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‘Living the tightrope’: The experience of maternal ovarian cancer for adult children in Australia

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ABSTRACT

Purpose: The purpose of this article is to explore and interpret the experience of maternal ovarian cancer (prior to recurrence) for adult children living in Australia. Although it is well recognised that cancer impacts upon the lives of family members, the experience of maternal ovarian cancer for adult children has been neglected in the literature.
Method: Data for this qualitative study were collected via unstructured in-depth interviews with nine adults from three states of Australia. Participants' mothers had been diagnosed with ovarian cancer but not recurrent disease. Hermeneutic phenomenology provided a philosophical framework for data collection and analysis.
Results: Three themes were identified: living in a dread-full world; living in a solicitous world; and living in a terminable world. Children experienced ovarian cancer as an ongoing life-changing ontological phenomenon and Being-in-a-changed-world was revealed as the essence of the experience.
Conclusions: The findings revealed that the lives of adult children are directly impacted by their mother's ovarian cancer. The themes and essence arising from the study provide a simple conceptual model with which health professionals might approach care of such children. Findings are not limited to ovarian cancer but may be directly applicable to other cancer experiences.

1. Introduction

In Australia, approximately 1300 women are diagnosed with, and 900 women die from ovarian cancer (ovca) each year (Australian Institute of Health and Welfare, (2014)). In the USA these numbers rise to approximately 22,000 women diagnosed and 14,000 women dying from the disease annually (National Cancer Institute (NCI) 2014). Ovarian cancer is typically associated with a late diagnosis and a correspondingly poor prognosis. It is the most lethal form of gynaecological cancer (Cancer Australia, 2012a, 2012b) with a five-year survival rate of approximately 43% (Cancer Australia, 2012b). Treatment for ovca depends upon such factors as the stage of the cancer and the health of the woman. Approximately 75% of women are diagnosed with advanced disease (NCI, 2014; Tracey et al., 2009) and of these, the majority will develop recurrent disease within a median of 15 months (Hennessy et al., 2009). Recurrent disease cannot be cured (Hennessy et al., 2009).

2. Background

Cancer can be considered as both a disease and an illness. The term ‘disease’ refers to a biological entity, such as cancer, whilst ‘illness’ refers to one's associated subjective experience of the disease (Benner and Wrubel, 1989; Lupton, 2012; Svenaeus, 2009). Thus, whilst only a woman with the cancer experiences the disease of ovca, their loved ones may experience the phenomenon of the ovca illness.

Despite the impact of cancer illnesses upon family members being well acknowledged, previous authors have noted that little has been documented about how adult children experience their parent's cancer (Levesque and Mayberry, 2012; Mitschke, 2008; Mosher and Danoff-Burg, 2005). Mosher and Danoff-Burg (2005) identified children's experience of specific parental cancers as an area of research need. Ovca impacts not only the lives of women with the disease but also their spouses and family (Ersek et al., 1997; Ferrell et al., 2003; Howell et al., 2003; Petterson, 2006; Ponto, 2008). A recent review (Jayde, 2015) found that the family experience of ovca has been little explored. Two studies were identified which described the experience of having a family member die from ovca (Shepard, 2002; Tarraza and Ellerkman,

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1999). Tarraza and Ellerkman (1999) reported family feelings of fear and helplessness as their family member succumbed to the disease. The relevance of Shepherd's (2002) study to the Australian situation was limited as it explored family experiences within the context of the Peruvian amazon. Another study assessed family group experiences of ovca over the period of one year (Koldjeski et al., 2007). The authors identified shifting roles and responsibilities as family members adjusted for the impact of the cancer on their lives. The experiences of individual members, however, were not separately reported in the three family studies and therefore any specific voices of children could not be identified.

The experiences of caregivers of women with ovca have been explored in a small number of studies (see for example, Armstrong, 2012; Beesley et al., 2011; Ferrell et al., 2002; Le et al., 2004; Price et al., 2010). However, such research specifically situates participants as caregivers, rather than as individuals with their own experience of the cancer. This approach is reflected in the public arena. For example, some publications designed to ‘help’ family and friends of cancer patients do so from the perspective of their role as ‘helpers’ of the person with cancer (Australian Cancer Network and National Breast Cancer Centre, 2004; Cancer Australia, 2012d), rather than as persons with individual support needs.

