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The experience of ovarian cancer in Australia: A phenomenological study.

Victoria Jayde

A thesis submitted in fulfillment of the requirements for the degree of Doctor of Philosophy

Sydney Nursing School

University of Sydney

2015
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I wish to sincerely acknowledge and thank the women and men who participated in this study and who shared their experiences of ovarian cancer with me. Thank you for honouring me with your trust.

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DEDICATION

I would like to dedicate this thesis to my father, who passed away during my candidature.

I finally did it, Pop. I hope that this work makes you proud.
DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: [Signature]

Date: 6/2/15
ABSTRACT

This study explored the lived experience of ovarian cancer in the Australian context utilising hermeneutic phenomenology as the philosophical framework. Specifically, the study aimed to explore, interpret and describe the lived experience of the phenomenon of ovarian cancer prior to disease recurrence.

There is abundant literature on this most lethal form of gynaecological cancer, most of which investigates particular aspects of the disease. However, reports of studies that explore the lived experience of ovarian cancer in a qualitative, holistic way are meagre in Australia and inadequate in the international context.

The study approached the phenomenon of ovarian cancer illness from the perspective of three participant groups – women with or who previously had ovarian cancer without disease recurrence and partners and adult children of such women. Circling the phenomenon in this manner enabled the study to capture the nature and depth of meaning of the experience. A total of 40 participants from six Australian states contributed to the study through interviews and written reflections. Thirty-three were primary participants: 15 women, nine male partners and nine adult children. The remaining seven participants were interviewed to ‘test’ the resonance of the developing interpretation ensuring rigour of the analytic process.

Thematic analysis was conducted through a process of interpreting data initially word-by-word, then sentences and ideas until significant aspects of their experience could be theorised and organised into clusters of themes following the suggestions of van Manen (1990). It was identified that participants lived in a world characterised by pervasive aspects of the phenomenon. Three major themes were identified: ‘ruptured assumptive world’, ‘uncertain world’ and ‘liminal world’. Within these three worlds, the experiences of the phenomenon of each participant group are described in different, sub-thematic worlds. Findings from the study, accompanied by verbatim quotes from participants, are presented within the three major themes. The three major thematic worlds illuminated the fundamental essence of the phenomenon – that of Being-in-a-changed-world.
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Mindmaps:
Throughout this thesis, I have used mindmaps to illustrate concepts. The program iMindMap was used to create all mindmaps. Mind Map is a registered trademark of the Buzan Organisation Limited 1990, www.thinkbuzan.com.

Confidentiality:
Each of the participants in this study has been assigned a pseudonym. Vignettes in chapter four provide some understanding of the context of the participant’s experience of ovarian cancer. In order to help protect privacy, details are kept general regarding their age, occupation and residential area. Where verbatim comments are included in the discussion, which might have ramifications for the personal life of participants or which might lead to a breach of privacy, I have used the pseudonym ‘anonymous’ or indicated an anonymous comment by using the term, for example, ‘one woman said…’.

In order to protect confidentiality of health care professionals, individuals will be presented as she, which is to be read as s/he throughout the thesis.

Identification of quotations:
Verbatim quotes from participants are written in italics, in blue, with single quotation marks. For example: ‘The nurse said…’ Quotes are followed by reference to the participant and transcript line number of that quote. In the transcript line references women are denoted by a W, partners by a P and children by a C - for example, (W6.489). Words placed in square brackets denote strong emotion or are letters or words inserted to help the reader make sense of the quotation. For example ‘I was frightened about it [the surgery].’ [crying]

Literary devices:
Quotes from other sources, such as literature are written with double quotation marks. I have included any emphasis present in original quotes from literature. Thus, italics in a literature-based quotation can be assumed to be in the original version. For example: “There was no doubt the ….”

Words with special significance within a sentence are placed in single quotation marks. When I wish to emphasise a point within the text I have underlined the word/s.

Abbreviations:
Cancer Care Coordinator (Specialist nurse whose role is to coordinate care and support services) CCC
General Practitioner (Family doctor – typically the first point of contact in the Australian health system) GP
Health Care Professional/s (for example, nurses, doctors, physiotherapists, social workers and psychologists) HCP/s
For example e.g.
United States of America USA
Quality of life QOL
CHAPTER ONE: INTRODUCTION

Ovarian cancer is the most lethal form of gynaecological cancer (Cancer Australia 2012a, 2012b). In 2010, in Australia, 1305 women were diagnosed with the disease and in 2011, 903 women died from ovarian cancer (Australian Institute of Health & Welfare (AIHW) 2014). It was estimated that in 2014, in the USA, there would be almost 22,000 women newly diagnosed with ovarian cancer and that over 14,000 women would die of the disease (National Cancer Institute (NCI) 2014).

This phenomenological study provides insight into the lived experience of ovarian cancer within the Australian context. The intention of the study is to explore, interpret and describe the experience of the phenomenon of ovarian cancer. In particular, this study is concerned with the experience of ovarian cancer prior to development of recurrent disease.

About ovarian cancer

Ovarian cancer is a collective term for malignant disease of the ovaries, fallopian tubes and/or peritoneum (Prat 2014). Growing use of the term ‘tubo-ovarian cancer’ reflects the aetiology from either the ovary or the fallopian tube. In this thesis, ‘tubo-ovarian cancer’ will be referred to as ‘ovarian cancer’ as this is the term commonly recognised and used by participants.

The risk of developing ovarian cancer increases with age with most diagnoses occurring after the age of 60 (Cancer Australia 2012b). The disease is typically characterised by non-specific symptoms, delay in diagnosis, late disease stage at diagnosis and a correspondingly poor prognosis. Ovarian cancer differs from many other cancers because there is currently no reliable, effective screening tool recommended for general use (Cancer Australia 2009; Tracey et al 2009).
Staging and treatment

Ovarian cancer is typically described by ‘stage’ – that is, histopathology and the extent of spread of the disease (Prat 2014) – which is usually based on findings at surgery (Jelovac & Armstrong 2011). The staging system commonly used in Australia is the International Federation of Gynecology and Obstetrics system, which has four levels. In this thesis, Stages I and II ovarian cancer will be described as ‘early’ disease whilst stages III and IV will be described as ‘advanced’ disease.

Approximately three quarters of women with ovarian cancer are diagnosed when the disease is at an advanced stage (NCI 2014; Tracey et al 2009). The treatment for ovarian cancer depends on a number of factors such as the stage of the disease and the age and health of the woman. Treatment for advanced stage ovarian cancer is usually a combination of major abdominal (cytoreductive) surgery and chemotherapy (Goff 2013; Hennessy, Coleman & Markman 2009), whilst treatment for early stage disease may consist of surgery alone (Jelovac & Armstrong 2011).

Prognosis and survival

Ovarian cancer is associated with a poor prognosis and more women die from the disease than from all other gynaecological cancers combined (Cancer Australia 2012a). The five-year relative survival rate for ovarian cancer is approximately 43% (Cancer Australia 2012b). This compares unfavourably with most other cancers including breast cancer, which has a rate of 89% (AIHW 2012).

The stage of disease at diagnosis has important implications for the prognosis of the disease (Tracey et al 2009). In 2007 in New South Wales (a state of Australia), stages I & II ovarian cancer were associated with a five-year survival rate of 78% compared to 34% for stage III and 17.5% with stage IV (Tracey et al 2009, p.593). These statistics are similar to ones from the USA (NCI 2014). Put simply, an average of three quarters of women with ovarian cancer are diagnosed at an advanced stage. Of those women, an average of three quarters will not survive to five years following diagnosis.
Recurrent disease is the term used for ovarian cancer, which reappears after treatment has been completed. After recurrence, which occurs in the majority of advanced stage patients within a median of 15 months following diagnosis, the disease cannot be cured (Hennessy et al 2009). In a very real sense, recurrent disease can be considered to be ‘a game changer’ for women— that is, something that alters the focus and the probable outcome of their situation. The diagnosis of recurrent disease (also known as relapsed disease) represents a boundary between different foci of treatment. Prior to recurrence, treatment is focused upon ‘cure’ as women may be cured of their cancer. After recurrence, the focus changes to slowing progression of disease, maintaining quality of life (QOL) and prolonging the woman’s life (Edwards 2003; Jelovac & Armstrong 2011). A minority of women will become long-term survivors. At best, recurrent disease heralds the likelihood of a future filled with years of ongoing treatments and uncertainty. At worst, recurrence signals the likelihood of death from the cancer within years and perhaps months.

**Impetus for the study**

The idea for this study arose out of my work as a Research Nurse in the field of ovarian cancer. Part of my role involved talking with women and families affected by the disease and I was struck by the impact the cancer had on them. I wanted to better understand the nature and meaning of the experience for women and the family members involved and this inspired me to investigate the healthcare literature.

In 2007 I conducted a descriptive systematic review of the literature surrounding the experience of ovarian cancer (Jayde 2007) for a Masters (Honours) degree and much of it remains unchanged in 2012. The review revealed certain gaps in healthcare literature relating to the experience of ovarian cancer. For example, the majority of research addressing psychosocial issues of ovarian cancer is based on the experiences of Canadian, American and/or British women. It is not known whether these experiences reflect those of Australian women with ovarian cancer (but without recurrence), as there is little literature that specifically explores the lived experience
of Australian women with ovarian cancer prior to recurrence. A small number of Australian studies were identified which explored aspects of the lived experience; however they included both women with recurrent ovarian cancer and those whose disease had not recurred. Notably, the only three Australian studies, which specifically examined the overall lived experience of ovarian cancer, did so from the perspectives of recurrence alone (Ryan, 1997, 2005) and the combined perspectives of women with and women without recurrent disease (Petterson 2006). In addition, there are few studies, worldwide, which specifically investigate the lived experiences of partners of women with ovarian cancer (Armstrong 2012; Arden-Close 2008; Frost et al., 2012; Ponto, 2008, 2010; Ponto & Barton, 2008). I found no literature, worldwide, which specifically describes the lived experience of children of women with the disease. The review indicated that healthcare provided to Australian women and family members affected by ovarian cancer may be based upon research that: is not disease specific; is international in context; and/or is an amalgamation of both the experience prior to recurrent disease and the experience after recurrence.

The impetus for this study was the apparent scarcity of literature relevant to the Australian context that could provide insight and a better understanding of the experience of ovarian cancer prior to recurrent disease. With recurrence, the paradigm of care changes from cure to control and comfort and eventually palliation. In this thesis, in particular, I wanted to explore how ovarian cancer is experienced after diagnosis of the cancer and prior to confirmation of recurrence. It is likely that the diagnosis of recurrence changes the experience for all concerned. Therefore, the experience of ovarian cancer before recurrence became the focus of my study.

**Aim of the study**

The aim of this research study was to explore, interpret and describe the lived experience of the phenomenon of ovarian cancer, prior to development of recurrent disease, within the Australian context. More specifically the study aimed to explore and articulate the meaning of ovarian cancer by circling the phenomenon from the three perspectives of Australian women, partners and adult children.
The research question was: ‘What is the nature and meaning of the lived experience of Australian women with ovarian cancer that has not recurred and what is the nature and meaning of the experience of partners and adult children of such women?”

The phenomenon of interest

The focus of this study is the experience of the phenomenon of ovarian cancer. A phenomenon is “a fact or situation that is observed to exist or happen; … the object of a person’s perception” (Oxford Dictionary 2014a). It has been defined as “an event or a lived-through experience as it shows itself or as it gives itself when it makes an appearance in our awareness” (van Manen 2014, p.65). Merleau-Ponty (2002) stated the “experience of phenomena” involves “an intentional analysis” (p.68). The explicit intention of my study was to explore and interpret the experience of the phenomenon of ovarian cancer prior to development of recurrent disease. Where appropriate in this thesis, this will be referred to as ‘ovarian cancer (without recurrence)’.

In particular my study focused upon the phenomenon of ovarian cancer illness. Kleinman (1998) suggested, “Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (p.3). Ovarian cancer can be conceptualised as both a disease and an illness. For the purposes of my thesis, the term ‘disease’ refers to the biological manifestation of the cancer and ‘illness’ refers to the subjective human experience associated with the cancer (Benner & Wrubel 1989; Lupton 2012; Svenaeus 2009).

Whilst it may be argued that only women can experience the disease of ovarian cancer, I believe that a range of people whose lives are impacted by the disease may experience the phenomenon of ovarian cancer illness. It is this phenomenon that my study explored. For the purposes of brevity, throughout this thesis the phenomenon of ovarian cancer illness will be referred to as ‘the phenomenon’ or ‘ovarian cancer’.
Introduction to the three groups who informed this thesis

This research study focused upon the Australian experience of the phenomenon of ovarian cancer. The study approached the phenomenon from the perspectives of three groups of people: women with ovarian cancer (without recurrence); partners of women with ovarian cancer (without recurrence); and adult children of women with ovarian cancer (without recurrence). By circling the disease in this manner, my study has captured the depth and complexity of the phenomenon in a way perhaps not possible from one perspective alone. This is illustrated below.

![Visual representation of circling the phenomenon]

Figure 1: Visual representation of circling the phenomenon

Significance of the study

Few Australian qualitative studies have specifically focused upon the experience of ovarian cancer (Gleeson et al 2013; Jayde, Boughton & Blomfield 2013; Jordens et al 2010; Morrell et al 2012; Petterson 2006; Ryan 1997, 2005). One qualitative study and one mixed-method study were located, worldwide, which explored the holistic experiences of partners of women both with and without recurrent disease (Armstrong
I was unable to locate any study that specifically explored the experience of partners of women with ovarian cancer (without recurrence), or any study that specifically explored the experience of children with mothers who had ovarian cancer. This is despite ovarian cancer being the most lethal form of gynaecological cancer in developed countries (Chu & Rubin, 2006).

The significance of this study lies in the depth of its exploration of the ovarian cancer experience. It also addresses those gaps in ovarian-cancer-related-experience literature that were identified by the initial literature review, that is research which specifically explores the overall experience of ovarian cancer (without recurrence) for women, partners and/or adult children in the Australian context.

De Casterle et al (2011) suggested that multiple perspectives of a phenomenon enhance and enrich our understanding of the meaning of a health-related experience. My study is unique in that it explored the lived experience of the phenomenon of ovarian cancer from the perspectives of three intimately involved individually identified groups. As such, my study has illuminated and uncovered the phenomenon from a deep and comprehensive range of standpoints.

A thorough review of the extant literature on this topic highlighted that my study is also the first qualitative study to specifically explore the Australian overall lived experience of ovarian cancer (without recurrence) for women and/or specifically explore the Australian experience of partners of women with ovarian cancer (with/out recurrence). My study is also the first, worldwide, to explicitly explore the experience of adult children of women with ovarian cancer (with/out recurrence).

Whilst my study did not overtly aim to improve quality of healthcare provision, the study does have significance and relevance for healthcare professionals (HCPs) who wish to provide informed, holistic health care for those impacted by ovarian cancer. By exploring and articulating the experience of the phenomenon, this study offers HCPs an opportunity to enhance their understanding - perhaps to think differently - of what it means to experience ovarian cancer. In addition, by facilitating an enhanced understanding of the impact of ovarian cancer upon the lives of women, partners and
adult children, the findings from my study may prompt HCPs to reflect upon their practice and the persons with whom they deal in that practice. The more clearly we can understand the way ovarian cancer is experienced, and the personal meanings of that experience, the better we can provide appropriate and optimal healthcare (de Casterle et al 2011; Lawler 1998).

This study also has significance and relevance for the participants. Women, partners and adult children have taken the opportunity to speak about their experiences and articulate what was important to them during this process. Their participation in this study has given recognition and acknowledgement of the experience of ovarian cancer. This in turn, has given a ‘voice’ to those whose lives have been or will be impacted by the disease.

**Organisation of the thesis**

This thesis is written in the 1st person as this is the most appropriate rhetorical style for a qualitative study (Creswell 2007). The thesis is organised into distinct chapters:

**Chapter one** has introduced the disease of ovarian cancer. The impetus for the study has been explained and the rationale presented. The aim of the study and the research question have been articulated. The phenomenon of interest has been defined. Finally, the significance of the study has been declared. This chapter concludes with a summary of the thesis organisation.

**Chapter two** examines the literature to present an overview of what is currently known about the experience of ovarian cancer (without recurrence) for women, partners and adult children.

**Chapter three** explains the methodological and philosophical foundation of the study. It introduces hermeneutic phenomenology and discusses its relevance and appropriateness in relation to the study aim.
Chapter four explains the implementation of the methodology and processes undertaken throughout the study. It describes conduct of the research process guided by the philosophical principles of hermeneutic phenomenology. This chapter discusses the maintenance of rigour, trustworthiness and credibility throughout the study. This chapter provides a general introduction to the 40 study participants. This number included seven participants, who were interviewed to ‘test’ emerging interpretations. Of the primary participants, 15 were women, nine were children and nine were partners. These are introduced via vignettes.

Chapter five is the first of four chapters in which the study findings are presented and discussed. It introduces the first of three major themes theorised from the data, which led to identification of the essence of the experience. The chapter presents the concept of ‘ruptured assumptive world’ and explains how this relates to the ovarian cancer experience. Each of the participant groups experienced ovarian cancer within a ruptured assumptive world. Their experiences are described under three sub-themes.

Chapter six introduces the second major theme of ‘uncertain world’. Experiences are presented, interpreted and discussed within participant group’s sub-themes, utilising the concept of uncertainty to gain further insight into the phenomenon.

Chapter seven presents and discusses findings related to the third major theme, ‘liminal world’. The concept of liminality in relation to participant experiences is explored and interpreted as it related to the ovarian cancer phenomenon.

Chapter eight concludes this thesis and culminates with the essence of the experience of the phenomenon of ovarian cancer. The three major themes explicated in chapters five, six and seven all contribute to understanding the essence of the experience of the phenomenon as one of ‘changed world’. Key findings of the study are discussed in relation to ‘changed world’. Implications for HCP practice and limitations of the study are discussed and suggestions made for future research. The thesis concludes with a summative statement describing the lived experience of the phenomenon of ovarian cancer illness.
CHAPTER TWO: LITERATURE REVIEW AND
BACKGROUND TO THE STUDY

This chapter presents an overview of ovarian cancer literature. It focuses upon literature that is relevant to the aim of this current study, the lived experience of ovarian cancer (without recurrence) within the Australian context. The search strategy is described and a general introduction to ovarian cancer literature given. The literature relevant to the experience of ovarian cancer (without recurrence) is presented. The review also describes literature, which explores the experience of ovarian cancer for partners, family members and caregivers. It concludes with an overview of what is known about the experience of the phenomenon of ovarian cancer (without recurrence).

Background to the present study

In 2007, I conducted a descriptive systematic review of the literature surrounding the experience of ovarian cancer for women and partners for a Master’s (Honours) degree (Jayde 2007). The review identified a number of ‘gaps’ in published literature including a lack of research that specifically explored the experience of ovarian cancer (without recurrence) within the Australian context and an absence of literature that specifically explored the experience of being a partner of a woman with ovarian cancer. It incidentally identified a dearth of articles that specifically explored the experience of children of women with ovarian cancer. My current study sought to illuminate the unexplored ‘gaps’ in documented knowledge, identified in the systematic review. Since commencing my PhD study in response to these identified spaces in documented knowledge, a number of publications have arisen which have narrowed some of the perceived gaps. Despite these newer publications, some ovarian cancer experiences remain unexplored in the literature. This thesis aims to address some of these identified gaps. As stated earlier in chapter one, the intention of this study was to circle the phenomenon of ovarian cancer (without recurrence) by
exploring the experience from the three perspectives of women, partners and adult children.

The probable impact of recurrent disease upon the experience of ovarian cancer

As identified in the previous chapter, the majority of women with ovarian cancer are diagnosed at an advanced stage of disease. The majority of these women will develop recurrent disease and many will succumb to the disease within five years.

Previous authors have suggested that one’s experience of ovarian cancer will be changed by the diagnosis of recurrent disease (Ding, Zhu & Zhang 2007; Ekwall, Ternesdedt & Sorbe 2007; Ekwall, Ternesdedt, Sorbe & Graneheim 2011; Elit et al 2010; Howell, Fitch & Deane 2003; Jordens et al 2010; Petterson 2006; Powel, Midler & Steiner 1998; Ryan 2005). Ryan (2005) identified that once women were diagnosed with recurrent ovarian cancer they knew that their disease was incurable and that they would live with the cancer until they died. “The diagnosis of recurrent ovarian cancer guarantees an untimely death which could occur months or years after the diagnosis” (p.1). In a very real sense, recurrence ends women’s hopes of ‘beating’ the disease (Hennessy et al 2009). Ekwall et al (2007) suggested that women diagnosed with recurrent ovarian cancer confront their mortality differently than before that diagnosis. Taking this into consideration, and in accordance with the aim of my study, the primary focus of this review is upon literature, which explores the experience of ovarian cancer prior to development of recurrent disease.

This literature review

Prior to commencing my research, in order to determine what was known about the broad experience of ovarian cancer (without recurrence), I revisited and updated my previous (2007) review including exploring the literature for children’s experiences of the phenomenon. The process of identifying and examining publications for this current review continued until June 2014. All identified, full-text English publications, between 1993 and June 2014, which explored aspects of the lived
experience of ovarian cancer (without recurrence) and which were available to be either borrowed in ‘hardcopy’ or downloaded online, are included in this chapter.

Search strategy

There is an abundance of literature regarding ovarian cancer and a general search of health-related databases identified a multitude of articles with many of them related to pathology and physiology of the disease. For the purposes of this review I used a search strategy to focus upon publications, which discussed aspects of ovarian cancer that could be seen to inform understanding of the lived experience of the phenomenon, particularly from the perspectives of women, partners and/or children. The search utilised key words such as: ‘ovarian neoplasms’ and ‘ovarian cancer’; ‘experience’; ‘lived’; ‘treatment’, ‘diagnosis’, ‘symptoms’ and ‘quality of life’; ‘partner’, ‘spouse’, ‘significant other’ and ‘husband’; ‘woman’ and ‘women’; ‘child’, ‘children’ and ‘offspring’. I also searched for phenomenological studies of the experience of ovarian cancer.

My search strategy included papers written between the years of 1993 and June 2014. These dates were chosen to include the papers reviewed in 2007 and those identified and/or published since the previous review (Jayde 2007). Major databases searched included Medline, Cinahl, PsychINFO, Google Scholar and Philosopher’s Index. I also searched for full-text theses and dissertations using databases such as ‘Trove’, ‘ETHOS’, and ‘ProQuest Dissertations and theses – full text’. The reference lists of publications were scrutinised to identify additional studies.

This review includes studies that illuminate aspects of the lived experience of ovarian cancer. For example, I only included studies that solely explored the experience of ovarian cancer, rather than those that incorporated other cancers. This strategy produced a substantial number of publications with the majority including women with recurrent disease in the sample. Guided by the focus of my study, which was to exclusively explore the experience of ovarian cancer prior to recurrence, I organised the publications according to whether their sample included women with or without recurrent disease. A limited number of publications were identified which were
specific to women’s experience of ovarian cancer prior to any recurrence. These studies are described later in this chapter. Research samples in the majority of studies are either unclear (e.g. Alichin-Petardi 1998; Browall, Carlsson & Horvath 2004; Schaefer, Ladd, Lammers & Echenberg 1999), unstated (e.g. Cesario, Nelson, Broxson & Cesario 2010; Ferrell, Smith, Ervin, Itano & Melancon 2003) include women both with and without recurrent cancer (e.g. Burles & Holtslander 2013; Guenther, Stiles & Champion 2012; Hagan & Donovan 2013) or focus upon recurrent disease experiences (e.g. Ekwall et al 2007; Johnson et al 2009).

Introduction to literature that explores the experience of ovarian cancer.

A considerable body of research has examined women’s experience of ovarian cancer (Jayde 2007). The majority of publications arise from the USA (e.g. Armstrong 2012; Guenther 2008), with others arising from Canada (e.g. Burles & Holtslander 2013; Power, Brown & Ritvo 2008), Britain (e.g. Fisher-Morris 2009; Ziebland, Evans & McPherson 2006) and Scandinavia (e.g. Browall et al 2004; Seibaek, Petersen, Blaaker & Hounsgaard 2011). A number of Australian studies have emerged within the past few years (e.g. Beesley, Price, Butow et al 2011; Morrell et al 2012; Price et al 2010) and these are discussed later in this chapter.

Women’s symptoms and the process of diagnosis have been extensively explored (e.g. Bankhead, Kehoe & Austoker 2005; Bankhead et al 2008; Goff et al 2007; Jayde, White & Blomfield 2009-10; Ryerson et al 2007). The QOL of women with ovarian cancer has also been broadly studied, both internationally and in Australia (e.g. Bezjak et al 2004; Le, Hopkins & Fung 2005; Norton et al 2004; von Gruenigen et al 2011). In particular, two authors have contributed a substantial number of studies related to the experience of ovarian cancer. Fitch explored aspects of the Canadian experience of ovarian cancer (e.g. Fitch, Deane & Howell 2003; Fitch, Gray, DePetrillo, Franssen & Howell 1999; Fitch & Steele 2010; Howell et al 2003) and Ferrell explored the experience through correspondence from the USA and 30 other
countries (e.g. Ferrell, Smith, Cullinane & Melancon 2003a; Ferrell, Smith, Cullinane & Melancon 2003b; Ferrell, Smith, Ervin et al 2003).

‘Holistic’ studies of the experience, compared to studies of ‘specific’ aspects

I conducted this literature review to primarily determine what has been documented about the all-embracing experience of ovarian cancer (without recurrence). This decision was guided by the focus of my study, which was the experience of ovarian cancer (without recurrence) as described by participants. Whilst it was planned that participants in my study would discuss their experience in any way they desired, it was assumed that most would describe an holistic overview of their experience of the phenomenon.

The analogy of a jigsaw puzzle can help explain the difference between research that explores the holistic experience of a phenomenon and research, which focuses upon a particular aspect of that phenomenon. Like a complete jigsaw puzzle, an holistic overview illuminates multiple dimensions of a phenomenon from one viewpoint. Within that viewpoint are individual aspects that can be seen and examined independently but which are always experienced in context and so are always components of the greater picture. Similarly, literature that explores individual aspects of the experience of ovarian cancer (such as diagnosis) can be understood to focus upon smaller parts of an overall, holistic experience.

All research is impacted by the method used for the study. Whilst my literature search identified a number of publications that explored the ovarian cancer experience, only a minority explored the holistic experience of the phenomenon (particularly the experience prior to recurrence) with most studies focusing upon specific, pre-determined aspects (for example, Quality of Life (QOL)). By setting parameters for study in advance, such research may limit or restrict the level of understanding that might be attained in relation to the topic. Iseminger (1997) suggested that studies that examine an experience in a pre-determined way present fragmented views of the experience and prevent understanding of “the totality of another’s situation” (p.11). This can be understood when one considers how the
method used for the conduct of research impacts upon the possible depth of understanding of a phenomenon. For example, whilst valuable for other research purposes, quantitative studies such as surveys may limit our understanding of how a phenomenon is experienced because respondents answer questions specified by the researchers. Similarly, studies that examine a phenomenon through a conceptual lens will add that perspective to what is known, but may not ‘see’ or allow for other perspectives. An additional factor to consider when exploring what is known about a phenomenon is the depth of discussion able to be presented in a thesis or dissertation compared to a short journal article. In this review, theses and dissertations are clearly described as such.

The experience of ovarian cancer prior to development of recurrent disease.

Holistic studies of the experience

Little appears to be documented about the holistic experience of ovarian cancer without recurrence as few studies were identified which explicitly studied this phenomenon (Bowes 1998; Mizrahi, Kaplan, Milshtein, Reshel & Baruch 2008; Reb 2007a). The only full-text research publications located for this review, which explored the holistic experience of ovarian cancer (without recurrence), utilised specifically pre-determined topics of interest and/or conceptual lenses such as hope or optimism. By this I mean the research focus was determined by the researcher/s, rather than driven by the participants. For example, an exploration of the ovarian cancer experience of eight Russian immigrant women in Israel used the lenses of coping and migration to find the experience was strongly related to cultural and societal factors that women perceived as being either stressors or benefits (Mizrahi et al 2008).

The role of anger was the initial focus of a Canadian study into the experience of women with ovarian cancer (without recurrence) (Bowes 1998). The focus of the thesis study later broadened as participants revealed that whilst anger was an
acknowledged aspect of their experience, their biggest concern was facing their possible early death. Bowes suggested that this concern was “unique” (p.42) to ovarian cancer and reflected its associated poor prognosis. Women coped with their fears by using strategies (such as religion or sharing their experiences with others) to find meaning in their lives. To do this, they needed to be physically ‘well’ and to be able to have ‘hope’ for their future. Nine years later, similar findings related to hope and fear of early death were reported in a doctoral dissertation from the USA. Reb (2007a) used ‘hope’ as a conceptual lens with which women’s global experience of living with advanced ovarian cancer (without recurrence) was examined. Three phases were described through which women integrated the menace of their possible ovarian-cancer-related-death. Women’s levels of hope were associated with the way they approached the possibility of their death. Strong support systems and positively perceived health care professional (HCP) communication contributed to women’s ability to cope with existential angst and hope was portrayed as being essential to enable women to manage the persistent threat of dying from their disease. Both Bowe’s (1998) thesis and Reb’s (2007) dissertation were later summarised in journal articles (Bowes, Tamlyn & Butler 2002; Reb 2007b).

Specific aspects of the experience

Various specific aspects of the experience of ovarian cancer prior to recurrence have been explored in a number of studies whose inclusion criteria specifically stated only women without recurrent disease. By arranging the articles to follow the typical temporal direction of the illness trajectory, insight is provided into selected aspects of women’s experience of ovarian cancer (without recurrence).

Symptoms and being diagnosed

Experiences surrounding diagnosis have been specifically explored. Chinese women who were surveyed described having at least one pre-ovarian-cancer-diagnosis symptom for which they sought advice within two weeks of the symptom onset (Chan, Ng, Lee, Ngan & Wong 2003). The experiences of Danish women in recognising, interpreting and responding to symptoms prior to diagnosis were
described in a mixed-method study, which noted that their response to symptoms was influenced by social, societal and systemic factors. In order to seek a diagnosis, women had to firstly recognise they had symptoms, then recognise that their symptoms indicated possible disease. They then had to successfully seek treatment (Seibaek et al 2011). However, neither of these studies elaborated on women’s lived experience of diagnosis.

More useful for informing my study into the lived experience of the phenomenon was a Master’s thesis in which Canadian women clearly recalled the moment of being told they had ovarian cancer, including the location, the manner of being told and who was with them (Stilos 2003). The thesis reported that women appreciated empathetic HCPs. Being accompanied by a support person was advantageous, as women often felt unable to absorb information at the time of diagnosis. Upon being told the news, women’s thoughts leapt to the uncertainty of their future and the possibility of their death. This study highlighted a number of themes, which were detected in the majority of publications describing women’s ovarian cancer (without recurrence) experience - that is, the importance of supportive relationships and the fear of cancer-related-death.

**Being treated for ovarian cancer**

The themes of relationships and/or of existential fear regarding recurrent disease and/or subsequent death were evident in a body of literature, which explored women’s experiences surrounding treatment for their primary ovarian cancer diagnosis. These research studies explored such diverse aspects of women’s experiences surrounding treatment as the period before and after surgery (Seibaek, Petersen, Blaaker & Hounsgaard 2012), chemotherapy decision making (Elit et al 2003), test results anxiety (Reid, Ercolano, Schwartz & McCorkle 2011), psychological distress during treatment (O’Sullivan 2011), QOL (Ding, Zhu & Zhang 2007; von Gruenigen et al 2010), social support during chemotherapy (Ding, Zhang & Zhu 2008), and chemotherapy-induced alopecia (Jayde et al 2013).
For example, women’s fears of dying were documented by a phenomenological study of Danish women’s experiences of undergoing surgery for ovarian cancer (Seibaek et al 2012). Women maintained hope in the face of their fears of dying and actively prepared themselves and their personal lives in readiness for the surgery. Relationships with family, friends and HCPs were significant influences on this period. Such relationships also significantly influenced Canadian women’s chemotherapy decision-making (Elit et al 2003). Although women knew the benefits and risks of chemotherapy, they felt overcome by their diagnosis and the subsequent threat to life and decisions regarding further treatment were largely dependent upon their doctor’s recommendations. Existential fear was evident in a USA-based analysis of nurse’s records, which briefly described women’s anxiety regarding the link between blood test results and possible recurrent disease (Reid et al 2011). The theme of existential angst was also evident in a USA-based dissertation, which reported a secondary analysis of quality of life (QOL) data collected from a randomised controlled trial of the impact of targeted nursing interventions (O’Sullivan 2011). Women’s ovarian-cancer-related psychological strain was described with the majority of women reporting high levels of psychological distress. Women’s emotional, functional and physical QOL were reduced in a group of women undergoing chemotherapy in a USA-based study (von Gruenigen et al 2010). However, the authors suggested that the receipt of social support might account for women’s social well-being levels, which were above the USA average for adult females. Alopecia arose as an important element of women’s experiences in early analysis of findings from my (current doctoral) study (Jayde et al 2013). Women experienced chemotherapy-induced alopecia as concrete confirmation of their cancerous state and as an aide-mémoire of their potential for an early ovarian-cancer-related-death. The alopecia negatively impacted women’s relationships with self and others. This was the only Australian publication identified in this group of literature.

Two studies were identified, which investigated women’s experiences of treatment for ovarian cancer through cultural lenses (Ding et al 2007; Ding et al 2008). Family relationships were described as being central to the perception of social support for Chinese women undergoing chemotherapy (Ding et al 2008). The authors also explored the QOL of Chinese women and found that whilst physical well-being
improved over time, social well-being, in particular relationships with HCPs, deteriorated (Ding et al 2007). The authors noted that women’s experience might change dramatically with the presence of recurrent disease.

After treatment ends

Aspects of the post-treatment phase for women with ovarian cancer (without recurrence) have been explored by a number of quantitative studies, including QOL (Wenzel et al 2002), long-term adjustment (Kornblith et al 2010; Matulonis et al 2008), QOL comparisons between women with early or advanced stage disease (Mirabeau-Beale et al 2009), current well-being (Stewart, Wong, Duff, Melancon & Cheung 2001), and views on the cause, prevention and recurrence of ovarian cancer (Stewart, Duff, Wong, Melancon & Cheung 2001).

While the relevance of quantitative studies may be limited in a review of literature that explores women’s lived experiences, such studies did provide evidence that women’s fears of recurrence were not confined to the diagnostic and treatment period. For example, USA-based QOL studies of women more than three years after diagnosis and treatment for either early or advanced stage ovarian cancer reported that the majority experienced ongoing fears of recurrence (Kornblith et al 2010; Matulonis et al 2008; Mirabeau-Beale et al 2009). A survey of women from Canada and the USA who were at least two years post diagnosis without recurrence also reported a majority experienced ongoing fears of recurrent disease (Stewart, Duff et al 2001). These fears may possibly abate after time as another USA-based survey of early-stage ovarian cancer survivors at least five years post-diagnosis reported 20% continued to experience fears of recurrence and 43% would like to have counseling if available (Wenzel et al 2002).

The importance of relationships in the continuing lives of women post-ovarian cancer treatment is suggested by the recurring theme of negatively impacted sexuality in the QOL survivorship literature (Kornblith et al 2010; Matulonis et al 2008; Mirabeau-Beale et al 2009; Stewart, Wong et al 2001; Wenzel et al 2002).
Studies that inferred they only included women without recurrent disease.

A difficulty encountered in conducting this literature review was determining whether studies included or excluded women with recurrent disease. This was an important consideration, because as explained earlier in this chapter, literature suggests that the experience of the phenomenon after confirmation of recurrence was likely to be different than prior to recurrence (Ding et al 2007; Ekwall et al 2007; Ekwall et al 2011; Elit et al 2010; Jordens et al 2010; Petterson 2006; Powel et al 1998; Ryan 2005). Whilst some studies specifically stated they excluded women with recurrence (for example, the studies described in the previous section), others were less clear. For example, studies might have commenced with women without recurrence but might have collected data many months after recruitment, when some women might have developed recurrent disease (see, for example, Cox et al 2008; Petterson 2006).

Holistic studies of the experience

Two articles were identified, which appeared to describe the holistic experience of ovarian cancer (without recurrence) but which did not explicitly state non-recurrent disease as inclusion criteria (Ekman, Bergbom, Ekman, Berthold, Mahsneh 2004; Fisher-Morris 2009). The previously described themes of fear of recurrence/death and the importance of relationships were evident in both studies.

The time following an ovarian cancer diagnosis was described as chaotic and the chemotherapy period as a time of facing the reality of the disease and its associated prognosis (Ekman et al 2004). The phenomenological exploration of Swedish women’s experiences of diagnosis and treatment for ovarian cancer found whilst some women received support from family and/or friends, others described having to maintain a façade of normality to ‘protect’ loved ones and maintain relationships.

The importance of support for women with ovarian cancer was highlighted in a British psychology-based dissertation (Fisher-Morris 2009). Women spoke at length about relationships with spouses and how these affected their experience of the
phenomenon. Relationships with HCPs were also examined, with some women openly comparing statements from different HCPs to support their personal interpretation of their illness. The women sought to make meaning from their illness experience. Once again, women’s fears of recurrence/death were frequently discussed, with some women denying the reality of their illness and prognosis and others describing dread about their future.

Specific aspects of the experience

A small number of quantitative studies were identified, which appeared to explore facets of the ovarian cancer experience prior to recurrence (Cox et al 2008; Hess et al 2010; von Gruenigen, Frasure, Jenison, Hopkins & Gil 2006; von Gruenigen et al 2011) and which provided fragments of information about the experience. Personal relationships were discussed with nurses by a majority of British women with ovarian cancer in follow-up conversations conducted up to ten months after completion of chemotherapy (Cox et al 2008). A third of the women discussed their fears of recurrence/dying and 41% discussed sexuality issues. The finding about sexuality reflects those reported in the QOL literature briefly mentioned in the previous section of this chapter. The feasibility of a lifestyle intervention for women during chemotherapy to promote exercise and diet changes (von Gruenigen et al 2011); declining cognitive function during chemotherapy (Hess et al 2010); and declining QOL during chemotherapy with improvement following completion (von Gruenigen et al 2006) have been documented in USA-based studies. None of these studies appeared to offer considerable insight into the lived experience of ovarian cancer.

Australian studies

A number of studies have explored the ovarian cancer diagnostic process for Australian women (e.g. Jordan et al 2010; Lataifeh, Marsden, Robertson, Gebski & Hacker 2005; Nagle et al 2011; Webb et al 2004). No Australian studies which specifically explored the holistic experience of ovarian cancer (without recurrence), were identified and obtained for this review. The only Australian study identified,
which explored an aspect of the ovarian cancer experience (without recurrence) has previously been described in this chapter (Jayde et al 2013) and arose from early findings from this current study. One Australian study was identified, which explored the holistic experience of ovarian cancer for 10 women (including six women who developed recurrence) using art therapy (Petterson 2006). Two Australian studies were identified, which specifically explored the holistic experience of recurrent ovarian cancer (Ryan 1997, 2005). A number of publications were identified which have been published since commencing my PhD. These studies either did not specify the recurrence status of participants (e.g. Gleeson et al 2013) or included women with recurrent disease (e.g. Beesley et al 2013; Jordens et al 2010; Morrell et al 2012).

Holistic studies of the experience

Three Australian studies were reviewed which explored the holistic experience of ovarian cancer for women (Petterson 2006; Ryan 1997, 2005). Petterson (2006) explored the experience of ovarian cancer using medical art therapy. Written in Australia, the thesis sample was not restricted to Australian women and included one woman who lived overseas. The experience was one of progressive loss and life dislocation as women struggled to cope with the illness demands on their relationships with self and others. Six women were diagnosed with recurrent disease and five women died during the study. The confirmation of recurrent disease was described as a time of increased fear and dread about dying, as the women realised recurrent disease ended their hopes of surviving the cancer.

Ryan (1997, 2005) explored the holistic experience of Australian women with recurrent ovarian cancer and described the emphasis placed on existential and psychosocial aspects of their experience. Women lived with gradual corporeal breakdown and an omnipresent awareness of their forthcoming cancer-related death. Women paradoxically experienced acute uncertainty whilst simultaneously experiencing certainty re the probable nature of their death (Ryan 2005).
Specific aspects of the experience

Various Australian studies have explored QOL of women with ovarian cancer, with a number of recent publications arising from a large, multi-centre study, ‘The Australian Ovarian Cancer Study’ (AOCS) and its associated QOL study. Some of these publications have focused upon psychological aspects of the experience of ovarian cancer, particularly depression and/or anxiety. For example one report found 44% of women surveyed suffered from insomnia (Price et al 2009). The authors suggested that insomnia was linked to anxiety, which might be linked to uncertainty, fear of recurrence and/or concern about others. Another report identified that women with invasive ovarian cancer had higher levels of depression than the community norm and their caregivers had significantly high levels of depression and anxiety (Price et al 2010). It was suggested that women’s anxiety and/or depression was linked to low levels of optimism, troubling symptoms and undergoing treatment for mental health problems, whilst caregiver’s anxiety and/or depression were linked to low optimism and low levels of social support. One article linked physical activity with increased psychosocial health for women surveyed seven to 64 months post diagnosis (Beesley, Price, Butow et al 2011). Many of the women had not regained their previous levels of physical activity years after their diagnosis. A further publication that arose from the AOCS QOL study found that women’s psychological and physical needs remained constant post-diagnosis (Beesley et al 2013). Of note was that many of the women continued to worry about future uncertainty, disease spread and/or recurrence up to three years post-diagnosis. Whilst only the Beesley and colleagues (Beesley, Price, Butow et al 2011; Beesley et al 2013) articles clearly stated the samples included women with recurrent disease, it is likely that all the studies arising from the AOCS QOL study included women with recurrent disease as data was collected from women up to four and a half years (Price et al 2010) and up to six years (Price et al 2009) post diagnosis. Women’s QOL in their last year of life was summarised in an additional article arising from the AOCS QOL study (Price et al 2013), which reported that symptoms increased and QOL declined significantly in the six months prior to the women’s death.
Other Australian studies have also focused upon psychosocial aspects of ovarian cancer. For example, women’s levels of depression and/or anxiety after treatment for early stage ovarian cancer were found to reduce as time passed although 27% of the women had raised anxiety levels, years after their treatment finished (Bisseling, Kondalsamy-Chennakesavan, Bekkers, Janda and Obermair 2009). (It was unclear if the sample included women with recurrent disease.) Morrell et al (2012) noted the way in which women with ovarian cancer (including recurrent disease) spontaneously compared themselves to other people, including those with other illnesses and people with good health. The majority of women preferred to avoid contact with other women with ovarian cancer. The results of the study have implications for the provision of support for ovarian cancer patients, including the conduct of ovarian-cancer-specific support groups.

Women with advanced ovarian cancer (including recurrent disease) were reported to monitor their bodies subjectively and/or objectively for signs of recurrent disease (Jordens et al 2010). The study described women’s experience of CA125 testing and found women interpreted CA125 levels in various ways, including as an objective measure of physical health and as a gauge of treatment efficacy. The authors refuted a commonly suggested link between CA125 testing and anxiety. (CA125 is a protein found in blood, which is commonly used as a ‘marker’ to indicate possible ovarian cancer, efficacy of treatment and possibility of recurrence.)

The information and communication preferences of Australian women with ovarian cancer regarding treatment-focused genetic testing were explored in a qualitative study which found that women wanted information about testing early enough in their experience to enable test results to be relevant and useful for planning their treatment strategies (Gleeson et al 2013). (Again, it was unclear if the sample included women with recurrent disease.)
The experience of ovarian cancer for partners

The majority of literature that explores the experience of the phenomenon of ovarian cancer does so from the perspective of women with the disease. As stated in the previous chapter, the focus of this study is upon the phenomenon of ovarian cancer illness, rather than disease. The study plan is to explore, interpret and describe the experience of ovarian cancer by circling the phenomenon, that is, taking into account perspectives of the phenomenon from the three participant groups of women, partners and children. Accordingly, this review includes literature that illuminates the experience of ovarian cancer for partners.

Although previous authors have noted the impact of ovarian cancer upon spouses (Howell et al 2003; Nattress 2002; Ponto 2008; Ponto & Barton 2008) spouses of women with ovarian cancer have been largely neglected in the literature and few studies were identified which specifically examined spouses’ experience with ovarian cancer (Armstrong 2012; Arden-Close 2008; Frost et al., 2012; Ponto, 2008, 2010; Ponto & Barton, 2008). Six authors (Bowes 1998; Jayde 2007; Jefferies 2002; Ponto & Barton 2008; Ryan 1997, 2005) have specifically suggested that research in the area of partners of women with ovarian cancer is needed. Despite this repeated suggestion, the first of which was 16 years ago, research has only recently been published.

No Australian studies were identified which specifically explored the experience of spouses of women with ovarian cancer. With the exception of one British study (Arden-Close 2008), all identified studies arose from the USA. No studies were identified, which specifically explored the experience of partners of women with ovarian cancer (but without recurrence). With the exception of Frost et al’s (2012) article (which strongly inferred the inclusion of women with recurrent disease) the other publications clearly stated samples included partners of women with recurrent disease. As explained previously in this chapter, the experience of ovarian cancer after diagnosis of recurrent disease is likely to be markedly different from the experience before diagnosis of recurrence. Prior to recurrence, there can be hope of ongoing remission from the cancer. After recurrence, the disease is no longer curable.
(Hennessy et al 2009). It is probable that spousal research findings will thus be impacted by the inclusion or exclusion of spouses with wives with recurrent disease.

For example, such impact is suggested by an examination of a study, which surveyed and compared the spiritual wellbeing and QOL of women and spouses over a three-year period (Frost et al 2012). Although the authors did not state that the sample included women with recurrent disease, this was inferred as a number of participants with ovarian cancer died during the study period. The authors reported that at three years spouses experienced worse QOL, worries and emotional and social well-being than previously. Although 24 couples commenced the study only six pairs completed it three years later. The degree to which poor spousal well-being may be attributed to wives having recurrent disease and perhaps dying from their cancer is unclear.

In addition to Frost et al’s (2012) study described above, three studies were identified which explored the experience of ovarian cancer of both women and spouses (Arden-Close 2008; Armstrong 2012; Ponto 2008), albeit from diverse viewpoints and with different methods. Whilst Armstrong (2012) took a broad approach to the experience, Arden-Close (2008) and Ponto (2008) explored specific pre-determined aspects of the phenomenon. For example, Ponto (2008) explored the relationship between a number of variables (such as uncertainty and marital quality) and the adjustment and growth of 32 women with recurrent ovarian cancer and their spouses in a dissertation study. Results indicated that spouses feared recurrent disease more than the women with ovarian cancer. The adjustment of both members of the dyad was related to their spouse’s appraisal of the illness. A secondary report of the dissertation research (Ponto 2010) suggested the spouses adjusted less when the woman had heightened symptom distress. Owing to the quantitative nature of the research, limited insight is given into spouses’ lived experience. Arden-Close (2008) also explored a specific aspect of the ovarian cancer experience by conducting a randomised controlled trial of the effectiveness of writing exercises in reducing stress and improving QOL for women and partners. Approximately half the women had recurrent disease. The intervention was not effective and partners reported increased intrusive thoughts three months later. Results indicated that partners experienced significant distress.
associated with the cancer, and similar to results reported by Frost et al (2012), partner’s QOL decreased over time.

Two studies were identified, which approached the experience of ovarian cancer for partners from a more holistic perspective. In the only study identified, which explored spousal experience of ovarian cancer without including their wives, Ponto and Barton (2008) explored the experiences of 11 husbands who were living with spouses diagnosed with ovarian cancer. The women had been diagnosed between 10 months and 15 years earlier and 45% had experienced at least one recurrence of the disease. The men described the impact of the disease upon their relationships with others and upon their lifestyle and priorities. (The phenomenological study was used as a pilot study for Ponto’s (2008) PhD research, described above.) The impact of ovarian cancer upon spousal lifestyle, priorities and relationships was also noted in a recent USA-based study. Like Ponto and Barton (2008), Armstrong (2012) also explored the holistic experience of spouses of women with ovarian cancer (including recurrent disease), although in this mixed-method dissertation study, wives were included and spouses were labeled “spouse/partner caregivers” (p.57). The inference of the label was that partner participants were caregivers of the women participants. This may have limited spousal participation in the study to those spouses who identified as caregivers. Dyads were either interviewed together in a group or separated into patient or partner groupings. Differences noted between the groups suggested that partners talked about different issues in front of their wives and without their wives. For example, in the partner-only group, participants discussed their experience of navigating the health system, being advocates for their wife and fear of their wife’s death. These issues were not discussed in the group of dyads.

The experience of ovarian cancer for family members

Previous authors have noted that the diagnosis and treatment of ovarian cancer affects not only the individual but also their spouse and family (Ersek, Ferrell, Dow & Melancon 1997; Ferrell, Smith, Ervin et al 2003; Howell et al 2003; Petterson 2006; Ponto 2008). As with partners, the experience of families with a member diagnosed
with ovarian cancer has been identified as a need for future research (Bowes 1998; Howell et al 2003; Ryan 1997). Only three (very different) studies were located, which explored the family experience of ovarian cancer (Koldjeski, Kirkpatrick, Everett, Brown, & Swanson 2007; Shepard 2002; Tarraza & Ellerkmann 1999) although none of these were conducted in the Australian context. No studies were identified, which specifically explored the experience of ovarian cancer for adult children. Therefore, this chapter section presents literature that describes the experience of ovarian cancer for family members.

Two studies were identified, which described aspects of the family experience of having a loved one die from ovarian cancer. Shepard (2002) described family members response to the diagnosis and subsequent death of a woman with advanced ovarian cancer, who lived in a remote Amazonian tribe. Whilst this essay throws little light on the likely experience of ovarian cancer in Australia, it does highlight the impact of culture in illness, death and grief. Tarraza and Ellerkman (1999) conducted the only study identified which set out to specifically explore the experience of ovarian cancer for family members, after their loved one had died. An un-validated seven-item questionnaire was posted to 34 families who had had a family member die of ovarian cancer at least 12 months previously. The most common response described witnessing the woman’s suffering as the most distressing aspect of the illness. Responses obtained from spouses, daughters, sisters and a brother were not discussed in terms of the respondent’s relationship to the deceased.

The experience of ovarian cancer for 18 family groups was assessed at five periods over one year (Koldjeski et al 2007). Discussions revealed a family-focus upon facilitating optimal care for the ill woman, adjusting to and integrating the cancer within ongoing family life and the management of communication and relationships with HCPs. Similar to the study by Tarraza and Ellerkmann (1999), individual family member’s responses were not recorded, so the voices of spouses and offspring cannot be identified in the results. The term ‘family’ was not defined and the 18 families, consisting of 50 members overall, were not described. It is not known if the sample included families of women with recurrent disease.
The experience of ovarian cancer for caregivers

A number of studies have explored the experience of caregivers of women with the disease (Armstrong 2012; Beesley, Price, Webb et al 2011; Ferrell, Ervin, Smith, Marek, & Melancon, 2002; Le et al 2004; Price et al 2010). Although my study does not explore the experience of caregivers, the studies are mentioned briefly here as most samples had a majority of spouses. All studies focused upon aspects of QOL and no research was identified which specifically explored the experience of caregivers for women with ovarian cancer without recurrence.

Two caregiver studies arose from the Australian context, in particular from the AOCS QOL study. Beesley, Price, Webb et al (2011) explored changes in health following the onset of caregiving for a family member with ovarian cancer in Australia. The majority of caregivers reported a negative impact on their health after becoming a caregiver, for example, exercising less and/or increasing weight. Another report of Australian women and caregivers was introduced earlier in this chapter under ‘Australian studies’ (Price et al 2010). Caregivers had significantly higher anxiety scores than their ovarian cancer spouse/partner. Independent predictors of depression and/or anxiety for caregivers included lower optimism and lower levels of social support. Whilst these studies provide some insight into Australian caregiver’s lifestyles and QOL, detailed exploration of their lived experiences is absent.

