



Hoping to reach a safe haven - Swedish families' lived experience when a family member is diagnosed with breast cancer



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A B S T R A C T

Purpose: When a woman is diagnosed with breast cancer, it affects all family members. Therefore, the aim of this study was to elucidate family members lived experience when a family member is diagnosed with breast cancer.

Method: The study had a hermeneutic phenomenological design including individual conversational interviews conducted face-to-face with six women with breast cancer and their family members at two different points of time, in order to elucidate families' lived experience, both as individuals and as a unit, from each family member's perspective.

Results: Living as a family in the presence of breast cancer is a challenging endeavour to regain an ordinary, safe life, *hoping to reach a safe haven*. The families felt that life as they knew it had disappeared and they were *fumbling in the dark*, trying to find support and guidance on their path to ordinary life. The family members were *pursuing balance* by attempting to keep the family together and maintaining a positive attitude while battling against fear and treatment-related side effects. Finally, the families were *struggling with guilt and inadequacy*, due to their difficulties in communicating the emotional distress that the illness brought upon them, at the same time as they felt abandoned by the healthcare professionals.

Conclusions: Families experience an unmet need of information and support, which implies that healthcare professionals may want to acknowledge and include the family already at the time of diagnosis in order to help them endure and cope with the distressing experience and thus increase their wellbeing.

1. Introduction

Women diagnosed with breast cancer describe their experience in terms of shock, fear, anger, distress, and anxiety (Fu et al., 2009; Schubart et al., 2014), and research shows that breast cancer and its subsequent treatment also have an impact on family members (Coyne et al., 2012). There is a growing interest in how the family experiences the woman's breast cancer diagnosis, although few studies elucidating family experience have included both the patient and her family (Robbins et al., 2013). Instead, previous research has explored family experience focusing on the spouse's experience (Lewis et al., 2008; Lopez et al., 2012), the child's experience (Edwards et al., 2008), or a couple's dyadic experience (Belcher et al., 2011; Sprung et al., 2011). Knowledge of individual experience is important, but insights from several family members may offer a wider overview of family experience when a family member is diagnosed with breast cancer.

2. Literature review

Breast cancer is the most common female malignancy worldwide (Siegel et al., 2013). Research has shown that women diagnosed with and treated for breast cancer experience distress, fear of recurrence, and worry about their children (Lebel et al., 2013; Stinesen Kollberg et al., 2013), and that young women in particular emphasise their unmet supportive needs, and their lack of information and counselling (Adams et al., 2011; Schmid-Büchi et al., 2013). Women have also expressed a need for professional and emotional support when communicating their cancer diagnosis to their children (Asbury et al., 2014; Semple and McCance, 2010), which implies that the woman should be seen in the context of her family.

Family responses to breast cancer have been explored by recruiting the patient and one family member, often the spouse, to provide information, and these studies have highlighted the fact that spouses and other close relatives may experience increased levels of anxiety and depression (Fletcher et al., 2010; Lewis et al., 2008; Schmid-Büchi et al., 2011), as well as reduced quality of life (Duggleby et al., 2013;

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Wagner et al., 2006). The spouses also express a perceived lack of support and information from healthcare professionals (Northouse et al., 2005).

Other researchers have elucidated children's experiences of parental cancer, finding these children affected by distress, emotional and behavioural problems, as well as unmet informational and supportive needs (Huang et al., 2014; Vannatta et al., 2008), but also equipped with strength to adapt to and normalise their situation (Clemmens, 2009). Further, researchers have found that an enhanced adjustment to parental cancer may be associated with better family function (Krattenschacher et al., 2012; Vannatta et al., 2010).

