supervisor at a crucial stage of the thesis. She gave me both encouragement and challenge in exactly the right amounts.

My colleagues at CHERE were a continuous source of support and understanding as well as practical assistance. In particular, Liz Chinchen assisted with literature searches and referencing as well as cheerfully and carefully editing a number of chapters, Richard De Abreu Lourenco was always able to help with computing enquiries and Rosalie Viney provided much needed encouragement, advice and critical appraisal. Jordan Louviere gave freely of his expertise in facilitating the design of the SPDCM experiment and assistance with analysis was generously given by Peter Sainsbury, Jordan Louviere, Patsy Kenny and Paul Burke. The staff of Surveys Australia with whom I dealt, Ben Dixon and Peter Blansjaar, were a pleasure to work with.

A number of clinical staff at Westmead and Royal Prince Alfred Hospitals provided advice on the empirical aspects of the thesis and assisted in recruiting research participants. I would like to acknowledge the support of the following people: Gerry Wain, Tish Lancaster, staff of the Westmead Hospital Gynaecological Oncology Team, David Tiller, Adrian Gillin, Liz Ray, staff of the Department of Renal Medicine at Royal Prince Alfred Hospital and Karen Bedford.

I am most grateful to the nearly 200 patients and members of the public who voluntarily gave their time and effort to participate in the research. Personal contact with them was a source of great pleasure for me, not just the means of obtaining information. Finally, my very special thanks go to my family, in particular to Eleanor, who kept my feet firmly on the ground and Katherine who, as ever, handled the ups and downs with tolerance and love.

## Contents

<b>THE BENEFITS OF HEALTH CARE BEYOND HEALTH: AN EXPLORATION OF NON-HEALTH OUTCOMES OF HEALTH CARE</b>	<b>1</b>
<b>PREFACE</b>	<b>2</b>
<b>SUMMARY</b>	<b>3</b>
<b>ACKNOWLEDGMENTS</b>	<b>4</b>
<b>CONTENTS</b>	<b>6</b>
<b>LIST OF TABLES</b>	<b>9</b>
<b>CHAPTER 1:INTRODUCTION</b>	<b>12</b>
1.1 Background	12
1.2 Health outcomes and evidence based medicine	19
1.3 Patient satisfaction	20
1.4 Non-health outcomes	21
1.5 The need for research into non-health outcomes	23
<b>PART ONE: IDENTIFYING NON-HEALTH OUTCOMES IN THE LITERATURE AND EXAMINING THEORETICAL AND CONCEPTUAL ASPECTS OF NON-HEALTH OUTCOMES</b>	<b>26</b>
<b>CHAPTER 2:IDENTIFYING NON-HEALTH OUTCOMES IN THE LITERATURE</b>	<b>27</b>
2.1 Introduction	28
2.2 Identifying potential non-health outcomes in the literature	28
2.3 Critique of health outcomes, including HRQOL and patient satisfaction in relation to non-health outcomes	41
2.4 Potential solutions	51
2.5 Conclusion	53
<b>CHAPTER THREE: A MODEL OF NON-HEALTH ASPECTS OF HEALTH CARE</b>	<b>56</b>
3.1 Introduction	57
3.2 Reassurance	58

3.3	Information and knowledge	65
3.4	Trust in health care professionals	80
3.5	Dignity	86
3.6	Legitimation and labelling	88
3.7	Recognition of and support for emotional distress	91
3.8	Participation in decision making	98
3.9	Conclusion: a model of health and non-health outcomes of health care	110
<b>PART TWO: METHODOLOGICAL ASPECTS AND EMPIRICAL EXAMINATION OF NON-HEALTH OUTCOMES</b>		<b>114</b>
<b>CHAPTER FOUR: USING QUALITATIVE AND QUANTITATIVE METHODS TO EXAMINE THE RELEVANCE AND IMPORTANCE OF NON-HEALTH OUTCOMES TO PATIENTS AND THEIR PREFERENCES FOR NON-HEALTH OUTCOMES</b>		<b>115</b>
4.1	Introduction	116
4.2	Using in-depth interviews to investigate the relevance and importance of non-health outcomes to patients	117
4.3	Using Stated Preference Discrete Choice Modelling (SPDCM) to assess the importance of non-health outcomes to patients and their preferences for them.	125
4.4	Combining qualitative and quantitative research methods	134
<b>CHAPTER FIVE: THE IMPORTANCE OF NON-HEALTH ASPECTS OF HEALTH CARE TO PATIENTS: AN EMPIRICAL EXPLORATION</b>		<b>138</b>
5.1	Introduction	139
5.2	Methods	139
5.3	Analysis	140
5.4	Results	141
5.5	Study of people with chronic renal failure	142
5.6	Study of women eligible for Pap smears	172
5.7	Conclusion	190
<b>CHAPTER SIX: USING STATED PREFERENCE DISCRETE CHOICE MODELLING TO EXAMINE PREFERENCES FOR NON-HEALTH OUTCOMES</b>		<b>193</b>
6.1	Introduction	194
6.2	Aims of the study	195