The remaining three studies arose from the USA (Armstrong 2012; Ferrell et al 2002) and Canada (Le et al 2004). Armstrong’s (2012) study was described in the previous chapter section as the study specifically recruited ‘spouse/partner caregivers’. Ferrell et al (2002) explored correspondence from family caregivers of women with ovarian cancer sent to the editor of an international ovarian cancer support group. The analysis revealed family caregivers had needs in each of four QOL domains (physical, psychological, social and spiritual well-being), with spiritual well-being receiving the most comments. Le and colleagues (2004) compared QOL of caregivers with QOL of women with ovarian cancer undergoing chemotherapy and found the QOL of caregivers was adversely affected by increased dependency of the women. Again,
whilst these studies might provide insight into the QOL of caregivers internationally, they provided limited information of relevance to my study.

The experience of ovarian cancer in art and other literature

In accordance with the philosophical basis of my study, in addition to published and unpublished research studies, I explored other sources, such as internet blogs, memoirs, poems, plays and artworks, which helped me to understand and interpret the experience of ovarian cancer. Whilst the majority of these sources included the experience of recurrent disease, they are mentioned and acknowledged here as I felt their ‘first-hand’ nature offered me alternative, non-research-based perspectives of the phenomenon.

Women’s experience of the phenomenon was illuminated by a number of sources. A script for a play (Edson 2000) and published accounts of women’s experience of ovarian cancer (Brett 2002; Cristo 1995; Di Giacomo 2003; Spano 2007; Stacey 1997; Strumpf & Buhler-Wilkerson 2010; Tilberis 1998; Torrens 2006; Van Billiard 2005; Vande Berg & Trujillo 2008) facilitated my understanding and interpretation of the complex experience of the phenomenon. Two memoirs arose from the Australian context, including one from an indigenous Australian woman (Torrens 2006) and a creative arts PhD thesis (Brett 2002). Edited books also provided insight into the experience (Carter and Elit 2009; Gregory and Russell 1999; Kraus 2008; Miron 2004; Montague & Burley 1997). Poems written (Brett 2002; Petterson 2006) and artworks drawn (Petterson 2006) by women with the illness illustrated the experience from diverse viewpoints.

Spousal experiences of ovarian cancer were identified in a few memoirs (Marsicano 2006; Piver & Wilder 1998; Strumpf & Buhler-Wilkerson 2010; Vande Berg & Trujillo 2008). One husband created artworks such as sculpture to express the experience of ovarian cancer, symbolising such aspects as chemotherapy, hair loss, appointments, exhaustion (Magnan 2000) and, later, the essence of his deceased wife
Apart from conversations on Internet blogs, I was unable to locate any relevant ‘additional’ sources of insight into children’s experience of ovarian cancer.

Review summary

This chapter has presented a synopsis of current documented knowledge about women’s experience of ovarian cancer (without recurrence). Only two explorations of the holistic experience were identified. A number of themes recognised as being common to the experience arose from a small body of Australian and international literature. Women feared the development of recurrent disease and/or feared dying from their disease. These fears were omnipresent throughout their experience and were documented and described in various ways. Women experienced existential angst in the face of their uncertain futures and supportive relationships were critical in enabling the women to cope with their illness.

No Australian studies were identified which explored the holistic experience of ovarian cancer (without recurrence) for women. Three holistic Australian studies (which included or focused upon women with recurrent disease) described women’s fear of recurrence/death. Australian QOL studies focused upon psychological aspects of the experience of women with ovarian cancer, including anxiety about future uncertainty and fears of recurrence and/or disease spread.

No Australian, and few international, studies were identified which specifically explored the experience of ovarian cancer for spouses. Reduced QOL over time, fear of recurrence/death and the importance of relationships were noted to be repeated themes.

There were no studies identified, which explored the experience of ovarian cancer for adult children, and the experiences of ovarian cancer for family members have
received limited attention in the literature. The experiences of caregivers of women with ovarian cancer have been explored through QOL studies. Caregivers were negatively impacted by their experience and had documented needs across all domains of QOL.

Sources that facilitated my understanding and interpretation of the phenomenon are illustrated by the iMindMap in Figure 2.

![iMindMap](image)

**Figure 2: Sources that provided background to the study**

**Chapter conclusion**

This review has identified gaps in literature regarding the experience of ovarian cancer. In particular, documented knowledge of the holistic experience of ovarian cancer (without recurrence) for women, partners and adult children, within the Australian context is currently lacking. The focus of this current study aligned with the identified gaps and sought to address these absences in knowledge.

The following chapter will present the philosophical foundation of the study, that is, hermeneutic phenomenology. Phenomenology will be introduced and the application and relevance to my study explained.
CHAPTER THREE: PHILOSOPHICAL FOUNDATION OF THE STUDY

Wonder is a beautiful style of perception; when you wonder at something, your mind voyages deep into its possibility and nature. You linger among its presences. You do not take it for granted and are not deceived or blinded by its familiarity. (O’Donohue 2000, p.279.)

Hermeneutic phenomenology forms the philosophical framework for this qualitative study and is introduced and discussed in this chapter. The methodological choice for the study is explained and rationalised and the term ‘lived experience’ elucidated. The chapter then presents an overview of phenomenology and an introduction to hermeneutic phenomenology. Philosophical understandings and key phenomenological concepts of four phenomenologists in particular guide this study. These are discussed in relation to their relevance to this study.

Methodological choice for the study

The choice of methodology for this study was guided by the study aim and research question. The aim of my research was to gain a deep understanding of the nature and meaning of the lived experience of ovarian cancer. In particular, the focus of the study was to develop understanding of what is was like for Australian women, partners and/or children to live through the diagnosis, treatment and aftermath of ovarian cancer, prior to any recurrent disease. As the focus of the study was upon lived experience of the phenomenon, qualitative research was an appropriate methodological choice. Qualitative research aims to understand “how people think and feel about the circumstances in which they find themselves” (Thorne 2000, p.68). Qualitative research methods “offer ways to approach individuals in experiences, to encourage them to give voice to their experiencing, and to care enough to search for meaning within the experience” (Munhall 2012b, p.61). My decision to explore the meaning and nature of the lived experience of ovarian cancer reflected the value I
place upon the meanings of experiences for others. This value influenced my approach to my research and permeated all stages of the research process.

‘Lived experience’ and the phenomenon of interest

In this study, ‘lived experience’ refers to the participant’s experience of the phenomenon of ovarian cancer. The term ‘lived experience’ is translated from German and does not translate easily to English (Burch 1990). It can be taken to refer to an experience of something, which is remembered as being significant and memorable for that person and which has been integrated into his/her sense of self. “Something becomes an “experience” not only insofar as it is experienced, but insofar as its being experienced makes a special impression that gives it lasting importance” (Gadamer 2004, p.53). Lived experiences are significant, meaningful and memorable experiences of such entities as activities, emotions and situations, (Ray 1994) that are incorporated into the dynamic continuum of our lives. They become integrated into one’s self and become part of one’s life (Gadamer 2004) and help determine who we are and who we become. “Our experiences serve to revise the way in which we understand our past and anticipate our future, and for that reason are tightly interwoven with our historic past and our present” (Holroyd 2007, p.9). A lived experience is how we experience a phenomenon before we reflect upon it (van Manen 2014). It contains an essence, basic quality or theme that makes it what it is (van Manen 1990). “Lived experience is simply experience-as-we-live-through-it in our actions, relations and situations” (van Manen 2007, p.16). Lived experiences are subjective rather than objective, because that is how things are experienced (Carel, 2008). The focus of the current study is upon the lived experience of ovarian cancer. Thus, the phenomenon of interest is the subjective experience of the ovarian cancer illness and this study aims to determine the nature and meaning of that experience.

Phenomenology: an overview

Phenomenology is a way of thinking (Merleau-Ponty, 2002), an attitude of wonder about the world (van Manen 2014). It is a philosophical style of inquiry, which
focuses upon the experience, perceptions and existence of humans (Carel, 2008; Morse & Richards 2002; van Manen 2014). Lawler (1998) used the term “phenomenologies” (p.104) to indicate that there are many forms of phenomenology, and that as a philosophical attitude phenomenology informs but does not prescribe how research is conducted. “Phenomenology asks the simple question, what is it like to have a certain experience?” (van Manen 1982, p.296). The focus is upon the meaning of the lived experience of a phenomenon (Creswell 2007; van Manen 2014) with the aim of describing the “essential nature” of the phenomenon (Thorne 2000, p.69). The use of phenomenology in this study appropriately reflects the impetus for the study, that is, my wonder and curiosity about what it was like to ‘live through’ the experience of ovarian cancer in Australia.

The history of phenomenology is well documented. The origins of phenomenology are generally credited to Franz Brentano, but it was Edmund Husserl who first formally introduced and fully developed the concept (Moran 2000). Phenomenology was further developed by Martin Heidegger, and by later philosophers including Maurice Merleau-Ponty, Hans-Georg Gadamer and Max van Manen. As such, under the umbrella of the term ‘phenomenology’ there are many schools, which share some similarities but are also different from each other (Dowling 2007). Whilst being open to other schools of philosophical thought, this study is informed by hermeneutic phenomenology and takes particular inspiration from the philosophies of Heidegger, Merleau-Ponty, Gadamer and van Manen. Key phenomenological concepts from these four philosophers are discussed below.

Hermeneutic phenomenology

Hermeneutics was originally used to interpret literature and biblical texts (Gadamer 2004). Hermeneutics means to interpret or understand (Heidegger 2008; Schmidt 2006), and is based on the assumption that language is our basis for understanding and experiencing the world (Gadamer 2004). “Language does not just reflect human being but actually makes humans be, brings about human existence as communal understanding and self-understanding” (Moran 2000, p.270). People make sense of their understandings of their world via language – their narratives contain the
meanings of their experiences, as they themselves understand them (Gadamer 2004; Kahn, 2000). My study is hermeneutical in that it is based upon the interpretation of language in the form of dialogue and written text.

Hermeneutics was an important concept for both Gadamer and Heidegger. Heidegger (2008) built upon Husserl’s descriptive phenomenology, believing that description was insufficient for phenomenology, and interpretation was necessary, as things are not always as they seem. For this reason, he linked phenomenology with hermeneutics. Often called ‘interpretive’ or ‘hermeneutical’, the aim of this style of phenomenology is to reveal meanings that may not be immediately clear (Heidegger 2008; Moran 2000). Thus, in phenomenological hermeneutics, the researcher describes and interprets the meaning of the lived experience (Creswell, 2007). There is no definite conclusion—rather the hermeneutic circle is an ongoing process of interpretation and understanding that promotes further questions and thus deeper understandings (Dreyfus 1991). Any interpretation is a product of its time and place and has the potential for being understood in another way by later interpreters (Heidegger 2008; Moran 2000). The hermeneutic circle and the process of interpretation in my study are discussed in detail in the following chapter.

**Methodological congruence**

Morse and Richards (2002) suggested that methodological congruence referred to the match between the focus of the research, the research question, the method used and the way the research is conducted. Phenomenology is appropriate to be used when the focus of a research study is to understand the meaning of a phenomenon for the persons experiencing it – that is, from their perspective (Cohen, 2000; van Manen, 1990). In a phenomenological study, the researcher “collects data from persons who have experienced the phenomenon, and develops a composite description of the essence of the experience for all of the individuals” (Creswell 2007, p.58).

The focus of interest in a phenomenological study is the participants’ experience of a phenomenon, and phenomenology has traditionally focussed upon one group of participants. This study is built upon the premise that phenomenology need not be
restricted to the analysis of one group of participants’ experience of a phenomenon but rather can be expanded to include multiple perspectives of the same phenomenon. By approaching the phenomenon from three different perspectives, I have been able to develop an in-depth and comprehensive understanding of the phenomenon.

Although not common, the use of phenomenology to interpret the experience of a phenomenon by diverse groups is not a new concept. Henry, Casserly, Coady & Marshall (2008) used phenomenology to explore the experiences of a phenomenon from the viewpoint of five groups of participants and Diekelmann (2001) used the methodology to explore the experiences of three groups. Three recent doctoral studies also explored the experiences of phenomena from perceptions of diverse groups (Dahl 2010; Finigan 2010; McEvoy 2013). Dahl explored a phenomenon from the perspective of two different groups and Finigan explored from the outlook of three. Further to these, McEvoy (2013) in her (Australian) PhD utilised three participant groups to illuminate the phenomenon of the first episode of hospitalisation for young people with schizophrenia.

Morse and Richards (2002) stated that different perspectives of the essence of a phenomenon potentially present “a different dimension of the experience” (p.47). They state that in order to determine the essence of a phenomenon, a phenomenological “researcher reflects on concrete experience, trying to imagine it from all aspects” (p.147). Munhall (2012c) described the value of capturing multiple perspectives of a phenomenon under study as all experiences happen in a context and do “not occur in isolation” (p.153). She suggested to increase the depth of a study, one might try to “capture the various meanings from different individuals who may not be “directly” having the experience but who are “directly” involved in the experience” (p.153). Accordingly, I have designed my study to include women who have the ‘direct’ experience of the ovarian cancer phenomenon and partners and children who are ‘directly involved’ with the phenomenon. Cresswell (2007) suggested phenomenology is suitable for studies in which “it is important to understand several individual’s common or shared experiences of a phenomenon” (p.60). Thus, in light of these understandings, phenomenology is an appropriate methodological choice for this study, which aims to explore, interpret and describe the meaning and nature of the lived experience of the phenomenon of ovarian cancer.
Key phenomenological concepts informing this study

A number of key phenomenological concepts informed this study. These include: ‘world’; ‘horizons of understanding’; and ‘lifeworld existentials’. These will be introduced and examined in the following section. The relevance to my study of each key concept is then considered.

‘World’

Merleau-Ponty (2002) stated, “true philosophy consists in relearning to look at the world” (p.xxiii). He suggested that phenomenology “offers an account of space, time and the world as we ‘live’ them” (p.vii). The term ‘world’ has a number of definitions. It can refer to an objective world or, as in the case in phenomenology, it can refer to the subjective world of lived experience. Merleau-Ponty (2002) stated “the world is not an object such that I have in my possession ... it is the natural setting of, and field for, all my thoughts and all my explicit perceptions” (pp.xi-xii). It is where we ‘find’ ourselves (Heidegger 2008; Merleau-Ponty 2002).

Heidegger (2008) defined the word ‘world’ in a number of interconnected ways, but primarily focused upon the concept of the world in which we ‘live’ and are involved (p.65/93). He stated, “‘worldhood’ is an ontological concept” (p.92) and thus he believed this ‘world’ related to the nature of Being. For Heidegger, people existed in the world as “Being-in-the-world” (p.92). Heidegger’s hyphenated ‘Being-in’ can be understood as meaning “being absorbed in the world” (Heidegger p.80). Rather than meaning that we are merely ‘in’ the world like objects such as trees, ‘Being-in’ reflects our reciprocal involvement and relationship with entities within the domain of our lives (Matthews 1996, 2002; Moran, 2000) and the ways in which we find and create meaning in that world (Matthews 2002). The ‘world’ is experienced individually, yet shared with others. Merleau-Ponty (2002) suggested, the ‘world’ is “the sense revealed where the paths of my various experiences intersect, and also where my own and other people’s intersect and engage each other like gears” (Merleau-Ponty 2002, p.xxii).
As humans, we do not view our world from an outsider’s perspective, but rather we view it from the situation that we are in – from within the world (Merleau-Ponty, 2002). We “live through” (p.xviii) the world. Experience of a phenomenon (such as ovarian cancer) “is lived by me from a certain point of view; I am not the spectator, I am involved” (Merleau-Ponty 2002, p.354). Heidegger (2008) and van Manen (1990) suggested that persons can live in a number of different ‘worlds’, according to their circumstances for example, the ‘world of the carer’ or the ‘world of the patient’. Leonard (1994) suggested that these worlds reflect the particular entities such as relationships, language and meanings that are related and significant to that person in that situation. The world is ‘their’ world – that is, the world that has meaning for them, in which they experience phenomena from a particular point of view. In other words, I understand the world from my personal perspective. I am the centre of my world, and I understand the world in terms of myself and what phenomena mean to me, in the particular context in which I am situated.

Persons have a relationship to their world in which they adopt the history, cultural meanings, family customs and language of the context into which they are born. Thus the individual situation of the person (including culture, family, and language) will significantly affect their self-understanding and the way they experience phenomena (Leonard, 1994; Munhall 2012a). The context of a situation in which an illness is experienced provides background understanding and a structure within which a person’s experience can be explored. Therefore, the context of the person’s life is critical in order to understand that person and to interpret the meanings they attach to situations and phenomena (Leonard 1994; Munhall 2012a) such as ovarian cancer.

In relation to this study, ‘world’ can be understood as the meaningful context in which participants found themselves and the situation from which participants experienced the phenomenon. The concept of ‘world’ includes relationships, historical, social and cultural contexts, temporality, emotions, spatiality and corporeality. It involves roles and responsibilities, hopes and fears. It is characterised by moods and feelings, which represent the meaning of the situation for a person and their life within that situation. Participants’ Being-in-the-world reflected their absorption with and situatedness within the world of ovarian cancer. They ‘lived through’ their experience from their
individual context, from the vantage point of being a woman with ovarian cancer, a partner of a woman with the disease or an adult child of a woman with the cancer. It is the meanings that arose for the participants out of their interaction between the phenomenon of ovarian cancer and themselves, within their personal contextual ‘world’ that my study was seeking to understand.

Horizons of understanding

In a phenomenological study, the context of the researcher is also important. The focus of hermeneutic phenomenological research is chosen by a researcher as a direct result of their situatedness in the world (Gadamer 2004). Researchers seek answers to questions, which are based on knowledge and understanding that they currently have. The answers they obtain in response to their questions may illuminate features of the subject matter that they had not noticed previously and thus may influence and change the way they think about the subject matter of the original question (Dreyfus, 1991; Moran 2000). The researcher must have some background understanding of the issue (for example, ovarian cancer) in order to ask the question (Heidegger 2008; Moran 2000). The background understandings provide a reflexive foundation from which the researcher conducts the research (Koch 1996,1999: Koch & Harrington 1998).

One’s understandings about a topic can be called their ‘horizon’ of understanding. Persons have their own horizon or way of viewing the world (Gadamer 2004). “The horizon is the range of vision that includes everything that can be seen from a particular vantage point” (p.301). One’s horizon is determined by what Gadamer called one’s “prejudices” (p.273) or “fore-meanings” (p.272). By ‘prejudice’ he meant the way we think and feel about a situation or entity before we have fully explored all aspects of it. Prejudices (or fore-meanings) are ideas derived from our personal historical context (Gadamer 2004). We cannot divorce ourselves from our prejudices, as they are a fundamental part of our being and form the basis from which we conduct our research (Moran 2000). As such, researchers bring their prejudices to the research process. Gadamer (2004) believed that the acknowledgment and recognition of our prejudices was a necessary component of any interpretation. By
developing such awareness, the researcher is able to be less biased and more ‘open’ to what others are saying (Gadamer 2004).

Gadamer (2004) described how we may achieve a “fusion of horizons” (p.305) between our point of view and another’s understanding, through open reciprocal communication with another. The ‘fusion of horizons’ is achieved by overlapping, merging and blending different points of view (Moran, 2000). As researcher, I approached my inquiry with my own horizon of meaning. By being receptive to other people’s reality and open to new ideas, my horizon as researcher will merge with that of participants providing new insights into the phenomenon being researched, thus prompting a revision of my prejudices (Moran 2000) and facilitating a new understanding to be co-created. That is, through participatory dialogue both participants in a conversation are able to arrive at new understandings – a fusion or synthesis of their horizons of meaning. This ‘fusion of horizons’ is the aim of research guided by hermeneutic phenomenology (Koch 1999) and is important if we want to understand the world of the participant. By engaging with another person in dialogue we can create “a common ground” (Merleau-Ponty 2002, p.413) of understanding between us. The result is “our perspectives merge into each other, and we co-exist through a common world” (p.413).

In relation to this study, the focus of my research reflects the presence of my horizon of understanding and prejudices regarding the phenomenon, which I developed as a Research Nurse employed in the field of ovarian cancer. Prior to undertaking my study, in order to be cognisant of my “bias” (Gadamer 2004, p.271) I critically examined my personal understandings about the experience of ovarian cancer. This process is described in greater detail in chapter four. I designed my study with the aim of exploring and articulating the meaning of ovarian cancer for participants. By approaching the phenomenon from three group perspectives, I planned to achieve a ‘fusion of horizons’ between participant horizons of understanding and my own. Gadamer (2004) suggested that a horizon signifies “breadth of vision” (p.304). This study sets out to achieve a ‘fusion of horizons’, which will facilitate a deep holistic understanding of the phenomenon of ovarian cancer. This will be discussed in greater detail in the following chapter.
**Hermeneutic circle**

Central to hermeneutic phenomenology is the concept of the hermeneutic circle of analysis (Crotty 1998; Dreyfus 1991; Heidegger 2008), which represents the circular nature of the hermeneutic research process. “The hermeneutic circle is a metaphor for describing the movement between the part and the whole” (Koch & Harrington 1998, p.887). Within the hermeneutic circle, the researcher examines parts of the dialogue (often spoken, then written as text) and compares the findings with the whole. The researcher is constantly moving back and forwards, interpreting and interacting with the text, questioning and reflecting upon what is said. The focus is upon discerning meanings that are not immediately obvious (Moran, 2000). My application of the hermeneutic circle is described in the following chapter.

**Lifeworld existentials**

Van Manen (1990) suggested that four “existentials” (p.101) are typically common to everyone’s world. He described temporality, corporeality, spatiality and relationality as being interconnected “fundamental existential themes” (p.101) that can facilitate phenomenological interpretation.

**Temporality**

“*Lived time (temporality)*” (van Manen 1990 p.104) refers to the subjective experience of time. Different to objective time, which is the objective, measureable time of clocks and calendars, lived time refers to the way we experience time within ourselves. Lived time is that which we sense in personal experience (Matthews 1996; van Manen 1990)

Temporality also reflects the temporal basis of our Being-in-the-world and includes the past, present and future as continuums of our lifetime. We are constituted by temporality and must be understood in terms of this (Heidegger 2008). Whatever we experience, we experience it “as happening ‘in time’” (Heidegger 2008, p.377/429). This means that our lives exist within time, and this temporality is directional - our
past influences our present and both past and present influence our future (Matthews 1996; Carel 2008). That is, our present moment is interpreted in light of past experiences and our future anticipations. For example, our historical context will influence how we experience an illness such as cancer (Munhall 2012c). For Heidegger, a person is a Being-in-time who can only be understood within the overall encompass of temporality – that is, any interpretations must take into account the person’s past, present and future as a form of continuum which is ended by his/her death (Heidegger 2008).

Heidegger (2008) believed that death is the ultimate proof of the temporality of human existence. Part of Heidegger’s emphasis on the centrality of temporality is reflected in the importance of one’s attitude or relationship towards death (Carel 2008; Heidegger 2008; Moran 2000). Our self-understanding is tied closely to our comprehension of the temporal nature of our existence (Carel 2008). Gadamer (1996) described “the repression of death” in society as a natural response to “the certainty that one day one must die” (p.64). Heidegger (2008) believed that having death awareness is a “basic state-of-mind of Dasein” (p.295) which facilitates one’s ability to live a meaningful and authentic life. He believed that “Being-towards-death” (p.304), that is, facing the inevitability of their death, encourages people to think seriously about the way they live their life. In this way, when we accept the certainty of our death, we might develop the insight to decide how we really want to live our life.

Based upon my prejudices about ovarian cancer (gained from my employment and from my initial review of the literature), I anticipated that temporality would be an important concept for participants in my study. Agich (1995) suggested the subjective perception of time could be altered by illness. In my study, I expected participants to reflect upon their past and to base their understanding of their present upon the implications the disease had for their future. For example, owing to the poor prognosis commonly associated with ovarian cancer, I anticipated death awareness to be mentioned by participants.
Corporeality

“Lived body (corporeality)” (van Manen, 1990, p.103) refers to the way in which humans exist within the world as embodied beings. For Merleau-Ponty (2002), ‘being-in-the-world’ is constituted by the fact that we are essentially embodied. He stated, “the body is our general medium for having a world” (p.169). The embodied self and the world are inseparable (Moran, 2000) and we experience the world through our body (Merleau-Ponty 2002). “We are in the world through our body and ... we perceive the world with our body” (Merleau-Ponty 2002, p.239). Central to Merleau-Ponty’s phenomenology is the paradigm of ‘lived body’, the medium which unites our minds and bodies, situates us in the world that we live and enables us to experience and interact with the world. We both are and have a body. It is with our body within the world that we share conversation, speech and thoughts with others (Merleau-Ponty 1964). Merleau-Ponty believed that our body is central to our self-identity. Van Manen (1998) suggested, “I see the other from my vantage point (with my body) and so I understand the other and even my own body ultimately in a mode of being that has my own existence somehow at the center” (p.20). Similar to Merleau-Ponty, he believed that our bodies are our mode of presenting ourselves to the world and of interacting with the world and others.

Our experience of our body and of the body of others can change according to many factors (van Manen, 1998). By considering various experiential dimensions of the body we might develop greater insight into a phenomenon such as illness (van Manen, 2014) when one’s relationship to one’s body is disturbed and the normal way of experiencing oneself within the world is altered (van Manen, 1998). For example, when we are unwell, we may notice our body more than normal. Similarly, when my mother is unwell, I might notice things about her body that I might not have noticed previously. The modes of experiencing our body or the bodies of others are anticipated to have particular relevance to this study. Women will experience their own body and I anticipate that partners and children will have an experience of their wife/mother’s body.
One’s body can be thought of as both an object (a ‘biological body’) and as a subject, (a ‘lived body’). The body is ambiguous – as ‘body-subject’ it is a combination of both object and subject and is not one or the other (Reynolds, 2006). Both these views describe the same body (Matthews, 2006) – that is, the biological body “is an aspect of the lived body” (van Manen 1998, p.16). Medical science typically views the human body as an object – a collection of different parts and systems. This view, (which talks, for example, about a woman having the disease ovarian cancer), is that of the biological body (Carel 2008). This has obvious relevance in a study, which explores the experience of ovarian cancer. One can experience one’s body like an object when one begins to notice unusual bodily symptoms and thus begins to focus upon that part of their body. In my study, this concept may relate to the way women experience unusual symptoms in their bodies. In addition, attending to objective bodily measures, such as blood test results can contribute to experiencing one’s body objectively. In relation to my study, this may be relevant in the way women observe blood test results, such as CA125 levels.

We can also experience our body as an object when others look at us in an objectifying manner – when they focus upon some aspect of our body, such as diseased body parts – when the gaze of another person “stops in my body” (van Manen 1998, p.17). The “other’s gaze transforms me into an object” (Merleau-Ponty 2002, p.20). In other words, as Sartre (2003) suggested, “with the appearance of the Other’s look I experience the revelation of my being-as-object” (p.375). This objective experience is expected to be described in this study, when a woman with unusual symptoms consults a health care professional.

One can also experience the body of another person objectively. When we meet someone, we might not particularly notice his or her body. However, if they seem ill, we might look at their bodies objectively. An example of the potential relevance in this study might be noticing the cachectic appearance of a mother or wife with ovarian cancer. When this occurs we experience “the other’s body as object for our scrutiny” (van Manen 1998, p.14) and thus “the body of the other whom I observe becomes my experience” (p.13).
In contrast to the objective body, the lived body view is subjective – it is the way that one experiences their biological body (Carel 2008, p.26). On this view, a woman lives with an illness – an experience of the disease. This is particularly relevant in this study, with its focus upon the experience of the phenomenon of the illness of ovarian cancer. Again, there are different modes of experiencing the lived body – the lived subjective experience of the person with the body and the subjective experience of the other’s body. One typically has an “unaware awareness” with one’s healthy body (van Manen 1998 p.11), meaning that in the midst of normal everyday life, we take our bodies for granted. It is like our bodies are “transparent” (Carel 2008, p.26) – we don’t really notice them. When we become ill, our body can no longer be taken for granted and aspects of the body that were never noticed before as being part of everyday life are suddenly brought into sharp relief (Carel 2008). In this way one might begin to experience that part of one’s body objectively. One’s ‘lived body’ is also the relationship that person has with their body. It is their sense of self and refers to one’s consciousness of one’s own body, which can be a positive and/or negative experience (van Manen 1998). The ‘lived body’ is how the body is experienced. It was expected to be relevant in this study because women ‘live’ their illness through and with their bodies. An example is that women might ‘live’ their body as fear, due to their ovarian cancer prognosis, or ‘live’ their body as reassurance, trusting it to heal itself.

One can also have a subjective experience of the body of another person. The lived experience of another’s body takes in the relationship held with that person. For example, spouses typically experience each other as separate people yet joined as a couple and children commonly feel an intrinsic link to their mother. One may ‘live’ the experience of another’s habitual body as comfort – with reassuring familiarity and ease. Alternatively, one may ‘live’ the experience of another’s body as changed – with discomfort and frightening unfamiliarity, despite the fact that one knows the person well. This extends the more superficial experience of the body of others with emotions such as appreciation, repulsion, sorrow or regret to understand the lived relationship with the body of the other. This was thought to have relevance to this study in the way partners and children experience the body of their wife or mother.
An example of this might be feeling sad when looking at the disease-ravaged body of a mother with ovarian cancer, but living that sorrow as fear of her death.

Van Manen (1998) described the way the body of another can be experienced as a type of appeal or call for help or care. Levinas (1969) described this as the ethical appeal of “the face” (p.213). This refers to the “moral experience that simply happens” (van Manen 1998, p.21) when another’s vulnerability is recognised and to which one responds with feelings of moral responsibility. Levinas (1969) stated, “To recognize the Other is to give” (p.75) and Heidegger (2008) suggested that caring for others is a basic characteristic of being human. Based upon my professional experience, this dimension is expected to be relevant in my study for those partners and children who experience the vulnerability of their wife or mother as a primordial ethical appeal and demand.

*Spatiality*

“*Lived space (spatiality)*” (van Manen 1990, p.102) refers to the way we feel within a space. It differs from ‘place’ in that it is subjective compared to an objective place. Spatiality may be understood to have ontological and existential meaning as well as geographical or navigational meaning (Fox 2009, p.134). It is an important lifeworld existential as phenomena are always experienced in context, “embedded” (Munhall 2012c, p.159) in spatiality. For instance, a hospital may represent fear or hope to a person, depending on the context.

In relation to my study, spatiality was considered to assist in understanding participants’ experience of related hospitalisations. For example, for a woman newly diagnosed with ovarian cancer who has to face surgery, a hospital may feel unfamiliar and unknown – perhaps even frightening or uncomfortable. However, to a nurse who has worked there for many years, the hospital may feel like a second home – familiar, safe and well known. The objective place is the same – but the lived space is experienced differently.
Relationality

“Lived other (relationality)” (van Manen 1990, p.104) or “intersubjectivity” (Todres, Galvin & Dahlberg 2007, p.57) refers to the relationships we have with other people and the manner in which we experience them. It is the way my life engages with the lives of others and the manner in which I experience, or feel, that engagement. This includes feelings such as love and worry, and senses such as comfort and support. We all share our world with other people and we interact and have relationships with them in various ways. As Heidegger (2008) stated, we live in a “with-world” (p.155), meaning that Being-with-others is a fundamental fact of being human and situated in our world. “Being-in is Being-with others” (p.155). Thus, relationality can be considered as a fundamental “dimension of experience” (Merleau-Ponty 2002, p.421).

Relationality was expected to be relevant in this study because the participants experience the phenomenon of ovarian cancer from within their world of relationships. Relationality may be especially relevant to partners and children, as their participation in the study will in part result from their relationship as partner or child of a woman with the cancer.

Chapter conclusion

This chapter has discussed the utilisation of hermeneutic phenomenology as the philosophical framework for this study. Hermeneutic phenomenology has been introduced and its applicability in this study explained and rationalised. The study has been informed by insights from phenomenology, particularly from the philosophies of Heidegger, Merleau-Ponty, Gadamer and van Manen. Key phenomenological concepts, in particular ‘world’, ‘horizons of understandings’ and the ‘lifeworld existentials’ of temporality, corporeality, spatiality and relationality have been introduced and described. The anticipated relevance of each concept in this study has been discussed. The methodological framework for my study is illustrated in the iMindMap, in Figure 3.
Figure 3: Methodological framework

The following chapter describes the method or process used to conduct the study. It will explain how the study was conducted, including the recruitment of participants, followed by descriptions of the methods used for data collection, analysis and interpretation.
CHAPTER FOUR: METHOD

The previous chapter discussed the philosophical framework of this study and presented concepts of hermeneutic phenomenology that have particular relevance and application to my study. This chapter details the research process used and describes how philosophical concepts were applied. The chapter also introduces the 33 primary participants via vignettes and concludes by addressing study trustworthiness and credibility.

Introduction to the research process

As a philosophy, phenomenology is a way of thinking about things (Merleau-Ponty, 2002). One of its many challenges is to utilise the philosophy as a framework for the conduct of research (Lawler, 1998). Unlike other forms of research, there is no one definitive clear method or series of steps for the conduct of phenomenological research. Rather, it is more of an attitude of wonder towards the research question than a series of steps (van Manen 1989, 2014). Van Manen (1989) described hermeneutic phenomenology as “fundamentally a writing activity” (p.41), from which insights and understandings develop. He outlined a series of methodological concepts, which may aid in the conduct of phenomenological research. These concepts are used in this chapter to describe the research process of the study. The conduct of this research was determined by the aim of the study, in association with the maintenance of a phenomenological way of thinking.

Participant selection

The selection of participants was determined by the aim of my study. Minichiello, Aroni and Hays (2008) suggested that sampling methods should be determined by a research study’s purpose. As my study aimed to explore the Australian experience of the phenomenon, I sought participant representation from different states of Australia.
Following suggestions by previous authors I utilised purposeful and snowball sampling methods to obtain rich descriptions from participants who had experienced the phenomenon of ovarian cancer (Carpenter 2007; Llewellyn, Sullivan & Minichiello 2004; Patton 2002), and who wanted and were able to talk or write about their experience (van Manen 2014).

It is generally accepted that “there are no rules” (Patton 2002, p.244) which stipulate sample size for qualitative studies. However, in phenomenological studies, enough “experientially rich” (van Manen 2014, p.353) descriptions should be collected to enable exploration of the “phenomenological meanings” (p.353) of the phenomenon.

In my study, I continued interviewing persons until elements of participant stories sounded familiar in each group of participants. That is, until data was being repeated, no new elements of data arose from ongoing interviews and I felt sufficient ‘experientially rich’ descriptions of the experience had been obtained to enable me to deeply explore and gain insight into the ‘phenomenological meanings’ of the phenomenon (van Manen 2014).

**Ethical considerations**

Prior to commencing the study, I sought and obtained ethical approval from the Tasmanian Human Research Ethics Committee. (Appendix A.) The University of Sydney Human Research Ethics Committee ratified this approval (Appendix B) and in 2013 additional Ethics approval was obtained to recruit further participants (Appendix C).

The conduct of a research project such as this involves both moral and ethical issues (Kvale & Brinkmann 2009). I conducted my study at all times with the participants’ welfare in mind. All participants received a copy of the Information Brochure and Consent Form and informed consent was obtained prior to interviews. Before commencing interviews, I offered to answer any questions about the study, ensured that participants understood the purpose of the study and they consented to audio recording and obtained written consent. Participants were reassured that they could
stop the interview and/or withdraw from the study at any time. I was aware that the nature of the study might cause participants to become upset when talking about their experience. I offered to stop or re-schedule interviews if I sensed that the participant was becoming upset or stressed. Despite several becoming visibly (or audibly) upset during interviews, each reassured me that they wanted to share their experience and continue with the interview. Initially I planned to transcribe each interview myself, but this soon proved to be too time consuming. I thus utilised the services of a professional transcription company. Interviews were transcribed verbatim and I checked each transcript for accuracy with the audio recording, before including it in the study.

Each participant was considered a valuable contributor to the study and I was conscious of acting sensitively and with integrity in the conduct of the study. Following suggestions by Minichiello, Madison, Hays and Parmenter (2004) and Minichiello et al (2008) I entered relationships with participants as a caring, interested researcher and was mindful of the importance of empathy in understanding the world of the participant. Measures were taken to help maintain the confidentiality of participants and people mentioned by them. Pseudonyms were allocated to each participant. Prior to the printing of each transcript, I changed the participant’s name to his/her pseudonym. Only I knew the identity of participants. Names of HCPs mentioned in interviews were changed to reflect their occupation, for example a doctor’s name might be changed to ‘surgeon’, or ‘oncologist’.

**Inclusion criteria**

Inclusion criteria for my thesis were based upon the study aim: to explore, interpret and describe the lived experience of the phenomenon of ovarian cancer (prior to recurrence) in the Australian context.

All participants self-identified as meeting the eligibility criteria, which stated that participants be adults (18 years of age or above) and normally residing in Australia. As the Information Brochure and Consent Form were written in English and
interviews conducted in English, participants had to be able to speak and understand English. Participants were required to provide written informed consent and be willing to participate in an interview or write about their experience of ovarian cancer. The sample was to include women, partners and children who had experienced the phenomenon of ovarian cancer in Australia and who could describe their experience. Specific inclusion criteria for the thesis stated: 1) Women with or who previously had ovarian cancer without disease recurrence. 2) Partners of a woman with or who previously had ovarian cancer without recurrence. (The partner did not have to be married to the woman with the disease and as my study did not aim to determine the meaning of the experience for couples there was no requirement that the partner’s spouse participate.) 3) Adult child(ren) of a woman with or who previously had ovarian cancer, without recurrence. (Children could participate without their mother participating. The age of the child at the time of his/her mother’s illness was not relevant. However, they had to be 18 years or over at the time of consent and participation in the study.) For the purposes of brevity, in this thesis the terms ‘child’ or ‘children’ will be used to represent participants who were adult children of women with ovarian cancer (without recurrence).

**Recruitment of participants**

A number of approaches to recruitment were taken in this study. The various approaches were necessary because I wanted to be sure that I could capture experiences of participants from the different groups. Tasmanian recruitment involved letters from the Gynaecological Cancer Care Coordinator (CCC) to women recently diagnosed with ovarian cancer. The letters (Appendix D) explained the study and invited recipients to contact me if they were interested in participating. The Information Brochure (Appendix E) and Consent Form (Appendix F) were included in the letter. The CCC also offered Information Brochures to women at one gynaecological cancer support group meeting. In addition, advertisements (Appendix G) were placed simultaneously in two major Tasmanian newspapers. Nationwide recruitment methods involved internet-based advertisements. Ovarian Cancer Australia, an Australia-wide ovarian cancer support group, placed a notice (Appendix
H) about my study on their website for approximately eight months. A second notice was placed to recruit further partners to the study. (Appendix I.) As data collection progressed, I obtained Ethics approval for the Tasmanian CCC to send a letter of invitation to another group of women (Appendix J). This letter focused upon recruiting participants with whom I could share my developing findings. This was undertaken to ensure rigour in my analysis.

Contact with me was initiated by participants via email, letter or by telephone. Once they had expressed interest in participating I explained about the study and answered any questions they had. I ensured each participant had received an Information Brochure and Consent Form. On receipt of signed Consent Forms, I arranged interviews. The response to recruitment approaches was generally successful. At times I felt almost overwhelmed by the number and intensity of the responses as I had people contacting me who expressed great eagerness to share their story. I soon learnt that I had to ‘stagger’ the interviews, to allow me time to think about and to ‘process’ the participant’s experience in my own mind, prior to the next interview. In retrospect, this was not always optimal as a number of potential participants developed recurrent disease in the interval between contacting me and their scheduled interview. This made them ineligible for my study.

The total number of participants in the study was 40. There were 33 primary participants, of whom 15 were women, nine were partners and nine were children. The remaining seven participants (four women, one partner and two children) were interviewed in the latter stages of data analysis, to check my developing interpretation and theorisation arising from the data.

**The research process of data collection**

Thirty-one primary participants were interviewed for the study whilst two wrote about their experience. The participants were invited for a face-to-face interview, which was conducted at a time and place convenient to them. However, where this was not feasible (for example due to distance), telephone interviews were conducted. The
seven additional participants were interviewed by telephone. In addition to interview transcripts, further participant data included letters, emails, a written speech, photos, and an online ‘blog’.

**Interview style**

In-depth, unstructured, recursive style (Minichiello et al 2004; Minichiello et al 2008) interviews were the primary mode for gathering data in this study. This interview style enabled me to obtain detailed descriptions of aspects of the experience that were important to participants as interviews followed their lead. I chose this type of open, conversational interview, as it was congruent with the research aim, philosophical framework of the study and my personal worldview.

I prepared for each interview by focusing upon the phenomenological purpose of the study. Van Manen (2014) suggested such focus should be kept “clearly in mind” (p.316) when approaching phenomenological interviews. Interviews began with a conversation about the study during which I would confirm the participant’s voluntary participation and his/her consent for audio recording of the interview. Some general conversation helped to establish rapport. The interview itself was started with statements like ‘I am interested in what you can tell me about your experience of ovarian cancer….’ and ‘I am interested in how it has been for you….’. Whilst I was a co-participant in interviews, I was also listening and thinking analytically about the participants’ comments. This reflects Minichiello et al’s (2008) suggestion that in in-depth interviews, the researcher is the instrument. The digitally audio-recorded interviews ranged from 30 minutes to two hours and were entirely directed by the participants. Essentially I conversed with the participants until they ended the conversation. Interviews ended in a ‘debriefing’ manner of general conversation such as suggested by Kvale and Brinkmann (2009).
The participants: an introduction

The following section introduces the main participants via vignettes. A further seven participants who contributed to the study for the purpose of confirming my early interpretations of the phenomenon will then be briefly described.

The 33 primary participants came from six states of Australia: Tasmania, Victoria, New South Wales, Queensland, South Australia and Western Australia. There were 15 women, with six in their 40s, three in their 50s, two in their 60s and four in their 70s. Ten women lived in Tasmania. Of the remaining five women, three lived in Queensland, and one each in New South Wales and South Australia. Six women had early stage and nine women had advanced stage ovarian cancer. Of the nine partners, two were aged in their 40s, three in their 50s, two in their 60s and two in their 70s. Seven lived in Tasmania, one in Queensland and one in Western Australia. Five partners described their wife’s cancer as advanced, whilst four believed it was early stage. Two children were aged in their 30s whilst the remaining seven were in their 40s. Six lived in Tasmania, one in Western Australia and two in Victoria. Eight children described their mother’s cancer as advanced, with only one believing her mother had early stage disease.

I did not specifically aim to recruit family members since the focus of the study was upon the experience of the ‘phenomenon’ of ovarian cancer. The majority of participants are not related. In cases where participants were related, their narratives were analysed independently of their co-participating family member/s and this study did not examine the experience of ovarian cancer from a dyadic or triadic perspective.

Women

Audrey (W1)
Audrey spoke with me at her home in a rural area. In her early 50s, she lived two hours from the nearest major town, with her husband and adult son. She had been diagnosed with early stage ovarian cancer 12 months before as a result of another health condition. She had previously enjoyed good health. She had undergone
surgery in her capital city which was three hours drive away and had travelled two hours each way to a major town to obtain chemotherapy treatment. Audrey had finished chemotherapy four months prior to our interview and was anticipating an imminent follow-up appointment with her oncologist to determine the success of her treatment.

Betty (W2)
Betty was a woman in her late 70s. She and her elderly husband lived in a major town; approximately four hours drive from their capital city. They had supportive adult children who lived in the same town. Betty had recently been diagnosed with advanced ovarian cancer. She had undergone cytoreductive surgery in the capital city and had had one cycle of chemotherapy, in a major town two hours drive from her house. Betty shared her story with me in her home for more than two hours.

Cathy (W3)
Cathy was a professional woman in her late 40s who lived with her husband in a major town four hours drive from her capital city. She had no children. She was diagnosed with early stage ovarian cancer six months previously after noticing a distended abdomen. Cathy had cytoreductive surgery in her capital city, two weeks after consulting her GP. She did not have chemotherapy. She was previously well and healthy and had had no major health issues. Rather than participate in an interview, she elected to send a written account of her experience.

Donna (W4)
Donna was a widow in her late 70s and lived in a retirement home in a suburb of her capital city. She had three adult children and a number of young grand children. Donna was diagnosed seven months prior to our interview with advanced ovarian cancer. She underwent cytoreductive surgery and had recently completed six cycles of chemotherapy at her local hospital. Donna responded to a recruitment letter from the CCC and agreed to participate if her two daughters could also participate and if they could all be interviewed together. The three women shared their experiences with me at Donna’s home. We spoke together for over two hours.
Ella (W5)
Ella was a retired professional woman in her mid 60s who had been diagnosed with advanced ovarian cancer ten months previously. She had experienced symptoms for some time, but had not addressed them due to other personal commitments. When her abdomen became very distended, she visited her GP who did some tests and informed her that she had ovarian cancer. She saw the gynaecological oncologist in her capital city, which was approximately two and a half hours drive from her home, and had an ascitic tap performed where five litres of fluid were drained from her abdomen. She underwent cytoreductive surgery in the capital city and was in hospital for two weeks. When we spoke via the telephone, she had completed six cycles of chemotherapy, administered at her local hospital, four months previously. She was married with two adult children.

Florence (W6)
Florence was a professional woman in her late 40s with a strong religious faith who responded to a letter introducing my study. She spoke with me at her rural home 30 minutes drive from a capital city, where she lived with her husband. They had no children. Florence had been diagnosed with early stage ovarian cancer five months previously after having a routine abdominal ultrasound for other reasons. She had completed five cycles of chemotherapy at the time of interview.

Gwen (W7)
A woman in her early 70s, Gwen lived in a coastal town approximately two hours drive from her capital city with her husband. They had three adult children. Gwen described her experience to me whilst she was having chemotherapy in her capital city. At the time she was undergoing her fifth chemotherapy cycle after having been diagnosed with advanced ovarian cancer five months prior.

Hilda (W8)
Hilda was in her early 50s with two adult children. She lived with her husband in a small rural community situated over 1,000 kilometers from their capital city. Four days after consulting her GP, she was scheduled to see a gynaecological oncologist in her capital city. She was diagnosed with advanced ovarian cancer. Her treatment of
cytoreductive surgery followed by six cycles of chemotherapy involved commercial flights between her hometown and her capital city. Throughout her illness and recovery, she kept a ‘blog’ of her experience. Hilda participated in the study via emails and her blog, providing a detailed account of her experience often written on a day-to-day basis. Hilda was diagnosed with recurrent disease two years after her diagnosis and so her input into this study ended with the last blog entry posted before she announced her recurrence.

Ida (W9)
Ida responded to a newspaper advertisement about my study. She shared her experience with me at her suburban home in a major town. She was a retired single mother of two, in her mid 60s who had been diagnosed five years previously after experiencing abdominal pain following gardening. As the local gynaecological oncologist was going on leave at the time, Ida travelled 450 km interstate for surgery. Her adult daughter and young granddaughter were living with her at the time and accompanied her as support persons. She later had chemotherapy in her hometown. She was awaiting a five-year post-diagnosis medical review.

Joan (W10)
Joan was a professional woman in her late 40s who lived with her husband and two children in a suburb of a capital city. She was diagnosed with advanced ovarian cancer. At the time of interview she had undergone four cycles of chemotherapy, which were administered in her local hospital. Joan was interviewed at her home.

Kate (W11)
Kate was a single professional woman in her late 40s who spoke with me at an office space near her workplace. She had no children. She lived in a suburb of a capital city and contacted me as a result of the advertisement on the support group website. Kate had experienced bodily symptoms for a while but had been reassured by her GP that they were not gynaecological. After several months and following a biopsy of an enlarged lymph node she was diagnosed with advanced ovarian cancer. Kate had completed six cycles of chemotherapy six months before our interview.
Leah (W12)
Leah was a semi-retired professional woman in her 70s who had been diagnosed with advanced ovarian cancer eight months previously. Her pathway to diagnosis had been a lengthy process, which was only resolved when one of her children suggested she be tested for ovarian cancer. Leah’s treatment consisted of an ascitic tap, followed by cytoreductive surgery. She subsequently became very unwell, having developed complications, which necessitated a further two operations. All treatment was administered in her local hospitals. Leah received six cycles of chemotherapy, which had finished three months previous to our interview at her home, situated in bush land ten minutes drive from a capital city. She lived with her husband who was also in his 70s. She had four children; two lived locally and two lived interstate.

Mary (W13)
Mary was in her 40s, married with two young children and lived in a suburb of a capital city. She was diagnosed with early stage ovarian cancer four and a half years previously following the birth of her last child. She had undergone cytoreductive surgery followed by six cycles of chemotherapy at her local hospital. Mary responded to the support group notice about my study and was interviewed at a café.

Nancy (W14)
Nancy was interviewed by telephone after responding to the notice about my study on the support group website. Nancy was a married woman in her 40s when she was diagnosed with early stage ovarian cancer. She lived with her husband and two young children in a coastal town approximately two hours drive from their capital city. Nancy had a history of breast cancer in her family and was vigilant for signs of cancer. Her ovarian cancer was diagnosed after removal of a ‘cyst’ detected at routine ultrasound. She had cytoreductive surgery followed by six three-weekly cycles of chemotherapy and attended her capital city for all treatment. She completed her treatment five weeks earlier and had just been given the ‘all clear’ two days prior to our interview.
Olive (W15)
Olive participated in my study after we met socially. She had been diagnosed with advanced ovarian cancer just over two years previously. Her husband was present with her when we spoke together about her experience by telephone. A married professional woman in her mid-50s, Olive had four adult children. She lived with her husband in a coastal town approximately two hours drive from her capital city where she underwent cytoreductive surgery and six cycles of three-weekly chemotherapy for advanced stage disease.

Partners

Bob (P1)
Bob was a retired professional man who had been married to his wife for 55 years. They were both in their late 70s and had adult children who lived in the same major town. His wife was diagnosed with advanced ovarian cancer three months previously and had undergone one cycle of chemotherapy following cytoreductive surgery. Surgery was conducted in the capital city; four hours drive from their home. Chemotherapy was administered at a major town; two hours drive from their home. Bob’s brother’s wife had died of ovarian cancer just before Bob’s wife was diagnosed with the disease. His nephew had died of bladder cancer shortly after. Bob was interviewed at his suburban home. His wife was present during the interview.

Charles (P2)
Charles was an employed man in his early 50s who lived in a rural area with his wife and adult son. His wife had recently completed chemotherapy for early stage ovarian cancer and was awaiting the results of blood tests to determine the efficacy of the treatment. She had surgery in their capital city, which was three hours drive from their home. Chemotherapy was administered at their nearest hospital, two hours drive from their home. Charles’ mother died of ovarian cancer when he was 15 years of age and other members of his extended family had also had the disease. Charles spoke with me by telephone.
David (P3)
David was a professional man in his early 60s. He lived with his wife in a capital city and had two adult children who lived overseas. David’s wife was 65 when she was diagnosed with Stage IIIC ovarian cancer, two years ago. She had six cycles of chemotherapy, then surgery, which was followed by a further four cycles of chemotherapy. She finished treatment a year ago and was well at the time of our interview. All treatment was conducted at a major hospital in the city in which they lived. David and I conversed by telephone after he saw an advertisement about my study on the support group Internet page. His wife was present with him whilst he talked.

Ewan (P4)
Ewan participated in the study at the suggestion of his wife. In his 40s, Ewan was interviewed at home. He and his wife had no children. He was on leave from his usual work with an injury and was very concerned about future work prospects. He was a man of strong religious faith, which had sustained him throughout his wife’s illness and treatment. His wife had undergone cytoreductive surgery and was about to complete six cycles of chemotherapy for early stage ovarian cancer. All her treatment was given at their local hospital. His wife was present during our interview.

Fred (P5)
Fred was a retired tradesman in his mid-60s who lived with his wife in a major town a few hours drive from a capital city. His wife had recently completed chemotherapy after having had surgery. He believed that the cancer was destroyed by the treatment. He had two adult children living interstate from a previous relationship. His wife had one adult child who lived interstate, also from a previous relationship. I interviewed Fred by telephone. He was alone when we spoke.