The emotional impact that an illness like breast cancer has on the individual family members reveals that a cancer diagnosis is always a family affair (Wright and Leahey, 1994). A family can be described as a system in which the family members interact mutually; they represent elements in relationship to each other and, when in balance, this system assures the members of predictability, security, and feelings of connectedness. A severe illness like breast cancer in a family member may lead to an imbalance and a loss of security for all members of the family system (Wright and Leahey, 2013). The strain that a breast cancer diagnosis can put on the family is something that needs attention from healthcare professionals. In the USA, for example, almost 20 per cent of adult cancer patients are parenting dependent children, parental cancer thereby affecting three million children in that country alone (Weaver et al., 2010). Having a family member with cancer may lead to mental and physical illness in partners and close relatives (Sjövall, 2011; Stenberg et al., 2010), as well as considerable levels of anxiety and supportive needs years after successful treatment (Hodgkinson et al., 2007). Nissen et al. (2016) also found that lower levels of perceived social support and quality of life in caregivers of advanced cancer patients could be associated with worse family function. However, partners and relatives are not only co-sufferers; they may also be the emotional support the affected woman needs in order to manage treatment and daily life (Arora et al., 2007; Coyne et al., 2012), which reinforces the need to include multiple family members in care and research. There seems to be a paucity of research focusing on both the affected woman and the members of her family, as well as on elucidating the family's lived experience, as individuals and as a unit, in the presence of breast cancer.

3. Aim

The aim of this study was to elucidate family member's lived experience when a family member is diagnosed with breast cancer.

4. Method

4.1. Design

The study design was descriptive and inductive, including individual, conversational interviews conducted face-to-face with six women diagnosed with breast cancer and their family members. The

methodological approach chosen was hermeneutic phenomenology influenced by van Manen (2001). The interviews were conducted at two different time points to generate deeper meaning and allow participants to reflect on their lived experience in accordance with the recommendation of van Manen (2001).

4.2. Sample and setting

The recruitment was done at a radiation therapy department at a university hospital in the south of Sweden, where 850 women yearly are treated with radiation therapy (henceforth referred to as RT). The inclusion criteria were Swedish-speaking women with breast cancer and their family members (husbands, sons, and daughters) aged 12 and older. The lower age limit was set at 12 years, since children begin to develop their abstract thinking by the age of 12, which means that they can have their own opinions and perceive multidimensional situations (Belmont, 1989; Piaget, 1972). Since a variety in sample size ranging between 3 and 10 (Dukes, 1984), 6 (Guest et al., 2006), and 6–10 (Morse, 2000) is recommended for phenomenological studies, we projected to include 5–7 families. Thus, a total of six women who met the study's eligibility criteria were consecutively approached during their first visit at the RT department and invited to participate in this hermeneutical phenomenological study. The women signed a consent form for the release of their contact information and received written information addressed to themselves and their adult family members, as well as age-specific written information for their children. In this study, Wright and Leahey's (2013) definition of a family was used: "the family is who they say they are" (p. 33). Hence, a family is constituted by those who feel that they belong to the family, regardless of how their relations are viewed from the outside. Eligible participants were therefore asked to identify close family members who shared the illness experience and whom they specifically defined as belonging to their family. A family is a system consisting of individuals interacting with and affecting each other (Wright and Leahey, 2013). Thus, to capture the whole family's lived experience, each family member was seen as equally important. After being given two days to reflect and discuss their participation with their family members, each woman was contacted by the interviewer (AHH), by telephone. All of the women asked consented to participate and the time and location for the interviews, chosen by the families, was scheduled. Six families consisting of a total of 19 family members, including the six women with breast cancer, were included; however, a father and a sibling, in two different families, declined to participate. Two siblings were younger than 12 years and were therefore excluded. All of the participating women had undergone surgery, chemotherapy, and RT for 25 days, except one woman who had received RT for 15 days. The time span from diagnosis to the second interview ranged from 7.5 to 8.5 months (md = 8.2). The characteristics of the participating families are presented in Table 1.

4.3. Data collection

Individual, conversational interviews were conducted face-to-face

Table 1
Family characteristics (n = 6).

Family members	Woman with breast cancer	Family member (age, gender and relation to woman with breast cancer)	Family member (age, gender and relation to woman with breast cancer)	Family member (age, gender and relation to woman with breast cancer)	Family member (age, gender and relation to woman with breast cancer)
Family 1	Woman, 50 years	Son, 12 years	–	–	–
Family 2	Woman, 41 years	Husband, 39 years	Son, 14 years	–	–
Family 3	Woman, 55 years	Daughter, 12 years	–	–	–
Family 4	Woman, 45 years	Husband, 48 years	Daughter, 14 years	Daughter, 18 years	Daughter, 20 years
Family 5	Woman, 51 years	Son 14 years	Daughter, 16 years	–	–
Family 6	Woman, 47 years	Husband, 58 years	Daughter, 14 years	Daughter, 18 years	–

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