This article reports findings from a larger study, which explored the experience of ovca for women, partners and adult children (Jayde, 2015). The paper addresses an identified gap in healthcare literature by exploring the experience of maternal ovca for adult children. Knowledge from the study has the potential to provide nurses and other healthcare professionals (HCPs) with insight into the ovca experience of such children and to inform the delivery of person-centred nursing care tailored to their needs.

3. Study aim

The findings reported in this article arose from a larger study, which explored the experience of ovca for Australian women, partners and adult children. The aim of the study was to explore, interpret and describe the Australian lived experience of ovca, prior to development of recurrent disease. This article presents findings related to the experience of ovca for adult children.

4. Ethical considerations

Relevant state and university ethics committees gave ethics approval for the study. Each participant provided written informed consent. Pseudonyms were allocated to each participant and the names of HCPs were changed to reflect their professional role (e.g. ‘nurse’). Only the authors had access to interview data, which was kept in a locked file in a locked room.

5. Participants

A sample of nine adult children participants were recruited using purposeful and snowball sampling. On its website, a national ovca support group included an advertisement about the study which called for expressions of interest. In addition, in Tasmania (a state of Australia), advertisements were placed in two major newspapers and a hospital-based cancer care coordinator sent letters to women diagnosed with the cancer within the previous 12 months, asking them to invite their children to participate. Inclusion criteria included living in Australia, being 18 years old or above, fluent in written and spoken English, and self identification as a child of a woman with ovca. English was a requirement as the study documents were written and interviews conducted in English. Children were excluded if their mother had recurrent disease or they were unable to provide informed consent.

Nine adult children with an experience of ovca (prior to recurrent disease) participated in the study. A potential further seven participants were excluded as their mother had recurrent disease or had died from her disease. One child lived in Western Australia, two in Victoria and six in Tasmania. Children were asked to describe their mother's illness. Eight of the children described their mother as having advanced ovca. All their mothers had undergone cytoreductive surgery followed by six cycles of chemotherapy for primary ovarian cancer. Roles of the children varied from being primary carers for their mother (two daughters), keeping mother company at appointments and treatments (three children) to supporting via phone calls and visits (four children). Some specific participant characteristics are provided in Table 1.

6. Data collection

Interpretive phenomenology was used to explore and interpret the children's experience of ovca. The first author used unstructured, in-depth recursive style face-to-face or telephone interviews (Minichiello et al., 2004; Minichiello *et al.*, 2008) to gather data from participants. Each interview was digitally recorded and subsequently transcribed verbatim. Interviews began with a general statement like “I am interested in what you can tell me about your experience of ovarian cancer …” Interviews were conducted between May 2010 and July 2011, lasted between 30 min and 2 h and ended when the participant indicated they had nothing more to add.

Data analysis commenced with the first interview and continued as further children were interviewed. Data collection ceased after interviews with nine participants because at this time elements of their stories began to be repeated, no new data was arising and enough “experientially rich” (van Manen, 2014, p. 353) descriptions had been obtained to facilitate interpretation of the “phenomenological meanings” (p. 353) of ovca for the children.

7. Data analysis

Hermeneutic phenomenology provided the philosophical framework for the study. A circular process of data analysis involved systematic thematic analysis of each interview transcript using van Manen's (1990) approach as it offered a logical means of immersion in the data. Each transcript was initially examined as a whole, then line-by-line and then word-by-word in a search for significance. Transcripts were then re-examined using the conceptual lenses from van Manen's (1990, 2014) lifeworld existentials (relationality, corporeality, spatiality and temporality).

During analysis, the concept of ‘world’ facilitated interpretation of participants' ovca experience. A ‘world’ can be understood as the meaningful context within which we live our lives (Heidegger, 2008; Merleau-Ponty, 2002; van Manen, 1990). The concept of ‘world’ refers to the subjective world in which we live and in which we involve ourselves (Heidegger, 2008, p. 93). It involves relationships, social and historical contexts, roles and responsibilities. It reflects our connection with these entities within our lives (Leonard, 1994) and the way we create meaning in our world (Matthews, 2002). We experience our lives from within our personal world – from our personal perspective on life. Heidegger (2008) and van Manen (1990) suggested that we can simultaneously live in various worlds, according to our circumstances. For example, one might live within a world of business at work and a world of family at home. The concept of ‘world’ arose from participant comments. Throughout data analysis, fundamental elements and themes became apparent leading to the concept of participants living in various ‘worlds’ characterised by key aspects related to their ovca experience. From these themes, the overall