Grant (P6)
Grant was a tradesman in his late 40s who lived with his second wife in a country town approximately two hours drive from the nearest large town and three hours drive from the capital city. He had three children from a previous relationship, who all lived interstate. His wife had recently completed treatment for advanced ovarian
cancer: she had undergone surgery in the capital city, followed by chemotherapy in a
town two hours drive away. Grant and his wife had a strong religious faith and
belonged to a supportive religious community. They had no family members locally.
Grant spoke to me by telephone.

Hugh (P7)
Hugh was a scientist in his late 50s who lived with his second wife in a major town
two hours drive from their capital city. His wife was diagnosed with early stage
ovarian cancer two and a half years previously and had undergone cytoreductive
surgery and chemotherapy. Since then she had remained well. Treatment had been
given at a hospital two hours from their home. He had four adult children. Hugh’s
first wife had died of cancer ten years previously. Hugh was interviewed by
telephone.

Ivan (P8)
Ivan was a professional man in his early 50s and lived with his wife and teenage
children in a capital city. His wife had been diagnosed with stage IV ovarian cancer
nine months previously. She had undergone chemotherapy, followed by
cytoreductive surgery, then more chemotherapy. She was currently well. Ivan and I
spoke at the local hospital where his wife had received treatment.

Jack (P9)
Jack was a semi-retired professional man, in his mid 70s, who lived with his wife in a
suburb of a capital city. He had four married adult children, two of whom lived
locally and two lived interstate. Jack’s wife was diagnosed with advanced ovarian
cancer eight months previously and had completed chemotherapy following
cytoreductive surgery. She had been treated in their local hospital. She was currently
well. Jack chose to speak with me at his home.
Children

Eliza (C1)
Eliza was a married professional woman in her 40s who participated in the study at the suggestion of her mother. She lived with her husband and three young children in a capital city, interstate from her parents, who were both in their 70s. Her mother had been diagnosed with advanced ovarian cancer eight months previously. Following surgical complications her mother had completed chemotherapy treatment three months prior to our telephone interview. She was currently well.

Kevin (C2)
Kevin was a married professional man in his 40s who lived interstate from his parents. He had no children. His mother had suggested he participate in the study and he was interviewed by telephone. His mother was in her 70s when she was diagnosed with advanced ovarian cancer eight months prior to our interview. She had completed her treatment three months prior. She lived in a large house with her elderly husband, in the capital city where she was treated.

Laurie (C3)
Laurie was a professional man, in his late 30s, who participated in the study at the suggestion of his mother. He lived with his wife and young children in the same city as his parents. His mother was in her 70s and had previously been robust with few health problems. She had been diagnosed with advanced ovarian cancer eight months prior to our interview, after a protracted diagnostic process. She had undergone cytoreductive surgery, plus further surgery for complications and had completed six cycles of chemotherapy three months prior to our telephone interview. All treatment was administered locally.

Mark (C4)
Mark was a professional man in his 40s at the time of our face-to-face interview. He was married with two young children and lived in the same city as his parents and one of his siblings. He participated in the study as a result of his mother’s suggestion. His mother, who was in her 70s, and who lived with her elderly husband on a large
block of land, had never been seriously unwell prior to her diagnosis of ovarian cancer. She had been diagnosed with advanced ovarian cancer eight months prior to our interview. Following cytoreductive surgery, she had completed chemotherapy treatment three months previously.

Tess (C5)
Tess contacted me as a result of the support group notice about my study. She was a businesswoman in her early 40s who was married with two teenage children and lived in a capital city. She was the eldest of four children and her mother had been diagnosed with advanced ovarian cancer six months previously. Her mother, who lived in the same town as Tess, was in her early 60s and had just finished six cycles of chemotherapy. She was due to hear the results of the chemotherapy in two days time. We spoke by telephone.

Una (C6)
Una’s mother was diagnosed with advanced ovarian cancer six months before our face-to-face meeting. Her mother, who was in her 70s, had undergone cytoreductive surgery and had just completed six cycles of chemotherapy at the local hospital. Una was a married woman in her mid 40s with two teenage children and lived in a suburban area in the same capital city as her mother and two siblings. She was interviewed at the same time as her sister and her mother.

Val (C7)
Val was a single, semi-professional woman in her mid 40s. She lived with her three young children in a suburb of a capital city near her mother and two siblings. Her mother, who was in her 70s, was diagnosed with advanced disease six months previously and was treated at her local hospital. She had undergone cytoreductive surgery and had just completed six cycles of chemotherapy. Val’s mother responded to a letter introducing my study and suggested that Val might like to participate. Val was interviewed at her mother’s home with her mother and her sister.
Wendy (C8)
Wendy responded to a newspaper advertisement about this study. We met at an office at her work place and spoke together for two hours about her experience with her mother’s advanced ovarian cancer. Wendy was a professional woman in her late 40s and lived with her two young adult children in a suburb of a capital city. Wendy’s mother was diagnosed with stage IV ovarian cancer five years before, following a protracted diagnostic process. Wendy moved in to live with her mother and was her mother’s carer whilst she had treatment for her disease. Her mother was well at the time of interview and had not had a recurrence of her disease.

Anna (C9)
Anna, a support worker in her mid 30s, was a single mother of a teenage child. Her mother was diagnosed with early stage ovarian cancer five years ago, at the age of 59 years. At the time of diagnosis, Anna and her child were living with her mother. Her mother underwent surgery interstate then received chemotherapy at her local hospital. Our interview took place at her mother’s home, where I was interviewing her mother. Anna briefly participated in the interview with her mother before she had to leave for work commitments.

Additional participants
Seven additional participants were individually interviewed by telephone for the specific purpose of discussing developing interpretations of the experience of the ovarian cancer phenomenon. Four women (three of whom were aged in their 50s and one in her 80s), one partner (aged in his early 80s) and two children (one aged in her 40s and one in his 50s) described their experience of ovarian cancer. Each additional participant had an experience of the phenomenon of ovarian cancer (without recurrence).
The research process of data analysis

Van Manen (1989, 1990) suggested that there are six activities that may facilitate the conduct of a phenomenological inquiry. These are not to be considered definitive, ordered steps to be followed in a linear fashion, but are inter-related concepts to be considered and perhaps utilised in the research process. I have used van Manen’s six activities (1990, p.30-34) listed below, as a structural guide for discussion of data analysis in this study.

1. Turning to a phenomenon which seriously interests us and commits us to the world.

As a result of working as a Research Nurse in the field of ovarian cancer, I was deeply interested in the lived experience of the phenomenon. Prior to commencing recruitment I immersed myself in philosophical literature to develop a deep understanding of hermeneutic phenomenology. This was a necessary first step for the study (Munhall 2012c) and was an ongoing process. I practised interviewing peers and received their feedback about my communication skills. This was important as the researcher is considered to be the tool or instrument (Minichiello et al 2008) for collecting data in phenomenological interviews.

I wanted to approach the research with what van Manen (2014) called “radical openness to the phenomenon” (p.224). This would be facilitated by becoming aware of my preconceived assumptions and remaining mindful of them as I collected and analysed the study data (van Manen 2014). I was aware that my situatedness within the world (as a Registered Nurse) and my preconceptions would be important influences upon the interpretation resulting from this study. Accordingly, prior to commencing data collection I thought, talked and documented what I felt I ‘knew’ (that is, my ‘prejudices’) about ovarian cancer (van Manen 1989). Having acknowledged my beliefs and assumptions, I kept them ‘to one side’ in my mind whilst interviewing participants and analysing data. In this way, I did not attempt to disregard or totally ‘bracket’ them during the study. Whilst they prompted me at times to ask questions, more often they prompted me to actively listen to what participants were saying. In this way, I participated within interviews without
dominating them with my prejudices and personal horizon of meaning. As I grew more practised it became easier to approach each new interview or analysis session with an open, receptive mind and with what Munhall (2012a, p.22) called my “third ear”. As I became more phenomenologically thoughtful, I found myself becoming more attentive to what the participants were saying and meaning. By participating in interviews in this phenomenologically aware manner, I contributed as a co-participant towards the resulting ‘fusion of horizons’.

2. Investigating experience as we live it rather than as we conceptualize it. Prior to interviews, I reflected on the aim of my study, the research question and on phenomenological concepts. I interviewed 31 primary participants who had experienced ovarian cancer and received written accounts from a further two. Participants were encouraged to describe how they experienced the phenomenon. Their written and oral descriptions combined with my field notes to form the basis for textual analysis in the study. Where possible, I drew my visual impression of the participants’ experience. (See Appendix K for two examples.) I searched published literature and the Internet for accounts of other people’s experiences of ovarian cancer and read biographical accounts of living with the disease. I aimed to use participants’ personal experiences and my notes and readings to explore and understand the experience as it was lived by the participants.

Before commencing formal thematic analysis, I carefully checked each transcript against the audio recording to ensure that it was a verbatim record of the interview. Reflective listening was utilised to identify significant phrases, words, pauses and emotions and these were carefully noted.

3. Reflecting on the essential themes which characterise the phenomenon. Themes are a way of reflecting and naming or describing the essential essence of a phenomenon (van Manen 1990). Demonstrating the concept of ‘hermeneutic circle’, the interpretation of the lived experience of participants was a circular process aimed at eliciting themes, which would illuminate and help me comprehend the meaning of participants’ experience of ovarian cancer. Within the processes of data analysis, I tried to be mindful of the impact of my preconceptions of ovarian cancer upon my
understanding of participant experiences. The exploration and acknowledgement of my preconceptions prior to commencing interviews had helped me to recognise my prejudices. This recognition was also important in data analysis as initially, I noticed that I was analysing some of the data through the lens of my past preconceptions. As I progressed with data analysis, I became more open to what participants were saying and meaning. Eventually, I was able to look beyond my preconceptions and fully explore participant data for meaningful insights into the phenomenon.

I undertook thematic analysis of participant data following suggestions by van Manen (1990). Initially, participant data was read as a whole document to determine the “overall meaning” (p.94) of the experience for that participant. The document was re-read and any words or sentences that appeared particularly significant were highlighted using coloured pens. The document was then examined “line-by-line” (van Manen 1990, p.94) and word-by-word to determine possible significance for the participant. I questioned what each sentence and noteworthy word was ‘saying’ about ovarian cancer. The focus was upon the possible nature and meaning of the phenomenon. This process was undertaken for each interview transcript and written account and was repeated in clusters of groups of participants. Hence, as far as possible, data from each group of participants was analysed in ‘blocks’. This facilitated a developing ‘sense’ of the meaning of the experience for that group. Once I had developed a beginning ‘grasp’ of the participants’ experiences, I made iMindMaps to illustrate emerging concepts and relationships between key elements.

Fresh copies of the participant data were printed and this was examined using van Manen’s (1990, pp.101-106) four lifeworld existentials of temporality, corporeality, spatiality and relationality as conceptual lenses. Again, highlighter pens were utilised to mark significant portions of the text and an electronic notebook was used to record all participant responses related to the four existentials. Verbatim quotes were noted, including line numbers and my thoughts and reflections were also noted. Later, the electronic notebook was printed and re-examined in order to gain additional insights into the meaning of the phenomenon for participants. Further insightful comments were handwritten into the journal. (See Appendix K for an example of an entry under the heading of ‘Body’.)
Other methods used to help illuminate the meaning hidden in participant data included: tracing the etymological source of key words; searching for idiomatic phrases; finding inspiration in art and literature; reading biographies of others who had experienced the disease in some way; and reading accounts of other phenomenological studies (van Manen 1990, pp.58-76). Demographic data were examined in a search for links between participant characteristics that might deepen my understanding of the meaning of the phenomenon. Examples of this include tables of participants’ age at diagnosis and age at interview, marital status, etc.

Concurrent with analysis were frequent ‘brainstorming’ sessions with my supervisor, during which we examined participant data in view of my developing ideas and insights. For example, after I had examined each transcript and written account using van Manen’s (1990) four existentials, my supervisor read through and discussed my reflections documented in the electronic notebook. These meetings facilitated my ability to reach a high level of theorisation from the data. It was following one of these meetings that I developed what van Manen (2014) called “inception” (p.237) – that is, a flash of insight into the fundamental meaning and essence of the phenomenon. It became clear to me that ovarian cancer changed the world that participants lived in.

Each transcript and written account was re-examined for possible key elements, in light of my developing understanding of the phenomenon. Significant themes and/or aspects were again identified and verbatim quotes were noted with line numbers. My early visual representations of participant experiences were examined for additional insights and the overall meaning of each transcript and account was summarised in a “sententious phrase” (van Manen 1990, p.93). The concept of various ‘worlds’ appeared repeatedly in my analysis and it became clear that the participants experienced the phenomenon in terms of worlds dominated by aspects of the ovarian cancer. Key concepts, such as ‘contracted world’ became identified as themes. From these, the essence of the experience was pinpointed – that which, in van Manen’s (1990) words, “makes a thing what it is (and without which it would not be what it is)” (p.177).
The circular phase of data analysis meant that I undertook “a journey of ‘thinking’ ” (Smythe, Ironside, Sims, Swenson & Spence 2008, p.1389) in which I was continuously re-visiting (and re-thinking about) transcripts, written accounts, published literature, field notes, my notebooks, my diagrams and my iMindMaps, whilst also being alert for insight from other sources.

4. Describing the phenomenon through the art of writing and rewriting.
For van Manen (1990, 2014), writing is an ongoing, intrinsic part of phenomenological research. It is through writing and reading and thinking that phenomenological insights emerge (Smythe et al 2008; van Manen 2006). In this study, writing began concurrent with data analysis. It continued throughout the research process helping me to both focus on, and distance myself from, what I knew and what I had been told about the experience of ovarian cancer. After interviewing participants, I made drawings, iMindMaps and notes and reflected about what I had seen and heard. As I listened to audio recordings and read and re-read transcripts, I highlighted text and made notes in the page margins. I maintained electronic notebooks for each group of participants, noting my thoughts about each individual, their interview or text, their experience and what I considered to be key elements of their narrative. As I ‘heard’ new ideas, I re-visited my previous thoughts and explored them in the light of the new concepts. I drew and re-drew tables and iMindMaps to illustrate relationships between contexts and experiences. I wrote and I re-wrote until the essence of the experience began to manifest and make itself clear. The concurrent process of writing and interpretation continued as I crafted this thesis with the intention of illuminating the nature and meaning of the phenomenon for the participants.

5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
Throughout the study, the interpretive framework, research question and aim of the study guided the processes of data collection, analysis and interpretation. As the study progressed I found that the process occupied my consciousness more and more. I began to derive inspiration from the world around me: from art exhibitions, poetry, billboards in airports and chance phrases heard or read in books. I read broadly, always with my research study in mind. I re-read the published literature about the
experience of ovarian cancer. Eventually, I carried a notebook with me so that I could always record my thoughts as they occurred. I found I had become thoroughly oriented to my study in what van Manen (1990) described as “a strong, original and thoughtful manner” (p.172).

6. Balancing the research context by considering parts and whole.

Whilst undertaking the collection and analysis of data for this study, I frequently ‘stepped back’ from what I was doing and ensured that it was appropriately related to the study’s research question and aim. The data was examined from many angles to ensure that I examined all parts that constituted the whole experience. This was an ongoing process, continuing until the final stage of interpretation and writing.

Following van Manen’s (1990) suggestion that discussions held for the purpose of “collaborative analysis” (p.100) may strengthen phenomenological understandings by ‘testing’ analytic themes, and after interpreting what I believed to be the meaning of the phenomenon for participants, I undertook short interviews with an additional seven participants, in order to ‘test’ my emerging interpretation and overall understanding. In these additional interviews, I took my developing understanding of the phenomenon to participants who had no prior input into the study and who had also been through the ovarian cancer experience, to determine if they recognised their experience in my interpretation. I wanted to ascertain if my thoughts and ideas ‘spoke to’ and resonated with participants. In effect, I was looking for what is termed the “phenomenological nod” (van Manen 1990, p.27), which indicates that a phenomenological description is recognised by others as something that we have either had or could have. In these collaborative interviews, participants initially described their experience of ovarian cancer. At times they inadvertently clearly confirmed my interpretation and understanding of the phenomenon. Where my interpretation (based on my analysis of data from the 33 primary participants) was not overtly confirmed by the participant’s description of their experience, I described my early understanding of the phenomenon and asked if my understanding coincided with their experience. The response of the additional participants corroborated my interpretation and understanding of the phenomenon and provided me with the audial equivalent of ‘phenomenological nods’. This process was a step in ensuring the rigour
of my findings. It provided both support for plausibility of the study findings and verification that I had a grasp and understanding of the meaning of the experience.

Trustworthiness and credibility

Deliberate, systematic steps were taken throughout my study to ensure trustworthiness and credibility. These steps were part of an ongoing process of ‘building’ the research from inception of the research idea to thesis completion. There is much debate in literature about what constitutes a high quality qualitative study (see, for example, Rolfe 2006; Reynolds et al 2011). In demonstrating the rigour of my study I am going to use the framework for “appraisal of rigour in interpretive phenomenological nursing research” suggested by de Witt and Ploeg (2006, p.215).

“Balanced integration” (de Witt & Ploeg 2006, p.224) refers to methodological congruence (Sandelowski 2006), that is, “internally consistent” components of epistemology, methodology and method (Carter & Little 2007, p.1326). It denotes the philosophical integration of the philosophy throughout the study process, including findings. In my study, the pre-reading and ongoing reading and use of the philosophy demonstrate ‘balanced integration’ of phenomenology, which is the foundation upon which my study is built. The method used is congruent with the philosophical tenets. Phenomenology is integrated throughout the analysis and findings are illustrated with, and supported by, verbatim quotations from study participants.

“Openness” (de Witt & Ploeg 2006, p.225) is concerned with rigour and transparency (Sandelowski 2006) and refers to accounting for decisions made throughout the research process. Carpenter (2007) suggested that audit trails were essential in phenomenological studies to establish “authenticity and trustworthiness of the data” (p.98). In my study, a systematic and ongoing ‘audit trail’ was kept from the inception. (See Appendix K for examples and further discussion.) This consisted of a combination of three types of notes – what Minichiello et al (2008) called “transcript files; personal files; and analytical files” (pp.227-249). Transcript and personal files were kept for each participant. Transcript files contained a digital audio recording of any interviews, plus typed verbatim transcripts of the interview/s. After each interview, I reflected upon what had transpired in our conversation. I dictated field
notes regarding: the location and time of the interview; my impressions of the interview, including rapport establishment and the ease of the interview; my impressions of the person’s experience; body language displayed by the participant/s; and key issues that I felt had been identified. These field notes were later typed verbatim and stored in the participant personal file. In addition, I sketched each room in which an interview had taken place to aid my accurate recall of the interview context. At times, I also drew an artistic impression of the person’s experience. These, plus any correspondence, were stored in each participant’s personal file. All working documents were filed, including transcripts and mind maps. Strict version control was kept on emerging interpretations and text drafts. I maintained a number of notebooks, including an analytical file in the form of a handwritten notebook in which I recorded diagrams and ideas for analysis. An electronic analytical file was kept as a “reflexive journal” (Bradbury-Jones 2007, p.296) of my thoughts, inspirations, self-critique and decisions throughout the research process. Budding ideas and concepts were recorded in this file as they were identified and were compared with developing insights. Reflexivity relates to researcher awareness of the influence they have upon the findings of the study (Jootun, McGhee & Marland 2009). In my study, reflexivity is demonstrated by my examination of my prejudices prior to commencing recruitment and documentation of them in my journal. They were discussed with my supervisor and formed the basis of frequent discussions throughout the data analysis and interpretation. Documented in my journal, I used the discussions and my ongoing awareness of self as a systematic method for monitoring the impact of my subjectivity upon the research process (Bradbury-Jones 2007; Koch & Harrington 1998).

“Concreteness” (de Witt & Ploeg 2006, p.225) refers to “utility” and “descriptive vividness and detail” (Sandelowski 2006, p.644). Van Manen (2014) called this “lived throughness” (p.285). It is demonstrated when reading a text raises the consciousness of the reader (Munhall 1994, van Manen 2014) – that is, when research findings are described which embed the reader in the experience of the phenomenon and when the reader can identify with (live through) aspects of the findings. In my study, it is achieved by verbatim quotes which place the reader firmly in the contextual world of the participants.
“Resonance” (de Witt & Ploeg 2006, p.226) refers to the lived experience of reading the research findings – the “transformative effect” (van Manen 1997, p.364) of the text, which resonates with and speaks to the reader. It refers to the “vicarious experience” (Sandelowski 2006, p.644) of reading a text and can be considered the “hallmark of trustworthiness” (Smythe et al 2008, p.1396) of a study. van Manen (2014) suggested “resonance means that the reader recognises the plausibility of an experience even if he or she has never personally experienced this particular moment or this kind of event” (p.240). Phenomenological research does not produce ‘the’ definitive meaning of a phenomenon. Rather, it suggests tentative “plausible insights” (van Manen 2014, p.281) into how a phenomenon might be experienced. Resonance reflects the ‘plausibility’ of a phenomenological interpretation, whilst acknowledging that the resulting understanding is not the only possible explanation or understanding of that phenomenon. By presenting the data interpretation in terms of themes, I have formulated a possible and plausible interpretation of the experience (van Manen 1990, 2014). “The phenomenological nod” (Munhall 1994, p.189; van Manen 1990, p.27) demonstrates resonance, which is determined by the reader of a phenomenological text. In my study, I received the ‘phenomenological nod’ from the seven additional participants recruited to determine the resonance of my understanding with their experience. I also received positive feedback about my early findings from peer review of conference presentations (Appendix L) and publications (Appendix M). In addition, when I discussed my emerging findings with cancer patients encountered socially and professionally, I have seen the ‘nod’ of recognition of the wider application of my interpretation.

“Actualization” (de Witt & Ploeg 2006, p.226) refers to the potential usefulness of a study, which may be recognised with the passage of time. This is something, which may not be recognised in my study, until long after the reader has read the text.

Chapter conclusion and introduction to presentation of the findings

In this chapter I have described the phenomenologically-based research method used in this study, including the research process before data collection. The 33 primary
participants were introduced via short vignettes and participation in the study by an additional seven ‘collaborative’ participants was described. The research method of data collection and the ensuing process of phenomenological data analysis and interpretation were comprehensively described. The circular process of data collection, analysis and interpretation is illustrated in the iMindMap, Figure 4.

Figure 4: Summary of the method

The following three chapters present the findings of the study, which arose from the thematic analysis. During data analysis and interpretation, key experiential aspects were identified, which suggested that participants had a sense of living in different ‘worlds’ to the one they had inhabited prior to experiencing the phenomenon. This had obvious relevance to Heidegger’s concept of Being-in-the-world. Further consideration of Heidegger’s philosophy led me to interpret the experience of the phenomenon under the thematic structure of ‘worlds’ of Being. The three ‘worlds’ described in the following three chapters were theorised from the data and reflect participants’ experiences of living in ‘worlds’ characterised by pervasive aspects of the phenomenon. Specifically, participants experienced the phenomenon as living in the three major thematic worlds of a ‘ruptured assumptive world’, an ‘uncertain
world’ and a ‘liminal world’. Within each major thematic world, sub-thematic worlds are described for each participant group. The three major thematic worlds are the findings of the study, which illuminate the multi-faceted, fundamental essence of the phenomenon, that is, Being-in-a-changed-world, which is presented in the final chapter.

The next chapter (Chapter five) introduces the first major theme of ‘ruptured assumptive world’. The usual worlds of participants were radically altered by the ovarian cancer diagnosis. Within their ‘ruptured assumptive world’, women lived in a ‘contracted world’, partners in a ‘world of crisis’ and children in a ‘dread-full world’.
CHAPTER FIVE: RUPTURED ASSUMPTIVE WORLD

We live in time and time is notoriously contingent. No-one can say with certainty what is going to happen to us tonight, tomorrow or next week. Time can bring anything to the door of your life. One of the terrifying aspects of life is this unpredictability. Anything can happen to you. Now, as you are reading this, there are people all over the world who are being savagely visited by the unexpected. Things are happening now to them which will utterly disturb their lives for ever. Their nest of belonging is broken, their lives will never be the same again. Someone in a doctor’s surgery is receiving bad news... (O’Donohue 1999, pp.248-249.)

This chapter is the first of three chapters, which impart the study findings. The concept of participants living within different worlds represents the manner by which the phenomenon of ovarian cancer is described and interpreted in my study. The chapter presents ‘ruptured assumptive world’ as the first of three major themes theorised from the data. The chapter describes how participants initially experienced ovarian cancer, as living in a world that was different to the world they were accustomed to and had anticipated. The major theme – ‘ruptured assumptive world’ – is presented in sub-themes that represent the experience of the phenomenon of ovarian cancer from the three perspectives – that is of women, partners and adult children. Circling the phenomenon in this manner enabled me to capture the depth and complexity of the ovarian cancer experience. The major theme described in this chapter, ‘ruptured assumptive world’, represents a “fusion of horizons” (Gadamer 1975/2004, p.305) – that is, a blending of the understandings of women, partners, adult children, and myself as researcher, in relation to the phenomenon of ovarian cancer.

In this chapter the experience of women, partners and children are presented separately yet they all constitute the experience of living in a ruptured assumptive world. The women’s experience was one of living in a contracted world; the men found themselves inhabiting a world of crisis; and the children’s experience was one
of living in a dread-full world. These worlds began to be experienced with the diagnostic process and continued to be experienced throughout the treatment period and beyond. These subthemes are illustrated by an iMindMap (Figure 5).

![Image]

**Figure 5:** Introduction to ruptured assumptive world

**The concept of assumptive world**

The term ‘assumptive world’ refers to the world individuals usually live in. It is formed by our worldview – that is, the perspective from which we experience and interpret the world. It includes our socio-cultural background and history (Brennan 2001; Cohen 1993b) and also includes the way experiences and people contribute to the way we anticipate our future and interpret things that happen (Lethborg, Aranda, Bloch & Kissane 2006). It is based upon our beliefs and interpretation of our world (Cohen 1993b; Janoff-Bulman 1989; Lethborg et al 2006; Parkes 1971), including experiences of our past and present and our expectations of the future. Our assumptive world forms a link between our past and our future (Cohen 1993b). It is the world we take for granted that we inhabit and anticipate inhabiting in the future.

Our assumptive worlds are usually taken for granted and remain unexamined unless a traumatic and/or threatening event occurs. Such an event fractures our assumptive world and highlights our vulnerability (Janoff-Bulman 1989), changing the way that individuals live in and experience the world. To cope with the ruptured assumptive
world, an individual needs to integrate the threat or traumatic experience into their sense of self and/or change what they think and feel about themself and the world (Janoff-Bulman 1989). That is, to adapt to their changed world, individuals need to re-conceptualise the way they view the world and live within that world (Parkes 1971; Persson & Sundin 2008).

In Australia, many people live in an assumptive world of relative good health – that is, they have had no personal experience of serious illness (such as cancer) and have no expectations of serious illness in the foreseeable future. They assume that they will live in relative health at least until they become quite elderly. The assumption is that their life will be relatively stable and their future fairly predictable. However, the diagnosis of cancer (in oneself or a close relative) is likely to be experienced as an abrupt and unanticipated challenge to one’s assumptive world (Lewis 1993; Persson & Sundin 2008). In my study, the diagnosis of ovarian cancer rapidly ruptured the assumptive worlds of participants impacting on the way they lived in the world and viewed the world – that is, it affected their Being-in-the-world.

**Living in a contracted world: the women’s perspective.**

What was it like to be told I had cancer? The future disappeared. Loved ones became faces I would never see again. I felt I was walking through a nightmare that was unreal but utterly real. This could not be happening to me, but it was, and it would continue to happen. My body had become a kind of quicksand and I was sinking into myself, my disease. (Frank 1991, p.27)

Women in the study described how their experience had radically altered their taken-for-granted life. The rupture of their assumptive world precipitated a sense of a diminished world – one in which their illness took precedence. Women’s worlds as they had known them shrank as their illness closed in on them. Women described feelings of existential loneliness prompted by their diagnosis and the loneliness was
heightened by knowledge of the associated prognosis of ovarian cancer, by fears for their future, and feelings of being alone in their illness and world.

The process of diagnosis instigated the world-shrinking experience of ovarian cancer for women, with most diagnoses typically following the process described by Koldjeski and colleagues (2004, 2005): a period of self-treatment followed by presentation to a GP, then referral to a gynaecological oncologist and subsequent diagnosis.

Those women who recognised abnormal symptoms prior to diagnosis experienced a world in which their symptoms progressively became the focus of their lives. Kate explained to her doctor how her symptoms were impacting upon her life. ‘I think my world is shrinking’. (W11.25.) Some women described a time consuming struggle to obtain a diagnosis. This is commonly reflected in the ovarian cancer literature (Ferrell et al 2003b; Fieler 2007; Fitch, Deane, Howell & Gray 2002; Ryan 2005). Leah persevered in her pursuit for an explanation of her symptoms. ‘I just kept going back every two-three weeks’. (W12.106-107.) Mary’s symptom concerns were dismissed by her GP. ‘He said, “Oh”, you know, “That’s nothing”. And he said, “It’s nothing to worry about”.’ (W13.43-44.)

Every woman described the moment when she was told that she had ovarian cancer. The moment of diagnosis delineated the instant when women’s worlds changed irrevocably. Betty recalled: ‘When he got the CT scan he said it, er – “You’ve got an ovarian, er, tumour. It’s probably cancerous and doesn’t look as though it’s operable”.’ (W2.181-182.) Most women were stunned by their diagnosis. Leah described ‘I was just so blown away by it all.’ (W12.295.) The majority had never heard of ovarian cancer prior to their diagnosis. Ida said ‘I’d never ever thought of it [ovarian cancer].’ (W9.330-331.) Cathy found it hard to believe that she was seriously ill: ‘I felt so strong and healthy.’ (W3.puta.3.) The ovarian cancer differentiated the women from others in their world as their understanding of themselves began to be changed. Previous studies have described how a cancer diagnosis alters one’s assumptive world by marking the moment of division between a pre-cancer world and a post-cancer-diagnosis world (Cohen 1993b; Fleischmann
In my study, the diagnostic moment marked a point of difference in the lives of women transforming their assumptive, everyday pre-cancer world into a contracted world dominated by their cancer.

**Contracted life possibilities**

Ovarian cancer meant women lost their customary everyday life in addition to their imagined future. They lost their “familiar world” (Toombs 1992, p.96). They suffered diverse losses as their worlds changed and collapsed around them. The women lost not only their health, but also their assumption of being healthy. They lost their usual way of Being-in-the-world. They lost previously held hopes and dreams of their possibilities and ways of being. As humans, we generally understand ourselves and live in the world in terms of possibilities and potential (Heidegger 2002; Merleau-Ponty 2002; Moran 2000). However, a serious illness, such as ovarian cancer, can demolish our potential for realising our dreams (Carel, 2008). Ovarian cancer threatened dreams and future possibilities for women in this study. They lost their assumptive future. In its place came new fears and a new reality – that of being a woman with ovarian cancer.

Women’s worlds shrunk or “closed in” as their lives became dominated by the illness. Some women’s worlds shrunk to mostly be lived at their home. Audrey described how she rarely left her house except for illness-related appointments. ‘Because I had eight months from the time it started ‘til when it really finished, just literally laying in bed or laying on the couch or sitting in a chair.’ (W1.1232-1234.) Her world had contracted to her home because she was debilitated from her treatment. Donna just wanted to be at home because she felt most comfortable there. ‘You just want your own surroundings, you know?’ (W4.2588-2589.) Mary’s world also contracted to her home as she didn't want to meet and speak to people in the street. ‘So I just couldn’t leave home. I was becoming very agoraphobic.’ (W13.171.) Spaces and places that might have been taken for granted were viewed or felt differently. Previously a very fit woman, Leah experienced stairs and open spaces as almost insurmountable obstacles. She described how she noticed the pace at which people walked. ‘They seemed to be going at such a quick pace and all I could do was just drag one foot
after another.' (W12.1198-1199.) A lover of open spaces and ‘nature’, Hilda described her single hospital isolation room as a ‘‘prison’’ room. (W8.1396.) Joan was confronted by the possibility of dying when a woman died in the hospital bed beside her. She remembered the ‘relentless’ (W10.156) awareness that she ‘could die.’ (W10.158.) ‘You’re certainly aware of your mortality.’ (W10.139-140.) Audrey explained how her personal ‘brush with death’ impacted upon her experience of illness and/or death related spaces. Her lived relationships were also impacted as she no longer felt comfortable visiting friends in hospitals or attending funerals.

Like, see, I can’t handle, I haven’t been to a funeral since I’ve been sick and it’s all I can do to make myself go and visit people in hospital. I just don't want to be around hospitals and death and yeah... 'Cause I, well I nearly died. (W1.1047-1053.)

Women lost corporeal confidence to enjoy their leisure time. Treatment side effects impacted upon previous hobbies and interests as bodily unpredictability and uncontrollability led to curtailed outings and activities. Women’s Being-in-the-world was altered as they experienced what Toombs (1992) called illness-related “disability” (p.96). Donna explained. ‘We have bus trips every month and I wouldn't go on those. I – just in case – ‘cause we go miles away... in case I got – didn’t feel well. Spoil it for everyone.’ (W4.990-997.) She felt embarrassed by her uncharacteristically weak body when she sat at a school assembly. ‘Everybody else was standing around me. Oh, I felt terrible. I really did.’ (W4.2185.) Ida had bowel disturbances over which she had little control and consequently ‘didn’t go too far’ (W9.544) from her home. Gwen gave up playing bowls. ‘Well I haven’t played since I’ve been having chemo because I just get too tired – and um – the soles of my feet – you know I try and rest them up if I can’. (W7.273-274.) Hilda’s world shrank to focus upon her body: ‘you would think that this would be the time for contemplation of life’s most serious questions but with pain, vomiting and enemas etcetera, I find I’m focusing on the basic bodily functions.’ (W8.313-315.) Changes in lived bodies resulted in loss of self-confidence and feelings of a body that was no longer predictable or trustworthy. (This will be discussed further in the next chapter, under the sub-theme of ‘uncanny world’.)
Being confronted by the ‘shadow’ of death

Heidegger (2008) described how death and dying are typically ‘glossed over’ by everyday society. The “constant tranquillization about death” (p.254/298) provided by society typically results in what he described as one’s “fleeing in the face of [one’s own] death” (p.255/298), that is, avoiding thoughts of our own mortality. He suggested that death is usually not thought about in terms of one’s own death. Rather, thoughts of death are typically related to the death of others and thus dying “belongs to nobody in particular” (p.253/297). The attitude of everyday society encourages us to consider our own death to be a far-off event. As such, we do not feel that our death presents a current danger. Although individuals know that they will die ‘someday’, people generally live their lives without considering their own demise.

As suggested by Heidegger, the women in my study, prior to their illness, considered death as a distant occurrence that did not immediately relate to everyday life. However, their diagnosis of ovarian cancer ruptured their assumptive futures and confronted them with their mortality. They equated their cancer with the likelihood of dying from their disease and thus their illness was interpreted as a clear and current threat and danger to their life. Rather than being a far-off possibility, their potential death abruptly became a possibility in the not-so-distant future. Every woman in my study referred to the poor prognosis associated with ovarian cancer and/or their possible cancer-related death. Fear of death and uncertainty regarding their future were major components of women’s discourses. Their worlds shrank to focus upon their disease and their possible death. Olive described her sudden realisation that she might die an early death. ‘Because it’s such a shock, you know, that huge confrontation and the whole, “Am I going to die?”, sort of thing.’ (W15.273-275.)

The women developed a heightened awareness of their mortality and their futures seemed at risk. Forty-six year old Florence described her reaction to her diagnosis:

\[
\text{I thought that was the end of my life, yes; that I didn't have, um, much of a chance; that it would've spread. So I thought, “Well, my life's come to an end and I might just have a few months, really, to live.” So I was, you know, really scared. (W6.860-866.)}
\]
Kate was confronted by fears of dying during her surgery. She described her sense of surgery being a momentous, life-altering event in her life.

*You know, like surgery, there’s no guarantee what happens to you after surgery? Like you might be routine or you might end up dying on the table - or you know, your life will change from entering surgery. Things will be different afterwards in some way.* (W11.199-202.)

Similarly, when asked about the worst part of her experience, Ida described her anxiety about the extent of her cancer and her fears of dying from the disease.

*In the beginning, the unknown. The unknown. When they open you up. When they’ll find, how far it’s gone. Then you think, well, yeah, what you’ve got to leave behind, that was the hardest part. That was the hardest part. I might not have seen daylight again. Yes I was a blubbering mess when I went into theatre, but I had good reasons, because you don’t know – and that sort of thing, so – what you’re going to come out like.* (W9.1110-1119.)

Betty proceeded with chemotherapy to prolong her life and thus spend more time with her family: *'I felt that, if I could do something to, give me a better length of life? I should do it.'* (W2.554-557.) Donna knew her cancer had spread throughout *'the whole lot'* (W4.1894) of her body. She had researched the meaning of the word ‘metastasis’ and knew the implications of her disease for her life. Joan quietly commented, *'the cancer - hasn’t been that bad. It’s just – it’s only bad when you think about it in terms of dying, which I try not to do.'* (W10.481-482.) Leah realised that her prognosis was *'really – this [was] really bad.'* (W12. 547.) (Emphasis audible in voice recording.) She struggled with her grief at the likelihood that she would not live long enough to see her grandchildren become adults. *‘I just felt like I was crying so much.’* (W12.1258.)

Almost half of the women in the study had early stage ovarian cancer. Despite the associated relatively good prognosis of early stage disease (Tracey et al 2009) all women in the study, but one, referred to their potential for dying from their cancer. Despite acknowledging the poor prognosis typically associated with ovarian cancer, Nancy, (who had early stage disease), expressed her expectation of surviving her cancer. *‘I guess in myself I knew that it was, the prognosis was going to be good, they
got it nice and early.’ (W14.1298-1299.) In contrast, Kate described how she had assumed that she would live with her cancer for a long period. However, she realised the poor prognosis associated with her advanced cancer after she attended a support group meeting and saw women with recurrent disease.

Because I was quite optimistic and you know, “She’ll be right” and you know, “The stats are bad, but” you know, oh, but “I’ll live for another five years” or... But you know, this was like a crunch point, you know, “Oh, hang on, it’s not that good and who’s to say it’s going to be good for me?” (W11.573-576.)

She described the days immediately after the support group meeting as being: ‘Like the dark night of the soul, like where I felt I went up, opened the door, came through the door and I came through the other side knowing what’s – what – how the deal really is’. (W11.584-587.) The support group meeting had ruptured her confidence of living into the future and confronted her with the realisation that she may die from the disease within the next few years.

Women also described fears about how they would die. Ten months after being diagnosed, Ella worried about her prognosis, the manner of her dying and her death. She had linked any possible recurrence of her disease with certain death:

Most that worries me well if it does come and – there’s going to be, there’s going to be a lot of pain you know – you just hope that when it does come back that it’s going to be reasonably quick, you know... The main thing I think is that you just hope you know that you don't linger a long, a long time, that’s about – that’s probably my thing that I think about mostly now at the moment. That if it does come back it’s not going to be a long drawn out thing.

(W5.569-577.)

Other women also expressed their concerns regarding the manner of their death.

Hilda wrote ‘I'd like to die a good death, to ease the suffering of my loved ones, but this is likely to be something I can't control.’ (W8.1069-1071.) Ida wondered ‘if this comes, ah, I know that you're going to have a lot of pain towards the end; how do I cope with that?’ (W9.711-712.)
Women responded to their ovarian cancer diagnosis with a heightened awareness of their potential for dying an early, cancer-related death. They linked their cancerous state to the probability of their death. Their death awareness was experienced as ontological fear and vulnerability. They anticipated having a foreshortened life due to a disease over which they had no control. Unlike many people in Australian society, women were no longer able to ‘flee’ (Heidegger 2008) from thoughts of their own death. Instead, women’s fears became a central focus of their lives. Their worlds shrank to a focus upon their disease and their pending death (now perceived to be much closer and more real), and this in turn, contributed to feelings of existential angst.

Living a ‘broken life’

As women’s worlds contracted in response to the ovarian cancer diagnosis and associated prognosis their focus turned inwards. Realisation of the life-threatening aspect of their cancer prompted a sense of intense vulnerability, which was experienced as heightened existential loneliness.

Existential loneliness refers to the fundamental fact that we are born alone, we live in our world as separate individuals (among other individuals) and we die alone (Moustakos 1972). The concept of existential loneliness is multi-dimensional (Ettema, Derksen & van Leeuwen 2010) and includes the “loneliness of a broken life” (Moustakos 1972, p.20), which refers to the life-shattering and world-altering impact of serious illness upon one’s sense of self. Serious illness alters the world in which one lives and changes the way one lives within that world (Toombs 1992). Tolstoy (2003) described existential loneliness experienced during serious illness as “a loneliness in the midst of a populous town and surrounded by numerous acquaintances and relations but that yet could not have been more complete anywhere – either at the bottom of the sea or under the earth” (p.146). A pervasive sense of isolation and loneliness emerges from one’s recognition that one’s illness is “a private affair” (Murphy 1987, p.63). A heightened sense of existential loneliness can be precipitated by an amplified awareness of one’s personal vulnerability for death, such as that triggered by being diagnosed with cancer (Ettema et al 2010).
In my study, ovarian cancer intensified women’s sense of vulnerability and illuminated their inherent Being-alone-in-the-world. Their illness confronted them with the inescapable and irrefutable fact that although they shared their world with other people, they were intrinsically alone. Their awareness of their vulnerability and their potential for ovarian-cancer-related-death threatened their assumptive future and resulted in living within a diminished world characterised by existential loneliness.

**Being let down, lonely and alone: a sense of abandonment**

To varying degrees, all women in my study described their experience of existential loneliness. Disappointing relationships and feelings of isolation contributed to women’s ruptured assumptive worlds and sense of existential loneliness. Women had assumed that family and/or friends would provide them with support and understanding through their illness. When this did not necessarily eventuate, feelings of being ‘let down’ accentuated women’s sense of feeling lonely in their illness. Many women described feelings of intense existential loneliness in spite of being married and/or having adult children and/or a large social network. They described physical, communicative and/or emotional alienation from (some) others in their life.

Some women described feeling emotionally abandoned during their illness when their partner was unsupportive and emotionally absent. For example, some women explained how their husbands wouldn’t accompany them to chemotherapy. One woman said: ‘[husband] wouldn't come to any of my appointments with me. Not one. He just – not to the doctor, not to the chemo, nothing.’ Another woman commented:

> You know if my husband had sucked it up a bit more maybe he could have, um, been there to support me... When really I – really needed someone to, um, be with me. I’m surprising myself about how sort of raw it still is, talking about it now. [Crying]

One woman recalled a distant relative accompanying her to chemotherapy, one day. ‘She came and sat with me one session which I will never be able to thank her enough for that, just her being there.’
Existential loneliness was intensified for women who felt unable to discuss their illness with their family and/or friends. The inability to share their illness led to feelings of not being understood and feelings of being alone with their cancer. Literature has shown that an illness such as ovarian cancer isolates people from their normal life and relationships - they and their world change, and this change may be accompanied by an inhibited ability to share their experience with other people (Charmaz 1983; Little, Jordens, Paul & Sayers 2001; Mazis, 2001; Toombs 1992). Participants in my study demonstrated this as they had begun to think and feel differently about themselves and their world, which had contracted in response to their cancer. One woman described feeling isolated by her husband’s apparent lack of understanding of her feelings. ‘[Husband’s] not a real, he’s not a real talker and not very good about talking. He’s not particularly in touch with how he feels about things.’ Despite being married, a number of the women spoke about wanting someone to talk to about their fears and other feelings. One woman, who was married with adult children, asked a nurse if they could talk about her feelings.

I said to her [the nurse], “Look, I feel so – awful. I don’t feel - I can just cope with my illness but with – with the diagnosis. It just feels overwhelming to me”. And I said, “Can I talk with you”? I didn’t – I didn’t know who else to talk to.

Roles and relationships changed within families as physical exhaustion led to less time spent with children and spouses. Some women felt ‘out of touch’ with their family: ‘But the whole – the whole – the whole diagnosis and the fact that it happened to me, has changed our relationship – our relationship significantly…’

Some women were disappointed by a lack of support and understanding from their social networks. A lack of recognition by others about the significance of the cancer experience for the women accentuated feelings of existential loneliness. This can be interpreted in view of Mazis’ (2001) suggestion that existential loneliness in illness might be eased by the receipt of support, emotional involvement and understanding from others - particularly acknowledgment of the ill person’s altered Being and world. This need for understanding from others is clearly reflected by women in my study. One woman explained that friends ‘don't realise what you're going through.’ Some women described feeling alienated or ‘distanced’ from their friends. One woman felt
as though she had a contagious disease her friends were afraid of contracting. She said, ‘a lot of people that I thought were friends backed away.’ Another woman explained how some of friends seemed unable to discuss her illness.

Sometimes you can talk about things what is happening. Others – don't know how to talk about it with you... because they don't know whether it is a tippy touch, you know, we’re walking on eggshells or ice, so we’ll skate away from it altogether.

One woman described how a very close friend ‘can't handle death at all.’ The friend stayed away from the woman until it became clear she wasn’t going to die in the near future. Another woman described how her friends ‘just stopped ringing me. Didn't come round to see me. It was all too – all too difficult [for them].’ Mary described how some friends disappeared just when she needed them most.

Unfortunately I was devastated to find that some people I considered friends were so frightened when they realised what was happening to me that they ran a mile. Perhaps it was because they didn't know what to say or that they may say the wrong thing. But there is no wrong thing to say and all I wanted was someone just to BE - just be there. I felt let down and honestly tried to make it easier for them but it didn't help and I wasted valuable energy in trying to comfort others when I really needed comfort myself. (W13.para.6.)

The sense of existential loneliness was increased by feelings of being alone. One woman felt most isolated and alone at night, when her world contracted to her self. ‘The night times are the worst.... But night time, when you’re on your own, you’re in pain or whatever, everybody else in the house is asleep and the house is quiet, is the worst time.’ Another woman spoke of her loneliness in hospital. ‘But it was a long lonely night – and I kept wanting the nurses to come in and sit with me ‘cause when you’re in a private room it’s very lonely?’ Donna described her dilemma when she was alone and she developed dreadful abdominal pains in the middle of the night:

And then they got – gradually got worse and worse. I said, “What will I do? What will I do?” This is where it’s hard when you’re on your own. What will you do? And, um, in the finish, at half past two, I rang the ambulance.

(W4.1047-1054.)
Physically absent husbands meant that some women had to continue household responsibilities, whilst others had to continue all household duties as their husband wouldn’t or couldn't help them, highlighting their sense of facing their disease alone. One woman described:

*Not sort of having, having anyone here. I had to do - yeah I had to do things. I just had to force myself to get up to do things, you know, including making sure children had done homework and things like that.*

Women in this ovarian cancer study spoke of being alone in their illness. This was experienced as an intrinsic ontological feature of the ovarian cancer phenomenon. They felt ‘apart’ from their family and friends in a deeply personal way. The sense that their world had shrunk to a focus upon their cancer was intensified by an inability to fully share their experience with others. At times, their expectation that others would understand and share their experience was not met. The women lived in what Mazis (2001) described as the “void of aloneness” (p.210) in serious illness – that is, existential loneliness. These women experienced an existential void in the realisation that although they had relationships with other people, ultimately it was they who had the ovarian cancer; they who had to undergo and endure treatments; and they whose life was threatened by the disease.

**Summary**

Women experienced ovarian cancer as a rupture of their assumptive world and as a contraction of their present world. This is illustrated by the iMindMap in Figure 6.
Figure 6: Women’s ruptured assumptive world

Experiencing a world of crisis: the partner’s perspective.

We had to do the right things and do them quickly, otherwise the evil that had invaded her body would kill her! It was that simple. I am usually calm and strong in the midst of a crisis, but not this time. (Marsicano 2006, pp.57-58.) (Written in response to his wife’s diagnosis of ovarian cancer.)

Partners in this study experienced their wife’s diagnosis of ovarian cancer as a crisis situation, which immediately altered their life and their assumptive world. A crisis is “a time of intense difficulty or danger” (Oxford Dictionary 2014b). It can be experienced as a traumatic time of upheaval and instability. It is a “searing disruption” (Charmaz 1991, p.35), based upon “disruption, immediacy, and immersion” (p.33). A crisis typically represents a threat or danger and is commonly associated with a sense of urgency. Research has described the diagnostic phase of serious illness as a time of crisis (Lethborg, Kissane & Burns 2003; Rolland 1990). Partners in my study, who typically began their interview with the pre-diagnostic period of their wife’s illness, reflect this description of a crisis experience.
Shocking diagnosis

The ‘quite intense’ (Ivan-P8.554) diagnostic process initiated a sense of crisis for the men. They waited ‘on tenterhooks’ (David-P3.873) to hear test results and to learn the reason for their wife’s abnormal symptoms. Hearing their wife’s diagnosis was a watershed moment in their lives. As also discussed in the women’s contracted world, the moment of diagnosis split the men’s lives into a pre-cancer and a post-cancer-diagnosis world and destroyed their assumptive world. It transformed their taken-for-granted world of marriage (all participants in the study were married or in long-term defacto relationships) into a world filled with unforeseen and unknown scenarios.

Partners described the ‘shock’ of the diagnosis, as they had not suspected cancer. Ponto and Barton (2008) suggested that husbands might be shocked by an ovarian cancer diagnosis because of the insidious nature of the symptoms. In my study partners described having no idea that their wife had cancer. Bob was ‘shocked’ (P1.2019) and Ewan was ‘just in utter shock.’ (P4.24.) For Grant it was ‘a shock to the system.’ (P6.36.) Fred explained that his wife’s diagnosis ‘was quite a big shock’. (P5.48.) David and Ivan explained that the diagnosis came ‘out of the blue’. (P3.77; P8.1811.) Ewan struggled to respond appropriately. ‘You just don’t know what to say or do really’. (P4.32.) Bob-P1 explained ‘We just looked at each other.’ (P1.2635.) As Charles said, ‘I wasn’t expecting that [ovarian cancer].’ (P2.122-123.) Partner’s bewilderment and surprise reflected their lack of preparation for the ovarian cancer diagnosis and reflects the abrupt nature in which they were flung into a world of crisis. Although some men had been concerned that something might be seriously wrong with their wife, once given the diagnosis, the sense of threat and danger crystalised. As David explained, ‘that was when it – it hit us, the gravity of the situation.’ (P3.877.) He said, ‘All the kind of fears came to – to fruition.’ (P3.125.) That was when his assumptive world was ruptured.

Some men experienced their wife’s diagnosis as a physical and/or mental blow. These bodily symptoms were a physical manifestation of partners’ sense of crisis and shattered world that accompanied the ovarian cancer diagnosis. David was ‘hit’ (P3.877) by the diagnosis. Ivan was ‘devastated’. (P8.624.) Bob described: ‘I had
never realised the really – the real dramatic effect it can have when you’re told it.’ (P1.2632-2633.) He further described how his wife’s diagnosis ‘knocked the stuffing out of us’. (P1.2635.) Charles was ‘just shattered’ (P2.122) by his wife’s diagnosis. His mother had died of ovarian cancer and he likened being told his wife had the disease to the devastation caused by a bomb. ‘It was just - like the bomb dropped.’ (P2.119.) His entire assumptive world was obliterated and he described his physical reaction and dread. ‘It makes the bottom fall out of your stomach. You know, you sort of think, “Oh God”.’ (P2.48-49.) Physical reactions have been previously described in relation to men’s response to their partner’s cancer (Bischke 2002; Vande Berg & Trujillo 2008). In my study they reflected the enormity of the repercussions partners associated with the word cancer.

