ORIGINAL RESEARCH

The transitional experience of women with newly diagnosed breast cancer

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ABSTRACT

The aim of the study was to provide insights into the transitional experience of women newly diagnosed with breast cancer progressing to their primary treatment. The psychosocial impact of patients in the recovery phase after breast cancer treatment has been investigated in recent years, however, little is known about the transition experience and psychosocial needs of Danish breast cancer patients during the phase of transition from diagnosis to treatment. This study employed a qualitative descriptive design with data collection including 12 semi-structured interviews with women undergoing radiation–or chemotherapy treatment. The transcribed interviews were analysed which identified five main themes; 1) Uncertainty, 2) Sense of powerlessness, 3) Sustaining normality, 4) Worrying about the future, 5) Fortunate only having radiotherapy. Understanding care needs of women in transition, from diagnosis to treatment, and how it impacts on their lives, is essential to enable health professionals to tailor individualized care. Early support is critical to ensure that women understand step-by-step what is involved in the treatment and care and thereby to assist them towards a positive psychosocial trajectory.

Key Words: Breast cancer, Interview, Psychosocial needs, Transition, Denmark

1. INTRODUCTION

Breast cancer is the most frequent cancer among women in the world. The estimated incidence of breastcancer is 1,7 million and the five year prevalence is 6.2 million and both are increasing.[1] Breast cancer is also the most common form of malignancy among women in Europe with a 5-year-survival of about 86% in Denmark.[2,3]

With one million new cases in the world each year, breast cancer represents a major public health issue.[1] In Denmark, 37,075 new cancer cases were registered in 2012. Of these cases, the number of newly diagnosed women with breast cancer counted for 4721 cases which makes breast cancer the most common cancer in women.[3] However, the number of breast cancer survivors has increased due to improved

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screening and treatment programmes.[2] Today breast cancer treatments are likely to have less external physical impact than half a century ago but are usually more complex and extend over a longer period of time. Traditionally, cancer has been conceptualised as an acute illness.[4] However, with cancer survivorship improvements, more people are living longer with the disease. Thus, it has recently been categorised as a chronic condition.[4] Yet little is known about women's psychosocial and physical needs during the crucial time between diagnosis and treatment.

1.1 Background

A cancer diagnosis and its treatments impose an immense physiological, psychological and social burden on the individual. People who are diagnosed with cancer face three major stress periods: diagnosis; treatment and survivorship phases.[5] Patients' information and support needs evolve over the course of their disease. At diagnosis, people experience considerable psychological distress and uncertainty about impending treatments and about the prognosis of their disease. During the treatment phase, patients experience the physiological outcomes of chemotherapy, radiotherapy and surgery and continue to experience fears associated with treatments as well as a sense of social isolation.[6,7] During the survivorship phase, many people experience ongoing side effects of their treatment as well as anxiety and depression.[6] Although clinicians are perceived to be the most credible source of medical information, treatment and care, their capacity for support cancer patients and their families is often limited. There is limited knowledge on how women diagnosed with breast cancer manage the transition from being healthy to living with a cancer diagnosis and about their specific health care needs during this transition. In addition, shared decision-making process and use of decision aids may be stressful.[7–9] The number of medical visits, procedures, and waiting times during the initial diagnostic process can be overwhelming on newly diagnosed women. A period of planning is then followed by the need to organize and navigate care with multiple providers (surgeon, radiation oncologist, medical oncologist, plastic surgeon) and often second opinions to assist in decision-making. A review from 2009 of breast cancer care and outcomes in 18 countries in Europe, Asia, and Latin America concludes that increasing disease burden and rapid changes are taking place in cancer care today. The review also conclude that a broad approach to research is needed in order to make registration more encompassing and relevant across countries with well defined and more patient-focused criteria for outcome assessments.[10]

