European Journal of Oncology Nursing 18 (2014) 521–526

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

The loss of a mother and dealing with genetic cancer risk: Women who have undergone prophylactic removal of the ovaries

Marie Kvamme Mæland*, Elin Overaa Eriksen, Oddgeir Synnes

Betanien University College, Institute of Nursing and Health, Vestlundveien 19, 5145 Fyllingsdalen, Norway

Keywords:
Hereditary ovarian cancer
Experience
Loss
Mother
Cancer risk
Narrative

A B S T R A C T

Purpose: The purpose of this article is to highlight some new findings from a qualitative study that have not been previously considered.
Method: The research was based on a qualitative phenomenological method. Data were collected by semi-structured individual interviews. A purposeful sample was recruited from West Norway of 14 women with a possible risk of developing breast and ovarian cancer. Data collection took place at least one year after prophylactic removal of the ovaries. Data from the study was analyzed according to the phenomenological method of Amedeo Giorgi.
Key findings: Two themes were revealed as essential factors of the interviewed women's experiences: "the loss of a mother" and "dealing with genetic cancer risk." For the most part, these two themes also appeared to be interrelated. When a mother died of ovarian cancer while her daughter was a child or a young woman, this often led to her daughter's strong desire to find an explanation for her mother's death, as well as to her efforts to undergo genetic testing and surgery to prevent cancer in her family in the future.
Conclusion: The study indicates that women's experiences in families at risk of hereditary cancer are closely related to an understanding of their life stories, particularly their "loss of a mother," and how this influences how they deal with genetic cancer risk. Health care workers can thus help patients identify connections and establish coherence through the act of storytelling, by listening to their illness experiences as part of their life stories.

Introduction

This article is based on data from an earlier presented study, conducted by the first writer, related to women's experiences in regard to treatment with hormones, as well as experiences related to information and guidance that they were given before prophylactic removal of their ovaries (Mæland et al., 2010).

When reanalyzing data from the study, we found that researchers had not previously attended to two important themes. These themes were the loss of a mother due to ovarian cancer and dealing with genetic cancer risk. We also found that the two themes were interrelated. Recommendations about preventive removal of the ovaries for women living in families with risk of hereditary breast and ovarian cancer are given on the basis of proven or risk of genetic defect in the breast and ovarian cancer genes BRCA1 and BRCA2 (Madalinska et al., 2005; Garber and Hartman, 2004; Møller et al., 1999). Quality of life effects of prophylactic oophorectomy for women living with risk of hereditary breast and ovarian cancer have been well documented. Research has demonstrated physical and psychological reactions following prophylactic surgery (Domchek and Rebbeck, 2007; Hurley et al., 2001; Hallowell et al., 2004). However, how the loss of a mother due to ovarian cancer affects women living with hereditary cancer risk has been given little attention.

Background

In the literature, we found research that focuses on mother–daughter relationships related to breast cancer (Baider et al., 2008; Boyd, 1989; Boyd, 1990; Brown-Guillory, 1996; Bush, 2011; Cohen and Pollack, 2005; Edelman, 2006; Fingerman, 2003; Raveis and Pretter, 2005; Vodermaier and Stanton, 2012; Wiggs, 2011). Wiggs

* Corresponding author. Tel.: +47 55 507292, +47 41502254 (mobile); fax: +47 55 507301.
E-mail addresses: Marie.Kvamme@betanien.no (M.K. Mæland), Elin.Eriksen@betanien.no (E.O. Eriksen), Oddgeir.Synnes@betanien.no (O. Synnes).

http://dx.doi.org/10.1016/j.ejon.2014.04.006
1462-3889/

(2011), for example, states that no relationship is more profound than the mother–daughter dyad. According to Wiggs each person in this relationship shares a physical, emotional, and spiritual link that is not experienced by others, a link which the intrusion of breast cancer dramatically alters. Articles relating to patients' experiences of ovarian cancer were also found (Burles and Hortslander, 2013; Guenther et al., 2012). However, these articles do not focus on the mother–daughter relationship.