Previous research facilitated my interpretation of men’s response to the ovarian cancer as representing a world of crisis. Lewis (1993) suggested that a cancer diagnosis in a family ruptures the assumptive world of all family members. It triggers grief as family members must surrender concepts of self and others that are no longer applicable. Cancer threatens the family with loss (Weihs & Reiss 1996) - of their everyday life (Rolland 1990), as well as with loss of their future together. A partner’s cancer diagnosis can prompt feelings of helplessness in men (Lethborg et al 2003; Wilson 1991; Zahlis & Shands 1991; Zahlis & Lewis 2010), as they feel powerless to do anything to change the traumatic nature of the diagnosis or its implications.

In my study partners experienced the moment of diagnosis as a sudden crisis for which they were unprepared. The cancer changed their everyday, assumptive world as it had altered the taken-for-granted nature of their wife’s health and threatened their wife’s life. Partners’ physical and emotional responses reflected their grief and devastation at the losses sustained in the present; the loss of the world they thought they knew; the loss of the future they thought they and their wife would have; and the losses they anticipated they may have to sustain in the future.
Life-threatening crisis

Ovarian cancer initiated a crisis for partners because they interpreted the disease as a threat to their wife’s life – that is, they equated their wife’s cancer with her potential death. The most pressing concern of most men in the study was whether their wife would survive her cancer. Every husband spoke of his wife’s prognosis and knew that her cancer was life threatening.

Partners’ assumptive worlds were destroyed by the possibility that their wife might die of her disease in the foreseeable future. David described how he used to ‘take things for granted, that, that we’ll be doing things this time next year and the following year and 10 year’s time and stuff’. (P3.933-934.) However, his ‘taking things for granted now has gone’. (P3.935.) His wife’s diagnosis had changed his assumptive world. Similarly, Grant explained: ‘But we weren’t expecting this to occur’. (P6.473.) For him, the ovarian cancer diagnosis ‘does sort of make you realise the sort of - [you] see other people going through the same thing but you feel to yourself that it would never happen to you. But it did’. (P6.486-488.) Ovarian cancer changed Grant’s assumptive world requiring a new way of approaching the world in which he now found himself.

That’s when you sort of realise that you know, everyone is prone to problems like these, that do crop up and when it does come up... you’ve got to step up to the plate, you have to try and refocus, really sort of reorganise – look at life in a different way, not the way that you originally came to have it. (P6.490-493.)

Ivan described, ‘it’s literally that thing that you hear about where your world just shatters in an instant.’ (P8.624-625.)

Partners were confronted by their previously seemingly healthy wife now having a life-threatening cancer. Bob realised his wife’s cancer was ‘something nasty’ (P1.1762) when her GP warned them that her cancer was ‘inoperable’. (P1.30.) He described his wife’s surgery as ‘a very, very serious operation.’ (P1.1779.) Jack realised his wife might have cancer when he read the words ‘gynaecological oncologist’ (P9.233) on the board outside his wife’s doctor’s rooms. ‘And that was
Assumptive futures were changed by the ovarian cancer diagnosis as men faced the potential for living life without their wife. Jack struggled with the thought that his wife might die within the next few years. ‘The hard thing right from the outset was that the prognosis, is that survival is only a few years.’ (P9.913-914.) Ewan commented on his uncertainty regarding his wife’s survival, saying, ‘you just don’t know, do you?’ (P4.114-115.) Charles worried that he ‘might lose’ (P2.218-219) his wife. At first, Fred wondered if the cancer was ‘terminal?’ (P5.56.) His thoughts leapt to his potential future as he tried to imagine his life without his wife. ‘I was thinking, what if I – I suppose everyone does the same, thinking, “Now what am I going to do if I’m on my own... if she – she’s not around?” ‘ (P5.196-200.) Ivan explained that he ‘had a few teary moments at the start’ (P8.282) – what he called ‘breakdowns’ (P8.286) - as he and his wife were ‘trying to adjust to our different future to what we had in our minds’. (P8.288.) He described, ‘the vision you have of the future just disappears and you look at your wife and think, “Will I turn over in bed and see her there in three month’s time, six month’s time?” ‘ (P8.627-630.) He added, ‘you just reprogram your future really. You’re just thinking through scenarios and changing the picture of what’s coming in. And that’s just an incredibly difficult thing to do.’ (P8.633-636.)

Assumptions about a certain quality of life and continuing lives together in relatively good health were challenged by both the cancer diagnosis and the prognosis. One partner, Bob, said,

And, as you get older, I think it’s fair to say, these things have a deeper effect... When you’re younger – you’re impregnable... And you get to 78, 79 and you’re not so sure... And when you’ve been married as long as we have and your partner gets this news out of the blue...’ (P1.2667-2675.)
He had been married for 55 years and the ovarian cancer was a very real threat to his wife’s life and to his expectation of their remaining years together.

The reality of the situation was impacted by previous experience for Bob and another partner Charles. Bob’s sister-in-law had died from ovarian cancer 18 months earlier and Charles’ mother had died of the disease when he was a child. Weihs and Reiss (1996) suggested that certain cancers might have particular significance for individuals and families. Bob’s and Charles’s experiences of the death of close family members from ovarian cancer help us to understand from their point of view, the magnitude of the threat the disease posed to their wife.

Experiencing a sense of urgency

Men experienced their wife’s cancer diagnosis with a heightened awareness of the importance of time. The sense of crisis associated with their wife’s cancer meant that they experienced lived time differently than previously. As discussed earlier in this thesis, time can be experienced in different ways. Objective time is that which clocks and calendars measure and by which we typically organise our lives (Heidegger 2011). Subjective time is ‘lived time’ – that which is ‘felt’. For example, it is the way one may feel time as passing very slowly, or very quickly.

An intense ‘sense of urgency’ (Ivan-P8.563) was evident in the partners’ interviews. This reflected their sense of ‘crisis’ initiated by the diagnosis of cancer and its associated threat of death. Men interpreted prompt treatment as being crucial. Delays were a ‘waste’ of time and represented increased risk for their wife’s chance of survival. There was also a sense of uncertain time, where men were unsure if passing objective time represented a danger to their wife’s life. For example, initially, David wasn’t sure if time was of the essence for his wife’s life, or not. ‘We just didn’t know how critical, time-critical it was. Do days matter or don’t they?’ (P3.128-129.)

Men experienced the ovarian cancer as contrasting times of speed and delay. Initially, their sense of a crisis was reinforced by the speed with which their wife had surgery. Ewan received a ‘big shock’ (P4.80) at the urgency of his wife’s surgery, which ‘had
to be right then.’ (P4.80.) David’s wife was treated ‘very quickly’. (P3.889.) Bob’s wife’s doctors also ‘moved pretty quickly.’ (P1.1747.) Grant’s wife had surgery a week after her diagnosis. ‘So they did move very, very fast’. (P6.230.) Ivan described the rapid onset of his wife’s treatment: ‘it just went bang, bang, bang, bang. Within three or four days it was happening.’ (P8.91-92.) In contrast to their wife’s urgent surgery, men described periods of waiting. They spoke of time ‘dragging’ whilst their wife was in surgery. Charles described the day of his wife’s surgery as one of the worst parts of his experience. As objective time passed, he became more concerned about his wife’s welfare and his ‘lived’ time seemed to stretch out.

She was in there for a long time and they were going to ring us...and I was expecting them to ring and they hadn’t rung. And, I was sort of, really starting to worry and then they, the doctor rang and said everything was okay. (P2.385-391.)

He experienced his increasing concern for his wife as impatience. ‘I was probably a bit impatient worrying, yeah.’ (P2.411.) Similarly, Grant recalled the day of his wife’s surgery as ‘a trialing day’ (P6.46) and time seemed to pass incredibly slowly for him. The surgery took ‘quite a long period of time’. (P6.142.) The day was ‘very, very hard’ (P6.47) and was ‘probably one of the longest mornings or days in my whole life’. (P6.48.) He worried his wife might die in surgery and found the day ‘pretty much a nerve-racking day’. (P6.136.) ‘It’s kind of scary and daunting, you don’t know whether they are going to come out on the other side.’ (P6.138-139.)

For Bob the crisis situation was heightened by what he considered a lengthy delay between his wife’s surgery and the onset of chemotherapy – a period of six weeks – which he experienced as an agonising time of danger. He knew his wife was desperately ill because their HCPs had told them, and also because he had experienced the disease killing his sister-in-law 18 months previously. He was desperately worried about the time taken as he knew his wife had residual disease post surgery. He feared delays would enable her cancer to proliferate and thus reduce her lifespan. He couldn’t understand why the cancer wasn’t being treated more promptly. ‘There seemed to be no air of urgency.’ (P1.2351.) He was almost frantic as he declared, ‘I can’t – I still can’t get it into my head that there ought to have been a little bit more – urgency – because [the cancer] was still in there!’ (P1.2372-2375.)
He added, ‘as a layman, you think the thing’s still there – “Why aren’t we doing something about what’s left?!”’ (P1.2453-2454.) Previous studies have described delays in cancer treatment as excruciating (Bischke 2002; Marsicano 2006). Heidegger (2011) suggested that the more one worries about time, the less time one has and “the more precious time becomes” (pp.60-61). For men in my study, there was a sense that the cancer had a “foothold” (Bischke 2002, p.20) in their wife’s body and that the longer the delay, the more likely the cancer would multiply. Ivan described his eagerness for his wife’s treatment to take place. ‘We both were really, very much, “Bring it on”’. (P8.884.) Delays were ‘quite challenging, you know, we didn’t want to wait a week! We wanted it to happen!’ (P8.889-891.) He explained, ‘I think surgery got delayed a week and it’s “No! We want it now!”’ (P8.893-896.) Bob experienced delay in commencement of his wife’s chemotherapy treatment as a potential disaster and an added crisis. He lacked information and badly wanted reassurance and an explanation about the delay in his wife’s treatment. He explained:

_It was the gap. The gap between coming out of [city] and finally getting the first chemo. Now maybe that’s normal, I don't know. It would be nice if someone had said, “Well, this is what happens and this is why we have to wait for the medication.”_ (P1.2580-2584.)

**Summary**

Men experienced ovarian cancer as a rupture of their assumptive world. The diagnosis of their wife was a defining moment, which split them from their previous life and propelled them into a world of crisis. This is illustrated in an iMindMap (Figure 7).
Living in a dread-full world: the children’s perspective

For me, my mother had always been there, and I had never seriously thought that some day, that soon I should see her go. Her death, like her birth, had its place in some legendary time. When I said to myself “She is of an age to die” the words were devoid of meaning, as so many words are. (De Beauvoir 1985, p.20.)

Children in my study described having a close and loving bond with their mother. There was a sense of mothers representing a foundation of love, safety and security – a home base from which the children operated in the world. Relationships with mothers were described as being strong and interdependent. Daughters, in particular, described symbiotic relationships with their mother. Literature often portrays mothers as being the central figure that holds a family together (Hollucky 1996; Oktay 2005). Adult children and mothers typically have strong, interdependent, trusting, enduring and satisfying relationships, which are central to the life of the child and may facilitate their individual sense of well-being (Conley, Moors, Ziegler & Feltner 2002).
Legge (2014) described mothers as an “emotional home” (p.22) for children. In my study, mothers were portrayed as being crucial figures in the children’s lives. Mothers constituted a pivotal part of the children’s assumptive worlds – past, present and future and were viewed as being a loving and dependable friend, who had always been there for the child. Their presence provided the children with a sense of security and formed part of each child’s assumptive world. Accordingly, children experienced their mother’s diagnosis of ovarian cancer as a rupture of their assumptive world. It destroyed their taken-for-granted nature of her health and in doing so threatened the foundation of their lives.

Children experienced their mother’s search for and receipt of a diagnosis of ovarian cancer as living within a world full of dread. The word ‘dread’ means “anticipated with great apprehension or fear” (Oxford Dictionary 2014c). Heidegger’s (2008) discussion of fear and dread informed interpretation of children’s experience of ovarian cancer. Heidegger stated that dread is a “state-of-mind” (p.179) that arises from fear of something “unfamiliar” (p.182). He identified various characteristics of fear including being fearful of something “detrimental” (p.179) which threatens us and which may eventuate or may not. He described existential fear as being fearful for others where the object of that fear affects one, yet at the same time one knows that in some ways one is unaffected. He suggested that in fearing about others, we are “‘being–afraid-for-oneself’” – that is, we are concerned that the Other “might be torn away” from us (p.181). In my study children viewed their mother’s death from ovarian cancer as something detrimental and threatening, which was a definite possibility in the foreseeable future. As Heidegger described, as an object of fear, children experienced their mother’s death as being “not yet within striking distance, but [is] coming close” (p.179-180). Children feared their mother would be ‘torn away’ from them. As a source of fear with which children were unfamiliar, their mother’s death was experienced with ‘dread’.

The context of children’s world and their mother’s world, in particular their relationship with their mother, provided a lens through which the ovarian cancer phenomenon was experienced and it helped determine the meaning of that experience for each child. All mothers had previously been fit and healthy and children were
unaccustomed to their mother being seriously unwell. Her ovarian cancer diagnosis ruptured their assumptive world. Feelings of dread and uncertainty related to cause of their mother’s illness was replaced by dread about her prognosis. The definitive diagnosis confronted children with the irrefutable fact of their mother’s mortality and forced them to surrender any naivety regarding their mother’s (assumptive) future.

Feelings of foreboding

The ovarian cancer experience began for most children in this study prior to their mother’s diagnosis. Children experienced feelings of perturbation with the realisation that something was physically wrong with their mother. Van Manen (1998) described how in everyday life we commonly “bypass” (p.11) (or not notice) another person’s body: their body is taken for granted as part of their embodied being until something about it attracts our attention. Children in this study began to notice their mother’s previously taken-for-granted body once they became aware that their mother was experiencing symptoms of illness. Val described her mother. ‘She couldn't walk four steps that day without stopping’. (C7.358-360.) Wendy recalled, ‘Swollen. She looked like she was eight months pregnant.’ (C8.1050.) Their once familiar mother’s body now seemed unfamiliar.

Children felt fearful and uneasy whilst they waited for a definitive diagnosis for their mother. Una and Val struggled with ‘not knowing’ (C6.1638; C7.1587) what disease their mother had. Tess explained:

_They say ignorance is bliss but in this case it isn’t, because it’s the unknown, and the fear of the unknown. If you know what it is at least you can confront it head on and you know what challenges you’ve got. But if you have no idea it’s just a mental nightmare._ (C5.97-101.)

For her, knowledge and certainty represented an opportunity for power and action. ‘The not knowing is – yeah, as I say, the not knowing is worse than knowing I think.’

Time was experienced differently – as prolonged - whilst the search for a definitive diagnosis was made. Almarza (2008) described how children experienced time with a sense of urgency when their parent was diagnosed with cancer: “time does not move
at a normal pace, rather it exists always as a state of urgency” (p.85-6). Diagnostic uncertainty meant that children in this study also felt a sense of urgency. Eliza said the delay in her mother’s diagnosis ‘kind of eats you away’. (C1.407.) The diagnosis ‘took a while’ (Wendy-C8.31) which felt ‘like a long time’ (Eliza-C1.56) to the children. Val described the wait for test results: ‘It took a long – well it seemed to take a long time.’ (C7.442.) Una said, ‘so it might have taken about a week. Which probably is not a long time, but it seemed like a long time when you’re waiting for, you know, all the results.’ (C6.451-454.) The passage of time and perceptions of delay heightened many children’s sense of urgency and uncertainty. Mark believed ‘every day counts… when it’s these sorts of cancers.’ (C4.522-523.) Tess explained: ‘It is because time’s – it’s time and time is your worst enemy when it comes to things like that, because you don’t know what you have got to confront.’ (C5.92-93.)

In response to their experience of lagging time, some children increased their involvement in the diagnostic process. One child (who was a HCP) worried her mother wasn’t taking her symptoms ‘seriously’ and ‘wanted to make sure that – it wasn’t being put onto the backburner.’ Another child (also a HCP) decided ‘I needed to ring the GP and sort of say to them; “Look I’m really concerned”. Um, you know, “I’m not going to be happy until she’s had a CT”’. Wendy spent months persistently taking her mother to hospital in search of a definitive diagnosis.

But – to get from [a] lady who was in and out of the inpatients who was lying on a gurney in the [hospital] having morphine popped into her, um, for 48 hours, um, to maybe up in the renal unit or maybe up in the tummy unit or maybe - it was a long process. A long, long process, until they finally got to, “Oh, your mum has ovarian cancer”. (C8.1022-1026.)

Children’s assumptive worlds changed as they realised their mother was unwell. Their feelings of concern turned to feelings of foreboding and fear as they awaited a definitive diagnosis for their mother’s symptoms.
World disturbance

The maternal diagnosis of ovarian cancer changed children’s interpretation of their mother’s symptoms from vague and uncertain to having dire implications for her future and consequently their own. Feelings of dread came to the fore as children learnt their mother had cancer. All children associated their mother’s diagnosis with her death. Val said: ‘Someone says that your parent’s got cancer ... you do think the worst.’ (C7.490-493.) Tess remembered hearing her mother had cancer. ‘[She] just looked at us and said “It’s cancer.” There was just stunned silence in the room. Then mum started to cry, then we started to cry.’ (C5.76-77.) Children’s dread increased as they learnt the poor prognosis associated with ovarian cancer. Una explained: ‘but what stands out in my mind when [sister] said we – you know, “It’s not – it’s not good”. And you think, “Oh crap.” ’ [Whispered.] (C6.2269-2270.) Eliza stated, ‘um, when she was initially diagnosed I guess it was just really hard because I really knew what was going on. I just didn’t want it to be true.’ (C1.137-138.)

The majority of children experienced the diagnosis as a ‘a big, big shock’ (Tess-C5.66) and ‘a very big surprise’ (Mark-C4.9) because of its ‘unexpectedness.’ (Kevin-C2.260.) The ‘shock’ (Tess-C5.18) was intensified because prior to diagnosis, all children in this study had believed that their mother was strong and well. The children had lived certain assumptions about their mother and her future that were linked to their own. Kevin had never considered that his mother might have cancer. ‘Because you know, she was otherwise, you know, a very, fit, healthy person.’ (C2.9.) Anna explained: ‘We thought it was sciatic.’ (C9.337.) The assumptive world of the children in my study was shattered by their mother’s diagnosis. Wendy described: ‘when they actually say the word [cancer] to you it’s like as if your whole foundation is just, boom, gone.’ (C8.36-37.)

Realising mother’s vulnerability

Central to all children’s experience was the realisation that their mother might die from her cancer. Children all knew the prognosis associated with ovarian cancer and
many described carrying this knowledge with them throughout their daily lives. The children experienced the prognosis as a threat of a looming absence in their life. All spoke of their fear of recurrence and/or the prognosis associated with the disease. Recurrent disease was dreaded as being the (almost certain) precursor to their mother’s subsequent death.

With the definitive diagnosis and associated prognosis, children further developed a subjective awareness of temporality. They lost their assumptive future and now viewed the future differently. They felt tied to their mother’s future as they waited to determine the outcome of her treatment. Their mother’s illness and prognosis became a part of the child’s world – part of their identity. They, along with their mother, had entered what Schwalbe (2012) described as the “country of the sick” (p.32).

Dread of their mother’s death was fundamental to children’s experience. Val was ‘freaked’ (C7.1881) by knowing her mother had metastatic disease. She described:

*It was in the lining on the stomach and it was on the lining of her lungs.*  
*So you know, that – it, it was a huge thing. ‘Cause you think well that’s all your – that’s all your organs. That’s from here to here. [Indicated on her body]. And yeah. So it was – it – yeah. It was pretty worrying, pretty worrying and scary and all those emotions.*  

(C7.1892-1902.)

Anna explained how her mother’s diagnosis had challenged her assumptive world. She had always known her mother would die someday, but it had never felt a ‘real’ possibility until her mother developed ovarian cancer. Suddenly, she realised her mother’s vulnerability. *It’s like when, you know, someone’s going to die and, you think, “Yeah”. But until it happens, you don’t know how you’re going to deal with it or how you’re going to cope, no matter how much you’re prepared*. (C9.731-733.)

Laurie found his mother’s ill-health *‘obviously fairly, you know, confronting.’* (C3.277.) Their mother’s death had ‘drawn close’ (Heidegger 2008) and was now a very real threat.

Ovarian cancer meant that children became aware of their mother’s vulnerability. The cancer demonstrated that their mother was not the strong ‘always-there’ foundation on which children depended. Rather, she was now an extremely ill
woman with a life-threatening cancer. Children looked ahead to an unforeseeable/unknown future with heightened feelings of fear, dread and trepidation as they worried about their mother dying in the near future. Suddenly the future seemed foreshortened. Her continued presence could no longer be taken for granted and her possible death was a threat with which the children had to learn to live. Tess worried that her mother might not live long. ‘What if this is our last Christmas?’ (C5.132.) Una was alarmed by a well-meaning comment from a HCP and wondered if her mother was likely to die almost immediately. ‘[The HCP] said, “We’re just trying to make her comfortable.” …And I thought, “Does that mean that she’s got a week to live?” And then when you hear that on TV you think they’re going to die the next day’. (C6.498-507.)

Medical emergencies heightened children’s awareness of their mother’s vulnerability and made imminent death seem possible. Mark described the sense of drama when his mother needed immediate surgery for complications. ‘And then it was really rather sudden that [pause] the surgeons, they’re doing some more surgery, right now or you’re going to die!’ (C4.48-49.) Post surgery, Eliza’s mother was critically unwell. ‘She was very sick and [crying] [doctor] and I thought maybe she wouldn't make it.’ (C1.134-135.) Children realised that they could no longer take their mother’s presence in their lives for granted. Wendy explained, ‘even when she was going through chemo there was no, there was no guarantee at the end, that it was going to be okay.’ (C8.131-133.) Lowdermilk & Germino (2000) suggested that the individual meaning of a mother’s cancer is determined by what it represents to the family member and how they view their future. Van Hooft (2011) described one’s fear of death as “the deepest anxiety” (p.68). For children in my study, maternal ovarian cancer represented the threat of their mother’s death and they viewed their future with foreboding.

The ‘silent killer’

Children developed knowledge about the prognosis associated with their mother’s cancer and understood that the disease was unlikely to be cured, providing them with a contextual framework for understanding the serious implications of her cancer.
Schou and Hewison (1999) suggested that once a diagnosis of cancer is made, patients and family members determine the likely prognosis in order to establish a “seriousness context” (p.67). The relevance of this concept to my study is demonstrated by comments made by some of the children. Wendy ‘knew that it was a bloody bugger that we were fighting.’ (C8.367.) Kevin felt ‘a sense of frustration and I guess disappointment and sadness’ (C2.391-392) as he struggled with accepting the ‘relative ineffectualness of the treatments available’. (C2.380-381.) He struggled with: ‘Coming to terms with the, um, realities of the prognosis. Um, that, it is, it’s a disease that you’re unlikely to recover from.’ (C2.21-23.)

Children voiced their expectation that their mother’s cancer would recur and subsequently kill her. Wendy spoke about recurrence of the cancer as inevitable. ‘When it does come back...’ (C8.654.) She had been warned to expect recurrence. ‘[Doctor] was very honest with us and said it will come back and it will come back with a vengeance.’ (C8.133-134.) Anna was warned by a HCP to expect her mother’s cancer to kill her.

Like I said to him, “You can’t guarantee [when she might die]”. You know, “You can say 12 months and it could be 12 years”, sort of thing. But [she’d] just turn around and say, “Well, I wouldn't be looking for two”. (C9.454-458.)

Mark spoke of the ‘likelihood that it will return’, (C4.397) acknowledging ‘the reality of [pause] particularly this sort of cancer that can, you know, go to [pause] go metastasis or... and go throughout the body.’ (C4.330-333.) Similarly, Kevin expected his mother to eventually die from her disease:

My understanding is that, um, you know, any time in the next few years it will come back and it will likely to come back in a way that’s not – readily treatable. Um, and that, you know, she’ll just sort of deteriorate I guess fairly rapidly, from there. (C2.46-50.)

Eliza also viewed recurrent disease as inevitable. ‘ ‘Cause I think I know it’s going to happen one day.’ (C1.206.)

A number of children in this study spoke about ovarian cancer as ‘the silent killer’. (C5.743; C8.1169.) In Australia, the notion of ovarian cancer being a ‘silent killer’ is often reflected in the media and perpetuated by reports in popular press. (See, for
example, The Australian Women’s Weekly September 2013, pp.149-155.) Literature has identified that one’s experience of cancer is influenced by cultural meanings (Kleinman 1988) and dominant social discourses (such as metaphors and nicknames) (Willig 2011). In my study, the term reinforced children’s association between ovarian cancer and their mother’s likely death, thus contributing to the dread they experienced.

Children were also confronted by the five-year survival statistics related to ovarian cancer. They saw this statistic applicable now to their mother – it was no longer ‘just’ a statistic – rather it was interpreted as a temporal boundary (or endpoint) for their mother’s life. Tess described: ‘there was a five-year time, pretty much. Well, they say five years for ovarian cancer patients.’ (C5.371-372.) Wendy found the disease ‘scary – to read about.’ (C8.1068.) Mark understood that ‘median life expectancy after these sorts of things is about five or seven years or something.’ (C4.399-400.) Similarly, Laurie explained: ‘the statistics sort of say that, you know, she’ll, she’ll survive another five years, you know, 50, 30-50 percent of the time or something like that. I can’t remember the stats now.’ (C3.500-502.) Una was told her mother ‘could have five months, she could have five years.’ (C6.540-541.) Unlike other children in my study who dreaded the five-year point as the time by which their mother would probably be deceased, Una experienced the temporal uncertainty as a ‘sort of timeframe.’ (C6.554.) It acted as a temporal space, provided her with ‘breathing’ room and relieved her fears that her mother might die almost immediately from her cancer. She hoped for ‘another good five years’ (C6.2757) before her mother succumbed to the cancer. Thorne, Hislop, Kuo & Armstrong (2006) suggested that numerical facts related to cancer prognoses have powerful potential for “shaping the cancer experience” (318). This influence is reflected in my study in the way children’s experience of the phenomenon was moulded by their understanding of their mother’s prognosis.

Candid discussions between mothers and children about fears of recurrence and the mother’s subsequent death were dependent upon the relationship between each duo. Children who described being very close emotionally to their mother described ‘surreal’ (C8.383) frank discussions with her about her death, funeral and/or Will.
These discussions were experienced as a reminder and acknowledgement of their mother’s potential to die from her disease. Wendy’s mother broached the subject of her funeral wishes. ‘*And she basically itemised everything she wanted me to do. Um, to the point of what songs she wanted. Um, everything. Everything.*’ (C8.374-375.)

Anna’s mother ‘*got a complex*’ (C9.386) about dying. She discussed her Will and disposal of her goods. ‘*She’d go through stages where she’d say, “Oh right, do you want this, do you want that?” and so on. And it’s like – “I hadn’t really thought about that”.*’ (C9.412-413.) Tess cried as she described how her mother had told her that she wanted to live long enough to be present at some family milestone events. ‘*She’s, she’s not afraid of dying. She’s afraid of leaving us behind... My mum’s only 60.*’ (C5.639-643.) She added, ‘*It’s still hard when I think about it. I think I’m coping real well, and I do most of the time, it’s just when you sit down and really think things like that. You think “Oh shit.”*’ (C5.658-660.)

Children’s dread of their mother succumbing to ovarian cancer was not always openly discussed within families. A number of children in this study described avoiding conversations with their mother about her possible recurrence and subsequent death. Eliza spoke of her dilemma in managing her fears for the future whilst not wanting to rob her parents of their optimism. She said:

*I think the main issue now, is the kind of the stress of the uncertainty of when it might recur? Um, and the practical aspects of trying to convey that sort of thing to mum without it really being a burden. Because, because of the way they are at the moment – her being very well – that I don't want it to be this, you know, thing that just shadows her the whole time.* (C1.10-15.)

Eliza’s quote demonstrates her desire to protect her parents from the ‘burden’ of realising the prognosis associated with ovarian cancer. She did not want to rupture their current assumptive world of (apparent regained) health by introducing the need to proactively plan for recurrent disease and subsequent ill health. The avoidance of talking openly within families about cancer and possible death can be conceptualised as being a “conspiracy of silence” (Brennan and Moynihan 2004, p.100), or “communicative avoidance” (Caughlin, Mikucki-Enyart, Middleton, Stone & Brown 2011, p.409) with the
aim of maintaining the cancer patient’s sense of optimism (Caughlin et al, 2011).
Kevin described avoiding communicating with his mother about her possible ovarian-cancer-related death. He had, ‘a little bit of difficulty in terms of how to interact with her about [her prognosis] because I’m not quite sure how much she, really acknowledges that.’ (C2.25-27.) Although his mother initially spoke with him about her fears for her prognosis, Kevin had not discussed it any further with her.

And I don't know that it's necessarily healthy for her to talk about, you know? It’s not something that I would push her to talk about or, you know, I don't, huh, you know. Maybe it's better just to ignore these things and, you know, so long as, they get planned for. (C2.61-66.)

Kevin felt that it was better for his mother not to discuss her possible death and thus he avoided discussing it with her as a form of psychological protection for her.

Most children lived with a steady awareness of their mother’s vulnerability. Their dread of her potential early death had been integrated into their Being-in-the-world. Laurie carried his dread as ‘stuff in the back of your mind.’ (C3.490-491.) Una described her constant awareness of her mother’s vulnerability. ‘It’s always there in the back of your mind though, and you think “Oh”, and then we get it – the phone rings and you think “Is it mum?” ’ (C6.1192-1193.) As the family spokesperson, Anna was never able to escape or deny the illness with its associated prognosis – it was a constant companion.

I think the hard part for me was like with the phone calls – sort of being the contact person and yeah, like friends and families would ring and you’d just have to sort of go back over it and then it’s like, well, ‘Mum’s got cancer. Mum has got cancer. She’s had it removed and it was just - .’ It all goes through your head, sort of thing, and then going back over it, and over it, yeah, I think that was the hardest part. (C9.740-746.)

She added, ‘I suppose it’s like most things. The more you say it, or it’s not until you say it out loud, that it becomes real. So yeah, you’ve got to keep saying it, and that just makes it more real.’ (C9.765-767.) Tess described her mother’s cancer as ‘this awful thing hanging over our head.’ (C5.201-202.) Five years after her mother’s diagnosis, Wendy quietly described her constant and persistent companion of fear:
Always, it’s there [fear of recurrence and death], yeah. I mean it would be silly – I couldn't lie to you and say it was not. It is always, you know. I wake up some nights, um and sitting in bed - and can visualise me saying her eulogy. (C8.1524-1528.)

Summary

Ovarian cancer ruptured the assumptive world of children in my study. They experienced the ovarian cancer phenomenon as living in a world full of dread. This is illustrated in Figure 8, by an iMindMap.

Figure 8: Children’s ruptured assumptive world

Chapter conclusion

This chapter has described the experience of ovarian cancer as Being in a ruptured assumptive world. The diagnosis of ovarian cancer destroyed participant’s taken-for-granted lives. It ruptured their assumptive worlds. Women’s lives contracted to a focus upon their illness and their self. Feelings of existential loneliness were heightened by knowledge of their potential for dying from their disease. Partners
experienced their ruptured assumptive world as a world of crisis. The shock of diagnosis precipitated a sense of crisis in which time became paramount. Prognostic fears occupied husband’s thoughts as they struggled to cope with the change in their world. Children’s worlds were rocked by the realisation that they mother had a life-threatening disease. The realities of the prognosis and its implications for their mother meant that children now lived with a very real and deep dread of their mother’s cancer-related-death.

The experience is illustrated in the iMindMap in Figure 9.

Figure 9: Summary of ruptured assumptive world

The following chapter further explores the ovarian cancer phenomenon – as the participants experienced it. It introduces the second major theme of ‘Uncertain world’, which provides an additional conceptual layer for understanding the complexity of the phenomenon of ovarian cancer. It can be understood to co-exist with ‘ruptured assumptive world’ as a constituent of participants’ lives.
CHAPTER SIX: UNCERTAIN WORLD

This chapter introduces the second major theme with which participants’ experience of the phenomenon of ovarian cancer is viewed and understood. Whilst participants initially experienced the disease as rupturing their assumptive world, they also experienced the phenomenon as living in a world of uncertainty. This chapter’s major theme – world of uncertainty – is presented in sub-themes that embody the experience of the phenomenon of ovarian cancer from the perspectives of participants. Women experienced the phenomenon as living in an uncanny world; men lived in a world of enmeshment; and the children’s experience was one of living in a solicitous world. Common to all participants were feelings of uncertainty, which underpinned their experience of ovarian cancer.

This chapter’s major theme and subthemes are represented in the iMindMap in Figure 10.

![Figure 10: Introduction to uncertain world](image-url)

Figure 10: Introduction to uncertain world
Uncertainty as a concept

The word uncertainty refers to “the state of being uncertain” (Oxford Dictionary 2014d). Something that is uncertain is “not able to be relied on; not known or definite” (Oxford Dictionary 2014e). Uncertainty is “the subjective perception of ignorance” (Han, Klein & Arora 2011, p.830) and is something with which we are all familiar – it is an intrinsic characteristic of human lives (Selder 1989). To some extent, we all live in a world of uncertainty where our future is indefinite and unknown. However, in this thesis, I suggest that the experience of ovarian cancer is dominated by uncertainty, with participants living with heightened awareness of uncertainty in their daily lives and in their anticipated futures. Ovarian cancer brought uncertainty to the fore, and it was central to participants’ experience. The cancer influenced (and at times, enveloped) their world and impacted upon their Being-in-the-world.

Uncertainty is a common theme in cancer narratives. Literature suggests that uncertainty is a fundamental element of cancer experiences (Babrow, Kasch & Ford 1998), which can distinguish cancer from the majority of other illnesses (Haddad, Pitceathly & Maguire 1996, p.258). It can promote feelings of stress, distress, and loneliness and can be experienced as an unwanted burden (Hansen et al. 2012). In early work on the concept, Mishel (1988) defined uncertainty in illness as “the inability to determine the meaning of illness-related events” (p.225) and suggested it can be appraised as representing danger and/or opportunity (1988, 1990). When uncertainty is interpreted as a danger with potential to harm, one typically responds by implementing coping strategies such as information seeking to minimise the uncertainty. When interpreted as an opportunity, one typically responds by implementing strategies to maintain the uncertainty (Mishel 1988, 1990). Uncertainty is a major element in stress appraisal and subsequent coping methods (Lazarus & Folkman 1984). Ongoing illness-related uncertainty can be conceptualised as a dynamic process that changes over time (Miller 2014; Mishel 1990). Ultimately, persistent uncertainty can provide a basis for viewing the world with a different perspective and can be incorporated into a persons’ worldview (Babrow et al 1998). Parry (2003) suggested similar, stating uncertainty in cancer “can be conceptualised
as a catalyst leading to profound changes in identity, personality and life outlook” (p.238).

Since Mishel’s theories were first published various aspects of the concept of uncertainty in illness have been explored in literature. For example, in an analysis of families’ experience of life-threatening childhood cancer, Cohen (1995) suggested that sustained uncertainty associated with serious illness could be conceptualised “as a second chronic condition situated within and dependent” (p.73) on the illness. The idea that uncertainty can be considered to be intimately associated with the experience of cancer facilitated interpretation of the experience of participants in my study. All participants described Being-in-a-world-of-uncertainty.

**Being in an uncanny world: the women’s perspective**

When we are beset by an illness, our bodies are out of synch with the world around us as we struggle to make sense of the objects and events that now seem alien to us, and as we seem alien to ourselves. (Ferguson 2012, p.316)

Women in my study experienced ovarian cancer as living in an unpredictable, uncertain and unfamiliar world - described in this chapter as ‘uncanny world’ – where their sense of Being-in-the-world was altered by their experience of ovarian cancer. The etymology of ‘uncanny’ includes “of a mysterious or weird nature” (Onions 1966, p.957) and “odd, strange, disturbingly different” (Online Etymology Dictionary 2014). Heidegger (2011) referred to the phenomenon of umheimlichkeit, which can be translated into uncanniness, whilst umheimlich is a feeling of being uncanny, unsettled or un-homelike (p.34). Heidegger (2008) believed that this sense of not-being-quite-at-home-in-the-world is basic to human existence but is usually glossed over in everyday routine life. Umheimlichkeit is associated with awareness of one’s Being-towards-death (Heidegger 2008; Svenaeus 2000a; Warsop 2011) and thus one’s existential angst. The sense of one’s individuality and umheimlichkeit within the world can be revealed by feelings of anxiety (Heidegger, 2008; Reynolds, 2006),
such as that experienced in recognising “the fragility and finitude of our bodies” (Warsop 2011, p.494), or that experienced in response to an illness-induced loss of one’s assumptive world. Used in this sense, the terms ‘uncanny’ or ‘unhomelike’ refer to “ontological states” (Tyreman 2011, p.306) – that is, they refer to one’s mode of Being in the world.

The ontological concept of umheimlichkeit in illness has been explored by a number of authors (Ahlzen 2011; Dekkers 2009; Ferguson 2012; Roing, Hirsch, & Holmstrom 2007; Sekse, Gjengedal, & Raheim 2013; Svenaeus 2000a, 2000b, 2000c, 2001, 2009; Toombs 1992; Tyreman 2011; Warsop 2011). This study extends previous reports to consider the experience of ovarian cancer as an uncanny phenomenon. Health can be conceptualised as a balanced state (Svenaeus 2000c; Tyreman 2011) of feeling at-home within the world (Ahlzen, 2011), whilst illness is a form of feeling uncanny or “unhomelike” (Svenaeus, 2000b, p.125). Being ill has been associated with feelings of alienation from oneself (Ferguson 2012; Sekse et al 2013; Svenaeus 2009; Tyreman 2011; Warsop 2011), where one experiences one’s body as being unfamiliar - “alien, yet, at the same time, myself” (Svenaeus, 2000b, p.131). When we feel comfortable and at ease within our familiar bodies we feel ‘at home’ with ourselves (Dekkers, 2009). Illness disrupts the taken-for-granted nature of our usual Being-in-the-world (Ahlzen 2011) and induces a sense of things being ‘mysterious’, ‘weird’ and ‘disturbingly different’ – in other words, uncanny. With uncanniness, things do not feel right; there is a “feeling of lack of control, of not being at home, of being controlled by someone or something other than oneself” (Svenaeus 2000a, p.5). With uncanniness, the world is characterised by uncertainty and is experienced as being unfamiliar, unnatural and uncomfortable. Gadamer (1996) suggested that illness is associated with “a state of unbalance” (p.55) that is, a “loss of equilibrium” (p.58). Sacks (1991) described the “intuitive feeling” (p.29) of uncanniness as a metaphysical sense of loss of wholeness of the self. As a cancer patient, Frank (1991) described losing his sense of self, “his sense of belonging” (p.36). Toombs (1992, p.20) stated that serious illness presents an ontological challenge to one’s sense of self and of being-at-one within the world. She suggested that in illness, one’s previous assumptive world becomes “a world in which one is no longer at home” (p.97), a world in which one is uncertain of one’s self, one’s life and one’s future.
Women in this study described a sense of umheimlichkeit, which was characterised by feelings of alienation, unfamiliarity and lack of control. It contributed to women’s overall feelings of uncertainty as they had no familiar sense of ‘self’ with which they could be in their world. Their foundational self became uncanny and unfamiliar, impacting women’s ability to decipher and deal with uncertain entities in their world. Women described how their illness had altered their relationship to their world; life became unpredictable and time was experienced differently. They no longer felt ‘at home’ in their world. Spaces and places felt different – strange. Women’s bodies, which had previously been taken-for-granted, dominated their lives as side effects of treatment intruded upon women’s consciousness. Bodies were experienced as being untrustworthy, unpredictable and out of control. Uncertainty and anxiety permeated lives and undermined women’s attempts to cope. Relationships changed – both with their-self and with others. Women’s sense of self and identity changed – that is, their Being-in-the-world changed. Relationships were paramount for helping women cope with their sense of living in an uncanny world.

**Experiencing uncanny and uncertain temporality**

In this study, women experienced time differently than before their cancer: time took on different dimensions as they lived in the world with constant uncertainty. Time became ‘precious’. It assumed heightened importance for women as they developed a heightened awareness of their vulnerability to and potential for a cancer-related death. Uncertainty and uncanny times meant that women felt temporally ill-at-ease in their world.

For Heidegger (2008), temporality was fundamental to understanding our Being-in-the-world. Temporality is “subjective time” (van Manen 1990, p.104). It is the qualitative way that we experience time. Merleau-Ponty (2002) suggested that “time is not a real process”, rather it comes from our “relation to things” (p.478). Literature has suggested that our experience of time is characteristically changed as a result of serious illness (Charmaz 1991; Cohen 1989; Ellingsen, Roxberg, Kristoffersen, Rosland & Alvsvag 2012; Rasmussen and Elverdam 2007; Toombs 1988). Little et al (2001) suggested that cancer patients enter a state of feeling ‘different’ from others in society once they begin to suspect that they might have cancer. The word ‘cancer’
brings close to home the possibility of a cancer-related death. Their subsequent realisation of their potential for an early demise distinguishes cancer patients from others in society and may help to explain women’s experience of time in my study.

Knowing that they had a life-threatening form of cancer, women experienced ‘past’ time differently. Women wanted their disease to be diagnosed and treated promptly and therefore long periods of time spent in pursuit of a diagnosis and/or treatment was considered to be ‘wasted’ time. Mary described the time taken to obtain a definitive diagnosis for her symptoms. ‘It’s funny because I kept going back and saying “There’s something wrong, I don’t understand what’s going on”. And kept going back, and having more blood tests for different things and they couldn’t figure out what it was.’ (W13.94-96.) Betty described the time ‘wasted’ between her surgery and her first chemotherapy treatment. ‘We just felt that it was a complete waste of time. We weren’t – we weren’t getting anywhere. We were stationary and we still didn't know what was, you know, ahead of us.’ (W2.1346-1351.)

Women ‘lost’ time during surgery. This was experienced as ‘uncanny’ time. Leah could barely remember the week she was hospitalised with a bowel obstruction. ‘I think this whole time in the hospital, at that time I was so unaware of what was going on.’ (W12.765-767.) Audrey also lost time when she was very ill. ‘And for three days I can’t remember anything. Like wouldn’t have a clue.’ (W1.166.) Ella described the strange feeling of losing her sense of self when she lost consciousness. ‘One minute you’re so conscious and so aware and the next, you know, that’s it. You know, you have absolutely no – you just seem to go so quickly, you know? ...that was a weird feeling.’ (W5.404-406.) There was a sense of living in ‘suspended time’. Audrey explained, ‘it’s just interrupted your whole life.’ (W1.690.)

The realities of ovarian cancer meant that women learned to live with ‘uncertain’ time. Time spent ‘waiting’ for results was experienced as an anxiety-ridden dragging time. Cathy described her anxious wait for results from her surgery. ‘Having to wait for a week to get the outcome for pathology results didn't help much either.’ (W3.para.6.) Nancy waited to be given the ‘all clear’ (W14.55) after chemotherapy finished. ‘So I ended up having to wait another week and having some more tests, so
that was a fairly untidy week.’ (W14.62-63.) Hilda explained how she lived with uncertainty on a daily basis. ‘Here I am, back [at home], and taking each day as it comes because you just never know what’s going to crop up!’ (W8.1364-1365.) She had learned not to rely on plans made because nothing was certain in regards to her treatment. For example, she sometimes had to cancel flights, transport and accommodation at the last minute, as her neutrophils were too low for chemotherapy. ‘I was all packed for flying to [city] today but now I will stay home ‘til next Tuesday. All subsequent cycles will also be one week later.’ (W8.1115-1117.)

**Experiencing uncanny and uncertain spatiality**

The usual routines of women’s lives disappeared as they were swept into an often unfamiliar world of medicine, hospitals and the health care system. Many women had never experienced serious illness and were unsure what to expect. Being ‘illness novices’ heightened their sense of vulnerability and uncertainty. Ida was anxious and unsure about traveling interstate to an unknown hospital for surgery. ‘Because it’s the unknown. I did not know where I was going, how I was going to come out of it.’ (W9.31-33.) Betty struggled to navigate the foreign world of the health system. ‘This is all very new.’ (W2.110.) She had no idea what to expect and was uncertain how to obtain the care she wanted. Hilda had no prior illness experience: ‘I’ve never had a general anaesthetic or epidural before, nor any operation or serious illness that I can remember, so this is all very new.’ (W8.192-193.)

Many women felt ill at ease and out of place in their new world of strange terms and unfamiliar procedures. They were ‘not-at-home’ in the hospital. Hilda commented, ‘the hospital is another world and has its own language. It reminds me of a massive insect colony. There are so many and varied different jobs for specialised teams of workers’. (W8.383-384.) Joan described a high dependency unit as an alien place where she felt ill at ease. ‘Like to me, I was in this other, altered – universe. I never saw the sky or the – the outside or – and you’re getting monitored all the time and it’s very, very weird’. (W10.143-145.) Audrey felt caged in the hospital setting. She ‘couldn’t bear’ (W1.538) being in a room without windows for her chemotherapy. ‘I found it very depressing.’ (W1.533.) She organised to leave hospital early after
surgery because she ‘couldn't cope with being locked up down there’. When she finally reached her home, ‘it was just like I’d been released from prison or something.’ Women were confronted by the reality of illness and death. Kate explained: ‘But they, um, there was someone dying in the corner and you know, really, I’m thinking “Oh bloody hell!”’, you know?’ (W11.476-477.)

The above quotations reflect women’s experiences of the unique nature of hospitals as being ‘uncanny’. Such places can be considered as both an objective space and a subjective space. van Manen (1990) suggested that objective space is that which can be measured – for example, a hospital building. In contrast, lived space is “felt space” (p.102), that is, the subjective way we feel within a space. Merleau-Ponty (2002) suggested that we “belong” to time and space, and that “my body combines with them and includes them” (p.162). Cresswell (2004) suggested that lived spaces are meaningful to people. A hospital is a building that becomes a ‘lived space’ once it has meaning for a person. Little and colleagues (2001) stated that cancer patients learn to operate within a “medical framework” which has its “own geography”, its own terminology, and its own views of time and space (p.29). Similarly, Lupton (2012) described hospitals as different worlds, where patients are rendered vulnerable and where they must conform to unfamiliar and/or unknown rules and practices. Lupton suggested that hospitals are institutions like prisons where inmates have little or no control over personal space and boundaries. One woman’s description of a ward round illustrates the vulnerability and lack of control to which Lupton referred. For her, the expectation that she would passively lay on her bed, exposing her body, whilst total strangers examined her body and discussed her disease was more than she could tolerate. She described:

   Well, it was like you’d undo the door and these 10 people would all march in.
   And that might be fine for someone who didn't give a hoot, but for me it was something I couldn't handle... and these people are all just there looking at you and poking and pushing and you're thinking, [whispers] “Go away”.

The ward rounds – a ‘routine’ aspect of the health care system - invaded this woman’s lived body, personal and hospital space and contributed to her sense of vulnerability and lack of control.
Lived home space was altered for some women as their feelings towards their own home changed. Some women described no longer feeling ‘at-home’ in their home space, which felt ‘uncanny’. For example, Kate normally lived alone. However, during chemotherapy she lived with her mother as she felt a constant level of uncertainty and anxiety regarding her health and didn't want to be alone. “Cause sometimes it would make me nervous, because if something happened in the night, you know, it was – once you’re on chemo you’re never 100 percent sure if something bad is not going to happen in the night.’ (W11.520-523.) Her home was no longer her ‘safe space’. Audrey could no longer sleep at home in the dark. ‘When I came home from the hospital I was frightened of the dark. Couldn’t bear to be in the dark... And I’ve never been frightened of it... Yeah, I’m not frightened of the dark. I was terrified of it.’ (W1.316-322.) In contrast, home became the only space where Mary felt safe. She described her struggles to leave her house. ‘I didn't feel safe away from the house. I didn't – I wasn't very trusting and I’m still not. Even less then, and I felt more secure and more safe just in my own little patch.’ (W13.218-220.) For Mary, home was the only place where she felt ‘at-home’.

Experiencing uncanny corporeality

The ‘lived body’ can be understood as being central to our experience of the world. O’Donohue (2000) stated one’s body “is the house of belonging; it is where we live” (p.57). Merleau-Ponty (2002) suggested our bodies are “our anchorage” (p.167) in our world. For him, our bodies are the means by which we experience our world. They enable us to “ ‘be at home’ in [our] world, ‘understand it’ and find significance in it” (p.275). In my study, women experienced their bodies as uncanny. Uncanny corporeality impacted upon women’s ability to feel ‘at-home’, to understand and to find significance in their uncertain world.

Treatment transformed the way each woman lived in the world. As their bodies intruded upon women’s notice, were no longer taken-for-granted and were ‘treated’ by doctors, women’s relationships with their bodies altered. Women learnt to regard their bodies differently – both objectively and subjectively. Donna described treatments as if they were performed on someone else. ‘They drained the fluid.'
Drained the fluid and ah – that was interesting. You see I found everything interesting!’ (W4.390-391.) Hilda reflected, ‘Sometimes this whole thing seems unreal, like a topsy-turvy dream. For example, I find it so weird to be struggling to eat.’ (W8.540-541.) Mary described the cancer as an ‘unwelcome intruder’ (W13 PARA.9) into her life. Audrey spoke of her body going ‘haywire’ (W1.2641) and being ‘out of whack’, (W1.393) whilst Ella described her post-operative body as ‘just unreal’. (W5.243.)

Frank (1991) suggested that in cancer, patients ‘hand' their body over to HCPs, whose objectifying way of understanding the patient’s body is radically different from the patient’s normal way of being. The difference in understanding and viewing the body means that patients feel ‘split’ from their diseased body. Zaner (1988) stated, “illness itself is alienating” (p.81). Toombs (1992) suggested that this sense of “bodily alienation”, central to illness experiences, results in feelings of bodily “uncanniness” (p.100). In my study, women spoke both subjectively and objectively about their body. It was as if they experienced a sense of alienation from their body which became a ‘thing’ - regarded as being attached to them, but from which they also felt a sense of detachment. They experienced their ‘uncanny’ bodies with ambiguity, both subjectively and as objective ‘Other’. Merleau-Ponty (2002) suggested that we can view our bodies in two ways – both as “my body for me and my body for others” and that these ambiguous views “co-exist” (p.122) in our world. However, as we experience our bodies differently from other ‘objects’ that can be removed from our presence, we cannot view our bodies exclusively as an object. Therefore, we cannot see our bodies as others do – our experience of ourselves will be different from their experience of us. My experience of my body is different from my experience of the bodies of others because I ‘live’ - inhabit - my body, which is the centre of my world (Matthews 2006; Merleau-Ponty 2002: Weiss 2008). In my study, women spoke of their body with ambiguity – as both subject and as a form of objective ‘Other’.

**Lived post-surgery bodies**

Women’s post-surgery bodies were experienced as uncanny as they were disturbingly different from previously. Joan listed body parts she had lost: ‘all my bits; you know,
the ovaries and the uterus and fallopian tubes... um, my omentum.’ (W10.113-116.)

Hilda listed an objective post-operative ‘stock take’ of her body:

*What I’ve lost: uterus, ovaries, fallopian tubes, a bit of diaphragm, a bit of bowel, and 100% of the cancer. What I’ve kept: liver, spleen, everything else. What I’ve gained: an intra-peritoneal (IP) port, which is a plastic plughole in my midriff for applying chemo drugs later.* (W8.482-486.)

The immensity of women’s surgery and the resulting changes to their bodies contributed to ambiguous feelings of their body being ‘Other’. Women’s familiar bodies had been irrevocably altered by surgery. Ella stated: *‘You had your tummy opened from your rib cage down to your pubic area.’* (W5.636-637.) Ida described her surgery: *‘I think they pulled everything out, searched all through it and then threw me back together.’* (W9.398-399.) Surgical scars altered the way women felt about themselves. Leah felt disfigured by her scar. *‘It was a deep cut. Oh, and it was awful, and, um – and I almost couldn’t look at it. It was just, it was awful. In my tummy. And it was – it looked terrible.’* (W12.459-462.) Mary’s children called her scars her *‘train tracks.’* (W13.para.3.) Audrey struggled to describe what she experienced as the mutilated appearance of her post-surgery abdomen:

*And when they did [the surgery], of course my belly button now is way down here. [Indicated on abdomen]. Because they pull it – ‘cause they cut it out as a square and sort of – where they join it at the sides, it’s got, sort of, like it’s been gathered together. Yes, puckered up. And of course, my belly button’s down here, which makes me feel a bit self-conscious too, yeah. Sort of think, “Oh, I don't want anyone to see that”.* (W1.1332-1343.)