A cancer diagnosis has widespread physical and psychological implications for the women, as well as restrictions in daily life.[7,8] Facing many potential months of treatment leads to disruption in social activities (childcare, work, caregiving) and decreases the ability to plan. This is exacerbated by the physical toll that the treatment often extracts[7,11] such as fatique, nausea, vomiting, hair loss, weight gain. The literature indicates that the relationship between psychosocial stress, adjustment and coping has a key effect on clinical outcomes in management of chronic illness and improved health outcomes.[12,13] Previous research has explored the transitional experience and health care needs in women undergoing chemotherapy,[14] however, the current study specifcially investigates the transitional experiences and health care needs in women undergoing chemotherapy as well as in radiotherapy. Understanding the transition process from health to illness is important to help health professionals plan and implement appropriate measures to assist people to achieve the best possible health outcomes and quality of life. Transitions are defined according to the disciplinary focus but most transitions involve people's responses during a passage of change.[15,16]

In nursing, the theory of transition provides a framework that can assist to describe the experience of individuals who are confronting, living with, or coping with a situation that require the development and mastery of new life skills.[17] Transition represents periods during which individuals make the shift from one life phase, situation, or status to another[17,18] as well as periods of vulnerability to risks inherent in health and the change from health to illness.[16,19,20] The work of Meleis and Schumacher has clarified the concept of transition and the implications for nursing.[17,20] Meleis et al.[20] argue that awareness, engagement, changes, time span, and critical points and events in people's lives are inter-related properties in a complex process. The properties and conditions inherent in a transition process need to be understood as congruent with the unique experiences of clients and families and taken into consideration in nursing practice. Meleis et al.[20] identified four types of transitions: developmental, situational, organizational, and health-illness. Meleis et al.[20] present examples on these categories. Among development, becoming a parent is a transition. The situational transitions is when your role as professional has changed. The organizational transitions represent transitions in the environment and health–illness transitions is related to the process of recovery from critical illness; this study focuses on health-illness transition experiences associated with early diagnosis of breast cancer. It is paramount that health professionals understand the complex decision-making processes operating during life changing events so they can collaborate with the people to put appropriate self-management strategies in place.[21,22] The current study addresses the psychological and social experiences of women with breast cancer in a unique life course contexts; hence adds specific knowledge about one of the most vulnerable times in the women's cancer trajectory. This specific knowledge will add useful and needed knowledge and assist health professorial when working with women in transition. Our findings will therefore contribute to the increasing knowledge about psychosocial and physical needs in breast cancer treatment.

1.2 Aim

The aim of the study was to explore the health –illness transitional experiences of women with newly diagnosed breast cancer during the crucial time between diagnosis and treatment, to provide insights into psychosocial health care needs of women newly diagnosed with breast cancer.

2. METHODS

2.1 Design

A qualitative study design was used to explore the experiences of women newly diagnosed with breast cancer. A qualitative approach is suitable for describing and analyzing the characteristics of the phenomena to be studied.[23,24] The interest in qualitative designs is directed toward discovering or uncovering new insights, meanings, and understandings.[25] Qualitative interviews provide insight into women's experiences from time of diagnosis to up to three months post diagnosis. An understanding of their psychosocial heath care needs during this critical period is essential to provide the best support to the women during their treatment. A hermeneutic approach inspired by Gadamer[26] was used to gain a deeper understanding of the health–illness transitional experiences of women with newly diagnosed breast cancer. Gadamer's philosophical hermeneutics provides the background to deepen understanding of basic life in both health and suffering as it acts in accordance with the research question's existential nature in search for the experiences.[26]

2.2 Participants and data collection

Data were collected from a Danish oncology clinic through semi-structured interviews. A total of 12 interviews were conducted while 12 women were undergoing treatment; six women undergoing chemotherapy and six women undergoing radiotherapy. The two groups of women going through different treatments were not included for comparative purposes but to capture more nuances in the women's experiences.

The purpose of the interviews was to identify specific issues experienced in the transition from healthy to newly diagnosed breast cancer and identify key health care needs. Eligible participants were identified via the patient lists in an oncology clinic and invited to participate in an interview during a routine visit. Women were invited by letter provided by a staff member not involved in the women's care at the oncology and radiotherapy clinics. The inclusion criteria were women newly diagnosed with breast cancer, in the middle of their treatment, who lived in a regional area and used the regional hospital's cancer clinic. Furthermore, the women spoke and read Danish and were over the age of 25 years. Women over 25 years of age have gone through life transitions and at this stage of their life, they have experienced numerous life transitions so they are able to compare and express their experiences. Furthermore, the women had no earlier experiences of cancer diagnoses. The interviews took place at the oncology clinic just prior to their treatment in a separate room where we were not disturbed. Women were aged 52-77, half of them were employed.