The first and second authors of this article are educated nurses and have experience from working as genetic counselors. During genetic counseling with women at risk of hereditary breast and ovarian cancer, we have experienced that when the topic of a mother who died of cancer arises, the women often have started to cry. Also, when reanalyzing the transcripts of the qualitative interviews in the study, it was noted that when themes related to a close relative of a woman's family arose, and particularly in regard to the death of a mother from cancer at a relatively early age, the woman often started to cry. Mosher and Danoff-Burg (2005) have stressed that observing a parent's extreme physical and emotional suffering, as well as the potentiality of preparing for bereavement, may be traumatic. Daughters who were adolescents at the time of their mother's diagnosis were significantly more uncomfortable about involvement in their mothers' illnesses than daughters who were 20 years of age or older at the time of diagnosis. Van Oostrom, et al. (2006) found that individuals dealing with parental cancer in childhood (under the age of 13) reported the highest level of cancer-related worry and risk perception.

The interviewed women in the current study had each lost her mother to ovarian cancer. Previous research has emphasized that the relationship between mother and daughter is significant for understanding women's experiences of genetic cancer risk. However, there is a lack of research on this subject specifically regarding genetic ovarian cancer. This article will thus bring new insights on this topic. The other main finding, "dealing with genetic cancer risk," is in accordance with much research on genetic cancer, e.g., the importance of relationships and feelings of ambivalence/uncertainty (Tilburt et al., 2011; Maheu, 2009; Katapodi et al., 2004; DiMillo et al., 2013), but a valuable contribution of this article is the argument that the loss of a mother due to ovarian cancer is related to how women in these families deal with genetic cancer risk.

Method

In this study, phenomenology has been chosen as the research design and Giorgi's (1985, 1997) approach has been applied for analyzing the data. The aim of phenomenological research is to understand the meaning of the informants' life world, and the question of validity is based on the degree to which the researcher has been able to grasp this meaning (Kvale, 1996).

The first author conducted qualitative research interviews with 14 women at least one year after they had undergone prophylactic removal of their ovaries due to a risk of ovarian cancer within their family. Data were collected through individual interviews from 2007 to 2008. The women in the study were asked open-ended questions regarding their lived experiences in families with a risk of hereditary breast and ovarian cancer. Examples of themes during the interviews were experiences concerning replacement therapy with hormones after prophylactic removal of the ovaries and experience of relationships (Mæland et al., 2010). When we reanalyzed the statements of the women interviewed, we found new important findings that are presented in this article.

The women gave consent to use an audiotape during the interviews, which lasted approximately one hour and took place in the participant's home or in a suitable office. The anonymization of the audiotaped interviews was emphasized before each interview began. Afterwards the interviews were transcribed and analyzed in accordance with Giorgi's four-step analysis (1985). Conversations regarding sensitive conditions demand an interviewer's ability to protect the interviewee's privacy. The women participating in the study were all given a telephone number of a genetic counselor, in case a woman, following the interview, would come to feel the need of communicating with an experienced counselor.

Ethical considerations

This study is approved by the Regional Ethics Committee in Western Norway.

Recruitment and sample

The women in this study were recommended by a geneticist to undergo prophylactic removal of their ovaries due to research indicating that women who have inherited mutation in the breast and ovarian cancer genes BRCA1 or BRCA2 have a substantially elevated risk of developing breast and ovarian cancer (Rebbeck et al., 2009).

In Norway, medical practice in terms of genetics changed in 2006: if mutation in the BRCA1/2 genes related to hereditary breast-ovarian syndrome has not been proven after full genetic testing with sequencing, the risk of belonging to a family with hereditary breast ovarian cancer is deemed low, and a woman will not be recommended to undergo risk-reducing prophylactic removal of her ovaries. The women in the current study, however, all underwent limited genetic testing, and had prophylactic surgery of their ovaries before this change in medical practice.

The intended sample of the study was women between 38 and 50 years of age with an uncertain genetic status who belonged to a risk group for hereditary breast and ovarian cancer. A written request was sent from a medical genetic department in Norway to 31 women who met the inclusion criteria. Of these, 15 women gave written consent to participate, and of these, one eventually dropped out of the study.

- The mean age of the women interviewed was 49 years.
- The mean age of the participants at the time of prophylactic removal was 44.5 years.
- The oldest woman interviewed was 57 years of age. The youngest (two) were 39 years old.
- The oldest woman at the time of surgery was 54 years old. The youngest woman was 37 years old.

Data analysis

Data materials from the study were analyzed by the authors to identify key areas and issues.

In accordance with the method of Giorgi (1985), the researcher made sure to be aware of any preconceived perceptions of the phenomenon being studied, and to remain open to the greatest possible extent.

The data analysis involved the following:

Step 1: – Getting a grasp of the whole by reading the interviews thoroughly.
Step 2: – Each interview was read again in order to discriminate meaning of units.
Step 3: – The everyday language of the units of meanings was transformed into professional terminology.