In my study, surgical scars changed the way women viewed their bodies and thus their self. Their bodies served to remind them of the uncertainty of their life by providing tangible evidence of the uncertainty of their past, present and future. Literature suggests that the way we think and feel about ourselves influences our sense of self and our identity (Little et al 2001; Lupton 2012) to which our bodily identity is intricately linked (Elson 2004; Merleau-Ponty 2002; Sacks 1998). Similarly, the removal of reproductive organs may have a deleterious impact upon women’s self-image (Elson 2004; Sekse et al 2013; Torrens 2006). Audrey was
uncertain about her ‘womanhood’ after surgery. She described, ‘I thought “I’m not a woman anymore. It’s all gone”.’ (W1.2133-2135.) Kate explained, ‘I’m very aware of my [menstrual] cycle. But I have no cycle now’. (W11.1348.) Their comments reflected their altered and diminished self-image as women, which resulted from their radical surgery.

Women’s bodies were experienced as uncontrollable – they behaved independently of the women who were powerless to help themselves. Hilda ‘felt trapped in a vicious cycle’ [of pain and nausea]. (W8.499-500.) Ella described ‘my legs and thighs swelled up to like the Michelin Man. It was just unreal.’ (W5.242-243.) Leah described: ‘I had this huge bulk of tissue all around me.’ (W12.395.) Ella endured post-operative nausea for five days: ‘I was like, you know, “Just let me die in peace”.’ (W5.214.) When asked what stood out for her about her entire experience she replied: ‘The days after the operation, just, yeah, they’re really – I think about them and think “Oh no”. It sends a shiver down my spine.’ (W5.420-421.) Audrey felt humiliated by her powerlessness to care for her body. ‘I mean [husband] even had to cut my toe nails. How degrading is that?’ (W1.3202-3203.) One woman remembered walking to the bathroom ‘and I just weed everywhere on the floor’. Van Manen (1998, 2014) described how we might experience our body objectively when our body behaves unusually. For example when ill, we might begin to focus on aspects of our body that are swollen or in pain. This break in the “unity of our existence in the world” leads to a sense of “un-easiness” (2014, p.329), that is uncanniness. Svenaeus (2009) suggested that a sense of corporeal alienation in illness reflects our awareness of the independent nature of our bodies, that is, because our bodies behave unpredictably, they are experienced as being ‘uncanny’. In my study, women’s bodies were experienced as being unpredictable. They were weird - alien - and out of women’s control. Women experienced their bodies as ‘Other’. As Leah said, ‘I just felt so, unlike me’. (W12.527.)

Lived chemotherapy bodies

In this study, 14 out of 15 women underwent chemotherapy, which further upset the equilibrium of women’s worlds, already impacted by surgery. Stacey (1997) described chemotherapy for her ovarian cancer as “trauma… it was like paddling in
shallow waters and being hit by a tidal wave” (p.185). Similarly, women in my study experienced chemotherapy treatments as a series of assaults that were typically administered in cycles of three weeks. Once women started to regain some sense of strength and self after each cycle of treatment, they were ‘hit’ by the next cycle. Ella explained: ‘but, then three weeks and another lot of chemo. Go back to square one sort of thing.’ (W5.310-311.) Ida said that whilst she was fine on the days she actually had chemotherapy, it was afterwards that she would ‘Go down, you go down in a heap.’ (W9.911.) Florence explained: ‘Well as soon as I get – feel a bit better I get hit on the head again with this chemo.’ (W6.386.)

Women’s bodies became (more) unpredictable and unfamiliar as they developed strange side effects to chemotherapy. All women who had chemotherapy reported having to deal with unwanted side effects. The women no longer felt ‘at home’ within their bodies and their sense of alienation, of their body as ‘Other’, increased with their chemotherapy experience. At times the illness experience seemed unreal – almost as if it was happening to someone else. For example, Cathy found it hard to believe she had cancer: ‘it seemed surreal that there was something seriously wrong with me’. (W3.para.3.) Olive explained, ‘if you want to know the experience, it’s like, um, it’s happening to someone else. So that out of body, kind of, it’s not really happening.’ (W15.135-136.) Audrey graphically described feeling like she was outside of her body:

You felt like you were just sitting there watching them work on someone else. “That’s not me. They can’t be doing that to me.”.... It was just like they were doing that to someone else and the, you sort of had to pull yourself back into line and think “No, no, no, no. They’re doing this to me”, you know.

(W1.3040-3047.)

She continued:

Oh, I was up on the ceiling, I was merrily watching them and it was – it was very horrifying. ... And it was like I was there watching them. Do things to me. It was a bit frightening really. It was like I was off to heaven you know.

(W1.3064-3070.)

These comments reflect women’s sense of alienation from their reality. They described a sense of watching their bodies from the sidelines, as onlookers. Frank
(1991) described a similar feeling of alienation from his corporeal reality. He stated that as a cancer patient, he lost his sense of self and became a “spectator to [his] own drama” (p.56). Olive described, ‘that whole period goes in a blur because it’s happening to someone else. It’s not you there. Out of body experience.’ (W15.519-524.) She added, ‘It’s someone else there. Awful.’ (W15.532-534.)

Unfamiliar side effects of treatment changed the way the women existed in their world, heightening women’s sense of ‘uncanniness’ and alienation from their self. Chemotherapy-induced peripheral neuropathy prompted Ida to consider suicide. ‘I could have walked outside here and thrown myself under a bus or car.’ (W9.87-88.) She explained, ‘It just drove me mad... I couldn’t handle that pain.’ (W9.308-309.)

Gwen’s feet were affected. ‘The soles of my feet get very sort of burning, sore.’ (W7.57-58.) Ella’s life was consumed by fatigue. ‘It just sort of drains your whole life out of you, you know. I could hardly get out off the couch.’ (W5.294-295.) For some women, menopause occurred almost immediately after surgery and added to their burden of disease. Mary described ‘It was like I’d stepped into a shower.’ (W13.390.) Body image was further destroyed by unintended weight loss as the women struggled to maintain some control in their lives. Leah stated,

‘I looked – just looked skin and bone. I looked terrible. Um, anyway – and I – I was. And I couldn’t - I could almost not bear to look at myself because I looked so unwell and I – I looked like pictures of very malnourished – a very malnourished person.’ (W12.1163-1166.)

Some women became anxious and depressed, as chemotherapy seemed to overtake their lives. Florence explained: ‘I felt quite, at times, agitated, and a little bit depressed, because, um, I want to do things but I feel I get really tired?’ (W6.387-388.) Kate was depressed by thoughts of her chemotherapy drugs: ‘the day after chemotherapy I was a little bit depressed? Thinking I felt sort of poisoned? And sort of a bit dirtied?’ (W11.363-364.) Ida described how during treatment, she felt she lived ‘in a very black forest ... I [couldn’t] see any light at all.’ (W9.56-57.) She said, ‘I just felt defeated and it really started to take over.’ (W9.90-91.) Donna described:

*People have got a lot of bad thoughts about chemo but it’s the after – the days after you have the chemo that you suffer a little bit. You... you get very*
depressed. I get depressed. Don't want to eat. All I want to do – all I did was lie down on the couch for a couple of days. (W4.923-929.)

The way that we experience our body has implications for our Being-in-the-world. Merleau-Ponty (2002) stated, “the body is the vehicle of being in the world” (p.94) and is central – pivotal – to our perception of the world. Literature has suggested that illness influences the way we experience our bodies (Benner & Wrubel 1989; Carel 2008; Svenaeus 2009). In illness “bodily events become the events of the day” (Merleau-Ponty 2002, p.98). For example, unfamiliar corporeal symptoms may be perceived as being strange and uncontrollable and may influence our experience of our world. Heidegger (2008) suggested feelings of unfamiliarity lead to feelings of ‘not-being-at-home-with-oneself’. In my study, women ‘lived’ their bodies as being unfamiliar and uncontrollable, further prompting a sense of ‘uncanniness’. As Ella stated, ‘It’s just a strange feeling, like what it does to you.’ (W5.330.)

**Being hairless**

The majority of women spoke about hair loss. Alopecia was described as the worst corporeal feature of their ovarian cancer illness and was perhaps the most constant reminder of the unhomelike and uncertain world in which the women now lived. Although chemotherapy-induced alopecia is well recognised in literature as typically being a traumatic experience (Hansen 2007; Lemieux, Maunsell & Provencher 2008; Power & Condon 2008; Trueb 2009), little is known about the experience of alopecia for women with ovarian cancer (Jayde et al 2013).

Women in my study associated alopecia with a shifting sense of self. It emphasised their sense of no longer ‘being-at-home’ within themselves. Kate described ‘*Um, I am dealing with the whole loss of my former self thing.*’ (W11.797.) Audrey felt diminished by her alopecia. ‘So I was thinking: “Well they take all your female bits away and then you lose your hair. There’s not much left is there?”’ (W1.945-946.) Hilda stated: ‘*This disease definitely doesn’t fit with my self image!*’ (W8.1491.) Audrey lost the long hair that she had grown since childhood. ‘*I mean, I knew I had cancer. I knew I could die if things went wrong, and blah, blah, blah. But - my hair,*
my hair's gone! ‘Cause it had always – I’ve had it long since I was a child.’ (W1.1004-1006.) Her alopecia was ‘devastating... well for me, it was more devastating than having cancer, was the fact that I lost my hair.’ (W1.3005-3006.) Alopecia had destroyed a fundamental aspect of her identity and she wasn’t sure who she was anymore. Florence found alopecia ‘quite distressing.’ (W6.132.) Ida described ‘I think that was the hardest thing, of trying to take the word cancer in, was losing my hair? I mean, we all as females always take that our hair is our thing.’ (W9.92-94.) The association between a shifting ‘sense of self’ and alopecia was also evident in a seminal report which examined the experience of alopecia for women with breast cancer. Freedman (1994) suggested that hair “can be considered a metaphor for a woman’s identity and sense of herself” (p.334). Loss of hair, therefore, can be conceptualised as heralding a “loss of the self” (p.336). In my study, women experienced alopecia as devastating evidence of their uncanny state.

Women in my study struggled to accept their altered appearance. When they looked in a mirror, they saw an unfamiliar face – one that was ‘alien’ yet familiar. Their faces seemed unnatural, strange, and women felt uncomfortable looking at themselves. The person who was reflected in their mirror seemed uncannily disconnected from their usual self. Leah stated: ‘I just found it was really hard to look at my face.’ (W12.1216-1217.) Olive explained: ‘because I looked like an alien. I didn't look like myself. It was really traumatic.’ (W15.480.) Hilda said: ‘It is a shock to see myself looking like a “derro” ’. (W8.570-571.) Donna said: ‘I look so horrible, you know.’ (W4.199.) Leah couldn't bear to see herself without hair. ‘So I just wore a cap. And um, I did it pretty continuously.’ (W12.1224-1225.) Olive described: ‘No hair. No eyelashes, no hair on your arms or your legs. No fanny hair, no hair anywhere. You’re just this white, white moon face.’ (W15.514-517.) Mary described herself as looking like ‘ “Shrek” ’ (W13.para.4.) ‘I don't hardly have any eyebrows’ said Gwen. (W7.144.) Loss of eyebrows reinforced women’s growing sense of identity as a cancer patient. Nancy explained:

I think it’s that, it was at that point that I thought, “Yes, now I look like a, I look like a cancer patient”. Um, I think that there’s a certain level of similarity in appearance between lots of people when there are no eyelashes and no eyebrows and no hair. (W14.315-316.)
Merleau-Ponty (2002) stated our body “is the mirror of our being” (p.198). In other words, my body is “the self I understand to be me” (Clark 2011, p.62). In my study, women understood the uncanniness of their alopecia to mirror their uncanny self. Their hairloss signified their ruptured self and world and emphasised the uncertainty of their new life with ovarian cancer.

Feelings of umheimlichkeit were intensified by women’s inability to control the loss of their ‘crowning glory’. Olive described ‘huge, thick things of your hair coming out.’ (W15.495.) Ida remembered: ‘But I was standing in the shower there, and I mean, you’ve got it all coming out in lumps. The water wouldn’t go down through the hole because my hair had just all fallen out after the chemo.’ (W9.94-96.) Being forewarned didn't prepare Ida for alopecia. ‘They told me it would. But telling you and it coming to reality is two different things. Two different things. You expect it, but it’s hard when it’s – yeah, your handfuls are just, yeah.’ (W9.857-860.) Women were unsure how to cope with the practicalities of alopecia. Leah described the loss of her hair. ‘Oh it was – yes, it was terrible – it was awful. Yeah, kind of felt if you moved – and so I just knew – I didn’t comb my hair, I didn’t brush – touch my hair. It just fell as it would.’ (W12.1156-1158.) Hair loss was experienced as an alien and distressing process over which the women had no control, and which at the same time, affected them intimately.

Merleau-Ponty (2002) suggested that our bodies are our “means of communication” with our world (p.106). Women in my study spoke of how their hair communicated their illness to their self. For the women, alopecia represented irrefutable, tangible evidence of their disease and served as a reminder of the uncertainty of their future. The uncanniness of their alopecia confronted them with their “Being-towards-death” (Heidegger 2008 p.236/279; Warsop 2011). Donna explained:

    But when my hair started to fall out, that’s when it struck me. That’s when I got upset. I went to that – the mirror one day and I was combing my hair and I looked at the comb, and there were masses of hair there. And I thought, “Oh my gosh.” And I cried that day. I cried. (W4.89-94.)

Ida described: ‘Losing my hair. I think that was the hardest part. Cancer, the word cancer, yes, you can accept, but it was losing my hair. I took that harder than the
Alopecia was a tangible reminder of the prognosis associated with ovarian cancer and thus the uncertainty of their life. Donna felt she resembled her long-deceased father. ‘But er, it was sad when I – it was awful – actually it’s awful, looking – I still look in the mirror and I think, “Oh golly”, you know. “Poor dad.”’ Her appearance reminded her of his painful death from cancer. Some women, like Gwen were keeping their wig ‘just in case’ their cancer returned and they needed further chemotherapy. Literature has noted that alopecia acts like a ‘reality check’ that forces individuals to acknowledge the reality of their cancer and thus their mortality (Freedman 1994; Hilton, Hunt, Emslie, Salinas & Ziebland 2008; Rosman 2004; Sun et al 2005). In my study, hair loss presented women with confirmation that they did, indeed, have cancer and could die from the disease.

Alopecia also challenged women in their social relations. Part of being an embodied person is seeing oneself reflected in the eyes of others. Women described how alopecia emphasised feelings of ‘not-being-at-home’ with themselves in interactions with others. For example, Audrey described how acquaintances no longer recognised her without her long hair. 

*People didn’t know who I was. They’d walked past me and then come back. And I used to think: “Oh God, was my hair that big a piece of me?” You know? They’d walk – they’d walk past me and then they’d come back and they’d say: “It is [Audrey] isn’t it?” And I’d say “Yeah”. You know, your hair is more important than what you think it is.* (W1.2077-2085.)

Mary dreaded going out in public because she struggled to cope with comments from strangers about her alopecia. She could never know what people might say.

*You think you just can’t go out another time and… you can’t face the fact that you just – sometimes people can – people can be pretty cruel, you know. You’d be out and they’d make comments. Little, little kids don't understand, they’re not sure what’s going on. “Oh mummy, why is that lady - hasn’t got any hair?”* (W13.796-799.)

She added: *‘I’d go home and cry but I wouldn't let them see me get upset.’* (W13.823.)
Heidegger (2008) used the term ‘the “they”’ (p.164) to refer to people in everyday society. This neutral, anonymous person or group is characterised by “averageness” (p.164), which determines how one should ‘be’ or ‘act’ to blend into society. The “averageness” enables society as a whole to keep “watch over everything exceptional that thrusts itself to the fore” (p.165). In this way, “the ‘they’ prescribes one’s state-of-mind and determines what and how one ‘sees’” (p.213). Thus, Heidegger argued that society dictates “the range of the familiar, the attainable, the respectable – that which is fitting and proper” (p.239). For example, the ‘average’ woman in Australian society is ‘expected’ to have hair on her head. Going out in public with obvious hair loss ‘sets apart’ women from others in society. Society then ‘sees’ the women as being ‘different’ and noticeable. In my study, alopecia did not conform to Australian society’s norms and ideals and women accordingly felt out of place and uncanny in their social world. Their previous, transparent, sense of comfort at Being-in-the-world-with-others changed as alopecia adversely impacted social interactions. Mary described going out to dinner. ‘I was like the white elephant in the room. Everybody saw it but didn’t want to say anything.’ (W13.741-742.) She added,

And then we had to sit down for dinner and everybody’s kind of looking everywhere but at me like this [demonstrated] and in the end I said – and the air conditioning wasn’t very cold, I said “It’s really cold in here, my head is freezing.” And people looked at me, I had a smile on my face and they started laughing. And then they started asking me questions. (W13.755-759.)

Carel (2008) suggested a visible sign of illness (such as alopecia) typically impacts upon interactions with others because they are uncertain how to handle the ‘differentness’ of the ill person. Thus, their visible sign of illness “often becomes the elephant in the room” (p.50). In my study, the ‘elephant in the room’ of women’s alopecia also impacted family members. For example, Nancy’s daughter was embarrassed by her mother’s appearance. ‘She said, “You can”, you know, “You can just stay in the car mum”. I said “Why?” She said “Because, because it looks a bit funny with no hair.” ’ (W14.174-176.)

Public pressure to conform to societal ideals of beauty meant that women in my study sought to camouflage their alopecia with wigs, hats or scarves. Gwen stated ‘I wear
[the wig] around home quite a bit. Late in the afternoon, when I think there’s no more visitors going to call on me, I put the ah – I put the scarf on.’ (W7.157-159.) Hilda’s occupational therapist ‘said to “Wear the wig when flying” because security will ask me to take off any hat or scarf to check for bombs under there.’ (W8.952-953.) Women also camouflaged their baldness for their family’s sake. Joan covered her head to protect her children from feelings of ‘standing out’. ‘And I wouldn't go to the school to pick them up without something on my head. You know, I wouldn't do that to them; just ‘cause, you know, how kids are self conscious.’ (W10.747-749.) Joan covered her head at home as her family was uncomfortable with her alopecia. ‘They didn't like that – how confronting that was, because it shrieks cancer.’ (W10.745.)

These comments can be interpreted in view of suggestions in literature that chemotherapy-induced alopecia declares one has cancer to the world (Frank 1991; Rosman 2004; Trueb 2009) and deprives cancer patients of their privacy (Harcourt & Frith 2008; Trueb 2009). Frank (1991) wrote “one wears cancer” (p.92). Carel (2008) suggested visible signs of illness (such as alopecia) expose the illness to the gaze of others. “Intimate details become the first thing a stranger sees about you” (p.58). It can change the way one is perceived by others (Carel 2008). Rosman (2004) suggested that wigs and hats are typically worn to hide the “visible stigma” (p.337) of cancer-related alopecia. Women in my study described trying to disguise their baldness in order to hide their disease, to ‘blend in’ to society and to protect their family’s sensitivity to their appearance. Their efforts can be interpreted as women deliberately seeking to fit in with “the ‘they’” (Heidegger 2008, p.127/164) in order to feel less conspicuous and more ‘at-home’ in their world.

Experiencing (un)canny relationality

Women’s Being-in-the-world was altered by their ovarian cancer experience. Shifting experiences of lived time, space and bodies contributed to women’s feelings of ‘not being myself’ – that is, feeling ‘unhomelike’ or ‘uncanny’. Women’s lived relationships with their self and with others also altered as a result of their ovarian cancer experience. For example, women spoke of boarding an ‘emotional
rollercoaster’ from the moment of diagnosis. Kate stated ‘So that just started the roller coaster from then on.’ (W11.114.) A combination of existential loneliness with an overall sense of vulnerability contributed to women’s sense of feeling out of control and out-of-place in their new uncertain life with ovarian cancer. Mary said she felt she had ‘embarked on the biggest and longest rollercoaster of your emotional life, and at times it feels as if you can never get off.’ (W13.para.3.)

Some women tried to reduce some of the uncertainty in their uncanny world by ‘taking on’ the role of cancer patient. In this way, they attempted to assimilate the ovarian cancer experience into their sense of self. They described using various means to gain some sense of control over the cancer that was dominating their lives. For example, women’s use of complementary therapies can be interpreted as proactive efforts to lessen illness-related uncertainty. Audrey took ‘a heap of vitamins’ (W1.1592) and Olive ‘learnt a lot of meditation skills.’ (W15.242.) Their rationale was explained by Joan, who said, ‘at least I’m doing something.’ (W10.685.)

Kate described how she tried to adapt to life as a cancer patient.

So you go: “Oh, this is what I do now”. Not: “Oh poor me I haven’t – I’m no longer able to work”. You can go: “Oh, my job is to be a cancer patient now. So I can do this, this and this.” It’s got, you know, a duty statement, that you’ve got to walk around with a scarf on and, you know, go to support groups, and you know, get pity and sorrow from your friends and family. And um, and you just fulfill those duties. (W11.1314-1318.)

Relationality and health care professionals

Lived relationships with HCPs had the potential to either reduce or increase women’s feelings of uncanniness and uncertainty. Health care professionals embodied women’s hope that they would survive their disease. There was a sense in women’s interviews of HCPs being ‘gatekeepers’ to women’s futures and that HCPs held the key to women’s survival from ovarian cancer. Women’s fear of succumbing to their disease triggered intense feelings of anxiety and uncertainty. Combined with lack of control over the outcome of their disease women’s fear, anxiety and uncertainty led to feelings of vulnerability and exposure within the health care system. Ella explained,
You’ve got - you put your life in, in the doctor’s hands, don’t you? You know it’s not – it’s out of your – you can’t control anything, so you sort of have to, um, put all your faith in the medical profession. Haven’t you, really? And, er, just, er. And, hope for the best. You know, you’re powerless in the whole situation. So you have to, you just become another statistic – you’ve got cancer and you have to, er, put the faith in them really. (W5.535-543.)

Hilda, who had ‘great confidence’ (W8.111) in her HCPs, demonstrated the potential for HCPs to alleviate women’s feelings of uncertainty and powerlessness. She felt ‘glad to relax and feel others have everything under control.’ (W8.109-110.)

Women’s perceptions of HCP competence were fundamental to women’s feelings of confidence in their care, as they provided reassurance that they were ‘in safe hands’. Betty felt ‘in the right hands.’ (W2.1500-1501.) Similarly, Joan commented, ‘once I was in her hands, I felt really, um, that I was in very capable hands.’ (W10.92-93.)

Trust that their HCPs were knowledgeable, competent and skilled provided women with some sense of certainty, stability and security in their uncertain and unfamiliar world. It was as if competent HCPs offered women a ‘lifeline’ (Joan-W10.898.)

Cathy valued ‘[her doctor’s] quick and caring action.’ (W3.para.3.) Similarly, Joan appreciated ‘incredibly capable and competent’ (W10.169-170) ward staff. Skilled staff and a well functioning health system provided women with reassurance that they were on a definite and defined pathway towards (their hope of) regained health. Joan explained, ‘everything just felt right, once I got to the ward.’ (W10.170.)

Those interactions with HCPs, which women described as being ‘positive’, provided women with a sense of being ‘seen’ and cared about within the unfamiliar health care system. Women felt comforted and reassured when they felt that HCPs had their best interests at heart. The resulting sense of trust and security offered women some certainty amidst the uncertainty and uncanniness now inherent in their world. It helped them to feel more ‘at-home’ within the health system. For instance, Hilda explained, ‘these good consultations were the foundation for my feelings of safety and trust, which is all anyone can hope for at a ‘nightmare’ time of dealing with cancer.’ (W8.email.) Florence was comforted by a HCP who ‘kept praying and checking up on me’. (W6.696.) Gwen was reassured by the knowledge that her doctor would be
‘watching out’ for her. She explained, ‘[Doctor] said “I’ll be keeping a close eye on you from now on” and I said “Yeah, that’s alright”… yeah, so [doctor] ’ll watch out for me.’ (W7.327-329.) Stajduhar, Thorne, McGuiness and Kim-Sing (2010) suggested that cancer patients appreciate HCPs demonstrating personalised caring towards them – leading to a sense of what Thorne et al (2005) described as “being known” (p.890) by the HCPs. In my study, demonstrations of individualised HCP care reassured women that their HCPs were ‘looking out for them’ and that they were not ‘just a number’ in the health system, but were recognised by HCPs as individuals who mattered. Clear communication by HCPs, (for example, providing information and acknowledging women’s concerns), helped allay some of the women’s anxieties and uncertainties. Comprehensive explanations reduced Nancy’s uncertainties by helping her to ‘know exactly what to expect.’ (W14.473-474.) Hilda appreciated ‘the doctor’s patience and attention devoted to explaining absolutely everything and answering questions. They clearly get it about minimising fear of the unknown and foreseeing possible freak-out factors that can be eliminated.’ (W8.180-182.)

Adversely experienced interactions with HCPs added to women’s sense of uncanniness and uncertainty by intensifying women’s feelings of vulnerability and powerlessness. Prior to diagnosis, Mary sought medical help for her intuitive sense that something was wrong with her body. The dismissal of her concerns by several HCPs added to her sense of ‘uncanniness’ and led to her doubting her own reality. ‘I felt like there was something wrong, but nobody thought that there was. And so I felt like I was turning into a bit of a hypochondriac.’ (W13.402-403.) Lack of confidence in the competence of some HCPs added to the uncertainties and fears already being experienced by women in my study. Kate ‘didn’t trust’ (W11.308) HCPs who seemed inexperienced. Betty had no confidence in the expertise of her oncologist. She explained, ‘we’ve had – [big deep breath] we think, a lot of trouble, [big sigh] seeing [doctor] (W2.212-213.) ‘It um, ah, seems to have gone wrong from there on.’ (W2.221.) She added: ‘The more it went on, the more it got that I wasn’t sure that I wanted to go back to [doctor] at all.’ (W2.265-266.) Her lack of confidence in her doctor’s skill and knowledge added to the uncertainties already associated with her very advanced ovarian cancer.
Health care professionals in some situations embodied hope of survival for the women. Health care, when viewed negatively, intensified women’s feelings of ovarian cancer-related uncertainty and vulnerability. In contrast, positively perceived health care acted as a source of reference, an anchor of reassurance and security amidst women’s vulnerability and the uncertainty of their illness. It helped moor them in their uncanny world.

**Being supported - finding solace from others**

The importance of support for the women was evident throughout their interviews. At times there was a sense of ambiguity about the support women received from others. In the previous chapter, women’s feelings of existential loneliness were described as an intrinsic ontological feature of their illness experience. Their loneliness was inextricably linked to their possible ovarian cancer-related death and their subsequent realisation of Being-alone-in-the-world. Existential loneliness was heightened by feelings of not being able to share their experience with others. However, women in my study also spoke about finding some solace and comfort through supportive relationships (although support was not always received from those people women had expected to provide it). Although receipt of support could not alleviate the fundamental nature of women’s existential loneliness, it did offer women some sense of ‘home-coming’ – that is, some respite from their world of uncertainty, fear and uncanniness.

Women gained comfort and reassurance from others who were emotionally present for them. This can be conceptualised as others ‘being there’ for the women. Women interpreted other people ‘being there’ for them as meaning that others cared about them. ‘Being there’ meant that women felt they shared their journey with others. Emotional support provided women with a sense of belonging and Being-at-home. For Olive it was ‘kind of a linchpin’ (W15.145) which helped her through her treatments. For Hilda it was ‘the hand holding I’ve needed to get me through this!!’ (W8.512-513.) She added: ‘The love and support of family and friends and the wonderful unforgettable sharing with those closest to me ameliorates the painful time.’ (W8.1060-1062.) Cathy wrote: ‘my husband was with me all the way... I cannot
imagine what it would be like for someone to go through this diagnosis and surgery experience, without someone holding their hand.’ (W3.para.4.) Religion provided Florence with a framework of meaning and emotional support. It helped her by ‘just psychologically knowing that there is someone out there.’ (W6.529.) Family members often motivated women to achieve their aim of completing recommended treatments. Ella explained: ‘And you know, it would probably be family support, I would say, would be my main – reason for getting - you know, trying to get better.’ (W5.492-493.) Audrey’s husband’s support enabled her to complete her chemotherapy regime. ‘And I said to [husband], “I don't know if I can do the sixth one. I just don't know if I can put myself through that again”. And he said: “I’ll be with you, you know”.’ (W1.672-675.) She added: ‘If [husband] hadn’t been with me I don’t think I would have done it.’ (W1.676-677.)

The concept of ‘meaning’ in one’s life facilitated interpretation of the importance of support to the women in this study. Ovarian cancer confronted the women with the reality of their potentially dying from the disease – that is, the reality of “Being-towards-death” (Heidegger 2008, p.279). Heidegger suggested that anxiety about the facticity of one’s death reveals one’s world and the requirement to respond to it. Thus, in the face of the inevitability of one’s death, anxiety forces one to examine one’s roles and the meaning in one’s life (Reynolds 2006). Global meaning is the “general sense that one’s life has order and purpose” (Lee 2008, p.779). It provides one with a scaffold of existential beliefs (Lee, Cohen, Edgar, Laizner and Gagnon 2004) consisting of one’s “basic goals and fundamental assumptions, beliefs, and expectations about the world” (Park and Folkman 1997, p.116). By linking one’s past, present and future, global meaning influences one’s understanding of the present moment – that is, we typically understand situations based upon our preexisting global beliefs (Lee et al 2004; Park & Folkman 1997). “Situational meaning” refers to how one interprets one’s global meaning in a particular context (Park and Folkman 1997, p.121; Folkman and Moskowitz 2000, p.651). Park and Folkman (1997) suggested that personal global beliefs are sustained by interpreting situations in ways that correspond with one’s fundamental beliefs. In a meta-model of ‘meaning’ King (2004) proposed three key pathways by which people find ‘meaning’ in day-to-day life: a sense of belonging with others; beingmeaningfully engaged in activities; and
understanding themselves and their world. These can be summarised as “belonging, doing, and understanding” (p.82). These pathways to meaning can also be interpreted as facilitating a sense of well-being (Seligman 2011). Miller and Ray (1994) suggested that within the provision of social support, the meaning of the support was critical to the recipient.

In my study women interpreted the presence and support of others as meaning that they were not totally alone in their illness; they experienced the receipt of emotional support as evidence of their value to others. By confirming their ‘global meaning’ beliefs, emotional support provided women with a sense of stability which contrasted with the uncertainty inherent in their world. Thompson (2007) suggested that the presence of a receptive Other can provide a relational ‘space’ for women with ovarian cancer which may reduce their sense of “interpersonal alienation” (p.339). Parker (1999) said that significant others provide “a sense of home” (p.70) for critically ill persons. Stolorow (2007) suggested that when significant others accept and understand one’s emotional pain, one is provided with “a relational home” (p.382) in which one is able to live, articulate and think about one’s reality. Similarly, O’Donohue (2000) submitted that the understanding of another “shelters” (p.246) someone who is suffering. In my study, the emotional support of others can be interpreted as providing a sense of belonging, shelter and ‘home’ amongst the unhomeliness and uncertainty of women’s worlds.

Others with cancer provided women with a reciprocal sense of being understood. O’Donohue (2000) suggested, “The most intimate community is the community of understanding. Where you are understood, you are at home” (p.370). Women in the study valued having confidantes and being honest about their feelings. A close friend with cancer was ‘there’ for Mary. ‘Because we really did know, even though our cancers were different, really could understand what the other was going through.’ (W13.908-909.) Support groups offered a sense of ‘feeling-at-home’ for some women. Leah bonded with her support group companions. Nancy found unconditional support and could be herself at her support group. ‘It’s just a lovely environment with no pretense at all. I don't have to, you know, have to pretend to be Wonder Woman.’ (W14.1012-1014.) Mary found solidarity, support and
companionship from the local Cancer Council branch: ‘These wonderful people helped me reconnect to the world.’ (W13.para-7.)

‘Being there’ often took the form of physical presence. Nancy’s sister was ‘there’ for her during chemotherapy. ‘Every time, my sister used to come in and sit with me.’ (W14.162.) Gwen’s son flew 3,700 kilometres to ‘be there’ for her. ‘My middle boy, [name], came home from [town] to bring me here for my first lot of chemo.’ (W7.292-293.) Ida and her family were ‘in this all together.’ (W9.253.) However, physical presence was not necessary for women to feel that others were ‘there’ for them. Caring gestures provided solace and support, even when others were unable to be physically present. Olive explained, ‘my sister used to make me little snack boxes for my chemo days. And I had lovely little sandwiches and yoghurts and nuts and things.’ (W15.1249-1254.) Hilda’s family recorded text and email messages from friends onto a MP3 player, which she could listen to at all hours of the day and night. This meant she had their ‘love there ready anytime I need it.’ (W8.302-303.) Olive’s son recorded relaxing music for her to play at chemotherapy. Kate’s brother ‘bought me an iPod with speakers and he put that on and programmed that, so I could listen to it.’ (W11.288-289.)

The emotional support of others reinforced women’s sense of belonging and confirmed their beliefs in the value of close relationships. Leah’s son shaved his head to demonstrate his solidarity with her. This ‘just took [her] breath away. It’s just so lovely.’ (W12.1241-1243.) Donna described: ‘you know, everyone’s been so kind. Oh, that’s a great experience. Because the kindness of people, you realise how people are concerned. And, well, I didn’t think people could be so kind.’ (W4.2093-2096.) Leah described the gift of knowing how much her family and friends loved her. ‘I just – I feel really overwhelmed with it and it’s just like, knowing how important I am to them, it’s just – just lovely.’ (W12.1510.) The demonstration of love and social support in this study buffered women against the uncanniness of their world. It confirmed personal ‘global meanings’ by reinforcing women’s beliefs and goals. By providing women with a sense of belonging and understanding, it helped soften the existential loneliness prompted by the realisation that they had a life threatening illness. Joan explained:
You know, it really has – it really has astonished me in - I mean, I knew I had friends and I knew I had good friends, and I knew I had loyal friends and I knew that I was part of a very loving family, um, but nothing to this extent, you know. It’s really been, um, humbling and, and nurturing. And I think that when you feel loved and nurtured like that it’s actually – I think, surely, it helps you get better. Because if you’re on your own – I’m sure the experience is quite different. (W10.501-507.)

Women interpreted the support of family members working together to provide support as a reassuring validation of their family bond. Betty felt her family now ‘cooperate better.’ (W2.1320.) Donna described how her children ‘pulled together, much closer’. (W4.2701.)

Others provided women with other forms of emotional support, which indicated to women that they were being remembered, and thought about; they interpreted cards, flowers, phone calls, text messages and emails as demonstrations that they mattered to people. These caring gestures validated women’s sense of worth and meaning. Leah was moved to tears by the thought of being cared about by so many people: ‘... and to me the overwhelming thing was so many people caring. It was just lovely. And, you know, it just – I just felt like crying a lot of the time.’ (W12.639-642.) She commented: ‘I had never seen so many flowers.’ (W12.1001.) Florence gained strength from knowing that many people cared about her: ‘I had so many cards and flowers sent, so that – that in itself was a boost as well.’ (W6.278.) In an exploration of chronic illness, Charmaz (1991) stated that having contact and interaction with others reinforces one’s sense of self and identity in spite of one’s illness. “Even superficial sociability can assume weighty symbolic significance to an isolated ill person” (p.97). In this way, even acquaintances helped to create a sense of belonging and community for women in my study.

In addition to emotional support, women commented on practical support including making meals or transportation provided by family and friends. This support demonstrated to women that they ‘belonged’ with loving family and friends, who cared about them. In an early study about uncertainty in gynaecological cancer, Mishel and Braden (1987) suggested that the knowledge that there is a “stable core”
(p.56) of people to help us in times of trouble can be experienced as reassurance that we are not alone and will not be alone in the future. In my study, tangible support enhanced women’s sense of belonging to a community by prompting a sense of security that others were ‘there’ to share their burden.

To make meaning of their experience, women in my study examined their selves, their lives and their relationships. Demonstrations of support were interpreted as providing the women with a reassuring and stable link between their pre-cancerous self and life, their present moment and their uncertain future. The caring and support of others added depth and quality to women’s lives and facilitated the integration of ovarian cancer into their lives. Demonstrations of support by others confirmed women’s global beliefs in the kindness of others and in the value of their close relationships. Support meant women had ‘someone alongside’, to ‘hold their hand’ in their cancer journey. It enhanced women’s self-esteem and gave them a sense of belonging. In this way, the support of others may have eased the sense of existential loneliness that accompanied women’s ovarian cancer.

**Summary:**

Women experienced ovarian cancer as living in an ‘uncanny’ and ‘uncertain’ world. This is illustrated in an iMindMap (Figure 11).
Being in a world of enmeshment: the partner’s perspective

Partners experienced Being enmeshed with the phenomenon of ovarian cancer in a world characterised by uncertainty. ‘Enmeshed World’ reflected their past, present and anticipated future care and concern for their wife. It was not a chronological phase of their experience; rather, it began prior to the diagnosis of ovarian cancer and continued throughout their wife’s illness and into the survivorship period. Once their wife had been diagnosed with ovarian cancer men realised the serious nature of their wife’s symptoms. The cancer dominated every aspect of men’s Being-in-the-world; it directed what they did, how they spoke, how they behaved, what they thought and how they imagined their future. The cancer was viewed as a mutual dyadic challenge that blurred boundaries between individual spousal lives. Partners’ worlds remained enmeshed with the phenomenon to varying degrees after treatment concluded. For some men, the sense of enmeshment remained as a strong ‘foreground’ mindfulness, which took the form of ongoing awareness of the illness including preparation for,
and anticipation of, recurrent disease and possible death. Other men’s sense of enmeshment receded towards ‘background’ awareness once their wife had completed treatment. These men sought to live a ‘normal’ life without the cancer.

The term ‘enmesh’ means to “involve (someone) in a difficult situation from which it is hard to escape” (Oxford Dictionary 2014f). It is derived from the word ‘mesh’ which can be defined as being an “interwoven or intertwined structure; network” (Dictionary.com Unabridged 2014). Interpretation of partner’s world of enmeshment was facilitated by the philosophy of Heidegger, particularly the concept of being ‘thrown’ into a situation, and the way in which we find ourselves in and respond to that situation. Heidegger (2008), used the term “throwness” (p.174) to suggest that we ‘find ourselves’ in a world, which is not of our choosing but which is determined by such things as culture and history. Although we are ‘thrown’ into our world, we can shape our lives within that world (Fox 2009), for example by choices we have made in our past and possibilities we imagine for our future.

“Befindlichkeit” describes “the state one finds oneself in” (Heidegger 2011, p.26). Our Being-in-the-world “is based on how one finds oneself in any given situation” (p.26). Befindlichkeit has been translated as our “state-of-mind” (2008, p.172). It is an ontological state, which describes our “being found in a situation where things and options already matter” (Dreyfus 1991, p.168). It is this ontological ‘state-of-mind’ that enables us to feel that things matter to us (Heidegger 2008). We understand ourselves “in terms of possibilities” (p.185). Possibilities are what we are capable of doing or experiencing (Boedeker 2001) in any situation. What I do in a situation is determined by the way I find myself in the situation and the way I understand myself and my possibilities (Heidegger 2008, p.188).

Heidegger (2008) discussed the importance of ‘Stimmung’ (p.172), which translates as ‘mood’ or ‘attunement’. Moods include public, personal and social moods, such as fear (Dreyfus 1991). For example, in Australian society, a public mood towards cancer is typically one of fear. Heidegger (2008) suggested that public moods in everyday society determine “the basic way in which Dasein lets the world “matter” to it” (p.213). The ‘mattering’ of something to someone, for example, a frightening
situation, is “grounded in one’s state-of-mind” (Heidegger 2008, p.176). Our mood determines how we respond to our ‘thrownness’ (Heidegger 2008) and is an ontic manifestation of our ontological ‘befindlichkeit’ (Dreyfus 1991, p.169).

By the nature of their spousal relationship, partners ‘found themselves’ in the situation of being a husband of a woman with ovarian cancer where their actions and responses to finding themselves in the situation of their wife’s cancer were conditioned by the mood of their ‘befindlichkeit’, which also determined their understanding of themselves and their possibilities in the situation. Being-in a world enmeshed with the ovarian cancer phenomenon was something which men viewed as being ‘a good thing’ – it mattered to them. Active enmeshment was something that the majority of partners sought and embraced.

For Heidegger, befindlichkeit “always has its understanding” and “understanding always has its mood” (p.182). Our understanding is directed towards something – we “always press forward into possibilities” (p.184). Heidegger called this “projection” (p.185). Our understanding of possibilities is directed towards those that are possible and which make sense in any particular situation (Dreyfus 1991). For example, partners ‘pressed forward’ into possibilities that reflected their identification as husbands thrown into a world enmeshed with ovarian cancer. That is, they interpreted possibilities from their understanding of themselves as husbands of women with the cancer.

Interpretation of partners’ experience was also facilitated by understandings of uncertainty and meaning-making. Cohen’s (1989, 1993a) work on uncertainty offered insight. Cohen (1993a) suggested that after diagnosis of a life-threatening illness, uncertainty “spreads to every aspect of family life” (p.138). She described possible elements of illness-related uncertainty: existential; etiological; treatment; situational; biographical; and social, some of which were identifiable in partners’ interviews. “Existential uncertainty” (p.139) relates to prognostic uncertainty – whether the patient will survive their disease and if not, when death might occur. “Situational uncertainty” (p.142) refers to uncertainties associated with unfamiliar hospital
settings. “Biographical uncertainty” (p.143) refers to the impact of the cancer upon family members’ own lives. Each of these will be discussed.

King’s (2004) meta-model of meaning making also facilitated interpretation of partners’ experience. The model, introduced earlier in this chapter (see pp.137-138), suggested that meaning making in life is achieved by a sense of belonging with others; meaningful endeavours; and understanding oneself and one’s world. Men in the present study searched for a way to make sense of their wife’s ovarian cancer. The phenomenon dominated partners’ lives as they lived in an uncertain world that influenced their understanding of themselves, of others and of their world. The enmeshment of their lives with the ovarian cancer phenomenon can be interpreted as a commitment to their wife, from which men found meaning.

**Experiencing uncertain relationality**

Men found themselves ‘thrown’ into a world of ovarian cancer by their wife’s diagnosis. As a result of their close relationship with their wife, most partners automatically assumed that they would share her ovarian cancer journey and viewed their enmeshment as natural. They experienced her cancer as an ‘appeal’, which represented the possibility of Being-there-for-their-wife; something that mattered to them. Van Manen (2014) described how we might experience the needs and vulnerability of another person as an ethical cry for help or care, with the consequence that “we are decentered toward the other” (pp.339-340). He stated, “responsibility is experienced as ‘being there’ for the other” (p.339) and this is how partners in my study responded to the vulnerability of their wife. The partners ‘decentered’ themselves towards their wife by becoming ‘enmeshed’ with her illness. Fred explained his involvement in his wife’s illness as ‘a commitment.’ (P5.438), which prompted him to care for her. One man stated that he ‘fell into’ his role. Ivan’s wife was ‘the core focus’ (P8.1036) of his life. He explained,

> I’ve just gone with her to every single thing. I felt I needed to be with her through the whole journey. I knew she needed me there. And I wanted to be there and that was the commitment I made from day one, really, to her and to myself that I’d be there for the journey. (P8.925-934.)
Men responded to their ‘throwness’ by concentrating on their wife’s needs. Fred
explained, ‘And then the operation, well, there was nothing else to focus on other than
getting [wife] down to [city] and going through her operation and thinking about
that.’ (P5.473-474.) When his wife was diagnosed, Ivan focused exclusively on her
and her cancer. He temporarily lost track of other things in his life. ‘I couldn’t tell
you really what happened with the kids in those first couple of days.’ (P8.1028-1029.)
Grant initially struggled with his enmeshment with his wife’s illness. ‘I just didn’t
feel comfortable in the beginning... it was hard because I didn’t know how – how to
handle it, how to sort of go with it, it was just so hard for me.’ (P6.245-249.) He
described it as ‘scary to have that situation happening, all these things that she was
going through, the literature she was reading.’ (P6.327-328.)

Partners prioritised Being-with their wife. For example, Hugh waited at the hospital
‘while [his wife] was having her surgery.’ (P7.75.) Ewan drove his wife to
appointments and ‘visited her’ (P4.1076) in hospital. Bob said, ‘I was at the hospital
most of the time.’ (P1.2068.) He wanted ‘Just, just to be there. And spend a fair bit of
time in there.’ (P1.2074-2075.) Charles also accompanied his wife to treatments and
appointments. ‘I could be with her and, you know, go with her.’ (P2.162-163.) Fred
described his experience as a time of ‘intense looking after [his wife], running her all
over the place and – and nursing her and being by her side right through her
operation and holding her hand, all that really.’ (P5.168-170.) Jack concentrated on
providing his wife with loving support. ‘I was just keen to be with [wife] and, and
support her.’ (P9.272.)

Partners in the study acknowledged their limited options and possibilities in their
enmeshed situation. Charles said, ‘you’re sort of, your hands are tied. You can’t do
[any]thing, you know – worry probably.’ (P2.486-488.) Knowing that ‘fixing’ his
wife was not a possibility for him in this situation; Jack focused on ‘just being
alongside and I, I know I just concentrated on that.’ (P9.1163-1165.) Hugh believed it
was important to ‘give your partner as much support as possible.’ (P7.224.) David
got to every appointment with his wife. ‘I haven’t missed one.’ (P3.548.) He added,
‘I just felt that it was important for me to be there as much as I could.’ (P3.746.)
Grant explained that he tried to ‘be there’ (P6.649-650) for his wife. Ivan felt ‘a
determination to help my wife with what she was dealing with.’ (P8.507-509.) As Bob explained, ‘It was just a case of being there and there was nothing else I wanted to do.’ (P1.2087-2088.)

Being-there-for their wife: ‘there for the ride’

Heidegger (2008) stated that we live in the world with others. “Being-in is Being-with Others” (p.119/155). We encounter and engage with our world through concern (2011). He suggested that care is a fundamental aspect of Being-in-the-world. Our ‘care’ for another, is “solicitude” (p.121/157). He describes this as “Being with another understandingly” (2008, p.125/161) – that is, with “empathy” (p.125/162). (‘Solicitude’ is further explored later in this chapter.)

Men described their experience in terms of the ovarian cancer being a mutual experience, something shared with their wife. Their ontic descriptions represented their ontological Being-understandingly-with-their-wife. Partners used the term ‘we’ when describing ovarian cancer-related events. For example, Charles described travelling for surgery. ‘We had to go to [city].’ (P2.53-54.) For the men in my study, ovarian cancer was a mutual ontological phenomenon, not solely their wife’s disease. As Grant explained, ‘even though [wife] is the one that’s being affected, but - it also affects the husband as well.’ (P6.709-710.) Initially, he felt somewhat excluded by his wife’s illness. ‘I felt the feeling of being the outsider? for a bit. I knew I was just there for the ride.’ (P6.321-324.) However, he ‘adjusted his mindset’ (P6.352-353) and focused on ‘being there’ for his wife. For Grant, it was critically important to be: part of what [wife]’s gone through and going through it with her, even though I don’t feel all the pains, the discomfort that she gets, but I try to be there with her and try to understand what she’s going through. (P6.516-518.)

He added, ‘we’re together as a husband and wife too and that really does help us, I suppose, to get through it.’ (P6.737-738.) Jack was ‘with [wife] daily so that the two of us were handling things’ (P9.1395-1397) as a team. For David, involvement in his wife’s illness was a ‘given’ and he ‘more or less took over everything’. (P3.342-343.) Ivan felt ‘very close to [his wife].’ (P8.493.) Bob felt that sharing the ovarian cancer experience together with his wife of 55 years ‘drew us a bit closer.’ (P1.2018-2019.)
Fred said he had ‘done everything I can possibly do to, ah, to assist [his wife].’ (P5.128-129.) He added,

I enjoyed doing it for her and looking after her and getting her meals and, ah, and, yeah, that was good, that was good... it was nice to think that I could – I could give her as much comfort and support as I could, by doing that for her. (P5.267-271.)

Prioritising wife above self

The phenomenon of ovarian cancer impacted partners personally and/or professionally. Charles watched his wife ‘battling’ (P2.78) with her illness. ‘I think about it now and I think, “Oh God”, you know, you sort of think what you went through. ... You think it was a big thing, you know?’ (P2.79-81.) Jack found it ‘a strain’ (P9.714) and ‘awfully hard’ (P9.1087) to see his wife in hospital ‘because of her unwellness’ (P9.716) and ‘just how dreadfully hurt she had been.’ (P9.1083.) Some men used terms such as ‘not easy’ (Fred-P5.398) to describe their experience. For Ivan, it was ‘just incredibly demanding’. (P8.497.) One man struggled to cope with his wife’s changed affect. He explained, ‘Because there’s a change of mood. A change of mood, a snappy mood. Ah, it’s hard to, um – it’s quite hard to deal with someone that’s – day after day – that’s down’. He described being uncertain how to cope with his wife’s moods and illness: ‘just sitting, waiting, watching, not knowing where to go, which way to go, it can be fairly daunting.’ Fred said the responsibility of caring for his wife fell ‘pretty heavily on my shoulders.’ (P5.117.) Ivan described himself as being ‘in the middle’ (P8.254-255) of his family, trying to ‘hold [his] wife together’ (P8.257) whilst caring for their two teenage children and meeting working commitments. This was a ‘pretty challenging thing to take on.’ (P8.259.) He added,

I guess I was conscious of it pretty well every minute of every hour of every day during that period - that I had to cope. I had to keep it together. I had to focus on what everyone else needed during that period and my needs pretty well disappeared. (P8.263-266.)

Men frequently put their own needs – including work commitments - aside. For example, following the diagnosis, Grant worried about the logistic problems of
balancing work commitments and taking his wife 300 kilometres for surgery. ‘I was thinking, “How am I going to work this business and be with [wife] as well?” So I knew I had to sort of put the business behind me for the time being and put [wife]’s interests first.’ (P6.43-45.) Ivan described how ovarian cancer dominated his life from the outset. ‘I can remember at the start – I literally just forgot about work during those first three or four weeks.’ (P8.1586-1587.) He added, ‘I remember at a particular point thinking, “There is no way I could add the burden of a job to the burden I’m carrying at the moment.” I just could not add that to my load.’ (P8.1593-1596.)

One partner was unable to explain absences at work because he had promised his wife he would not divulge her illness. The impact on his professional standing was ‘quite significant, quite substantial.’ Another man, David, described how supportive his employers had been as they had allowed him to ‘just come and go as I wanted to.’ (P3.383.) Charles also organised his working life around his wife’s needs. ‘Some days if she was real sick, I wouldn’t go to work, I’d stay with her.’ (P2.300-301.) He felt pretty lucky’ (P2.86) because he was able to use up accumulated leave to care for his wife. His employer ‘let me have time off, plenty of time off. I had a fair few sick days and holidays and stuff.’ (P2.87-88.) Initially, Grant hoped to maintain his normal working life whilst his wife had chemotherapy. However, he found his thoughts remained with his wife and he had difficulty concentrating on his work. He explained:

I couldn’t concentrate fully because while I was [working] I was thinking of “How is [wife] over there?” So, it’s a sort of time when your mind is like a jelly bowl. It’s just like a bowl of jelly because it just – shaking around just doing everything else, but its not staying still or not concentrating on anything else. (P6.375-383.)