We tested the interview questions with one woman, discussed the findings, reviewed, and designed the interview guide based on the findings from the test interview. Data were collected in 2013 through semi-structured audiotaped interviews and key issues were explored using an interview guide, and was followed by open exploring questions that encouraged the women to elaborate on their experiences. Questions were open and gave the women ability to independently reflect on each question. The interviews commenced with a broad question; Can you please tell me about your experience when you were told that you had breast cancer? The question was followed up with in-depth questions to gain a as clear picture as possible of the women's experiences. Examples of other questions were: What impact has it had on your life that you have breast cancer? What challenges do you encounter in your work that are associated with breast cancer? What support do you experience getting from the nurses while you are in treatment? Each of the interviews lasted approximately one hour.

2.3 Ethical considerations

The study was approved by relevant ethics committee according to Danish law.[27] A nurse in the oncology clinic, not directly involved in the care of the potential participants, invited the women to participate and gave oral and written information about the study. Additionally, the women were informed about anonymity and privacy and was given time to consider participation in the study before they gave consent.

2.4 Data analysis

The twelve interviews were transcribed verbatim, and analyzed following methods as described by Kvale.[23,24] The analysis was descriptive and the analysis was progressed step by step. The first step, namely self-understanding, occurred as three experienced researchers independently analyzed the transcribed interviews by applying a line-by-line analysis. The second step involved the transcriptions to be re-read several times to achieve in-depth comprehension. Next, the researchers discussed the individual analysis. Five themes were identified and related to the purpose of the study in meaningful units. The third step combined and condensed the units into meaningful categorization. In the final forth step, these categories were described in details and further analyzed and compared with theoretical perspectives concerning health-illness transition and living with breast cancer. This step-by-step aligns with the hermeneutic approach and underpins the interpretation of the data.[26,28] Findings were repeatedly discussed by the researchers throughout the analytic process and pre-understandings were challenged. Differences and similarities between the women's experience and descriptions were systematically explored by three researchers until consensus was reached. One of the co-authors, who speaks and writes Danish and English fluently, ensured the translation of the quotes from Danish to English. By this process, it was ensured that the data not loosed the richness.

Table 1 illustrates examples of the analysis:

Table 1. Examples of the analysis

Themes	Meaningful units	Quotes
Sense of uncertainty	Feeling alone, and don't know what to do.	It felt like a no-mans-land", and I really needed a lifeline.
Worrying about the future	What is going to happen?	"Sometimes I think: Will I be here for Christmas? Perhaps I am not going to be here tomorrow."
Worrying about the future	What is going to happen?	What happens afterwards the radiotherapy?
Fortunate only having radiotherapy	I am well compared to others.	Others are much harder hit-chemo is hard at them (women's who get chemotherapy).
Fortunate only having radiotherapy	I am well compared to others.	"I am lucky. Others are worse than me."

3. FINDINGS

The analysis identified five themes. Four main common themes emerged concerning women's experience of their transition from being diagnosed with breast cancer to their early treatments: Sense of uncertainty, Sense of powerlessness, Sustaining normality and Worrying about the future. The four themes went across all the women. A fifth theme was only identified in the group with women in radiotherapy as they were 'feeling lucky only having radiotherapy'.

3.1 Sense of uncertainty

Uncertainty was intensely experienced in the period from point of diagnosis to treatment commencing. The experience of uncertainty was intensified due to health services located in multiple and geographically spread hospital departments involved, especially in this early phase. The majority of women experienced a kind of inability to adjust with shifting departments in charge of different aspects of their treatment. A perception of not knowing the next step was consistently reported:

> "It felt like a no-mans-land, and I really needed a lifeline."