6.3	Methods	195
6.4	Analysis	203
6.5	Results	204
6.6	Discussion	214
6.7	Conclusion	218
<b>CHAPTER SEVEN: DISCUSSION AND CONCLUSIONS</b>		<b>219</b>
7.1	Introduction	220
7.2	Using qualitative and quantitative research methods to examine the relevance, importance of and preferences for non-health outcomes	220
7.3	Comparing the results of this research with previously published research	229
7.4	The need for further research	230
7.5	Lessons for the evaluation of health care from the patient's perspective	231
7.6	Conclusion	234
<b>REFERENCES</b>		<b>236</b>
<b>APPENDIX ONE: INFORMATION SHEET, CONSENT FORM AND QUESTION GUIDE FOR CHRONIC RENAL FAILURE INTERVIEWS.</b>		<b>258</b>
<b>APPENDIX TWO: INFORMATION SHEET, CONSENT FORM AND QUESTION GUIDE FOR CERVICAL SCREENING INTERVIEWS.</b>		<b>261</b>
<b>APPENDIX THREE: INFORMATION AND CONSENT FORMS AND AN EXAMPLE OF THE SPDCM QUESTIONNAIRE</b>		<b>264</b>
<b>APPENDIX FOUR: FIGURES 4 – 8 ILLUSTRATING THE EFFECTS OF GP TREATING PATIENTS WITH DIGNITY, RECOGNISING EMOTIONAL DISTRESS, LEGITIMATING THEIR CONDITION, PROVIDING REASSURANCE AND ACCEPTING THEIR DECISIONS.</b>		<b>282</b>

## List of Tables

<b>Table 1: General characteristics of the 37 included articles and books</b>	<b>26</b>
<b>Table 2: Non-health aspects of care by type of care as discussed in the 37 included articles and books</b>	<b>29</b>
<b>Table 3: Grouped items of non-health aspects of care</b>	<b>30</b>
<b>Table 4: Potential non-health outcomes</b>	<b>30</b>
<b>Table 5: Number of articles describing non-health outcome by type of care</b>	<b>48</b>
<b>Table 6: Number of research articles by non-health outcome</b>	<b>98</b>
<b>Table 7: Outcomes of seeking health care</b>	<b>105</b>
<b>Table 8: Interview guide for Pap smear interviews</b>	<b>124</b>
<b>Table 9: Topics covered in the research interviews</b>	<b>127</b>
<b>Table 10: Age and sex of participants</b>	<b>157</b>
<b>Table 11: Age of participants</b>	<b>180</b>
<b>Table 12: Attributes and levels in the SPDCM experiment</b>	<b>182</b>
<b>Table 13: Respondents' evaluation of the last consultation with their GP</b>	<b>182</b>
<b>Table 14: Example of first eight scenarios</b>	<b>183</b>
<b>Table 15: Example of scenarios from the full factorial design</b>	<b>184</b>
<b>Table 16: Example of scenarios from the full factorial design</b>	<b>187</b>
<b>Table 17: Responses to the assessment of the last visit to their own GP</b>	<b>187</b>
<b>Table 18: Results of SPDCM estimation using attributes only</b>	<b>190</b>
<b>Table 19: Results of SPDCM estimation using demographic and health information</b>	<b>192</b>
<b>Table 20: Outcomes of seeking health care</b>	<b>210</b>

## List of Figures

<b>Figure 1: Effect of least and most favourable attribute levels</b>	<b>195</b>
<b>Figure 2: Effect of perceived trustworthiness</b>	<b>195</b>
<b>Figure 3: Effect of provision of information</b>	<b>196</b>
<b>Figure 4: Effect of being treated with dignity</b>	<b>265</b>
<b>Figure 5: Effect of GP recognising emotional distress</b>	<b>265</b>
<b>Figure 6: Effect of GP providing legitimation</b>	<b>266</b>
<b>Figure 7: Effect of GP providing reassurance</b>	<b>266</b>
<b>Figure 8: Effect of GP accepting patients' decisions</b>	<b>267</b>