In contrast, being retired meant that Jack was able to spend time with his wife. ‘I was so pleased that I’d been retired. Could spend the whole day doing whatever I needed, to be with [wife] and help.’ (P9.300-303.)
Being well for their wife

Part of men’s enmeshment with ovarian cancer meant that they worried about their own ill-health and the impact this had or might have upon their wife. For example, Ewan was incapacitated with a back injury. Initially he didn’t realise that his wife was unwell. ‘I didn't realise ‘cause I had a bad back at the time.’ (P4.1051.) He later understood the severity of her illness and regretted not doing more for her. ‘When someone is walking around you don’t realise how bad it is, you know?’ (P4.1071-1072.) Bob had a chest infection and tried to ‘keep his distance’ from his wife. He explained his reason: ‘it’s been drilled into us, that she stays away from any sort of infection.’ (P1.1897-1898.) There was a sense of partners ‘willing’ themselves to remain strong and well for their wife. For example, Jack was grateful for his ‘good health’, (P9.548) which allowed him to ‘look after’ (P9.544) his wife. During her illness he would tell himself, ‘I am not allowed’ (P9.677) to be ill. At one stage, David underwent emergency surgery whilst his wife was having chemotherapy. The day of his surgery, his wife ‘had the worst possible day.’ (P3.816.) He added,

So it just highlighted the fact that when I wasn't there, you know, I was – it was what the kind of situation could be like if I wasn't there, and it just kind of reinforced the fact that I should be there. (P3.825-827.)

Partners experienced the phenomenon of ovarian cancer as blurring the boundaries between their life and that of their wife. They embraced the opportunity to mesh their lives with their wife’s illness. Being-there-for-their-wife was a ‘possibility’, which men knew they could undertake and fulfill. The disease was a mutual concern, which the couple tackled together, as a team. By being emotionally and/or physically present with their wife, men were able to both give her support and to share in her illness. ‘Being there’ with their wife transformed the illness from her disease to their problem. Ontologically, ovarian cancer became a “we-disease” (Kayser, Watson & Andrade 2007, p.404).

Literature has identified that other men prioritised their wife’s needs in the event of her cancer (Bischke 2002; Hilton, Crawford & Rarko 2000; Wilson 1991). Ponto and Barton (2008) described how their wife’s ovarian cancer “created a whole new
focus/priority in life” for husbands, which was “commonly viewed as negative” (p.1228). In my study, ovarian cancer also became the focus of life for partners – in the form of enmeshment with the cancer. However, partners in my study experienced their enmeshment as a positive aspect of life. The men seized the possibility and opportunity to support and ‘Be-there’ for their wife. This correlates with King’s (2004) theory about finding meaning in life – being actively involved and feeling a sense of belonging. “A sense of purpose is needed for life to feel worth living” (p.83). ‘Being-there’ gave the men in my study a sense of purpose and a sense of belonging. It gave them a way to Be in the midst of their uncertain world.

Experiencing uncertain temporality

Whilst the focus of partner’s uncertainties shifted with chronological time, their sense of uncertainty was experienced as ongoing throughout their experience of the phenomenon of ovarian cancer.

The uncertainty began prior to their wife’s diagnosis. For example, Grant was initially uncertain what illness his wife’s symptoms might represent. He explained, ‘it was sort of hard at first, to sort of, um – to understand exactly what was happening.’ (P6.39-40.) Jack found it ‘hard to handle’ (P9.728-729) his uncertainty – his lack of understanding about the cause of his wife’s symptoms. He described feeling ‘worried’ (P9.1144) prior to her diagnosis. This was ‘hard’ (P9.1145) for him, ‘because I didn’t know what it was.’ (P9.1150-1151.)

With the diagnosis of ovarian cancer, the root of partners’ uncertainty changed to the implications of the diagnosis. The present and future were lived as uncertain time. Ewan stated, ‘you just don’t know what is going to happen.’ (P4.1207.) Similarly, Ivan explained, ‘we didn’t actually know, ourselves, what was ahead.’ (P8.135.) Bob wasn’t sure how long he and his wife would be in their capital city whilst she had surgery. He ‘went down prepared to stay three days and stayed three weeks.’ (P1.1772-1773.)
The nub of men’s uncertainty shifted with the onset of treatment. Ivan described feeling uncertain and worried about his wife’s surgery. ‘We didn't know what the outcomes from surgery were going to be.’ (P8.994-996.) Similarly Grant explained why he felt particularly anxious during his wife’s ‘life-threatening sort of operation’. (P6.576.) ‘Because we didn’t know how the outcome would be’. (P6.47-48.) ‘I didn’t know what was – what was happening and how to – to handle it.’ (P6.54-55.) Bob desperately hoped that ‘nothing untoward’ (P1.2451) was happening whilst his wife waited for chemotherapy. He was uncertain why no HCP seemed to be concerned about the six-week gap between his wife’s surgery and her first chemotherapy. ‘Now, maybe to the doctors and the professionals there is no urgency. Maybe. But to the people who are not professionals there seems to me, anyway, to be a need for urgency.’ (P1.2649-2651.) Ivan lived with daily uncertainty during the treatment phase of his wife’s ovarian cancer. ‘Every day there’s a different thing that you’re dealing with. Day one after chemo and day two is different to day three, which is different to day four and so on.’ (P8.566-570.) Grant was unsure how long his wife would need chemotherapy. He remembered explaining to his family why he couldn't plan his life in advance. ‘[I said.] “I don't know how long this chemotherapy is going to go for. She might – they might have to continue on with the chemotherapy, I don't know”.’ (P6.555-556.) (Uncertainties persisting into the future, post-treatment, are discussed in the following chapter.) Partners suffered anxiety alongside their wife in an illness which they shared, but which did not belong to them.

Cohen (1989, 1993a, 1993b, 1995) described protracted uncertainty experienced in relation to life-threatening illness. She argued that diagnosis precipitates multi-dimensional uncertainties, which interact and impact each other (1993a). Literature suggests that uncertainty is often experienced as an intrinsic feature of the cancer experience (see for example, Armstrong 2012; Burles & Holtslander 2013; Weihs & Reiss 1996). In this study, partners experienced the phenomenon as a progression of uncertainties. Men sought understanding of their experience as they described their past, present and future uncertainties. Whilst ontically these uncertainties were described as having various foci, ontologically they were lived as an overwhelming inability to predict what might happen in the future.
Ovarian cancer influenced partners’ experience and awareness of temporality where time was experienced and measured in terms of the cancer. Lived time became ‘her time’ and men suspended ‘their own’ time. For David, it was like living ‘another life. It was definitely a different world that we were in. I mean, because everything was dominated by [the cancer].’ (P3.900-901.) He added, ‘that lasted for a long time.’ (P3.912.) Grant’s daily calendar was filled with appointments for his wife. ‘Each day I had [wife] on it.’ (P6.567.) He had to ‘keep her as priority.’ (P6.568.) His life was intermeshed with his wife’s chemotherapy schedule and he had to ‘keep that calendar totally empty and not make any plans on it’ (P6.564) in order to be able to meet his wife’s needs. Ivan described the period of treatment as a time of abnormality that needed to be endured. He explained, ‘for that period there was no normality whatsoever, really. It was really just appointment to appointment as you get on the treadmill and work through it.’ (P8.106-111.) Fred ‘basically put [his] life on hold’ (P5.539) whilst he devoted his time and energy to helping his wife endure chemotherapy. He expected that this enmeshed phase of his life would be for a finite period of time:

Time-wise I thought, “Oh well, we’ll just have to wait it out.” But it’s only going to be – I -- I basically said to myself, “Righto. It’s going to be three, four, five months – five months”, I think I said. “Five months and that’s it. I’m dedicating myself to [wife] for the next five months. And won’t worry about anything else.” Just -- just be concerned with her – her wellbeing and concerned with doing what needs to be done, for her treatment and looking after her. And don’t worry too much about what’s going to happen after that. (P5.528-537.)

Existential uncertainty

Central to men’s experience was uncertainty about whether their wife would survive her cancer. Their “existential uncertainty” (Cohen 1993a, p.139) was experienced as omnipresent and dominated the men’s thoughts affecting their Being-in-the-world. David’s fear and uncertainty regarding his wife’s possible cancer-related death
dominated his world. ‘So it’s never – it’s never, ever far from my thoughts in everything I do’. (P3.482-483.) Some men lived their uncertainty as ‘worry’. Charles and Ewan both ‘worried’ (P2.85; P4.1208) about their wife dying from her cancer. Charles commented, ‘It was quite a worrying time really.’ (P2.367.) Jack spoke of ‘the worry of the wretched disease.’ (P9.136.) Hugh had previously experienced the death of an ill loved one, after s/he was left alone for a short period of time. He expressed his concern and insecurity about his wife’s survival by ensuring that his wife always had someone with her – ‘she was never really alone.’ (P7.176.)

From the outset David struggled with uncertainty about his wife’s prognosis. He described being ‘desperate, absolutely desperate’ (P3.168) to ‘get an understanding or just an idea, of how long you’ve got, or what your chances are, or whatever, you know?’ (P3.168-170.) He explained, ‘And you kind of always try and guess how long she’ll survive’. (P3.357.) Fred also struggled with the uncertainty of the prognosis. He and his wife ‘both knew the – the, ah, severity of the, ah, the illness. But we didn’t know to what degree.’ (P5.60-62.) Jack struggled with the uncertainty of his wife’s survival. ‘It was the kind of, you know, the nature of [the cancer] and the prognosis that was, uh, was the problem.’ (P9.1614-1616.) Ivan ‘didn’t know whether [his wife] was going to be alive in six month’s time.’ (P8.175-176.) He knew the statistics associated with his wife’s cancer: ‘Seventeen percent of people survive beyond five years.’ (P8.200.)

For some men existential uncertainty was experienced as being almost unbearable. By ‘shutting down’ their awareness and fear of the future they were able to sustain their Being-in-the-world as self and as Other for their wife. David explained that he ‘got to a point where I – I’d had enough and I needed to – to focus on – have a positive focus’. (P3.346-347.) He realised that ‘emotionally I’d kind of just – just lost my, ah – lost my checks and balances.’ (P3.399.) He described ‘a curtain’ (P3.351) that he ‘just drew across’ (P3.351) his uncertainty regarding whether his wife would survive her cancer. ‘I can’t keep on kind of anticipating things’. (P3.352.) His fears for his wife’s life and his uncertainty regarding the probability of her death from the disease were ‘just so great, it was - it was just overwhelming, just all-consuming’. (P3.375-376.) He found ‘just trying to sleep was – was terrible’. (P3.376-377.)
Similarly, Ivan described how he also had to control his uncertainty about his wife’s potential for dying from her disease. He said he ‘just put down the shutter and said, “Oh, I just can’t think that way anymore.”’ (P8.640-643.) He deliberately stopped himself thinking of the long-term implications of his wife’s ovarian cancer. ‘But there was a point where you just – I just had to stop myself from, from getting that far ahead and not thinking about those things anymore. Because I wouldn’t sleep. I wasn't sleeping and I couldn't cope.’ (P8.471-477.)

Partners in my study ‘found’ themselves in a situation where their wife’s survival ‘mattered’ as they feared their wife would succumb to her cancer. “Fear is a mode of state-of-mind” (Heidegger 2008, p.181). As such, partners’ fear was an ontic manifestation of men’s befindlichkeit. As discussed previously, Heidegger (2008) described existential fear as being fearful for others, where we experience our fear as “threatening” (p.179). It is because their wife’s death from ovarian cancer had become a distinct possibility, which was “close by” (p.180) but not yet, that men experienced the threat as mattering to them.

*Biographical uncertainty*

Men grappled with “biographical uncertainty” (Cohen 1993a, p.143) about their own future. David tried to actively manage his uncertainty and anticipatory grief by philosophically accepting his inability to change the outcome of his wife’s disease process.

*I’ve just got to say, “Well. It’s there.” Um, and I just chose to kind of close it off and just say, “Well, I’ll focus on every day.” And just – just, um – and just know that – that what will be will be.* (P3.355-357.)

Similarly, in order to manage his uncertainty, Jack (P9) focused upon the short-term future, rather than ‘think about the long term prognosis.’ Some partners wondered aloud how they would cope if/when their wife died. Ivan’s biographical uncertainty began with his wife’s diagnosis. His worries about how he would manage life without his wife were ‘there from that very first week.’ (P8.1582.) Once Fred heard that his wife had cancer, ‘I was thinking, now, what – if it is the worst case scenario,
what would my next step be?’ (P5.67-68.) He was unsure how he would fare without her. ‘How do you cope when you are on your own?’ (P5.225.)

Men lived with biographical uncertainty. Their assumptive future had been shattered by their wife’s diagnosis. Their wife’s possible prognosis meant that partners’ previous dreams and plans for the future may not occur. Their future was unknown and hinged on their simultaneous hope for their wife’s survival and fear of her death. Partners managed their futural uncertainty by focusing upon the ‘here and now’.

Experiencing uncertain spatiality

Men inevitably experienced hospitals and the health system. Initially, hospitals represented men’s uncertainty about their wife’s treatment, her care, and/or her likelihood of survival. Over time, hospitals came to represent hope of their wife’s recovery, reassurance that she was in ‘safe hands’ and/or some relief from the uncertainty characteristic of partners’ world.

At first, hospital buildings were typically experienced as being unfamiliar places in (often) unfamiliar cities. For men, hospitals were an (often) unknown world – a foreign land – a cancer space. The hospital space ‘felt’ strange and somewhat alien – a place where men felt ‘uncanny’. For example, Bob had little prior experience of hospitals and no experience of serious illness. He was swept along into the foreign world of illness and faced navigating the health system with trepidation and uncertainty. ‘We were entering brand new territory.’ (P1.1857.) At first, Bob felt ovarian cancer was something unique that had happened to him and his wife. ‘It just seemed to be – I wouldn’t say the great unknown but it does have an aura about it. An aura of mystery or something.’ (P1.2340-2341.) He added, ‘I guess it struck me as being something special because it was us, it was our family, it was [wife]. But when we got to [city] and we got into the [hospital], she was just another patient.’ (P1.2343-2345.) He experienced the ‘felt space’ of the hospital as demoralising where he and his wife were not regarded as being special or singular. His sense of discomfort was intensified by the ‘felt space’ of the intensive care unit where he felt out of place and ‘in the bloody way’. (P1.1810.) Initially, David experienced the
atmosphere of the hospital as ‘crazy’. (P3.259.) He felt uncertain ‘what was going to happen with the chemo’ (P3.264) and ‘where [his wife] was going to be.’ (P3.265.) Similarly, Ivan ‘didn’t know the ropes’ and was unsure what to expect with chemotherapy. He explained, ‘the first time was a bit scary?’ (P8.904.) Partners’ subjective discomfort felt within the environs of the hospital was what Cohen (1993a) referred to as the disorienting nature of “situational uncertainty” (p.142). The hospital was a large mystery with which most men were unfamiliar.

Creswell (2004) suggested that the notion of ‘lived space’ enables us to conceptualise and comprehend the world in which we live. Initially, partners described ‘not knowing’ what to expect at hospitals, which were experienced as foreign places of mystery. As time passed, however, men described experiencing less uncertainty and more confidence in being within the hospital space. Heidegger (2011) suggested that when we become familiar with a place, we take it for granted. It takes on the character of “inconspicuous familiarity” (p.15). This helps explain how growing familiarity with the hospital setting, personnel and jargon reduced men’s sense of uncertain spatiality.

Experiencing uncertain corporeality

Partners described their wife’s surgery and physical symptoms objectively. There was a general sense in the data of restraint - of a lack of ‘feeling’ descriptions about men’s lived experience of their wife’s unwellness. For example, Charles said that his wife would ‘get pretty sick’ (P2.296) with chemotherapy. ‘Some days she’d hardly get out of bed.’ (P2.296-297.) David’s wife was ‘desperately sick’ (P3.277) with her chemotherapy. Ewan’s wife also became ‘sick.’ (P4.1143.) Grant described ‘the repercussions that happened from this chemotherapy, with the hair loss and change of skin and everything else that happens.’ (P6.314-315.) Hugh’s wife ‘lost her hair’. (P7.101.) Jack’s wife also ‘had no hair.’ (P9.1715.) However, partners’ ‘objective’ descriptions about their wife’s symptoms disguised the subjective way men lived with their knowledge. Van Manen (1998, 2014) described how we take the bodies of others for granted in everyday life, but if the other is obviously unwell, we observe their body as an object for our regard. We are confronted by the “encumbrance”
(1998, p.13) of their body. Following this concept, partners’ descriptions of their experience of their wife’s corporeal response to treatment can be interpreted as a confrontation with the ‘encumbrance’ of her body, that is, as evidence of the broken unity between her and her world (2014, p.329).

Some men described their affective response to their wife’s corporeality. For example, one man described his wife as looking like ‘images you see in refugee camps in Africa. Just a skeleton.’ Jack described his wife as ‘just miserable’ (P9.1087) and ‘bashed down’ (P9.982) by post-operative complications. This made him feel ‘miserable’ (P9.1089) too. One partner described the impact of his wife’s changed body upon their relationship.

It just totally devastated – in our case, it just totally devastates your personal physical life, because there’s such dramatic changes to your wife’s body that affects her, as well as me and um, I think that is a really big factor for partners going through? Um, having to cope with those changes in the relationship on top of everything else, especially when it just comes out of the blue, as a diagnosis.

Van Manen (1998) described how we might experience “an affective response” (p.19) to the body of another. Our experience may be negative, positive or ambiguous. Partners experienced their wife’s body with ambiguity: on the one hand, they experienced her body as an objective manifestation of ovarian cancer and on the other hand, they experienced her body as a deeply felt loss of the embodied women she had once been.

Partners’ objective descriptions also revealed the subjective, lived meaning of the success of their wife’s surgery. For those partners who knew that surgery had been ‘successful’, the knowledge acted as a paradoxical form of hope for their wife’s future despite their knowledge of the prognosis commonly associated with ovarian cancer. It helped suspend some of their uncertainty about the future. For example, Ivan was relieved his wife ‘had a really positive outcome from surgery’ (P8.735) which gave him and his wife some ‘breathing space’ from the almost unremitting existential (un)certainty associated with her stage IV ovarian cancer. Hugh’s wife’s doctor ‘removed 100 percent’ (P7.83) of her cancer. Charles was told his wife’s cancer was
'contained.' (P2.267.) Men experienced successful removal of the cancer as giving their wife a ‘head start’ for surviving the disease. Fred explained, ‘I found out it’s not going to be the worst case scenario.’ (P5.478-479.)

In contrast, those partners who knew that surgery had not been entirely successful, lived with the knowledge that this increased the gravity of their wife’s situation. David’s wife’s cancer ‘had spread to the bowels’ (P3.236) and was unable to be totally removed. Jack’s wife also was left with ‘little bits’. (P9.703.) Bob knew his wife’s doctor ‘got most of the nasty stuff out but she couldn’t get it all.’ (P1.2353.) He understood that his wife had residual disease and was desperate for chemotherapy to commence. ‘Nobody seemed to be worried. Not outwardly anyway, about the bits that we were told, so we knew, were left.’ (P1.2355-2357.) Men in my study knew the prognostic implications of residual disease after surgery. They experienced the presence or absence of remaining disease (after surgery) as contributing to or reducing their existential (un)certainty. They lived their wife’s body as hope and/or fear for their shared future.

Experiencing epistemological uncertainty

Ovarian cancer changed partners’ life foci, as they lived with a multitude of ‘unknowns’ about the cancer contributing to their overall uncertainties. For example, partners ‘didn’t know what to expect’ (David-P3.144.) For David ‘the most distressing thing was the fact that you just didn’t have any knowledge.’ (P3.142-143.) Ivan explained, ‘we had no preparation for what was coming.’ (P8.137.)

In Heideggerian terms, partners had been ‘thrown’ into a situation in which their wife had life-threatening ovarian cancer and they interpreted their situation as frightening because it threatened the life of their wife (which mattered to them). Men’s response to their enmeshed situation was dependent on their understanding of the possibilities open to them. They sought information and knowledge about the phenomenon to reduce the uncertainty in their world and to determine their options - what they could ‘do’ in the situation. For example, Jack explained, ‘the things I find hard are where I don’t know. But if I understand the situation, my attitude seems always to have been,
“Okay. What’s best to do in this real situation?” [Spoken very thoughtfully.]’

(P9.718-721.) He added that he struggled with: ‘those times where there’s something that I don’t understand and I don’t know what to do about it and I don’t know how I can do anything about it.’ (P9.1159-1161.)

Knowledge and information were tools with which partners tried to understand and make meaning of the phenomenon in their lives. Grant described his experience as ‘a box full of pieces of a jigsaw puzzle’. (P6.398.) Once he gained some understanding about the ovarian cancer, he made sense of his experience and ‘it all sort of eventually started clicking in.’ (P6.396.) Bob was reassured by knowing what to expect during his wife’s hospitalisation for surgery. ‘It couldn’t have been more thoroughly explained as to what was intended, what would happen during the operation, what would happen afterwards.’ (P1.2564-2565.) Ewan was relieved when a doctor ‘summed’ up the situation. (P4.1111.) For David, ‘Just having an understanding of – of what was likely to happen, was the important thing.’ (P3.219-220.) Hugh also believed it was important for him to ‘have a full understanding of what’s going on.’ (P7.228.) As Jack said, ‘Somehow I, if I know what’s going on, then I can handle it.’ (P9.1141-1142.)

Men wanted to know how they should anticipate the future. Ivan wanted specific details and ‘needed to know the logistic[s]’. (P8.1060.) He said ‘I probably wanted to know more’. (P8.156.) He explained, ‘because I was trying to plan, you know. I had two kids, I had mortgages, I had all that stuff to try and manage.’ (P8.160-163.) For Grant, information was important ‘because it gives the partner the peace of mind that, um – that they need.’ (P6.671.) For Fred information about his wife’s condition ‘took away some of [his] fear.’ (P5.526.) Knowing ‘what to expect’ helped men ‘cope’ with the uncertainty in their life and with their fear of their wife dying. As Grant said, understanding what might happen in the future ‘does take a lot off pressure off the mind.’ (P6.680.)

“Information seeking” (Mishel, 1988 p.230) is a commonly used tactic to reduce feelings of uncertainty and increase feelings of control (Folkman and Moskowitz 2000) in worrying situations. Literature has suggested that knowledge and
understanding provide structure to illness events (Kazimierczak et al 2013) and thus reduce uncertainty (Mishel et al 2002; Mishel and Braden 1988). In a study of couples in their first year post breast cancer diagnosis, Picard, Dumont, Gagnon and Lessard (2005) reported that involvement in information seeking “demystifies” (p.120) the cancer for partners. Other authors have suggested information provision may help reduce uncertainty and address unmet needs of family members (Adams, Boulton & Watson 2009; Andreassen, Randers, Naslund, Stockeld & Mattiasson 2005). Informed anticipation was crucial for partners in the present study who placed emphasis upon knowledge and understanding of the phenomenon. Gender studies have noted that men utilise learnt skills and competencies, such as information seeking (Calasanti 2010) and management and organisational skills when coping with spousal illness (Russell 2007).

King (2004) suggested that meaning in life is facilitated from feelings of “belonging” (p.72). Partners in my study sought information and understanding about ovarian cancer in order to reduce their uncertainties and to integrate the phenomenon into their lives. Understanding enhanced their sense of ‘belonging’ to the couple and emphasised their sense of meaningful involvement in the cancer experience. For the partners in my study, information seeking was a meaningful action (King 2004), which represented their commitment to their wives and facilitated their understanding of the uncertain world in which they now lived.

Summary

Partners experienced their wife’s illness as Being enmeshed with the phenomenon of cancer within an uncertain world. This is illustrated in the iMindMap, in Figure 12.
Being in a solicitous world: the children’s perspective

The theme of living in a world of solicititude describes a further aspect of children’s experience of the phenomenon of ovarian cancer. Children lived the illness with solicititude for their mother and sought to integrate their experience of their mother’s illness into their world. Heidegger (2008) believed care was a fundamental component of the Being of Dasein and stated that “Being-in-the-world is essentially care” (p.237). He said, “care is always concern and solicitude” (p.238). He described caring about something as “concern” and caring for something or someone as “solicitude” (p.237). Solicitude means “care or concern for someone or something” (Oxford Dictionary 2014g). Solicitude for others can be linked to caring responsibility. In recognising the need of another, we may experience an instinctual call to ourselves to respond. Levinas (1969) called this “the epiphany of the face” (p.213). Heidegger (2008) believed that “solicitude is guided by considerateness and forbearance” (p.159) and is characterised by “Being-with” others (p.169). This means that ‘Being-with” and caring for others is an intrinsic part of being human (Fox 2009).
Later authors have suggested similar. Benner (2001) believed that caring is a fundamental part of Being and suggested that we live in a world comprised by “ontological care” (p.356). By this she meant that part of being human and individual is to experience a “range of connectedness and mattering” (p.356) within one’s world. Van Manen (2002) linked caring with worried concern felt about another person and described the lived experience of caring as “care-as-worry” (p.262), meaning, “to care for someone in a worrying kind of manner that is not carefree” (p.266). He suggested that this caring worry is a natural feature of the relationship between parents and children. “Worry – rather than duty or obligation – keeps us in touch with the one for whom we care” (p.264). In this study, children described worrying about their mother. They responded to their mother’s ovarian cancer by demonstrations of solicitude and every child spoke of ‘being there’ for their mother.

**Solicitous Being-there**

In this study, children’s experience of the ovarian cancer phenomenon precipitated a changed lived relationship with their mother who was no longer there-for-them; rather they became there-for-her. All the children lived their mother’s illness with care, worry and solicitude. They experienced ovarian cancer as awareness of their mother’s potential for dying an early death from the disease and responded to the resulting uncertainty as heightened Being-in-the-world-for-others.

Children valued becoming involved with their mother’s illness and found meaning in ‘being-there-for’ her. They became involved with the illness, attended appointments, made meals, visited and/or provided transport for their mother. They also provided emotional support by ‘being-there-with’ her via phone calls and visits. Laurie was concerned that his mother had company for her appointments. ‘The main thing I wanted to make sure, was that whenever mum was at, you know, an appointment or seeing someone, that she had someone else with her.’ (C3.428-429.) Una and her sister took their mother ‘back and forth from the hospital when we could. Going to the doctor.’ (C6.2282.) Val explained ‘We’ve – we’ve always tried to go with mum.’ (C7.1772.) She felt ‘guilty’ (C7.1931) if she couldn't attend appointments. For the children, ‘being there’ demonstrated their love for their mother. Val explained, ‘I
suppose it’s that supporting thing, you’re wanting to be there to support [your] mum.’  
(C7.1954.) ‘Because you just – you just want to be there to support your mum.’
(C7.1964-6.) Una would take her lunch break to fit in with appointment times. ‘I’ll try and get my lunch then and go then.’  
(C6.1778-1779.) Wendy believed ‘all you can do is be there.’  
(C8.1619.)

Time with their mother felt precious. Tess described time at chemotherapy as ‘a nice “us” time... As awful as it was, it was nice to be there with her.’  
(C5.252.) Eliza experienced the quality of the time spent with her mother as a gift. ‘It was like I could manage really intensive time with her.’  
(C1.274.) She added ‘it was really good.’  
(C1.280-281.)

Geographical distance between child and mother added layers of complexity to the experience for some children. Initially, Eliza phoned her mother daily from interstate. ‘I was like hassling her every day.’  
(C1.298.) After surgery, she gradually decreased the time spent emotionally supporting her mother. ‘Depending how sick she was would be depending on how many times I rang her...So now that she’s well, I leave her alone a bit more.’  
(C1.299-303.) Geographical distance meant Kevin felt isolated and uncertain about his mother’s condition. ‘It’s very difficult to know, you know, exactly what was wrong? Um, because of the distance.’  
(C2.536-539.) He wished he ‘had more time and more opportunities to go and visit.’  
(C2.274.)

Children in this study lived a heightened “care-as-worry” (van Manen 2002, p.276) for their mother. The majority of their lives were greatly impacted by their ovarian cancer experience. Tess was proud that she ‘took time off work’  
(C5.242) to accompany her mother to each chemotherapy session. ‘I was the only one that took her.’  
(C5.242.) The assumption of the role of carer and/or companion for their mother reflected the close relationship between mothers and children. Wendy explained ‘There was never any question of that.’  
(C8.1123-1124.) She added: ‘She looked to me. I didn’t ask for the role. She chose me.’  
(C8.1281-1282.) Tess said her mother ‘calls me her um, her soul mate.’  
(C5.252-253.) Anna responded to her mother’s diagnosis immediately by ‘being there’ for her mother. ‘So rang [work] and yeah just said that “I wasn’t sure” how long I’d be off.’  
(C9.185-186.) Tess commented, ‘I
must admit my home life did suffer? There was never food in the fridge or the
cupboard, the washing was never done.’ (C5.305-308.) She added: ‘It’s a long day,
being at the hospital and then having to catch up with work and catch up at home. It
just, it was, I felt like I was constantly behind the eight ball.’ (C5.351-353.) She
described her mother’s illness as ‘a big thing for us all to go through.’ (C5.46.)

Wendy’s mother’s illness and treatment dominated Wendy’s life. ‘When she was
having her surgery I was living out of a suitcase, literally.’ (C8.113.) Her experience
was a whirlpool of events and emotions. ‘Like, you know, a tornado.’ (C8.1544.)

Laurie’s mother’s illness had

A fairly large impact because I was, you know, spending a bit of time there,
you know, from work and after work and that sort of stuff as well. Um, so you
know, that, that obviously had an impact and that sort of um, you know,
distracts you from other things. (C3.36-41.)

Anna was employed as a carer and was living with her mother when her mother was
diagnosed with the cancer. She then became her mother’s carer and assisted her with
activities of daily living (ADLs) such as hygiene (Katz, Ford, Moskowitz, Jackson &
Jaffé, 1963) and with instrumental activities of daily living (IADLs) such as meal
preparation (Lawton & Brody 1969). Anna felt like she was constantly working. ‘It
had its ups and downs. Going to work and come home to work, yeah.’ (C9.677.)

‘Juggling’ the needs of others

Children were ‘there’ for their mother as much as possible with their worried concern
adding an additional dimension to the caring roles they already had. Children
balanced the demands and responsibilities of various life roles whilst incorporating
their mother’s illness into their lives. Literature has described role strain and/or
conflict as children of parents with cancer struggle to balance rival demands on their
time and energy (Germino & Funk 1993; Oktay 2005). Competing demands of ill
parents and an adult child’s own families have been described as “the paradox of dual
loyalties and demands” (Davies, Reimer, Brown & Martens, 1995, p.31). Most
daughters in this study ‘stepped up’ to the role of being a carer for their mother. They
attempted to reconcile and balance their perceived responsibilities and different roles as children, parents and employees.

Most children cared for their own offspring, whilst also solicitously supporting their mother. Various authors have referred to this phenomenon as being “sandwiched” between generations (DeRigne & Ferrante 2012; Miller 1981; Rubin & White-Means 2009; Tebes 1998;). Brody (1981) coined the phrase “woman in the middle” (p.471) to describe middle aged women in the middle of multi-generational families who are torn between competing demands upon their time, energy and self. Daughters, in particular, in my study were ‘in the middle’ between their mother and their own family and struggled with weighing up commitments to mothers, children, partners and employers. They felt a tension between competing needs, dependencies and obligations. McGrew (1998) described this as “the dance between self and other” (p.57).

‘Being-there’ for mother and offspring

Some children in my study put the needs of others in front of their own needs and endeavoured to provide thoughtful support to those they loved. They spoke of juggling their time and energy to care for the family member they perceived as being most in crisis and need. Wendy prioritised Being-there-for her mother over living with and caring for her teenage offspring.

Mum didn't want people to see her when she was really ill. Especially not the grandchildren – she was very close to the girls. Um, so I was feeling quite isolated ‘cause I wanted my babies – and I wanted my mum. And I had to choose who needed me more. [Crying] (C8.261-266.)

She wanted to ‘be there’ for her offspring as well as her mother. ‘I’m their protector. I was their protector as well.’ (C8.588.) Anna ‘just juggled’ (C9.647) competing dependencies in her life. She travelled interstate with her mother for surgery and had to take her 10 year-old with her. She found this

A bit hard because like, I had my daughter there, sort of thing and she was there while all the doctors and that were there, sort of thing... You’d think she
wasn't really listening but, then all of a sudden, you know, she'd pop up and say something to mum and, yeah, she was taking it all in. (C9.212-216.)

Anna struggled to ‘be there’ for both her mother and her own offspring. She further explained: ‘[I’ve] got to be there for mum, but then not having [offspring] in the hospital all the time.’ (C9.772-773.)

Mark was caring for his two young offspring when his mother phoned in distress. ‘I wasn’t sure whether, you know, I should race off and... I was thinking well, where do I take the kids?’ (C4.79-81.)

Living interstate, Eliza struggled to reconcile wanting to ‘be there’ for her mother whilst ‘being there’ for her own young family. She regretted being unable to ‘be there’ for her mother in person. ‘I would like my job to be more than I feel that I can. Ah – yeah – I don't know really how to get around it. I can’t see any way. [Crying]’ (C1.201-2-3.)

Children took care with their offspring’s exposure to facts about the cancer. Those older than five years were given carefully worded explanations. One of Eliza’s children heard her crying during our telephone interview. She went to soothe him because ‘now I’ve made him cry as well.’ (C1.150.) One of Tess’s teenage offspring overheard her discussing her mother’s prognosis. ‘I just knew that she heard and she went running into her brother’s bedroom and cried.’ (C5.376-377.)

Una, Val & Anna told their young children that their grandmother had cancer just after she was diagnosed. Val said, ‘I think we just told them. I think just – it just came out. It had to come out.’ (C7.1666-1670.) Una explained, ‘And so you just have to say it out straight.’ (C6.1678.) She described: ‘I sat on the bed and I’m sobbing. And my youngest one said, “What’s wrong?” I said, “Oh, nanny’s not well.” “She going to die?” [In high pitched voice]... I said, “Well, we don't know.” [Crying]’ (C6.2237-2239.)

Children censored what they said, to protect their offspring from unnecessary distress. Anna was honest but guarded with her daughter. ‘She’d hear everything, sort of thing, and I thought it was best to keep her informed. You just, you don't actually tell, you know, her the worst case scenario.’ (C9.230-232.)

In contrast, Mark had very young offspring. ‘We told them grandma was sick and in hospital... we didn’t actually take them in to see her in hospital.’ (C4.562-563.) He added: ‘So in a very real sense they really had no idea.’ (C4.610.)
‘Being the strength’

‘Being there’ also meant ‘Being strong’ for others. For example, daughters spoke of dealing with their offspring’s fears and uncertainty in addition to managing their own emotions about their mother’s cancer. Anna found this dual role ‘a bit hard.’ (C9.212.) Tess’s teenager cried ‘“I want my nana to be at my wedding” ’ (C5.377-378.) Wendy described: ‘my daughter said to me the other night “Will I get cancer, mum?”’ (C8.1453-1454.) In order to provide their offspring with a sense of stability and security, some daughters described having to conceal their worries and maintain a façade of strength in front of offspring. Whilst they personally felt uncertain and insecure, for their offspring’s sake, they projected strength and confidence. Val explained, ‘and they just – I mean they go on with what – well, how you are. How you are, how you’re feeling.’ (C7.1660-1664.) Una explained her offspring’s attitude: ‘“Mum’s coping okay”. Then they’ll cope okay.’ (C6.1680.) Anna recalled ‘trying to keep [herself] together’ (C9.748) in front of her offspring because she didn’t want her upset. ‘If I’m upset, well, something is wrong. She knows granny’s got cancer but, you know, if mum loses it, then that’s going to scare her more.’ (C9.753-755.)

Changes in family roles added another dimension to ‘being there’ for some children. Daughters were struck by the resemblance between mothering their offspring and mothering their mother. For Tess, a formally organised therapeutic makeup session with her mother ‘was almost like a role reversal when your kids are playing with makeup and learning to put it on and stuff like that.’ (C5.621-625.) Wendy described: ‘I mean from simple things, from being – um, I’m her child – to me being her carer.’ ‘It was from my mum to me becoming her mum.’ (C8.1360-1361.) She likened providing physical care for her mother to care she had provided for her own children. And she used to sit on the floor and I’d towel her down and wrap her up, and we’d go in the lounge room. And – I’d dress her in front of the fire like I did my children.’ (C8.461-464.) She continued, ‘I mean when my children got ill I used to always dress them in front of the fire, keep them warm. Mum was the same. Mum was a child.’ (C8.470-471.)
Responsibilities increased as daughters strove to provide sympathetic, optimal support for their mother. Eliza described her ‘concern’ (C1.356) about her mother. She would ‘try and encourage’ (C1.335) her to be proactive about planning for her future, without wanting to ‘interfere.’ (C1.339.) Val and Una provided their mother with a strong foundation of support by ‘being-there-for’ their mother at appointments. Wendy balanced solicitude with a façade of strength, which supported her mother. ‘If you crumble, they’ll crumble.’ (C8.1358.) She offered the following advice to someone in her position.

*Put yourself in their shoes. Um, but then upon saying that, don’t become a walkover. I mean, because they, they, they’ve got to have the strength and you’ve got to be the strength, so you can’t be the strength if you’re namby-pamby to them all the time either. And that’s a really hard thing when you know that person’s so, so sick.* (C8.1338-1343.)

Most daughters assumed much greater responsibility in the relationship than previously. As eldest daughter, Tess temporarily took over the role of matriarch in her extended family ‘It was definitely a role reversal. And Mum would say to me, “This is getting you in practice for when I go.”’ (C5.629-630.) She assumed the role of family cheerleader, organising the family and ‘gluing’ the family together. ‘It was a case of me organising things, keeping the family involved, you know what’s going on with mum, how we are going to tackle it as a family.’ (C5.126-128.) Wendy struggled with feeling responsible for her mother’s life. ‘Your role from being a child became very much the parent, the protector.’ (C8.138-139.) She explained,

*Whilst I was the protector – I felt very vulnerable of making wrong decisions for her, of, um, not having her around. I was like a knife – I don’t know. I was like a person in an armour. You put the armour on, but underneath you’re just – I was – self-doubting. “Am I doing the right thing here?” [Whispering] “If I go this way will it mean she lives longer, or, go that way...?” So very – don’t know if vulnerable’s the right word. But anyway, that’s how I felt. I felt very alone, isolated. Extremely responsible. Extremely responsible for her, for everyone really.* (C8.1098-1106.)
Anna remembered times when her mother would feel suicidal. ‘There’d be days when, yeah, mum would say, “I can’t do this any more” ’ (C9.490) and Anna would have to help her through her despair. She took responsibility for her mother’s emotional and physical health and her role became almost like that of a gentle cheerleader. She explained: ‘you’d never know whether she’d say well, “I’m not going to see my granddaughter get married.” ’ (C9.501-502.) Anna likened caring for her mother’s emotional upheaval to a rollercoaster ride of highs and lows. ‘It’s like just top and tailing.’ (C9.502.)

Shifts in family roles and responsibilities in major illnesses are not uncommon (Davies et al 1995; Oktay 2005). Whether the shifts are called “role borrowing” (McGrew 1998, p.56) or “role reversal” (Raveis & Pretter 2005, p.56), “the moral responsibility of care has been reversed” (Almarza 2008, p.99) and the children “now parent their parents” (Davies et al 1995, p.38). In my study, daughters lived the phenomenon of ovarian cancer as role reversals and increased responsibilities.

**Experiencing their (m)Other**

Ovarian cancer altered the way most children experienced their mother’s corporeality. Sartre (2003) described how we experience our own body as a body-for-itself. This is the body we live and it situates us in our world. He also described how one’s body can be experienced as a “body-for-others” (p.363) – that is, viewed with an objective lens (Reynolds 2006). In this study, children’s experience of their mother’s body changed their experience of her.

Prior to her illness, children experienced their mother as Mother. They had a lived, existential relationship with their Mother in which she represented a strong and vital embodiment of motherhood. They had “a fundamental identification with [her] body at the pre-reflective level such that there [was] no perceived separation between body and self” (Toombs, 1992, p.51). They did not experience her body as a body; rather they experienced a lived relationship with her as their Mother-for-herself (Toombs 1992). Her body was taken for granted (Zaner 1964).
However, children noticed their mother’s body changing in response to her disease and treatment and viewed their mother as different, no longer the person she had been. Taken (changed) by the disease. Their normally robust mother grew physically weak and vulnerable and unwell. The previously taken-for-granted-ness of their mother’s body disappeared. The mothers’ bodies behaved erratically, forced themselves upon the children’s notice and were no longer not-noticed by the children. Children learnt to view their mother’s body with an objective as well as a subjective lens. At a reflective level they learnt to look at their mother’s body as her body-for-others. Their relationship with their Mother altered to incorporate aspects of her body-as-other. This did not mean that children now regarded their mother as an object, as if she was an insect (see Merleau-Ponty 2002, p.420). No one is “ever quite an object” (Merleau-Ponty 2002, p.521). Rather, this means that children learnt to view their mother with dual lenses – she became their (m)Other. They experienced her as both their lived mother and also as their mother-as-objective-body – a woman of “flesh and blood” (Leder, 1990, p.66).

Previous studies have described the impact of parental illness upon adult children’s perception of their parent/s. A study of families with a terminal illness found that parental illness challenges and changes the “vital and capable and more competent than themselves” image adult children may carry of their parent (Davies et al, 1995, p.6). Studies of maternal breast cancer noted how the illness challenged daughters’ previously held perception of mothers as invincible and confronted them with their mothers vulnerability and mortality (Raveis & Pretter 2005; Wiggs 2011). De Beauvoir (1985) described how her mother’s illness had

Wrenched her out of the framework, the role, the set of images in which I had imprisoned her: I recognized her in this patient in bed, but I did not recognize either the pity or the kind of disturbance that she aroused in me. (p.21)

In my study, ovarian cancer changed children’s perception of their mother. The illness experience revealed their mother as a psychologically weakened vulnerable woman. Kevin’s mother’s embarrassment about some incontinence contradicted his prior experience and expectation of his mother being strong and self-confident. *Well, I have this impression of my mother as being, you know, really in control, able to deal*
with issues like that and, um, because, you know, that's my experience of her.’
(C2.476-479.) During treatment, she appeared vulnerable and different to the mother he thought he knew. Suddenly he saw her as (m)Other, as someone other than the strong and seemingly invincible mother she had always been. Wendy saw her mother change from being ‘quite a strong, um, stoic lady’ (C8.47) to one who was vulnerable and afraid. ‘And watching this lady and her whole personality change from being strong to being so, so, so scared? Could see the fear in her eyes.’ (C8.144-147.) Mark commented: ‘Mum was scared.’ (C4.42.) Mother’s obvious vulnerability reflected children’s fears and highlighted the fragility of their mother’s life. Laurie remembered how his mother appeared ‘psychologically exceptionally battered um, and, and, and fragile.’ (C3.230-232.) De Beauvoir (1985) described her mother as having “all the sadness of a defenceless animal in her eyes” (p.65). Similarly, Wendy explained: ‘I saw such vulnerability in her eyes. [Crying]’ (C8.165.) ‘It was at that point that I, um, I really knew – that my mother was vulnerable and – like all of us – and she was scared.’ (C8.172-173.) She described her mother as broken. ‘Mum was a child. Mum was back to very vulnerable, broken. Broken. And I had to fix her. Body and soul. Body and soul.’ (C8.471-476.)

Children were confronted with the altered physical reality of their mother. Wendy described her mother post-surgery: ‘I remember when she opened up her eyes and she was – so did not look like my mother. She was all bloated and – [deep breath] and then everything hanging out of everywhere. [Crying] She had beeping. [Referring to the sound of medical machinery.]’ (C8.222-226.) Similarly, Mark described how his mother: ‘had tubes in and everything and [she looked] pale.’ (C4.566.) Children noticed their mother’s visible frailty and vulnerability and a number of children described their mother as becoming ‘very frail.’ (Laurie-C3.228; Wendy-C8.291.) Her changing body provided visual evidence that their previously seemingly indestructible mother was now vulnerable, mortal and at risk. Her vulnerability was experienced as an uncertain future - and a reminder and confirmation that they could lose her from the cancer. They attended to her body as a symbol of her potential for death and experienced her body as worried concern for her mortality. Laurie said that his mother: ‘got very frail. And I think just very, very run down.’ (C3.228-230.) ‘It made me think, “Oh gosh, she, you know, she looks frail.” And, you know, I’d never
really seen mum look particularly frail before.’ (C3.654-656.) He understood his mother’s physical vulnerability as a threat to her life. ‘It sort of, it made me sort of...yes, I guess look at her and think, “Well,” you know, “If this part doesn’t get better then, you know, this could well be enough to, to, um, to finish her off.” ’ (C3.685-686.) Similarly, Kevin stated: ‘it was a real worry when she was that sick.’ (C2.459-460.) Una found it ‘a bit scary’ (C6.1018) when her mother was admitted to hospital with a low ‘blood cell count.’ (C6.1015-1016.) Mothers’ weight loss emphasised their potential-for-death. Una’s mother lost ‘a lot’ (C6.2040) of weight and Mark watched his mother ‘get even thinner.’ (C4.274.) Wendy described: ‘She got down to very, very tiny – forty-two kilos I think. It was just so tiny.’ (C8.694.) Her mother was: ‘Just nothing but skin hanging. No –definition – at all. And her head. Head on the bed.’ (C8.700-701.) She added,

I used to go in and check on her of a night time and I used to look and it used to be this little - oh, it wasn't a big head, but it looked big compared to her body – on the pillow. Head on the bed. (C8.711-715.)

‘On the sideline’ – living with the (m)Other’s body

Witnessing mothers’ distress and suffering added to children’s sense of seeing their mother as separate – as (m)Other. Treatment side effects emphasised children’s sense of uncertainty as mother’s bodies responded unpredictably to chemotherapy and were viewed as being out of their control.

Merleau-Ponty (2002) suggested people experience suffering differently, according to who suffers. For one, suffering is “lived through”, for the other, suffering is “displayed” (p.415) or shared. Both experience the suffering individually. Significant others of women with breast cancer have been described as suffering “at second place” (Lindholm, Rehnsfeldt, Arman & Hamrin, 2002 p.250), that is, whilst the disease was not happening to them, they were intimately involved. In my study, some children felt like bystanders whilst they witnessed their mother suffering from her treatment. For example, Wendy explained: ‘I wasn't experiencing what she was going through, you know. I was on the sideline.’ (C8.83-84.)
Experiencing a loved one suffer with cancer can induce overwhelming feelings of helplessness (Blindeheim, Thorsnes, Brataas & Dahl 2013; Lindholm et al 2002; Persson & Sundin 2008). Previous authors have described the harrowing impact of witnessing their parent’s cancer-related suffering. For example, Schwalbe (2012) found his mother’s cancer pain “terrible to watch” (p.183). De Beauvoir (1985) recalled her mother’s cancer illness, “I touched her, I talked to her; but it was impossible to enter into her suffering” (p.81). Broyard (1992) described his father’s cancer as “rotting his entire skeleton until the very marrow of his bones ran with pain” (p.110). He added: “His whole body had become a tongue, addressing its message to me” (p.110). Similarly, children in my study described seeing and/or hearing their mother’s pain and distress. Eliza explained: ‘It was very hard because she was, um, quite sick at, you know... with that initial treatment when she was very sick with the chemo.’ (C1.125-127.) Anna recalled her mother ‘being sick and all that. Sort of, so constipated and then diarrhoea.’ (C9.323.) Kevin’s mother had ‘pain and, you know, diarrhoea and things’ (C2.467) and ‘sometimes she didn't make it to the toilet.’ (C2.502.) Anna remembered ‘the cramps were a major thing. She’d just curl up in bed, just in pain with cramps.’ (C9.287-288.) Her mother would ‘sit there and bawl all night.’ (C9.302.) ‘Wake up in the night or in the early morning, screaming and sobbing.’ (C9.317.)

Merleau-Ponty (2002) described how we might ‘live’ another’s body.

Whether it is a question of another’s body or my own, I have no means of knowing the human body other than that of living it, which means taking up on my own account the drama which is being played out in it, and losing myself in it. (p.231)

In my study, children suffered differently from their mother. The children lived the drama of their mother’s suffering as intense solicitude and feelings of helplessness. Wendy explained, ‘Sometimes I just wanted to run away. I couldn't bear to see her in pain. I couldn’t bear to see the shadow of a woman. I just wanted to run away. [Softly]’ (C8.1550-1551.)

Similar to other children in this study, Wendy found her mother’s corporeal changes distressing and confronting. De Beauvoir (1985) described the impact of seeing her
mother naked. “The sight of my mother’s nakedness had jarred me. No body existed less for me: none existed more” (p.19). She continued: “For the first time I saw her as a dead body under suspended sentence” (p.20). Like De Beauvoir, Wendy found her mother’s changed embodiment confronting as it reinforced for her, the fact that her mother was very ill and may die. ‘And I didn't want to look at her. I was too frightened.’ (C8.1214-1216.) She described how she experienced her (m)Other’s changed body. ‘Um, the first time I bathed her though, when she was physically hairless, no tufts anywhere – no eyebrows, no eyelashes, no nothing. Nothing. Body. [Made sweeping motion with her hands to indicate nothing there.] Um. I did go [gasped]’ (C8.666-672.) ‘But I did physically go [gasped], like that – ‘cause my heart literally – just stopped. And I just looked at this person, I thought, “My God, that’s my mother”. [Speaking softly]’ (C8.684-687.)

This person – this Other, was her mother.

‘Getting on with it’ – dealing with fears and uncertainty

Children utilised a variety of coping strategies to minimise their fears of their mother’s cancer-related death and to reduce their feelings of uncertainty. Some children used “affect management” (Mishel 1988, p.230) to control their emotions and thoughts. Mishel (1988, 1990) suggested that uncertainty in illness could be interpreted as either a threat or an opportunity. She suggested that uncertainty interpreted as an opportunity can occur in illnesses with a probable poor outcome. This interpretation “allows the person to forestall perception of an absolute negative outcome or reoccurrence” (Mishel 1988, p.230). In other words, uncertainty enables the maintenance of hope that the poor outcome may not eventuate. In my study, some children drew upon the uncertainty related to ovarian cancer and the prognosis as a positive - that is, as nothing was certain, there could be some glimmer of hope. The use of hope as a coping mechanism by some children in my study can be interpreted as a strategy to avoid thinking about the probability of their mother’s death and instead to maintain their (hopeful) uncertainty of their mother’s future.

Tess intentionally focused on cancer success stories to bolster her hope that her mother would survive. ‘Confidence, it gives me confidence.’ (C5.415.) Similarly, in
her mind, Wendy deliberately told her mother: ‘“You are going to get better.” In my mind it’s never anything else. If it was, I pushed it aside. “You are going to get better.”’ (C8.1409-1410.) Tess used determined hopefulness as a protective buffer against her fears. She tried to be ‘all positive and upbeat most of the time. But - you have to be. Otherwise I’d be a blubbery idiot and a mess every single day.’ (C5.687.) Una believed that hope was an essential tool, which enabled her to cope with her mother’s cancer.

And people have just got to stay positive. ‘Cause that’s how – You just have to stay positive. ‘Cause otherwise you could get – yeah, could get – get you down in the dumps ... it could do. But you have to be positive. (C6.3154-3161.)

Similarly, Anna described: ‘you’ve got to be upbeat and it’s – a lot of it’s your attitude, sort of thing and how you look at it.’ (C9.425-428.) Some children believed they had little choice but to cope with their mother’s illness. Una said, ‘You’ve just got to cope, because that’s how it is really isn’t it? You just get on with it.’ (C6.2007-2010.) Val commented: ‘You don’t dwell on it.’ (C7.2008.)

In an examination of hope, van Hooft (2011) suggested that hope is “intentional” (p.55) and is “a stance taken in the face of the fear that the worst can happen” (p 23). He defined hopefulness as a “future-oriented way of seeing the world that is trusting, confident and optimistic” (p.52). This helps us understand the importance of the maintenance of hope as a coping strategy for some children in my study. Hopefulness provided a lens through which children were able to exist in their uncertain world – it helped them ‘Be’ in their world. It reduced their feelings of uncertainty and helped balance their fear of their mother dying.

Mother’s attitudes influenced children’s approach towards the cancer. Una compared her father’s death from cancer with her experience of her mother’s illness. ‘He just gave up, whereas mum is obviously a fighter. Dad just gave up.’ (C6.255.) Her optimism was based on her mother’s personality: ‘And if you knew mum, like she’s a fighter. And you know that she’s not going to give up slowly.’ (C6.556-558.) Mark explained:
I’ve heard of other people with, with cancers who have sort of basically given up. And [pause] and she didn’t. And I think, I think that, you know, transfers to people around her. And sort of think well if she’s not giving up, I’m not giving up... I think that would make it much worse for me personally if she had given up because I think you shouldn't give up. [Pause] There’s always hope. (C4.701-712.)

In a study of adult children of women with breast cancer, Forsberg (2002) described how children used their mother’s attitude to her cancer as a “compass” (p.33), which guided their own interpretation of the disease. In my study, mother’s positive attitudes ‘set the tone’ for children and helped them maintain optimism towards her prognosis in the face of uncertainty.

Some children coped with the uncertainty of the future by focusing upon the short-term. Val commented: ‘there’s that point where you can’t think beyond.’ (C7.1612-1613.) Una lived from one phase of her mother’s illness to another. ‘After that it’s like, “Okay, well she’s had the chemo, that’s fine...Okay.” Then you can sort of breathe, I suppose and get back to normality?’ (C6.1647.) Tess explained: ‘Basically we looked to the next three months and what was going to happen.’ (C5.154-155.) Una used distraction as a coping mechanism. ‘That’s how I cope, I've got to keep busy.’ (C6.561-562.) She added: ‘I cope – by going to work and keeping busy.’ (C6.1638-1639.)

Feelings of security and trust in their mother’s HCPs relieved some of children’s uncertainties. They experienced the provision of care by trustworthy and competent HCPs as providing some respite from their constant solicitude for their mother. For example, once the gynaecological oncologist took over her mother’s care, Eliza felt she could relax her vigilance. ‘I felt like once she got to see [doctor] it all happened, and I was very happy with that.’ (C1.228-229.) ‘I kind of had faith in everything from then on.’ (C1.428.) Similarly, Wendy was determined to have the best care for her mother. ‘We were just lucky that we had the jewel here, mm, because I would have gone anywhere.’ (C8.1085-1086.) She felt great relief when the gynaecological oncologist took over her mother’s care and ‘the care was amazing.’ (C8.1020.) Val felt her experience was positive because her mother’s care ‘all just flowed really
Similarly, Una said ‘it’s all gone quite smoothly.’ (C6.3363.) Mishel (1990) suggested that reliable HCPs lessen levels of uncertainty by providing structure to illness-related events. This can be seen in the children’s descriptions of their mother’s care. As Wendy said, once the gynaecological oncology team took over her mother’s care, she and her mother ‘were on that path.’ (C8.989.)

**Summary:**

Children experienced the phenomenon of ovarian cancer as living in an uncertain world and responded to their fears for their mother’s life with solicitude and worry. This is illustrated by Figure 13, in an iMindMap.

**Figure 13: Children’s uncertain world**

**Chapter conclusion**

This chapter has interpreted participants’ experience of the phenomenon of ovarian cancer as living in an uncertain world. Within this world, the different participant groups highlighted various aspects of the phenomenon. Women lived in an uncanny world, men lived in an enmeshed world and children lived in a world of solicitude. Together, these individual yet linked worlds constituted the Uncertain World characteristic of ovarian cancer. This is illustrated by Figure 14.
Feelings of uncertainty underpinned participants’ experience of the phenomenon of ovarian cancer. Women experienced the uncertainty as living in an uncanny world. Feelings of ‘not-being-at-home’ within themselves were exacerbated by uncanny temporality, spatiality, corporeality and relationality. Men experienced uncertainty as living in a world enmeshed with the phenomenon. ‘Thrown’ into their situation, men responded to possibilities by ‘Being-there-for’ their wife. Enmeshment with the phenomenon was reflected by uncertain relationality, temporality, spatiality and corporeality. Children lived in a world of solicitude. They sought to ‘Be-there-for’ their mother, whilst juggling other responsibilities. They utilised different strategies to manage their concern for their mother, who they experienced as (m)Other.

The following chapter further illuminates the experience of the phenomenon of ovarian cancer and introduces the third major conceptual theme of ‘Liminal World’ for participants. ‘Liminal World’ can be understood to co-exist with ‘ruptured assumptive world’ and ‘uncertain world’ as key components of the experience of ovarian cancer for participants.
CHAPTER SEVEN: LIMINAL WORLD

Time present and time past
Are both perhaps present in time future,
And time future contained in time past.
If all time is eternally present
All time is unredeemable.
(Eliot 1959, p.13)

This chapter presents the third major theme of the study, ‘liminal world’, which co-existed with participants’ ‘ruptured assumptive world’ and ‘uncertain world’. Within a liminal world, women experienced the phenomenon as living in a transitional world; partners lived ‘in limbo’; and children lived in a terminable world. The sub-themes of liminal world are illustrated in the iMindMap in Figure 15.

Figure 15: Introduction to liminal world
Liminality as a concept

The term ‘liminal’ means “occupying a position at, or on both sides of, a boundary or threshold” (Oxford Dictionary 2014h). ‘Liminality’ comes from the Latin word for threshold (Onions 1966, p.528). van Gennep (1960) suggested the concept of liminality represents a threshold between different worlds stating that the process of passage from one world to another involved “preliminal rites”, “liminal (or threshold) rites” and “post-liminal rites” (p.21) which could be symbolic of endings and new beginnings. He suggested that illness includes the movement from one world to another and the liminal phase incorporated “a point of inertia” (p.182) during which one is re-energised. For van Gennep, the meaning of life is “to act and to cease, to wait and rest, and then to begin acting again, but in a different way” (p.189). Turner (1969) further developed the concept of liminality and suggested that the term means to be “neither here nor there”, to be “betwixt and between” (p.95). It can be understood to represent “a limbo of statuslessness” (p.97). Turner suggested that a liminal state has the ontological capacity of shaping one’s being in the world.

Several authors have explored the concept of liminality in the cancer experience (for example, Blows, Bird, Seymour & Cox 2012; Halliday 2011; Little, Sayers, Paul & Jordens 2000b; Thompson 2007) and illness (Bruce et al 2014). Little et al. (2001) explored the concept of liminality in association with survivorship from cancer and suggested that liminality is “fundamental” (p.40) to the experience of cancer. They identified two phases of liminality – an “acute” phase, which cancer patients enter at diagnosis and a “sustained” (p.40) phase, which can persist until death. My study examines the liminal experience of ovarian cancer for partners and children as well as women with the disease.

At times, we all live in a state of liminality - where we are on, or near, the boundary between one reality and another. In this study participants entered a liminal world with the ovarian cancer diagnosis. The rupture of their assumptive worlds signified their entry into an acute liminal phase. They no longer lived in the world as they did before the diagnosis but they had not yet become the people they would be after their ovarian cancer experience. This was what Little and colleagues (2001) described as
“acute” (p.40) liminality. Whilst my study participants’ liminal experience began with the diagnostic process their comments particularly focused upon the post-treatment phase of their experience – the ‘sustained’ liminality – that is the focus of this chapter.

**Being in a transitional world: the women’s perspective**

Women lived in a world characterised by liminality whilst they transitioned towards living a life after ovarian cancer. The term ‘transition’ means “the process or a period of changing from one state or condition to another” (Oxford Dictionary 2014i). A transition is a psychological process (Bridges 2009) of adaptation to change in our lives (Bridges 2004; Kralik, Visentin & van Loon 2006; Selder 1989) and is typically a time of uncertainty and vulnerability involving passage from one reality to another (Meleis, Sawyer, Im, Messias & Schumacher 2000; Selder 1989). Transitions can occur when one state ends (Bridges 2004), can be ongoing (Kralik & van Loon 2009) or can have an endpoint (Bridges 2004). They occur in many situations and can include health and illness (Meleis et al 2000), for example with the change from being a cancer patient to a cancer survivor (Pascal, Endacott & Lehmann 2009). Transitions involve making sense of and adjusting to change and incorporating new ways of Being-in-the-world (Bridges 2004; Kralik et al 2006).

It has been suggested that the experience of ovarian cancer is a series of rapid transitions (Schulman-Green et al 2012). However, in this thesis, the concept of women’s transitional world commences with the ending of their first lot of treatment (typically surgery and chemotherapy) for ovarian cancer when they were on the threshold of a new life post-cancer.

**Transitioning sense of self**

With the end of treatment came a new way of experiencing the world for women in this study - their ‘new normal’. They felt they were no longer the person they had been prior to their diagnosis and had somehow been changed by their experience.
Women were unsure of their ‘status’ – they were no longer active ‘cancer patients’ but were not ‘cured’ either. They were ‘neither one thing nor another’. They were in transition from being cancer patients to (hopefully) becoming long-term ‘survivors’.

Women’s feelings of uncanniness and of not-feeling-at-home-in-their-world (described in the previous chapter) persisted into remission. Women struggled to adjust and integrate their new sense of self into their lives after treatment. They described being aware of the transitional nature of their current situation. They felt they were on the threshold of ‘moving on’ and wondered how to regain their sense of ‘being-at-home’ with their self. For example, five weeks after completing chemotherapy, Nancy still felt ‘uncanny’ in her world and she wondered who she was and who she would become as she moved into her post-cancer future.

_I was a bit; I guess I’m still a bit concerned about how I would feel now? Um, particularly in a couple of month’s time when I don’t look like a cancer patient anymore. Um, I’m basically, you know, I’m not, I’m not a cancer patient anymore because I haven’t got cancer anymore. Um, what I will be, who I will be, what’s sort of left at the end there? Because that has obviously been something I’ve been able to identify with now for, you know, four or five months. That, that’s been a large part of my, my identity._

(W14.1303-1318.)

Women searched for a sense of belonging and ‘fit’ into their world. For example, after chemotherapy finished, Hilda experienced a strong sense of ‘now what?’ as she experienced the transition between treatment and her future. She grieved for her former life and former sense of self and struggled to sense who she was becoming.

_With the distractions of the busy treatment regime over, I find I’m beginning to ask myself if I can accept the realities of being a person with cancer. It must seem strange, but sometimes I still can’t believe any of it is true. I’ve been a little teary lately and I suppose there’s still plenty of grieving to catch up with. Even without the scary monster of cancer to contemplate, I do believe there’s grief with every transition – just letting go of the old expectations and moving to the new._ (W8.1485-1490.)
Leah felt that she was living a suspended life – in transition between her cancer treatment and her future. Whilst she hoped for a healthy recovery she was aware of probable disease recurrence. ‘Somehow remission doesn't quite fit how I feel.’ (W12.1693-1694.) Once diagnosed, Kate stopped work. In the first year after completion of treatment, she found herself transitioning between the worlds of treatment and returning to work. ‘So at the moment I’m just scratching my head about whether I’ll ever be able to demonstrate a full week’s work capacity.’ (W11.1077-1078.) No longer a cancer patient and unable to resume her previous work commitment, she missed her previous professional identity. She felt ‘betwixt and between’ statuses and wondered if she would ever be able to return to her previous world of well-being. ‘So I wonder how it’s all going to be in year two and three, if there is to be a year three, um, how it – what it will be like, as the upfront cancer experience fades away.’ (W11.800-802.) Little, Paul, Jordens and Sayers (2002) suggested cancer survivors face a “dilemma of self-creation” (p.176) associated with their post-cancer identity. This can be seen in my study as women sought to incorporate their ovarian cancer experience into their evolving sense of self.

Part of women’s evolving sense of self was demonstrated by their persisting identification with ovarian cancer. Paradoxically some women seemed to embrace aspects of their identity as an ovarian cancer survivor. One woman had ‘a teal ribbon’ – the emblem of ovarian cancer – tattooed on her back, which she wore like a badge of honour. Women highlighted the contrast in public awareness of ovarian cancer compared with other cancers such as breast cancer. Mary said, ‘they’ve done a fantastic job making everything pink but it’d be nice to see everything teal.’ (W13.1061-1062.) Referring to mammograms for breast cancer Audrey said ‘they don't tell you to do anything for ovarian cancer.’ (W1.2657-2658.) She added, ‘it’s not that well “out there”’. (W1.2812.) Ella stated, ‘it’s like the ovarian cancer doesn’t have the high profile breast cancer does, does it?’ (W5.668-669.) Ida stated ‘it does hurt me to think that all the [other cancers] are getting all this support and everything.’ (W9.1163-1164.) Whilst wanting to ‘move on’ to life without ovarian cancer, the women’s ovarian cancer experience persisted post-treatment reflecting the suggestion that cancer patients carry an enduring sense of being a cancer patient into survivorship (Little et al 2001; Little 2004). In my study ovarian cancer had become
an intrinsic part of their embodied Being in the world. Merleau-Ponty (2002) suggested that our past is “the atmosphere of [our] present” (p. 514). In my study women’s history of and identification with ovarian cancer determined the ‘atmosphere’ of their transitional Being-in-the-world.

**Being a ‘cancer veteran’**

There was a sense in the data that some women’s sense of identification as an ovarian cancer patient morphed towards that of being an experienced ‘cancer veteran’. With their acute ovarian cancer experience behind them, these women felt able to ‘reach out’ and ease the suffering of others. They described a heightened awareness of others undergoing illness. Leah explained, ‘It just feels as though there are many, many [ill] people and I don't know whether I’m just more aware.’ (W12.1569-1570.) Audrey also developed an awareness of the suffering of others. ‘You think you’re having it hard, but when you look around, there’s more having it harder.’ (W1.3379-3380.) Women described an increased sense of compassion towards people who were suffering illness. For instance, Cathy stated that when she met others with cancer, ‘I have a new-found empathy for their struggle – I have been in their shoes.’ (W3.para.11.)

Women responded to their heightened awareness and compassion for others by ‘giving back’ to their community and/or helping other people. For example, in response to a friend’s death from cancer, Mary became ‘determined to try and make a change’ (W13.956-957) in palliative health care delivery. Leah said she had ‘kind of had my share’ (W12.1535) of being cared for by others and wanted to reciprocate to others - to ‘kind of be supportive of them.’ (W12.1581.) Women explained their participation in the current study as a way of helping others. Audrey participated so she could ‘help someone in a quiet way.’ (W1.2817.) Ida explained her reason for participation: ‘if I can help someone, I don't think it’s any big deed. I just like to do it.’ (W9.1051.) Donna explained her altruistic reasons for participating in a clinical trial. ‘Well, really and truly I want to help others. ‘Cause that’s the idea of it. You’re helping somebody.’ (W4.748-750.) A common method described for ‘giving back’ to the community was educating people about ovarian cancer. Mary spoke to others
about her cancer in the hope that 'it might make a difference to someone.' (W13.601-602.) Hilda alerted friends to 'the warning signs for ovarian cancer.' (W8.2075.) Kate liked to 'volunteer for lots of research.' (W11.794.) She also acted as spokesperson for an ovarian cancer charity.

The sense of being an experienced ‘cancer veteran’ enhanced the self awareness of a few women who further developed their transitioning identity as cancer veterans by developing new professional opportunities related to health care. For instance, 18 months after her treatment completion, Olive described how her experience had broadened her personal and professional horizons, saying: ‘it’s been a really positive experience. Oh, in all sorts of ways.’ (W15.675-677.) She explained, ‘I’ve had new jobs, I had job opportunities open.’ (W15.681.) ‘I’ve had to learn so much. I’ve learnt so many new skills. My mind has broadened.’ (W15.694-696.) As a result, she aimed to work to ‘help other women’ (W15.701) with ovarian cancer. Similarly, Mary’s ovarian cancer experience gave her the ‘impetus’ (W13.597) to become ‘heavily involved in the health service management in our area’ (W13.132-133) as an active advocate for health reform. Four years after treatment completion, she explained, ‘That’s something I’m pretty passionate about because I – from an ovarian cancer point of view, I wouldn’t want any other woman to go [through] what I went through.’ (W13.146-148.) Her experiences with cancer ‘just made me determined to try and make a change.’ (W13.956.) Nancy also described a new professional focus as a result of her experience. She felt ‘there’s a reason that this, this has happened.’ (W14.1335-1336.) She responded to her experience by developing a business ‘to make it a bit easier for women who are ... losing their hair.’ (W14.1341-1342.) These women described new professional and/or personal directions resulting from their ovarian cancer experience. They found meaning in their cancer experience by actively seeking to enhance the cancer experiences of other people.

Literature suggests that increased compassion towards and desire to help others following a cancer diagnosis can be interpreted as an existential and moral response to heightened death awareness (Pascal & Endacott 2010; Pascal et al 2009). Pascal et al (2009) suggested that cancer survivors felt a heightened compassion for others resulting from their own difficult experiences. Their cancer experience facilitated
their ability to contribute and connect to others. In turn, this contribution to society helped survivors by promoting “meaning, purpose and reconnection to life after cancer” (Pascal & Endacott 2010, p.281). In this way, women’s concern and involvement, in my study, in the suffering of others can be seen as an interactive, mutually beneficial two way process. They helped others and by helping others, they helped themselves find meaning in their life, and reconnect to a sense of ‘self’. Nissim et al. (2012) suggested altruistic behaviour was a form of gift to society – a meaningful “living legacy” (p.377) for cancer survivors, enabling them to positively impact on the lives of others. Similarly, Kim (2010) described “leaving a legacy” (p.93) as a means by which women with gynaecological cancer coped with death anxiety and found meaning in life. King (2004) stated, “a sense of purpose is needed for life to feel worth living” (p.83) and O’Donohue (1999) suggested ‘every human heart seeks meaning; for it is in meaning that our deepest shelter lies’ (p.223). In my study, helping and/or supporting others assisted women to gain a sense of heightened compassion as well as a sense of belonging, purpose and meaning in their lives. Being able to experience heightened compassion towards others helped women make sense of what had happened to them whilst they searched for their ‘fit’ in their transitional world.

**Liminal corporeality – tethered to the past**

Despite having completed treatment women lived into their futures with ongoing bodily changes and vulnerabilities, hampering their transitional Being-in-the-world. Audrey said she had to learn ‘to live’ (W1.2146) with her ‘fear, that I wasn't a woman anymore’ (W1.2146-2147) as her evolving sense of self was impacted by persistent awareness of corporeal change. Donna explained: ‘I still have tingly feelings down my legs.’ (W4.2497-2498.) Five years after her diagnosis, Mary was still having ‘nerve pain’ (W13.381) explaining, ‘the last six months it's got worse.’ (W13.358.) Nancy had peripheral neuropathy, which she described as ‘numbness on the end of my fingers.’ (W14.411.) Audrey had ‘trouble with my legs swelling’. (W1.1226.) One woman described having ‘just a general atrophy of everything.’ Women described other persistent corporeal changes including deteriorated eyesight; weight loss or gain; ongoing fatigue; urinary incontinence; lymphoedema; menopausal symptoms;
and/or residual abdominal scars. Ida took care not to lose weight as she associated weight loss with cancer-related death. ‘I’ve got a little bit extra weight on at the moment but I don’t let that phase me, because I’m alive. I’ve heard of others that have lost the weight and they’ve gone down.’ (W9.162-164.)

Women experienced ongoing side effects of treatment as persistent embodied ‘uncanniness’. For example, Audrey felt ‘out of whack’ (W1.393) after treatment. Thirteen months after diagnosis, Kate still did not ‘feel right’ in her body: ‘there’s a lot of adjustment, adjustment to the physical. And I – I wonder if you ever really bounce right back after chemo.’ (W11.833-834.)

Regular ‘follow-up’ appointments with HCPs perpetuated women’s sense of corporeal ‘uncanniness’. After finishing chemotherapy, each woman had three monthly medical appointments to check for disease recurrence. These appointments reinforced women’s sense of ‘inertia’ and ‘status-lessness’, feelings which have been suggested as characterising liminal states (Turner 1969; van Gennep 1960). Cathy said,

*It would be lovely to think this illness is all in my past, forget about it and move on, but the reality is that I am going to be constantly reminded of it every three months when I go for my quarterly checkups.* (W3.para.12.)

The appointments, and associated sense of liminality, stretched into women’s futures. Olive explained, *‘I think they monitor you up to five years.’* (W15.377-378.) Almost five years post diagnosis, Ida lived from appointment to appointment. She said *‘five years is a bonus. I just get checked up all the time and we go from there.’* (W9.165-168.) Levels of anxiety increased for many women as their follow-up appointments approached and subsided after being given the ‘all-clear’. Regular phases of anxiety are typical of cancer remission experiences (Cohen 1993a). For example, Audrey described an imminent appointment. ‘*But I’m very anxious about it? I’m just sort of hoping and you sort of think about it and, mmm. The closer it gets the more I think about it.*’ (W1.3396-3401.)

‘Check-up’ appointments were preceded by blood tests to ascertain women’s CA125 level which for some women reflected their sense of being on the ‘brink’ of disease recurrence. Audrey had family members who had died from ovarian cancer and her
CA125 levels represented potential insights into her future. A low level meant she had a temporary reprieve from her fear of recurrence whilst a high CA125 had sinister implications signaling recurrence and probable death. ‘So [the doctor’s] going to do another [CA125 test] at the end of this month and if it’s still down after being off chemo for so long, he said, “Things are looking promising”.’ (W1.1110-1111.) Olive understood a continuing low CA125 level as hope for her future, interpreting her low CA125 levels two years after diagnosis as an indication that her chemotherapy had worked well. This meant that the chemotherapy drug could be used again if her disease recurred. ‘What’s good is it means I’m platinum sensitive. If it comes back, I can hopefully whack it again and have a bit more…[time].’ (W15.359-361.)

Women’s CA125 levels underlined their susceptibility to develop recurrent disease.

Ovarian cancer was experienced as a ‘hidden’ disease. There was a sense of women not being able to rely upon themselves to detect disease recurrence. Audrey worried whenever she felt an unusual pain. ‘You think “Oh.” You know you’ll get a bit of a pain and you think, “Mmm…”.’ (W1.1280-1281.) Olive described, ‘You imagine every ache and pain is the dreaded white, hard, invading stuff that will choke out your life.’ (W15.email.) Mary was advised by HCPs not to depend upon CA125 levels and to be vigilant for corporeal signs of recurrence. This was difficult for her as she struggled to believe that she could detect any recurrence.

Jordens and colleagues (2010) used the term “cancer gazing” (p.1555) and Guenther (2008) “perpetual vigilance” (p.124) to describe women monitoring their bodies for possible disease recurrence following treatment for ovarian cancer. Breaden (1997) called post-cancer-treatment bodies “the house of suspicion” (p.980) reflecting the embodied experience of persistent threat of recurrence. Jordens et al (2010) suggested, “it is difficult for patients to ‘read’ their bodies because a cancer diagnosis tends to undermine trust in it” (p.1554). In my study, as women struggled to believe in their ability to detect disease recurrence, most ‘kept an eye’ on their CA125 levels.
Without CA125 levels, women felt they could never know for sure whether the cancer was proliferating inside them, or not. Some women interpreted CA125 levels as an accurate indication of the presence or absence of recurrent disease in their body – as an indication of their physical well-being. They interpreted their CA125 result as literally a matter of life and death - their life and death. Jordens and colleagues (2010) suggested that for some women, CA125 levels tell “the truth” (p.1554) about their ovarian cancer status. Women in my study reflected this viewpoint. Two years after diagnosis, Olive described her anxiety prior to her regular CA125 blood tests. ‘About two weeks before a defining blood test, you start to churn.’ (W15.email.) Ida and Hilda both recorded their CA125 levels in a journal. Ida explained, 'I keep a diary of what I’ve gone through. You know, how my blood counts are each time I go. Monitor those and that sort of thing.' (W9.1962-1965.) Hilda wrote, ‘I’ve been to my 6-month check-up with the cancer specialist at the [hospital] and I’m still all clear. My CA125=5 and that’s a great low value.’ (W8.1915-1917.) She likened the results of CA-125 tests to passing or failing a test: ‘I passed the test yesterday (the blood test) – Phew!’ (W8. 2041.) (Five weeks after the above blog entry Hilda was diagnosed with disease recurrence.)

Little, Sayers, Paul and Jordens (2000a, 2000b) suggested liminality after cancer is characterised by awareness of the vulnerability of one’s body. In my study, women were unable to ignore or move on from their fallible body. They were not able to fully transition from their cancer-patient-status because persistent corporeal vulnerabilities, ongoing bodily vigilance and regular CA125 tests kept ‘bringing them back’ to their status as potential recurrent ovarian cancer patients. Their bodies tethered women to their past amidst their transition to their post-cancer self.

**Transitional relationality**

After treatment women became aware of changes in lived relationships with others and felt that people related to them differently. Kate worried about whether her friendships would persist into the future. ‘I’m a bit – going through a bit of a period at the moment where, especially now, I’m entering into year two. I think, “Oh” you know, “Will people lose interest in me because I can’t be as physically active?” ’
She knew she had been changed by her ovarian cancer experience - both physically and psychologically and was not sure if her friends would like the ‘eventual’ Kate. *Am I more boring now that I’m just like any old sort of sick person?’*

One woman wondered if she would ‘ever meet anyone in a romantic way, ‘cause, you know, I’m so physically changed.’

Some relationships were enhanced. For example, Cathy said, ‘*My relationship with my husband has grown even closer than it was.*’ She added, ‘*relationships mean everything to me now.*’ However, some women described feeling abandoned by loved ones after treatment stopped. There was a sense of a ‘disconnect’ between women’s liminal world and the expectations of others as friends and family members considered women to be well and expected them to resume their normal lives. The expectations of others emphasised women’s sense of isolation and existential loneliness already being experienced and didn’t correspond with their altered/altering identity. They felt they were still in the world of cancer although they were no longer cancer patients. They were in a liminal world, which they felt others did not understand. For example, one woman’s girlfriends held a regular morning tea for her whilst she was having chemotherapy, which she described as being ‘*hugely important*’ to her – a fundamental source of support. Once her treatment ended, the morning teas stopped. Her friends assumed that she no longer needed regular support. ‘*But then – it stopped. You know, once the chemo stopped, because then, you know, “You’re right”.’* Her friends’ assumption did not correspond to her sense of self as she did not feel ‘right’. She felt in limbo and needed their support to continue as she transitioned into a new sense of self – until she could regain a sense of ‘being-at-home’ with herself. The abrupt ending of the morning teas left her ‘hanging’. Similarly, whilst she was having treatment, a number of Olive’s children lived near her and were attentive to her needs. However, after she completed treatment, her children relaxed their attentiveness and moved away ‘*because they think I’m healthy.*’

Some women felt their husbands expected life to return to normal as soon as chemotherapy stopped. They didn't seem to understand that, for the women, the ovarian cancer had not ended. One woman explained:
I think he’s – he’s – he is of the opinion that, all right as soon as chemotherapy had finished (and he didn’t pay much attention to it anyway, um you know, my symptoms or anything like that). It was just, once chemo finished, “It was over”.

Communicating their sense of liminal self to others was difficult for the women who felt unable to share their liminal world with family and friends. Audrey explained, ‘you sort of just tell them the basics... you don't sort of go into detail.’ (W1.2030-2031.) Women felt that others did not understand the ‘betwixt and between’ state in which they lived. Literature has suggested similar. Writing after her ovarian cancer treatment, Stacey (1997) said, “The isolation of the suffering and the impossibility of articulating its enormity had left me feeling like a stranger surrounded by familiarity” (p.20). Thompson (2005, 2007) submitted that social contexts of women’s lives contributed to feelings of liminality by impacting their ability to share their ovarian cancer experience. Rasmussen, Hansen and Elverdam (2010) suggested that society imposes a “culture of silence” (p.158) upon cancer survivors, restricting the ability of the cancer survivor to discuss their experience. Little et al (2001) linked feelings of ‘separateness’ from friends and family to a sense of liminality for cancer patients, suggesting that cancer patients often felt a “sense of alienation” (p.35) from usual relationships based upon an inability to articulate their experience. In my study, Mary said, ‘it felt hard to talk to people about what was happening to me.’ (W13.172-173.) Leah clearly described her sense of ‘communicative alienation’.

Most people when they ask me how I am and I say, “I’m really fine, I feel really well.” People don’t ask me much more. They just say, “That’s good”. If they ask me more, I’m never quite sure what to say because I feel as though I haven’t quite got the words for it. (W12.1690-1693.)

Whilst women wanted to transition from their cancer experience, several women in my study experienced the end of treatment as a ‘loss’. For some women, this involved an absence of contact with others. Donna had enjoyed the contact with hospital staff. ‘I’m going to miss going in there.’ (W4.678.) She joined a clinical trial to continue her contact with the hospital staff. Kate regretted losing the support she received during her treatment. ‘I’m a bit grieving the loss of it now.’ (W11.753.)
Women also ‘lost’ the structure which regular treatment and appointments had given to their life. Olive found ‘there is that period when you think, “Oh, that’s not there anymore”.’ (W15.554-555.) She ‘filled that gap’ (W15.582) by keeping busy with attending cancer support groups and health centres. Similarly, Kate filled her time attending cancer-related appointments such as ‘support groups, psychologists, research meetings.’ (W11.1082.) Nancy also joined ‘some groups’. (W14.697-698.) It was as if the women searched for like-minded others, who could understand the liminal world in which they now lived. Leah went to support group meetings because she felt ‘a real connection’ (W12.1427) with the group members. Keeping busy with cancer-related appointments provided women with a sense of purpose and meaning to their lives whilst they transitioned to who they were becoming and how they might fit back into life.

An uncertain future - The ‘monkey on the shoulder’

Women lived into their future with an ongoing consciousness of the poor prognosis associated with ovarian cancer. They tried to integrate their awareness of their vulnerability to dying from their cancer into their developing sense of self. They lived with fear that the disease would recur and they would subsequently die. This fear developed after diagnosis and continued post-treatment. Their death fears took the form of uncertainty towards their future. However, unlike the ‘uncanny’ uncertainty discussed in the previous chapter, women’s fear of recurrence was experienced as a very deep and omnipresent menace – a ‘shadow’ cast over their efforts to resume a normal existence. Six months after surgery for early stage disease, Cathy wrote: ‘The shadow [of ovarian cancer] is going to hover with me for some years yet and I have to admit that I’m still learning how to live with it.’ (W3.para.12.)

Women’s efforts to transition to a ‘normal’ post-cancer life were hampered by their awareness of the possibility of their cancer-related death. They lived in an enduring liminal state of knowing that they were always on the threshold between health and terminal illness. Some women fully expected to develop recurrent disease. Ella had been ‘been dealt a kind of a bit of a blow’ (W5.598-599) by understanding that ovarian cancer was how she was almost certainly ‘going to die.’ (W5.600.) Donna
was realistic about her likelihood of recurrence. ‘I don’t suppose it has all gone – the cancer.’ (W4.2686-2687.) Kate lived in a boundary-world between health and life-threatening illness as she waited for her cancer to return. She said:

*Of course everybody – almost everybody has a good first year – after treatment. So it’s not like, “Oh, that’s good, you’ve come so far, things are going to get better now.”* [Different voice put on]. *Wrong, wrong, wrong, with ovarian it’s the opposite. Good first year and then you start to have your relapses.* (W11.1107-1110.)

Kate added, ‘*So this is my bad year for risks.*’ (W11.1114.)

Two years after diagnosis and treatment, Olive expressed lingering uncertainty regarding recurrence of her ‘quite advanced’ (W15.1110) cancer. ‘It might come back. I don’t know. No idea. I don’t know where I’ll fit on the bell curve.’ (W15.1136.) Years after treatment for early stage ovarian cancer, Ida glanced at her left shoulder and explained: ‘Yeah, I’ve got the monkey sitting there, so I just hope he doesn’t rear his ugly head’. (W9.707.) Four months after treatment ended, Audrey and her husband were ‘hanging on’. She stated, ‘*we’re here, we’re still battling.*’ (W1.3493.) Four years after completing treatment, Mary remained in a liminal state, where she was unable to fully ‘move on’ from her cancer.

*The world suddenly stops when you are told you have cancer but while you may be frozen with emotion, you mind begins a whirling race, which over time you learn to manage but I don’t think you finish. You learn eventually to live not looking over your shoulder all the time but it is okay to glance back once in a while to check – just in case.* (W13.para.9.)

Women’s fears of recurrence were directly related to the grave implications recurrent disease would have for their prognosis. Various authors have described this fear in relation to ovarian cancer as “dealing with an early death” (Bowes et al 2002, p.135), “facing the death threat” (Reb, 2007a, p.187), “living in the face of death” (Thompson 2005, p.72) and “Damocles Sword” (Cesario et al 2010, p.615). In my study, Mary tried to live a ‘normal’ life but was always aware of the threat associated with her disease. Her fear of recurrence and subsequent death was a constant
companion. ‘It’s a constant thing. It’s there in the background’ (W13.581-583) adding, ‘it’s constantly there.’ (W13.587.)

**Being-towards-death**

Heidegger (2008, 2011) suggested that accepting the inevitability of our Being-towards-death enables us to achieve insight into the importance of the way we live our lives. He thought that we typically feel anxiety in the face of the inevitability of our death and that this death anxiety was a means by which we could live more authentically. For Heidegger, living authentically meant living with a heightened appreciation that this moment may be our last. Heidegger (2008) suggested that we can either ignore or ‘face up to’ our death anxiety. When we truly understand and accept our Being-towards-death, “resoluteness” (p.354) enables us to authentically Be-our-self. Resoluteness is “authentic Being-one’s-Self” (p.344). His term ‘resoluteness’ can be understood as “openness” (Dreyfus 1991, p.318). For Heidegger (2008), being resolute in the face of our certain death meant being open, and intuitively responsive to possibilities in our world. It meant being true to our values and concerns so that the acceptance and anticipation of the inevitability of our death ‘freed us up’ to make meaningful life choices. Being resolute in a situation leads to authenticity, which changes the character of our Being-in-the-world. Our world doesn't change – rather the way in which we live in our world changes (p.344).

The relevance of these concepts to the women in my study becomes clear when one considers the liminal state in which women lived post-treatment. All women knew the poor prognosis associated with ovarian cancer and most believed that they were at risk of dying an early death from their disease. In response to their death awareness, women described ‘being open’ to changing the way they lived their life. Cathy explained, ‘facing a potentially life-threatening disease does wonders for setting priorities in life.’ (W3.para.9.) For example, death awareness changed the character of lived time for women and some women focused on living in the present. Ida valued the day at hand. ‘Yeah, I just try and put as much as I can into my life now. And you know, enjoy what I can, because you don't know what tomorrow’s going to bring. None of us do. And so I just sort of do that.’ (W9.930-934.) Cathy stated, ‘As I
now have a heightened appreciation of time, I do not want to waste a ‘Today’ by fearing about what may happen ‘Tomorrow’. ’ (W3.para.12.) Ella stated, ‘I just take one day at a time.’ (W5.471.) Hilda tried to ‘balance’ (W8.1498) her focus on the present with small healthy amounts of reflection and forward planning. ’ (W8.1498.) Rasmussen and Elverdam (2007) suggested, “cancer survivors find themselves unable to imagine a future and therefore concentrate on living in the present” (p.619). The majority of women in my study tried to focus on the present moment, whilst they simultaneously worried about their future.

Few women spoke of long-term plans. Ida was the only woman who described a goal, which reached years into the future. She had survived five years post-diagnosis and hoped that she would see another five’. (W9.679.) When diagnosed, Mary made a goal to see her youngest child reach school age. Four years past the end of treatment, she was just about to my goal.’ (W13.602.) For most women, the plan-able future stretched as far as their next follow-up appointment and no further. Stuck in a liminal space, it was as though they could not make any plans further away than three months. For example, anticipating her follow-up appointment, Audrey hoped that everything goes all right.’ (W1.1086.) Whilst few women spoke of future goals, several described actively anticipating their future, including their possible ovarian-cancer-related death. In a sense, for these women, the time of transition was experienced as a ‘hiatus’ between the cancer and their likely recurrence and subsequent death. For instance, some women spoke of ‘tidying up loose ends’ before they developed recurrent disease and died. Kate organised her affairs, to make things easier for her family in the event of her becoming too ill to care for herself. ‘I didn’t want to make a problem for them, by having cancer and dying on them.’ (W11.624.) She spent time sorting out my apartment and getting rid of things, cleaning things up, getting my will updated.’ (W11.1250-1251.) Hilda also cleared possessions. ‘It’s not so much downsizing as attempting to get realistic.’ (W8.2006-2007.) Leah expressed a sense of urgency about visiting friends whilst she was still physically capable of travel and before she died of her disease. ‘I really want to see people in [country] because I might – you know, some of them I might see anyway, but others, I might not.’ (W12.1774-1775.)
All women valued health and the continuation of their lives. Audrey prioritised her health and looked ‘for better things’ (W1.1612) to eat. She was proactive with her health, to increase her chances of being disease-free. For her what mattered was that ‘you’re alive, you’re healthy, you’re well.’ (W1.1538.) Two years post-diagnosis, Olive also prioritised maximising her health. However, her focus was directed towards building strength before she developed recurrent disease. ‘I want to make my immune system strong? So that when the cancer cells come back, my body can hopefully deal with it.’’ (W15.665-667.)

In the face of a future that they believed would most likely contain their ovarian-cancer-related-death, women changed the way they lived in the world. In the face of their Being-towards-death, women prioritised their health. Some women focused upon and valued living in the present moment, knowing that their health status would change dramatically with the diagnosis of recurrence, which would lead to their subsequent death. Several actively planned for their demise by sorting their affairs and minimising possessions. All lived in a suspended, liminal space where they could never quite escape their cancerous past as they transitioned towards their ominous future.

Summary

Women experienced life after ovarian cancer treatment as Being in a liminal world of transition. This is illustrated by Figure 16, in an iMindMap.
Being-in-the-world ‘in limbo’: the partner’s perspective

The sub-theme of ‘being in limbo’ describes the liminal world of partners as their wife transitioned out of treatment. ‘Being in limbo’ provides a further interpretation of partners’ experience of the phenomenon of ovarian cancer. ‘Limbo’ is defined as “an uncertain period of awaiting a decision or resolution; an intermediate state or condition” (Oxford Dictionary 2014j). The term ‘in limbo’ is used in this study to describe the sense of waiting for a situation to resolve.

Most men in my study had wives who had completed first-line treatment and they lived in a world of limbo whilst waiting for their wife’s ovarian cancer situation to resolve. Their assumptive world had been shattered by their wife’s diagnosis and their life remained intertwined with the phenomenon as they waited for their future to develop. Their vision for the future was framed by their concern for their wife. They lived a suspended life, where they wanted to ‘move on’ from the phenomenon of ovarian cancer but struggled with the reality of their wife’s potential for a cancer-related death. They were ‘in limbo’- living in an ambivalent situation characterised by a sense of being on the cusp of a new situation yet linked to a previous world. Their life remained enmeshed with and dominated by the spectre of ovarian cancer.

Being ‘in limbo’ – ongoing threat of death

All partners articulated the possibility of their wife dying from her cancer. They knew the bleak prognosis commonly associated with the diagnosis and understood their wife to be at risk of succumbing to the cancer. David explained, ‘Basically I think we’re, we’re under no illusion that what she’s got is um – is significant. And the outcome, for most – for most women with her situation is not very good.’ (P3.465-467.) Hugh acknowledged, ‘We think – no-one knows [what will happen].’ (P7.133.) Jack said that his wife’s ‘long term prognosis is not good.’ (P9.1624.) Some partners described anticipating the loss of their spouse. Fred wondered: ‘To lose your partner and – and that’s what would go through everyone’s mind. “What if I lose my partner, lose my wife?” ’ (P5.226-227.) David struggled to describe coping with his grief.
Sometimes you feel – it’s difficult to know, how to feel. Because emotionally I um – I – I think that the sadness is my loss if it occurs, you know, but then you think that’s selfish because what about – what about [wife] you know? (P3.483-486.)

Two years after his wife’s diagnosis, David cried as he described his ongoing fears for her life. He commented, ‘you think you are over it.’ (P3.300-301.) Months after his wife completed treatment, Ivan explained that thinking about the future was ‘still something I try not to do too much. It’s just too difficult to contemplate too much about that.’ (P8.650-656.)

Life ‘on hold’

With the completion of treatment, partners felt they were on the threshold of an unknown new life, which offered both hope and fear - hope of resuming a ‘normal’ life and fear of the threat of disease recurrence and subsequent death of their wife. Men interpreted their wife’s health as a form of thermostat, which set the tone and pace of their lives. Their wife’s health was the foundation upon which men lived in the liminal present and looked to the future. That is, her health directed their present and future, just as it had their recent past.

In the months following treatment completion, men spoke of waiting for their wife to regain her health. Fred said, ‘She needs – needs that support now as much – and still needs that support.’ (P5.131.) Grant’s wife was ‘so exhausted.’ (P6.439.) Partners’ lives were lived in a ‘holding pattern’ whilst they waited for their life to return to ‘normal’. Fred continued to put his life plans ‘on hold’ (P5.282) while his wife recovered from treatment. ‘It’s only for – not a long time, it’s only for a month or so.’ (P5.598-599.) Grant’s wife had recently completed treatment. ‘The beautiful thing now, she’s actually finished it now which is good. So its just a matter of her getting herself back on – back on track and back to a normal life.’ (P6.420-422.)

Men waited in limbo for the success of their wife’s treatment to be determined in time. Charles described, ‘you worry, but hopefully it’s turned out alright.’ (P2.369.) Grant and his wife had ‘requested a few more check-ups and CT scans just to make
sure that nothing will show itself up again.’ (P6.443-444.) Grant referred to five years as being the point when he could feel assured his wife’s cancer was cured. ‘We won’t know until really about five years if they know that it is totally, is all clear and um – and ah that’s it, and it won’t come back again.’ (P6.451-453.)

As wives regained their health after treatment, partners’ enmeshment with the phenomenon began to change character. Their lives were still directed by the cancer but were no longer necessarily dictated by it. Partners focused upon their wife’s apparent good health as a form of determined hope for the future. David described his wife’s current health as ‘excellent, excellent’. (P3.520.) ‘You wouldn’t know that anything had happened.’ (P3.523-524.) Jack was heartened by his wife’s fitness and vitality. ‘The cancer’s gone, um, or not showing itself. She was fit before, so right, she’s just back to normal!’ (P9.1761-1767.) Two years after her treatment concluded, Hugh described his ‘well’ (P7.356) wife. ‘She’s energetic and running around and wanting go for walks all the time.’ (P7.196-197.) Ivan’s wife’s current health offered the couple the opportunity to (hopefully) enjoy a few months together without dealing with recurrence and treatment. ‘I’d expect that she’ll – she’s going to have a reasonable period for at least the next, maybe months? Hopefully?’ (P8.673-674.)

Persistent concern and monitoring health

Partners were unable to escape their ongoing link with the phenomenon and they described ‘monitoring’ their wife’s health via her CA125 levels. For example, Hugh said, ‘I do keep a very close on her, what her, her, her blood composition is, so that’s the way I keep track of [wife’s disease] now.’ (P7.239-240.) He explained, ‘She has a blood test once every three months.’ (P7.211-212.) Regular CA125 tests were a constant reminder for partners of their wife’s disease. David remained in a state of perpetual insecurity about his wife’s prognosis. He explained,

There’s always – there’s always blood tests you know, there’s three-monthly blood tests to um – um to kind of contend with, I suppose. You know, that’s always going to be there. And so it um – and I’d just say you’re thinking about it constantly, I guess. (P3.496-499.)
Men interpreted reduced CA125 levels as a temporary reprieve from their ongoing concern for their wife’s health. For Jack his wife’s reduced CA125 level meant he felt his wife could regain her health after treatment and that she was temporarily safe from disease recurrence. ‘It gave me confidence for the medium term prognosis. That, okay, she’d be able to get her strength back.’ (P9.1199-1201.) David interpreted a reduced CA125 as a hopeful sign that his wife was currently free from disease. ‘So we’re very thankful and just looking – looking for any break we might get.’ (P3.464-465.) For David, the reduced CA125 meant ‘there’s nothing threatening at the moment.’ (P3.528.)

CA125 levels were viewed as an indicator that would give the couple ‘advance warning’ of recurrent disease. David explained his understanding.

\[It’s a very, very fast marker and so if – if it does change, then it’s not like [the cancer’s] back with a vengeance. It’s giving you some time to kind of – to prepare for the next stage, the next stage of chemo, you know.\] (P3.947-950.)

Jack also anticipated having a window of time between the development of recurrence and the commencement of any further treatment. ‘And apparently if the cancer does recur, there’s quite a number of months, um, before they say, you know, after you start to notice symptoms, before they say they will actually start to do anything about it.’ (P9.1680-1683.) Ivan was in limbo as he anticipated recurrent disease. For him, recurrence was just a matter of time.

\[Absolutely, there’s going to be a recurrence to deal with. We’re going to have a CA125 at one point that’s going to go up. Um, we’re going to have to go through everything we’ve been through again. That’s what I’ve got to prepare myself for, don’t I? I’ve got to prepare for that.\] (P8.752-761.)

Thorne et al (2006) suggested that numerical values influence the way cancer patients understand their cancer. In my study, it was apparent that family members also interpreted numerical values, such as CA125 levels, in order to make sense of their loved one’s cancer.
Men lived in limbo whilst they waited for their future to take shape. Future plans were conditional upon their wife’s health and the men lived with the knowledge that the status quo might change at any moment. David stated, ‘Uncertainty is the cruel thing. You can’t make any – any – you know, any significant plans and stuff.’ (P3.495-496.) He added, 

And you’ve always got kind of, I suppose, the ah – when you make plans you’re kind of thinking well, what if and what if and what if and stuff, you know. You still make plans, you know, but you – but you can never – you have to – you have to – you’ve always got an alternative kind of option there just in case. (P3.939-942.)

Ivan explained, ‘I really wouldn't want to think more than, you know, a month ahead. I find that really difficult to plan more than that ahead at the moment.’ (P8.680-684.)

Men tried to integrate the unknown future into their day-to-day lives. David stated, ‘You’re always wondering, you know – the future.’ (P3.932.) Ivan was on the threshold between treatment and follow-up of his wife’s cancer and he had ‘no idea’ (P8.1301) what ‘comes next’. (P8.1301.) The men utilised various approaches to manage their concerns. Grant lived on a day-by-day basis. He said it was ‘just a matter of working it through’ (P6.461) and managing ‘each day as it comes.’ (P6.462.) Confronted by his wife’s poor prognosis, Jack described deliberately trying to avoid thinking about the implications of recurrent disease. ‘The issue, yes, sort of in my mind now, is the long term, and there’s a kind of worry, that I’m leaving aside.’ (P9.1370-1371.) Hugh tried to be pragmatic and optimistic about the possible future. ‘I said, “Look, if it recurs, [wife], we’ll just – we’ll treat it.”’ (P7.358-359.)

David’s present was suspended between the past world of his wife’s treatment and his anticipation of recurrent disease. ‘Everything’s anticipating, you know, in terms of what – what’s likely to happen. And I suppose you know being prepared is the main thing, getting information, getting information for that.’ (P3.956-958.) Likewise, Ivan had ‘an expectation’ (P8.1687) that his wife would develop recurrent disease. He described holding himself ‘in check’ in the liminal period between his wife completing treatment and the recurrence he expected to occur. ‘Even though I’m
willing to start thinking a little bit ahead now, I’m still conscious that I’ve still got some huge things to deal with in the future. [Spoken quietly.]’ (P8.748-750.) He was actively preparing himself for his wife’s recurrence and subsequent death. ‘I’ve got to prepare for it emotionally and logistically.’ (P8.763.) He added, ‘that’s the role I have to play. I have to be ready.’ (P8.781.)

One man described living ‘in limbo’ as he actively prepared for his wife’s recurrence to occur.

*Just organising – do the – when you have a quiet weekend where she’s reasonably well... I’ll just have to try and do as many of those preparatory things, whether it’s fixing the front door, or loading up the wood box or whatever, you know, getting those things ready when there’s an opportunity to get them ready in anticipation of having a bad week next week, a bad month next month.*

David said, ‘the ultimate outcome is the most important thing I guess, you know. Time’s just going to tell, you know.’ (P3.852-853.)

Discussion

Partners in my study lived with a sense of watchfulness, whilst they waited for their future to eventuate. On one hand they anticipated their life returning to normal but they also experienced ongoing fears of recurrent disease and the implications for their wife’s life. Despite waiting to ‘move on’, partners couldn't escape the possibility of their wife developing recurrent disease.

Earlier literature described partners living “in limbo” after loved ones completed treatment for breast cancer (Harrow, Wells, Barbour & Cable 2008, p.349; Wilson 1991; Zahlis & Shands 1991). Wilson (1991) described spouses’ experience of the period after treatment for breast cancer and before possible recurrence as “marking time” (p.301). Bischke (2002) described the period of remission as “an eternal holding pattern” (p.262). Spousal expectations that life will return to ‘normal’ after cancer treatment completion do not always eventuate (Lethborg et al 2003; Little et al 2001) and ongoing fears of recurrence have been reported following a loved one’s

Heidegger (2008) suggested the concept of temporality was fundamental to understanding our Being-in-the-world. Our past, present and future are all inter-connected and each is interpreted in light of the other (Heidegger 2008; Merleau-Ponty 2002). In my study, partners experienced the present moment as being an intermediate, suspended state between their past and their future. Their present remained tethered to their past, which influenced their understanding of their future. Merleau-Ponty (2002) suggested, life “unfolds” and “there is no way of bringing it about other than by living that life” (p.491). This is reflected in my study where partners had no choice but to live through their current circumstances. They waited in limbo in the present for their life to unfold and their liminal situation to resolve itself, one way or another, through time.

In summary, partners experienced the phenomenon of ovarian cancer as living in limbo in a liminal world. This is illustrated by the iMindMap in Figure 17.

**Figure 17:** Partner’s liminal world
Being in a terminable world: the children’s perspective

Children’s experience of liminality is described in this chapter section under the sub-theme of ‘Being in a terminable world’, which describes their sense of bounded time as they lived with awareness of their mother’s illness into the future. The term ‘terminable’ means “coming to an end after a certain time” (Oxford Dictionary 2014k) or “terminating after a specific period or event” (Collins 2014). In my study, after their mother’s treatment finished, children found themselves living in a liminal space. Their experience of ovarian cancer had confronted children with the inescapable threat of their mother’s mortality and they now lived with the foreseeable loss of their mother. Their sense of being betwixt and between their mother’s current health and her potential recurrence (and subsequent death) meant that children lived with a sense of temporal limitation. They lived in the present moment, with the expectation that everything would dramatically change once recurrent disease was diagnosed. Children’s concerns and uncertainties about their mother’s prognosis stretched into their future. Children’s Being-in-the-world was characterised by a sense of temporal boundary; they understood their terminable world as existing until their mother’s ovarian-cancer-related death.

Temporal limitation: Living ‘the tightrope’

Children’s experience of maternal ovarian cancer was ongoing in terms of temporal uncertainty and existential awareness. Interviewed between six months and five years after their mother’s diagnosis, there was little current day-to-day impact on the lives of the children in my study. Their mother appeared to be strong and was neither ill nor diagnosed with recurrent disease. Laurie explained: ‘I suppose now that she’s much more healthy, and robust in terms of getting over the initial surgery and the chemotherapy, um it doesn't have a huge sort of day to day impact, in a lot of ways.’ (C3.9-12.) A lingering existential impact of the illness took the form of temporal limitation. Children lived their lives with a heightened awareness of their mother’s prognosis and potential for an early death. For example, Eliza explained how she lived in the terminable present, waiting for the future to bring her mother’s recurrent disease. ‘The impact is much less now. And it’s a fairly minor impact now. I think the
impact is the future, um, the concern about the future. That’s the impact; that it’s a background concern and that, you know, I can foresee, if it does come back, that there will be a big impact again.’ (C1.354-357.) After treatment ended, Kevin’s mother’s cancer had little practical impact upon his life. However, it continued to impact via his heightened death awareness and his accompanying sense of temporal boundedness. ‘It’s almost more of a philosophical impact than a practical impact.’ (C2.228-230.) May (2009) suggested we all “navigate our lives in the shadow” (p.34) of knowing we will die but not knowing when. In my study children navigated their lives knowing that their mother would probably die of her disease, but not knowing when that would occur. They lived in the present whilst waiting for news of recurrence to initiate termination of their liminal world. Persson and Sundin (2008) stated significant others of inoperable lung cancer patients viewed the death of their loved one “as the ultimate threat” (p.384). In the present study, children experienced their liminal world as tentative and uncertain and saw their mother’s death as being the end of the world as they knew it.

Similar to partners it was as if most children’s future hinged upon their mother’s health, which enforced temporal boundaries around their present and postponed their future. For Val, ‘It was the uncertainty’ (C7.1876) of her mother’s health that worried her the most. Follow-up appointments were seen as pivotal to children’s futures. Pending oncology appointments were viewed as ‘D-day’ (Tess-C5.593) and critical for determining how well their mother’s cancer responded to chemotherapy. Wendy described living from one appointment to the next: ‘As far as mum’s concerned and, and, and how she goes, um, we live the tightrope. We literally live that tightrope.’ (C8.1146-1147.) The tightrope constituted Wendy’s present terminable Lifeworld, bridging her past with her postponed future.

Children’s lives were changed by their mother’s ovarian cancer experience and they struggled to live in a present, which they understood as being finite. They had ceased taking their mother’s life for granted and lived with a lack of clarity about their mother’s future. Tess explained ‘No-one’s got the answers, no-one does. It’s just, this is reality. You know, this is what possibly will happen.’ (C5.666-672.) Children expected their mother’s disease to be the cause of her death. In a sense the uncertainty
of the future offered them more certainty than uncertainty. This paradox reflected the
certainty children felt regarding their mother’s death from her cancer, but their
uncertainty regarding the likely timing. This persistent (un)certainty of their mother’s
health tied children to their liminal, and terminable world and curtailed their ability to
project into the future. Tess explained: ‘Not knowing. Not knowing what’s going to
happen in six months or 12 months. Not being able to plan, I guess.’ (C5.462-465.)
Mark hoped that his mother’s ‘remission will be extended hopefully... [pause] for a
long time.’ (C4.489-490.) In the interim, children marked time, waiting for recurrence
of their mother’s cancer.

Eliza commented: ‘It’s difficult for everyone. ‘Cause I know that no-one will say that
she’s cured, but, um, I, I just find that difficult.’ (C1.106-107.) Mark wondered about
the likely timing of his mother’s death: ‘who knows whether it’s going to be five or
20.’ [years] (C4.402-403.) His comment reflects his sense of lived time. His
terminable world was experienced as ongoing yet ultimately finite. Tess described
living in a suspended present, waiting for the ‘Sword of Damocles’ (of recurrence) to
fall and end her liminal world. ‘We just know there’s something hanging over our
head that’s always going to be there, that can change in an instant.’ (C5.481-482.)
Wendy also lived in frozen time, bracing herself for recurrence of her mother’s
cancer. ‘You wait for the day when [doctor] says “Oh well”, [long breath and sigh]
you know, “It’s come back.”’ (C8.1397-1398.) Children lived betwixt and between
their mother’s current health and recurrent disease. Una explained her constant sense
of concern: ‘It’s always in the back of your mind, “Is she going to be okay?”’
(C6.2215.) Laurie explained: ‘I’m probably just a little bit more aware of time
limitations in mum’s, in terms of mum’s life.’ (C3.492-493.) Living interstate from
her mother, Eliza lived in anxious anticipation about how she would cope when her
mother’s disease recurred. ‘I’m sort of thinking of, ah, logistics of me being here with
three kids and I’m thinking it’s just going to be really hard when it does [recur].’
(C1.113-114.) Una asked: ‘What do you do when – if she’s not here?’ (C6.2216.)
Wendy was actively preparing for the end of her current terminable world. She
described how she woke at night thinking of her mother’s funeral and pictured herself
saying her mother’s eulogy. ‘I can actually visualise – what I’ll say. And the fact
that I won’t cry. So I’m preparing [for her death].’ (C8.1531-1533.)
Children’s quotations reflect their experience of living in a liminal, frozen, yet terminable present. Arceneaux and Myers (2011) suggested, “Hopelessness freezes time”. In my study children’s knowledge and experience of the phenomenon of ovarian cancer gave them a sense of certainty (and thus hopelessness) about the inevitability of their mother’s eventual ovarian-cancer-related death. This led them to a sense of being in a frozen temporal space; where time stood still. Carlander, Ternestedt, Sahlberg-Blom, Hellstrom & Sandberg (2011) reported that family members of a relative with a terminal illness felt their lives were on hold. Children in my study expressed similar sentiments. They felt they were living in the terminable present whilst waiting for their (recurrent-ovarian-cancer-related) future. Their future was tied to their mother’s health and they marked time on the threshold between their mother’s health and probable cancer-related death.

‘Carpe diem’: making the most of the present

Children understood their terminable world as existing whilst their mother was healthy. When the terminable world ended, their mother would have recurrent disease. Children automatically associated recurrence with their mother’s subsequent death. The terminable nature of their world prompted children to consider existential issues. Some experienced a heightened awareness of mortality. For example, Kevin commented: ‘It’s certainly made me think more about my parents and their mortality and perhaps even my own mortality and, you know, others that I love as well.’ (C2.202-204.) For Laurie, his mother’s illness meant ‘you sort of confront your own mortality and all that sort of stuff.’ (C3.45-46.) The experience of maternal ovarian cancer confronted these children with the impermanence of life. Values and priorities were also re-assessed. For example, Laurie described how his mother’s cancer had ‘made me sort of look at things again and reassess things again and make sure that I still prioritise what I think’s important for me and all that sort of stuff for my family.’ (C3.613-616.) Anna developed ‘some perspective’ (C9.522) in her life. Wendy said she had gained an appreciation of ‘values’. (C8.1319.) ‘You take away what’s really, really important.’ (C8.1322.) Tess felt she had become more aware of her values ‘because you just take everything for granted before.... but now we just have to tread a bit more careful.’ (C5.485-487.)
Children’s sense of Being in a terminable world – knowing that it could end at any time - led to their desire to ‘make the most’ of the moment. Anna described how her mother’s illness had inspired an attitude of ‘carpe diem’. ‘Just make the most of what you’ve got, sort of thing.’ (C9.693-694.) Tess said: ‘Don’t take things for granted? Don’t sweat the small stuff, and live for now.’ (C5.217-221.) She added, ‘I don’t save for the rainy day because every day is a rainy day. If I want something I’m doing it now.’ (C5.698-699.) Val also focused upon the present rather than the future. ‘I’m not even thinking about her future. Because, - well we just live for today.’ (C7.1990-1992.) Children anticipated that life would change for the worse in the future and opportunities to spend time with their mother were viewed as being precious and limited. Laurie explained: ‘I don’t want to miss opportunities to catch up.’ (C3.16.) Wendy described maximising the interim period between the present and the future. ‘We make every time of the year special – Christmas, Easter, Mother’s Day – always as if maybe, maybe not?’ (C8.1484-1484.) ‘We changed our values a little bit more now. It’s a little bit more, um, just taking the time to enjoy the time.’ (C8.1490-1491.) Laurie described living with a feeling of being in a terminable ‘no man’s land’, waiting for his mother’s disease to recur. ‘Despite her really good health at the moment, I guess I do have that feeling in the background – that, you know, we’ve got to make the most of the times that we have.’ (C3.508-510.) Eliza visited her parents ‘more frequently.’ (C1.345.) Mark spent much of his time ‘helping mum and dad.’ (C4.360.) Kevin said: ‘I guess it’s made me want to sort of visit them, you know, more often? And make sure that, you know, I do have sort of as much quality time with them as I can?’ (C2.206-209.)

Children described finding meaning in focusing upon ‘the important things in life’ within their terminable world. A number of authors have suggested that loved ones of cancer patients could find meaning from their experience (Lindholm et al 2002; Persson & Sundin 2008). Little and Sayers (2004) suggested that loved ones of cancer patients at risk of dying find comfort from bonding with others. In my study, children interpreted the terminable nature of their liminal world as inspiring them to enjoy time with their mother, whilst they still had the chance. They ‘seized the day’ and enjoyed the present moment, with the expectation that their liminal world would end with the recurrence of their mother’s disease.
Genetic liminality

The majority of daughters in the study feared the genetic implications of ovarian cancer for their own life. Genetic fears were experienced as an ongoing aspect of their liminal world, which stretched into the distant future. Wendy described a persistent shadow of concern regarding her potential for developing the cancer. ‘It’s always in the back of your mind. It’s always there. It lives with you…. “Will I, won’t I?” It just sits there.’ (C8.1446-1451.) She added: ‘Fear. Will I get it?’ (C8.1714.) Una ‘had the blood test’ (C6.2792) and described herself as ‘more aware than I was [of her health].’ (C6.2822.) Val had discussed her risk of ovarian cancer with her GP. Tess explained her fears of her own mortality.

Well they say it’s a silent killer. Yes I’ve gone and had my CA125 check. I know that’s not the be all and end all. I’ve even thought about having my ovaries whipped out, but maybe that’s an extreme – I don’t want to go through what mum’s going through. I don’t want to leave my kids behind. (C5.643-646.)

Referring to her concern that her own offspring might develop ovarian cancer, Wendy said, ‘It’s just there. Just sits there.’ (C8.1454-1456.)

Literature suggests that daughters of women with breast cancer wonder about the genetic implications for their health (Chalmers, Marles, Tataryn, Scott-Findlay & Serfas 2003; Raveis and Pretter 2005). Women with a family history of ovarian cancer tend to have more aggressive disease and worse prognosis than women without familial involvement (Ji, Forsti, Sundquist, Lenner & Hemminki 2008). In my study, the majority of daughters described living into their future with fear experienced both for their mother’s life and for their own future.

Summary

Children described Being in a terminable world after their mother had completed treatment. Their world is illustrated in the iMindMap in Figure 18.
This chapter has explored participants’ experience of Being in a liminal world. All participants lived in a liminal world (on the threshold between their ovarian-cancer-related-world and their post-cancer-world). Women were transitioning from being cancer patients to their post-cancer self. They were looking to their future and trying to determine who they were becoming and how they could live their life. Partners also looked to their future, which hinged upon their wife’s health. In a very real sense their lives were ‘on hold’ and they were waiting and watching to see how the situation would resolve. Children lived with a sense of a suspended present, whilst they waited for their mother’s disease to recur. They made the most of their time in the present with the expectation that their current ‘waiting period’ would end with their mother’s eventual cancer recurrence and subsequent death.
The experience is illustrated by the iMindMap in Figure 19.

![Figure 19: Summary of liminal world](image)

The following chapter presents ‘changed world’ as the essence of the phenomenon of ovarian cancer. The chapter draws the thesis to a conclusion as it considers the study findings and situates them within the current state of knowledge. Limitations of the study are discussed and suggestions for further research are made.
CHAPTER EIGHT – CONCLUSION OF THE STUDY:  
BEING-IN-A-CHANGED-WORLD

‘We shall not cease from exploration  
And the end of all our exploring  
Will be to arrive where we started  
And know the place for the first time.’  
(Eliot 2003, p.13)

This chapter draws together the findings of the study as discussed in the three previous chapters and identifies Being-in-a-changed-world as the essence of the lived experience of the phenomenon of ovarian cancer. The chapter identifies insights from the study and implications for nursing practice and discusses strengths and limitations of the study plus suggestions for further research. It concludes with a summative comment.

Being-in-a-changed-world

The essence of the lived experience of ovarian cancer is identified in this thesis as ‘Being-in-a-changed-world’. ‘Changed world’ reflects the overarching key interpretive concept of the study and represents a theoretical synthesis of the three major themes discussed in chapters five, six and seven. Participants’ ruptured assumptive world, uncertain world and liminal world all reflected aspects of Being-in-a-changed-world. This is illustrated by the iMindMap in Figure 20.
Discussion

All participants experienced the phenomenon of ovarian cancer as Being-in-a-changed-world. We build our lives based on our relationships with and understandings of others, our world and ourselves. Ovarian cancer radically altered the lives of participants by changing the foundation upon which they based their lives. Ovarian cancer altered the way participants interpreted their past, present and future and participants experienced Being-in-the-world differently than prior to diagnosis. Their horizons of meaning were transformed by the phenomenon. Ovarian cancer changed the way they lived within their world, and the way they saw and understood things and issues that mattered to them. The illness represented loss to the participants, who lost their normal way of living and their assumptions regarding their future. Ovarian cancer set them apart from others and removed their usual world. This meant that participants experienced their world as changed. This essence of the experience is reflected in the three major thematic findings of the study.

Chapter five presented the first of three key themes identified within the data. The diagnosis of ovarian cancer changed everything. It ruptured the participants’ assumptive worlds. Women’s worlds contracted to a focus upon their disease and their physical, emotional, spiritual and psychological self. Their assumptive worlds
were altered or destroyed, and women experienced existential loneliness as they confronted the possibility that they might die from their disease. Partners’ worlds were altered by their wife’s diagnosis, which was a seminal moment that split them from their previous life and thrust them into a world of crisis dominated by fear of their wife dying of the disease. Life changed for the children too. The foundations of their assumptive worlds were rocked by the knowledge that their mother was seriously ill. Ovarian cancer was experienced as a death-threat for their mother and the children lived in dread that their mother would succumb to her illness.

Chapter six introduced ‘uncertain world’ as the second key theme interpreted from study data. As time passed, participants’ lives continued to change. Uncertainty permeated participants’ worlds as the phenomenon dominated daily lives and in particular, prognostic uncertainty seeped into their consciousness and changed the way participants understood their world. Women experienced the phenomenon as uncanny temporality, spatiality, corporeality and relationality. With treatment, everything seemed surreal and women felt out of place in an unfamiliar world characterised by uncertainty and lack of control. Partners’ worlds also changed as their lives became enmeshed with the disease and they experienced uncertainty in relation to corporeality, relationality, temporality and spatiality. In response, partners focused their attention on supporting their wife and subjugated their own needs. Children’s worlds altered and their concern and solicitude for their mother intensified as they witnessed her frailty and vulnerability. Their experience of their mother changed as children learnt to view her with both an objective as well as a subjective lens – as their (m)Other. This heightened children’s fears and uncertainty regarding her future health.

Chapter seven presented the third key study theme of ‘liminal world’. Post-treatment, participants’ worlds continued to evolve and change as they found themselves living with a sense of liminality. Women described transitioning from their cancer-patient status to their post-cancer-self. Relationships were experienced as being different than prior to the cancer and women found meaning in connecting with and supporting others with serious illness. Women’s ability to ‘move on’ from their cancer was hampered by reminders of their potential for disease recurrence and subsequent death,
for which some actively planned. Partners found that post-treatment life did not return to pre-cancer normality, as they had hoped, but instead remained modified and directed by the cancer. Partners lived in limbo whilst they waited for the ambiguity of their wife’s health to resolve. That is, they lived a suspended life whilst they waited for their future to eventuate. Children’s post-cancer worlds also remained altered by the illness. They lived in a terminable world with a sense of impending loss whilst they waited for their mother to potentially develop recurrent disease and subsequently die. They understood their present world as being finite, and lived on a threshold bounded in time between their mother’s current health and her probable cancer-related death.

The three worlds led to the essence of the lived experience – that of Being-in-a-changed-world. Being-in-a-changed-world integrates and can be seen as the consolidation of the three major themes discussed within this thesis: ruptured assumptive world, uncertain world and liminal world, into one summative world, which represents the essence of the experience of the phenomenon, as illustrated in Figure 21.

![Figure 21: Visual representation of the relationship of the three major themes to the essence of the phenomenon of ovarian cancer](image-url)

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Thesis insights and implications for practice

Consistent with its aim, this study contributes to ovarian cancer literature by providing deep insight into the ovarian cancer experience. The thesis presents new ways of understanding the nature and meaning of the lived experience of ovarian cancer (without recurrence). Whilst the study did not set out to improve quality of healthcare provision, the resulting depth of understanding of the nature and meaning of the experience has potential to be translated into health care practice.

A theoretical understanding of participants’ experiences, developed from the data by using the phenomenological concept of ‘worlds’ has provided a new conceptualisation of the lived experience of ovarian cancer. Participants experienced the phenomenon as Being within different worlds. The worlds incorporated participants’ past, present and future and were experienced simultaneously, yet with different emphases at different illness phases. At times one world or another dominated participants’ Being-in-the-world, whilst the other worlds receded towards ‘background’ awareness. Just as our present is influenced by our past and our future, each world was related to the other worlds, as illustrated in Figure 21. In common to all participants were Being-in a ruptured assumptive world, Being-in an uncertain world and Being-in a liminal world. Every participant experienced Being-in-a-changed-world as the essence of the phenomenon of ovarian cancer. This study adds to previous understandings of ovarian cancer by specifically exploring and interpreting the experience as Being within a number of worlds. The findings suggest a framework for conceptualising the experience of ovarian cancer. The identification of ‘worlds’ as major themes and ‘changed world’ as the essence of the experience have the potential to enhance the way health care is planned and delivered by providing HCPs with a simple conceptual model with which they may approach the care of those experiencing the phenomenon.

Identification of the essence of the experience of ovarian cancer has provided a fresh way of comprehending the phenomenon. The study has documented the sweeping, life changing experience of ovarian cancer for women, partners and adult children. Ovarian cancer was an all-encompassing phenomenon, which dominated the lives of participants and impacted on their experiences of temporality, spatiality, corporeality
and relationality. In doing so, it changed the way they lived in and viewed the world. Ovarian cancer circumscribed the lives of all participants. Central to the whole experience was Being-in-a-changed-world. Figure 22 illustrates this.

Figure 22: Visual representation of the essence of the phenomenon of ovarian cancer

By illuminating the essence of the phenomenon as Being-in-a-changed-world, this study has provided deep insight into the multi-faceted nature and meaning of the experience of ovarian cancer. The resulting enhanced understanding of the world-changing nature of the phenomenon has the potential to provide HCPs with a fresh perspective for the future provision of health care. For example, insight into the essence of ovarian cancer for women and family members has the potential to enhance current HCP clinical practice by providing a targeted focus for conversations with clients about the potential wide-ranging impact of the illness. In addition, active acknowledgement of the life-changing nature of the phenomenon has the potential to validate the complex reality of the experience for women, partners and children. This
aligns with the concepts of person-centred-health-care, that is, recognition of the individual and provision of care, which is centred on them and their needs. Such recognition would also validate the importance of partners and children as members of the unit of care, and as recipients of health care in their own right.

This study identified that the phenomenon of ovarian cancer reverberates throughout the family. Although there was no intention of comparing participant groups in this phenomenological study, during the time I was immersed in the data it became very evident that the experience is one which deeply involves not just the woman with the diagnosis but also partners and children of such women. The phenomenon was a life changing ontological experience that changed the way women, partners and adult children lived within their worlds. This new understanding extends current knowledge of the phenomenon by identifying and documenting the experience of the phenomenon for family members. Currently, the needs and concerns of partners and adult children of women with ovarian cancer are given fleeting acknowledgement in assorted Australian guidelines and websites. Contemporary Australian recommendations for the care of women with ovarian cancer briefly recognise the impact of (any) cancer diagnosis upon family members (Australian Cancer Network & National Breast Cancer Centre (ACN & NBCC) 2004) but do not elaborate upon how they may best be supported by HCPs. An Australian Government website briefly acknowledges the possible impact of ovarian cancer on partners but redirects readers to a breast cancer site for further information (Cancer Australia 2012e). Similarly, an Australian Government website acknowledges the impact of ovarian cancer upon children but focuses upon dependent children. It recommends adult children contact a (general) cancer telephone helpline (Cancer Australia 2012c). In addition, publications that recommend the support of friends and family members often do so from the perspective of the role they play in helping the cancer patients cope with their illness (e.g. ACN & NBCC 2004; Cancer Australia 2012d). That is, they focus upon what the partner and family members can do to ‘help’ the patient rather than recognising them as individuals with support needs of their own. My study identifies that partners and children experience the phenomenon in their own right and not merely as adjuncts to the woman with the cancer. This new understanding has the
potential to inform the delivery of health care for those whose lives have been changed and impacted by ovarian cancer.

Findings from my study extend previous understanding of the phenomenon by providing deep insight into the experience of relationality and death anxiety for participants. These two themes were identified in the literature review as being commonly described in relation to the experience of ovarian cancer (without recurrence). Fear of recurrence and/or death for women was described in a number of studies (e.g. Bowes 1998; Reb 2007a) and was also identified as a major issue for partners by a small number of studies (e.g. Armstrong 2012; Ponto 2008). My study confirmed the centrality of death anxiety and relationality for all participants and built upon previous studies by illuminating the experience across the illness trajectory from the perspectives of the three participant groups. Participants knew that ovarian cancer was commonly associated with a poor prognosis and they described an omnipresent fear of recurrent disease and subsequent death. Findings from my study related to existential angst have the potential to shape the way information and education is presented to women with ovarian cancer and their family members.

My study increases current understanding of the significance of relationality for those experiencing ovarian cancer illness by providing an in-depth interpretation of its meaning for participants across the illness trajectory. The importance of supportive relationships for women has previously been described in a number of studies (e.g. Fisher-Morris 2009; Seibaek et al 2012; Stilos 2003). Findings from my study identified that women, partners and adult children have an ongoing need for support throughout the illness trajectory. This suggests the value of holistic psychosocial care, which incorporates the woman and family from the onset of the diagnostic period, continues throughout the acute illness experience and which extends the strategy of care beyond the usual three-monthly CA125 test and medical check-up.

The far-reaching consequences of ovarian cancer for women, partners and children have been documented by this study, which reveals how ovarian cancer dominated and directed their lives. All participants’ worlds were shaped by the interiority of the body of the woman with the disease. Previously ‘glossed-over’ and not noticed, the
interior of her body became visible (noticed) and an object of concern for all. Her ill/health directed the way participants lived in their world and the way they lived into their future. This new way of understanding of the ovarian cancer experience provides HCPs with insight into the significance of the woman’s health to not only herself but also her partner and child/ren.

This study is the first identified study to explore the holistic experience of ovarian cancer for women with ovarian cancer (prior to recurrence) in the Australian context and builds upon a small number of studies of the ovarian cancer experience for Australian women. It provides previously undocumented insight into the holistic lived experience of the phenomenon for partners of women prior to recurrent disease. It is the first study; worldwide, to specifically explore the experience of adult children of women with ovarian cancer (with or without recurrence). Findings from the study have the potential to inform the provision of context-specific, disease-specific health care to women with ovarian cancer and their partners and/or adult children.

This thesis presents a fresh way of exploring the experience of ovarian cancer by describing and interpreting it from the viewpoints of three participant groups. Each group of participants was intimately involved with the phenomenon and experienced it through the three major thematic worlds. By simultaneously exploring the phenomenon from three perspectives, my study reveals participants’ individual and interrelated experiences of the phenomenon. (These are illustrated in Figures 21 and 22.) Taken individually, their experience of ovarian cancer is described in its entirety. When combined, the lived experiences of the three groups provide a detailed exploration and in-depth interpretation of the phenomenon of ovarian cancer (without recurrence). This is unique in ovarian cancer literature. Munhall (2012a) suggested the purpose of qualitative research is to enlarge understanding and to comprehend an experience in another way than previously (p.30). From my analysis and interpretation of study data, I have identified the essence of the phenomenon and provided a new theoretical understanding of how ovarian cancer is experienced. The blending of the understandings of women, partners, children and myself as researcher represents a “fusion of horizons” (Gadamer 2004, p.305). Gadamer (2004) suggested that we should “look beyond what is close at hand… to see it better, within a larger
whole and in truer proportion” (p.304). In circling the phenomenon, from the perspectives of women, partners and children, I have looked both at, and beyond, each group’s experience and thereby obtained (in Gadamer’s words) a ‘better’, deep and detailed understanding of the ovarian cancer experience.

**Strengths and limitations of the study**

This study has a number of characteristics, which may be viewed as strengths or limitations.

Findings in the study are derived from participant interviews conducted at one point of time in their life. If I interviewed the participants at another time, they may have described their experience differently. As Heraclitus (1987) suggested, “As they step into the same rivers, different and (still) different waters flow upon them” (p.17), meaning that we never step into the same river twice and it is expected and natural that over time, things (including the perspective of participants) will change. Some readers could see this as a limitation of the study. However, it is consistent with the concepts and values of qualitative research and is characteristic of phenomenological research.

This study set out to explore the experience of ovarian cancer in Australia. The sample is comprised of Australian women and men, recruited from six states of Australia. Findings from this study relate to the study participants and it may be suggested that they may not be applicable to other women, partners and adult children in similar situations. However, I would argue that the essence and other findings of this thesis have potential transferability to other countries and other people. Further, whilst this study has focused exclusively upon the phenomenon of ovarian cancer, findings could have transferability to other cancer and/or serious illness experiences.

Interstate recruitment was achieved via the use of internet-based advertisements about the study. This limited participation to some extent, to those who had access and skills in use of the Internet. Local recruitment was achieved via the use of letters of
invitation and newspaper advertisements. This limited participation to those who received letters or who saw the advertisements. In addition, as participation was limited to those who could read and speak English, non-English speaking potential participants were excluded from the study.

Data collection techniques may be viewed as a limitation or strength. Participants were given the option of writing about their experience or participating in a face-to-face or a phone-based interview. It is possible that the two participants who chose to write about their experience shared less than those who spoke. It is also possible that those who spoke face-to-face disclosed more details than those interviewed over the phone. However, neither of these possible limitations was evident in the study. Written accounts provided in-depth descriptions and it was noted that some phone interviews produced more detailed data than some face-to-face interviews. In these cases, phone interviews were seen as potentially providing participants with a sense of anonymity, thus being a strength rather than a limitation of the study.

**Suggestions for further research**

Phenomenology is a philosophy of wonder. Its use for this study reflected the impetus for the study – that is, my curiosity about the nature and meaning of the lived experience of ovarian cancer. Whilst my study has illuminated many aspects of the lived experience of the phenomenon, it has also identified further foci of wonder about the phenomenon. These are presented here as suggestions for possible additional research into the lived experience of ovarian cancer.

This study has explored, described and interpreted the experience of ovarian cancer (without recurrence) for English-speaking women, partners and children within the Australian context. Further study into the Australian context could focus upon the experience of ovarian cancer for indigenous Australians or for people from a non-English speaking background and/or from different cultures and countries. This would have the potential for further informing the provision of context-relevant, ovarian-cancer-specific research-based care to all women and family members in Australia.
This study has utilised hermeneutic phenomenology to explore the phenomenon of ovarian cancer from three participant groups. This has proved to be a highly effective and illuminating method of research and has allowed me to circle the phenomenon, thus facilitating deep understanding and insight into the phenomenon. Research designed similarly to this study, using a number of participant groups, could explore and illuminate the phenomenon of ovarian cancer in other cultures and countries.

This study approaches family members of women with ovarian cancer as co-experiencers of the phenomenon rather than as caregivers of women with the cancer. The classification of caregivers is an important matter that needs clarification and consideration. Whilst some spouses and family members of women with ovarian cancer identify themselves as caregivers, others do not. Classifying partners/family members as caregivers positions their involvement in research from the perspective of being caregivers, rather than persons who experience a phenomenon as an individual, separate from the cancer patient, with unique needs and perspectives (Baider 1995; Northouse & Peters-Golden 1993). For example, since commencing my PhD, a few studies have emerged that specifically explore the holistic lived experience of ovarian cancer for partners. Only Ponto and Barton (2008) specifically recruited partners, whilst Armstrong (2012) recruited partner/caregivers. Similarly, aspects of the experience of family caregivers of women with ovarian cancer have been researched (Beesley, Price, Webb et al 2011; Ferrell et al 2002; Le et al 2004; Price et al 2010). Future research could focus upon the experiences of spouses and family members as individuals in their own right in addition to research into the experience of spouse-caregivers and family member-caregivers of women with ovarian cancer.

This study is the first to demonstrate the world-changing impact of ovarian cancer for children of women with the disease. Literature reviews have identified that children’s experiences of parental cancer have been investigated by a relatively small number of studies (Levesque & Mayberry 2012; Mitschke 2008; Mosher and Danoff-Burg 2005). Sons’ experiences of parental cancer have been little explored in psycho-oncological literature and it has been suggested that research be conducted into the experience of parental cancer for both daughters and sons particularly focusing upon their experience of specific types of parental cancer (Mosher and Danoff-Burg 2005).
Whilst my study represents an initial exploration of the experience of ovarian cancer for children, it did not specifically compare the experiences of daughters and sons. This is a facet of the experience of ovarian cancer that warrants further exploration. Also, my study focused upon the ovarian cancer experience for adult children. Further research might focus upon the experience of younger children. This is another area of research that merits investigation.

Findings from this study revealed the multi-faceted and deeply-felt experience of ovarian cancer for women, partners and children. Whilst the study did not aim to compare experiences or to explore the experience from the perspectives of the dyad or triad, these are possible areas for further research that merit further investigation.

This study provided evidence that ovarian cancer is experienced as a family illness. It has led me to wonder about the nature and meaning of the experience of the phenomenon for extended family members. Although the recruitment strategies for my study were specific about potential participants, at times parents, grandparents and siblings of women with ovarian cancer contacted me, hoping to participate in the study. I developed a sense of an unmet need amongst those whose lives had been affected by ovarian cancer to tell their story and communicate their experience. I have identified no literature that explores the experience of the phenomenon from the perspectives of extended family members. Therefore, I suggest that these requests represent an unexplored gap within healthcare literature and warrant research.

**Concluding comment**

This study explored the Australian lived experience of the phenomenon of ovarian cancer (without recurrence). By simultaneously exploring and interpreting the experiences from three vantage points – that of women, partners and adult children - the study developed a richly detailed understanding of the phenomenon. I have interpreted experience of the phenomenon as Being in different, yet inter-related worlds. The phenomenon ruptured the assumptive world of participants, introduced multiple uncertainties and left participants in a liminal world. The key finding or
essence of the experience of the phenomenon identified in this study was that ovarian cancer directly impacts and changes the lives of women, partners and adult children. The study demonstrates that for the participants, the essence of the phenomenon of ovarian cancer is Being-in-a-changed-world.
REFERENCE LIST


Burles, M., & Holtslander, L. (2013). “Cautiously optimistic that today will be another day with my disease under control”. Understanding women’s lived experiences of ovarian cancer. *Cancer Nursing, 36*(6), 436-444. Doi: 10.1097/NCC.0b013e318277b67e


McEvoy, M. (2013). “If life were a line, mine would be a circle”: A phenomenological study of hospitalisation in the situation of first episode psychosis for young people, family members and nurses (Unpublished doctoral dissertation). The University of Sydney, Australia.


*The Australian Women’s Weekly*. (2013). Our challenge. One woman every 10 hours is claimed by ovarian cancer. September, pp. 149-155


APPENDIX A: UTAS ethics approval letter dated 10/2/10

10 February 2010

AssocProf Maureen Boughton
Faculty of Nursing and Midwifery
University of Sydney
88 Mallett St
Camperdown NSW 2050

Dear AssocProf Boughton

REF NO:  H0010897
TITLE:  The experience of ovarian cancer for women, partners and adult children

- National Ethics Application Form
- Response to Ethics Committee dated 6 January 2010
- Response to Scientific Committee dated 24 November 2009
- Interview Framework and Sample Questions
- Introductory Letter
- Information Flyer
- Newspaper Advertisement
- In-principle agreement to distribute introductory letters or flyers from the Gynaecological Oncology Cancer Care Coordinator Tasmania, Ovarian Cancer Australia Ltd, the Cancer Council Queensland and the Cancer Council Northern Territory
- List of Cancer Support and Counselling Services in Tasmania, New South Wales, Victoria, Western Australia, South Australia, the Northern Territory, Queensland
- Participant Information Brochure
- Participant Consent Form dated 5 January 2010

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation on 9 February 2010.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the National Statement on the Ethical Conduct Human Research (NHMRC 2007).

Therefore, the Chief Investigator’s responsibility is to ensure that:

(1) The individual researcher’s protocol complies with the HREC approved protocol.
(2) Modifications to the protocol do not proceed until approval is obtained in writing from the HREC.
(3) Section 5.5.3 of the National Statement states:
Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution’s and ethical review bodies and take prompt steps to deal with any unexpected risks.

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested. [http://www.research.utas.edu.au/human_ethics/medical_forms.htm](http://www.research.utas.edu.au/human_ethics/medical_forms.htm)

(4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.

(5) The Committee is notified if any investigators are added to, or cease involvement with, the project.

(6) This study has approval for 4 years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due 9 February 2011. You will be sent a courtesy reminder closer to this due date.

(7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 2763.

Yours sincerely

[Signature]

Katherine Shaw
Health and Medical HREC Ethics Officer
On behalf of the Executive Officer
HREC (Tas) Network
APPENDIX B: University of Sydney ethics ratification letter

Ref: MC/KR
29 March 2010

Associate Professor Maureen Boughton
Sydney Nursing School
The University of Sydney
Email: m.boughton@usyd.edu.au

Dear Professor Boughton

Title: The experience of ovarian cancer for women, partners and adult children. (Ref. No. 12680)

PhD Student: Ms Victoria Jayde

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so the Committee has ratified your study to include the PhD student – Ms Victoria Jayde

The Executive Committee acknowledges your right to proceed under the authority of Human Research Ethics Committee (Tasmania) Network.

Please note, this ratification has been given only in respect of the ethical content of the study. The Human Research Ethics Committee recommends that you consult with The University of Sydney Audit and Risk Management Office [Contact: Vlad Nesic. Telephone +61 2 9351 4127, Email vlad.nesic@sydney.edu.au] to ensure that you are adequately covered for the purpose of conducting this research project.

It is mandatory that any modifications to the study are approved by Human Research Ethics Committee (Tasmania) Network before forwarding a copy of the approved modification, approval letter and any new approved documents to The University of Sydney HREC.

Please do not hesitate to contact the Human Ethics Office should you require further information or clarification.

Yours sincerely

Marietta Coutinho
Deputy Manager
Human Research Ethics Administration

cc: Ms Victoria Jayde [Email: victoriajayde@netspace.net.au]
APPENDIX C: Ethics approval letter for amendment to recruit further participants, dated 14/11/13

14 November 2013

AssocProf M Boughton
University of Sydney

Sent via email

Dear AssocProf Boughton

REF NO: H0010897
TITLE: The experience of ovarian cancer for women, partners and adult children

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The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above amendment documentation on 14 November 2013.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the National Statement on Ethical Conduct in Human Research (NHMRC 2007).

Should you have any queries please do not hesitate to contact me on (03) 6226 2764.

Yours sincerely

Heather Vail
Ethics Administrator
Office of Research Services
Email: Heather.vail@utas.edu.au
University of Tasmania
Private Bag 01 Hobart Tas 7001
APPENDIX D: Letter sent to women recently diagnosed with ovarian cancer. (Approved 10/2/10.)

Department of Health and Human Services
OBSTETRICS AND GYNAECOLOGY
ROYAL HOBART HOSPITAL

GPO Box 1061, Hobart. TAS 7001 Australia
Ph: (03) 6222 8049   Fax: (03) 6226 4864

Date

Dear

I am writing to draw your attention to a Research Study, which is being conducted to explore the experience of ovarian cancer – and to ask you if you would consider participating in the study? Women with cancer of the fallopian tube and peritoneum are also able to take part in the study.

The researchers would like to speak with women who have been diagnosed with ovarian cancer (or tubal or peritoneal cancer), and who do not have a recurrence of their disease. They would also like to speak with partners and adult children of women with the cancer.

Being in the study would involve participating in one (or perhaps two) interview/s with a nurse researcher. During the interview you will be asked to talk about your experience of ovarian cancer. You may choose to write about your experience, instead of, (or as well as) participating in an interview.

The researchers are interested in finding out what it means to have the cancer, and what it means to have a loved one who has the cancer. They are interested in how the disease has affected your life. Your ideas and viewpoints are important and they would like you to tell them about your experience with the disease.

Your privacy will be protected and confidentiality ensured.

Results from this study will be used to tell health care professionals about ovarian cancer from your perspective. This information will promote a better understanding about the impact of the illness on women and their families and will help health professionals learn how to best meet the needs of people in similar situations.

I have enclosed an Information Brochure about the study, so that you can read further details about what would be involved. If you would like to participate, please contact Victoria Jayde (one of the researchers) whose details are listed below. She will discuss the study further with you and answer any questions you may have.

Would you consider participating in the study? Would your partner and/or any of your adult children consider participating? If you are interested in finding out more details, please contact Victoria Jayde.

Thank you,

Yours sincerely,

Karen Campbell
Cancer Care Coordinator, Gynaecological Oncology, Tasmania

Researcher contact details:
Victoria Jayde
PO Box 37, North Hobart, TAS, 7000
Ph: 0439486416
Email: vjay0340@mail.usyd.edu.au
APPENDIX E: Information Brochure

THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

The University of Sydney
School of Nursing
Faculty of Nursing and Midwifery

ABN 15 211 513 464

CHIEF INVESTIGATOR:
Associate Professor Maureen Boughton

88 Mallett St
Camperdown
University of Sydney NSW 2050
AUSTRALIA
Telephone: +61 2 93510626
Facsimile: +61 2 93510679
Email: m.boughton@usyd.edu.au
Web: www.usyd.edu.au

PARTICIPANT INFORMATION BROCHURE
Research Project

THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

(1) What is the study about?

The purpose of this study is to explore the experience of ovarian cancer for:

- women with ovarian cancer;
- partners of women with ovarian cancer;
- adult children of women with ovarian cancer.

The aim of the study is to broaden understanding of what it means to experience ovarian cancer. Results from this study will be used to tell health care professionals about ovarian cancer from your perspective. This information will promote a better understanding about the impact of ovarian cancer on women and their families and will help health professionals learn how to best meet the needs of people in similar situations.

(2) Who is carrying out the study?

The study is being conducted by Victoria Jayde, a student at The University of Sydney, and will form the basis for the degree of PhD at The University of Sydney under the supervision of Associate Professor Maureen Boughton.

(3) Am I eligible for the study?

You are eligible for the study if you:

- are a woman with ovarian cancer;
- or are a partner of a woman with ovarian cancer;
- or are an adult child of a woman with ovarian cancer
THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

AND if you:

• are 18 years old or over
• normally live in Australia
• can speak and understand English clearly

(4) What does the study involve?

Being in this study will involve participating in an interview with the researcher. The interview will focus upon your experience of ovarian cancer. If you like, you may have someone else with you during the interview. The interview will be held over the telephone or at a time and place convenient to you and will be audio recorded. The interview will later be typed out onto a computer and used by the researcher, along with other interviews. It is possible that you may be later asked to participate in a follow-up interview.

If you would like, you can write about your experience of ovarian cancer. The information gained will be treated like that obtained from interviews and may be used to replace or supplement the interview.

(5) How much time will the study take?

You will determine the time taken to participate in the study. Normally, an interview will take approximately an hour – however, it may last for a shorter or longer time, depending on what you would like to tell the researcher. If you decide to write about your experience, the time taken will be entirely at your discretion.

(6) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the University of Sydney, or with any of the researchers. There will be no consequences to you if you decide not to participate, and this will not affect your treatment in any way. If you decide to discontinue participation at any time, you may do so without providing an explanation.

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

(7) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants.

Information gained from the research will be used to write a summary of the findings, which will be submitted as a thesis in support of the researcher's PhD. Findings may also be used in conference presentations or professional journal articles. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. All information will be treated in a strictly confidential manner, and your name will not be used in any publication arising out of the research. If you decide to participate in this study, you will be given an imaginary name (pseudonym), which will be used throughout the study. Only the consent form will contain your name and address and this will be stored securely. All of the research will be kept in a locked cabinet in the office of the researcher.
THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

(8) Will the study benefit me?

There may not be any direct benefit to you from taking part in this study. However, it is intended that findings from this study will be used to help health professionals understand the experience of ovarian cancer from the perspective of the woman with the disease, their partner and their adult children. This knowledge may be used to improve care for persons affected by the cancer in the future.

(9) Can I tell other people about the study?

You are very welcome to discuss the study and your possible involvement in it, with other people. We would especially welcome enquiries from other potential participants.

(10) What if I require further information?

When you have read this information, Victoria Jayde will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact one of the following researchers.

Victoria Jayde
PO Box 37,
North Hobart,
TAS, 7002.
Ph: 0439486416
Fax (03) 62783781
Email: vjay0940@mail.usyd.edu.au

Associate Professor Maureen Boughton
Ph: (02) 93510626
Email: m.boughton@usyd.edu.au

Associate Professor Penny Blomfield
Ph: (03) 6222 8049
Email: penny.blomfield@dhhs.tas.gov.au

(10) What if I have a complaint or concerns?

This study has been approved by the University of Sydney Human Ethics Committee. Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on (02)8627 8176 (Telephone); (02) 8627 7177 (Facsimile) or human.ethics@usyd.edu.au (Email).

This study has also been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study you should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote HREC project number H0010897.

This information sheet is for you to keep

APPENDIX F: Consent Form

The University of Sydney
School of Nursing
Faculty of Nursing & Midwifery

ABN 15 211 513 464

CHIEF INVESTIGATOR:
Associate Professor Maureen Boughton

88 Mallett St
Camperdown
University of Sydney NSW 2050
AUSTRALIA
Telephone: +61 2 93510626
Facsimile: +61 2 93510679
Email: m.boughton@usyd.edu.au
Web: www.usyd.edu.au

PARTICIPANT CONSENT FORM

I, ........................................................................... [PRINT NAME], give consent to my participation in the research project

THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

I am:
A woman with ovarian cancer ☐
A partner of a woman with ovarian cancer ☐
An adult child of a woman with ovarian cancer ☐ (Please tick the appropriate box)

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.

THE EXPERIENCE OF OVARIAN CANCER FOR WOMEN, PARTNERS AND ADULT CHILDREN

Version 1/f.5.10

Page 1 of 2
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to: — Audio-taping
   YES ☐  NO ☐

Signed: ........................................................................................................................................

Name: .......................................................................................................................................

Date: ........................................................................................................................................
APPENDIX G: Newspaper advertisement

OVARIAN CANCER

*Does your partner or mother have ovarian cancer?*

We are conducting a research study into the experience of ovarian cancer for partners and adult children and are looking for people who might be interested in participating. Being in the study would involve writing about or being interviewed about your experience with the disease. Your privacy will be respected.

If you are the partner of a woman with ovarian cancer, or if you are an adult child of a woman with ovarian cancer, then we would love to hear from you!

For further details, please contact Victoria Jayde: Ph: 0439486416
Address: PO Box 37, North Hobart, TAS 7002 or Email: vjay0340@usyd.edu.au
APPENDIX H: Notice about the study on Ovarian Cancer Australia website

Research And Clinical Trials
What is your experience of ovarian cancer? -Research Participants Needed
- Do you have ovarian cancer?
- Are you the partner of a woman with ovarian cancer?
- Does your mother have ovarian cancer?

If you have answered ‘yes’ to any of the above questions, we would love to speak with you!

We are conducting a research study into the experience of ovarian cancer. For the study, we want to talk with people affected by ovarian cancer - namely women with the disease and/or their partner and/or their adult children.

Being in the study would involve participating in one (or perhaps two) interview/s with one of the researchers. During the interview you will be asked to talk about your experience of ovarian cancer. You may choose to write about your experience of ovarian cancer, instead of, (or as well as) participating in an interview. Every effort will be made to protect your privacy and ensure confidentiality.

We are interested in finding out what it means to have ovarian cancer, and what it means to have a loved one who has the cancer. We are interested in how the disease has affected your life.

Results from this study will be used to tell health care professionals about ovarian cancer from your perspective. This information will promote a better understanding about the impact of ovarian cancer on women and their families and will help health professionals learn how to best meet the needs of people in similar situations.

If you are interested in finding out more about this study and how you might be able to be involved, please contact the investigator listed below. We will send you a detailed information brochure about the study.

Investigator: Victoria Jayde
PO Box 37, North Hobart, TAS 7002
Ph: 0439486416
Email: vjjer0360@mail.usyd.edu.au

We would very much appreciate the opportunity to hear your story!
APPENDIX I:  Second notice about the study on Ovarian Cancer Australia website
APPENDIX J: Second letter of invitation sent to women recently diagnosed with ovarian cancer. (UTAS approved 14/11/13.)

Date

Dear

I am writing to draw your attention to a Research Study, which is being conducted to explore the experience of ovarian cancer – and to ask you if you and/or your partner and/or adult children would consider participating in the study? Women with cancer of the fallopian tube and peritoneum are also able to take part in the study.

The researchers would particularly like to speak with partners of women who have been diagnosed with ovarian cancer (or tubal or peritoneal cancer), and who do not have a recurrence of their disease.

Being in the study would involve participating in an interview with a nurse researcher. During their interview, your partner will be asked to talk about their experience of ovarian cancer.

The researchers would also like to speak with women with ovarian cancer and adult children of women with the cancer. During the interview, the researcher will discuss the study findings to date and her understanding of what it is like for women, partners and adult children to live with ovarian cancer. The purpose of this interview is further explore findings and to incorporate your thoughts and understanding of the illness into the study. This is being done to make sure that a full understanding of the impact of the disease can be portrayed.

The researchers are interested in finding out what it means to have the cancer, and what it means to have a loved one who has the cancer. They are interested in how the disease has affected your life and that of your partner and/or adult children. Your ideas and viewpoints are important and they would like you to give them feedback on their ideas of what it is like to experience the disease.

The privacy of participants will be protected and confidentiality ensured.

Results from this study will be used to tell health care professionals about ovarian cancer from the perspective of women and family members. This information will promote a better understanding about the impact of the illness on women and their families and will help health professionals learn how to best meet the needs of people in similar situations.

I have enclosed an Information Brochure about the study, so that you can read further details about what would be involved. If you and/or your partner and/or adult children would like to participate, please contact Victoria Jayde (one of the researchers) whose details are listed below. She will discuss the study further with you and answer any questions you may have.

Would you consider participating in the study? Would your partner and/or any of your adult children consider participating? If you are interested in finding out more details, please contact Victoria Jayde.

Thank you,

Yours sincerely,

Karen Campbell
Cancer Care Coordinator, Gynaecological Oncology, Tasmania

Researcher contact details:

Victoria Jayde
PO Box 37, North Hobart, TAS, 7000
Phone: 0412126373
Email: vjay0340@uni.sydney.edu.au
Appendix K: Discussion and examples from data analysis audit trail

Example of field notes dictated immediately after interview:
The following excerpt is taken from field notes dictated immediately after interviewing Donna:

“She was very expressive, screwed up her eyes and made faces a bit when she was talking about stuff... like when she was talking about losing her hair she screwed up her eyes and shook her head and shuddered and said it was horrific... When she was talking about the pain going down her legs, she was rubbing her right side, from her groin area down to under her knee and when she was talking about restless legs, she was moving her legs up and down and in and out and from side to side and wriggling her bottom on the chair as if she just couldn’t keep still. When she was talking about her eyebrows, she took her glasses off and she was showing me the fact that she had no eyebrows. When she was talking about her eyelashes, she was feeling her eyes, to see if she could feel some eyelashes. When we spoke about leg hair, she pulled up her trouser legs and rubbed them, to see if there was any. When we talked about veins, she pulled up her sleeve and showed me the big sinuously veins on her arms.”

Examples of drawing after interview:

Figure 23 is a copy of a drawing I did following reflection on my interview with Wendy.

Figure 23: Drawing of Wendy’s experience.

A drawing I did following reflection on my interview with Jack is reproduced in Figure 24.
Figure 24: My impression of Jack’s fears following our interview

Description of my data analysis:
Initially I dealt with each transcript separately. I read the whole transcript then read line by line, highlighting any phrases or words of paragraphs that seemed to be significant. Then I read each transcript again, word by word, noting when words were used frequently. For example, Charles used the word ‘worry’ a lot and Jack used the term ‘bashed down’ quite frequently when he was talking about his wife. The meanings of frequently used words were checked in a dictionary and in an etymological dictionary. Transcripts were re-read for relevance to van Manen’s four existentials and notes were taken, detailing quotes, line numbers and my reflections on the meaning. Later, I added to these notes. (See Figure 25.) I then re-read the transcript, noting what I considered to be key elements.
The process was repeated with each transcript. Once I had read transcripts for each member of a group (for example women), I made iMindMaps and drew tables to summarise emerging concepts and relationships between key elements. (See Figure 26.)

![Figure 25: Example of beginning thematic analysis](image)

**Figure 25: Example of beginning thematic analysis**

Analysis was a circular process of ‘stepping back’ from each transcript to consider the whole, then re-examining it line-by-line and word-by-word, then considering it alongside other transcripts. I frequently checked my emerging ideas with my supervisor and we met often and ‘brainstormed’ developing concepts with butcher paper and textas. I read and re-read phenomenological texts and began to take inspiration from art and poetry. For example, I was inspired by a visit to an art
gallery where I saw Edvard Munch’s painting ‘The Scream’ (1895). This helped me understand children’s feelings about their mother’s possible death. Pablo Picasso’s painting “Girl before a Mirror” (1932) helped me to interpret women’s experience of seeing themselves with chemotherapy-induced alopecia. Wendy Oliver’s poem “When death comes” (2003, pp.3-4) echoed women’s sense of ‘carpe diem’.

Eventually, concepts began to emerge from the data. For example, an early conceptualisation was that women lived in a constricted world. After discussing that concept with a cancer patient I met personally, I changed the concept to ‘contracted world’ to better fit the sense of a ‘closed down’, ‘huddled’ sort of life.

Figure 27: iMindMap of factors which change the women’s worlds.

I began to amalgamate the various concepts and elements from the three groups, to discern what was common to all. As time passed and I had immersed myself in the data, it became clear that key concepts were beginning to emerge until finally the three worlds were found to be common to all three groups I had interviewed. I made iMindMaps of possible key themes, which depicted relevant concepts. An example is given in Figure 28.
Figure 28:  Example of factors leading to concept of liminality for women.

After much writing and thinking and consideration and many conversations with my supervisor and peers, I had arrived at the final conceptual lenses with which I interpreted participants’ experiences.
APPENDIX L: CONFERENCE PRESENTATIONS OF FINDINGS ARISING FROM MY STUDY.

National conferences:

Jayde, V.
“*The experience of chemotherapy-induced alopecia for Australian women with ovarian cancer.*” Oral presentation at the Victoria Comprehensive Cancer Centre Ovarian Cancer Symposium, Melbourne, 5-7 August 2013.

Jayde, V, Boughton, M
“*‘There is nothing of me left.’ The experience of alopecia for Australian women with ovarian cancer.*” Poster presentation at the Clinical Oncological Society of Australia (COSA) National Conference, Brisbane, 13-15 November 2012.

Jayde, V, Boughton, M

Jayde V, Boughton M, Blomfield P
“*Ovarian cancer – communication preferences and needs of family members*”, oral presentation at the Cancer Nurses Society of Australia 14th Winter Congress, Sydney, 21-23 July 2011

Jayde V, Boughton M, Blomfield P
“*Communication, ovarian cancer and the family: what works and what doesn't?*”, poster presentation at the Australian New Zealand Gynaecological Oncology Group (ANZGOG) Annual Scientific Meeting, Gold Coast, 23-26 February 2011

Jayde V, Boughton M, Blomfield P
“*Ovarian cancer: the need for a person-centred approach to diagnosis*”, oral presentation at the Consumer-Centred Health Care: Policy Innovation and Empowerment National Conference, Melbourne, 22-23 March 2010

International conferences:

Jayde V, Boughton M, Blomfield P
“*'She is a jewel' - the link between professional practice and the experience of ovarian cancer*”, oral presentation at the 4th International In Sickness and In Health Conference, Denmark, 4-6 May 2011

Jayde V, Boughton M, Blomfield P
APPENDIX M: PUBLICATIONS ARISING FROM MY STUDY