The constant change of staff resulted in the women feeling a sense of instability as they had to continue to build rapport with changing staff as well as familiarise themselves with new departments' routines.

> "Every time you get to know you have a contact nurse. But (...) just like when you finish the place, it's not relevant anymore, well".

> "I just might think that it has been a little confusing, so there are so many different ones you are in contact with too. You get a card with your contact nurse and a phone number every place; you can just call if there are any problems."

The changing staff and unfamiliar environment also made most of the women concerned about their future, which made them reflect deeply on their existence and purpose of life.

> "It [the diagnosis?] is a gigantic interference in my existence and life. I try to live in the present."

The reflections made the women scared and worried as well as enhanced their sense of uncertainty. One of the women said:

> "I just can't stop wondering [about the future] and worry. I'm scared."

The majority of women tried to adapt with the take-one-day-at-a-time strategy, which helped the women to cope with the uncertainty of not knowing what the future brings. Thinking about the future also brought the thought of death to their minds. One of the women said:

> "Sometimes I think: Will I be here for Christmas? Perhaps I am not going to be here tomorrow so I am taking one day at a time."

The women reported they could not emotionally manage to be confronted with death constantly. Hence, the women did not make plans for the future, as they did not know if they would be well enough to carry through to the next event. This made them focus on the day-to-day challenges rather than making plans for the future:

> "Right now, I am just fighting one day at a time?"

The women also experienced feelings of vulnerability and disappointment when they could not accomplish things such as daily routines, which made them feel that they had lost control.

3.2 Sense of powerlessness

In the context of losing control, the women reported experiencing sense of powerlessness in almost every part of their lives in the transition from healthy to ill. Being diagnosed with cancer and living with the consequences from the treatment was an unexpected event in life:

> "The cancer came as a thief in the night. It came as an attack and I am still powerless".

The powerless feeling was in many instances related to the body changes as well as a longing to get their previous lives back. This was a common experience, for example, loss of hair was perceived as both losing control and their 'life'.

> "I want my hair and my life back."

Some women reported feeling healthy during their transition, however the treatment made them feel sick. Their sense of powerlessness was also expressed as losing control, which is a major issue for the women and exacerbated their experience of uncertainty by the feeling of "life being on hold". The powerlessness is illustrated by highlighting the limitations experienced during this time period:

> "I cannot plan anything. I am more at home. I really feel tied and bounded to the soil."

The feeling of powerlessness related particularly to the disruption in social activities and decreasing the ability to plan and multitask their everyday activity. They could not plan anything because of tiredness, nausea and worries.

3.3 Sustaining normality

The transition from healthy to ill was particularly experienced in relation to ability to continue to work or to continue to be engaged as volunteers. Being employed or working as a volunteer during this period were very important for the women because employment was perceived as the manifestation of having a sense of normality, cohesion, networking and self-efficacy.

> "The biggest challenge has been that I could not go to work. I missed a lot, the contact I have with all the teachers at school and something like that."

Being employed helped the women in their transition as work provided a network, support and a sense of being a part of a community. Employment also helped them to sustain their identity.

> "And it really helped a lot too. The things that I'm doing, are something that would not have been made otherwise."

> "It was very difficult to cross the threshold there and go to my colleagues there [. . .] it was the same when the hair fell off."

Half of the interviewed women were still working at the time of the interview. Employment helped the women to cope in their daily life. It was expressed:

> "The biggest change in my life since my diagnosis is that I am no longer able to work".

Even though the women have a difficult time showing up at work wearing a wig, they found help and support in being employed. Additionally, the feeling of being normal was important:

> "I know I have cancer, but I am not 'leprous'".

A woman, who worked as a volunteer said:

> "I am a visiting-friend and I visit her the two weeks when I feel good. You have to experience something, I think".

The possibility to work or being volunteers to some extent made room for the sense of normality in the transition.

3.4 Worrying about the future

The women reported experiencing more worries and being more easily emotional affected due to their situation and treatment. They were particularly worried about the future, including worries about time left to live in. The women's thoughts about death are periodic.

> "Everybody's is able to walk from here, right? I hope to survive, right? I certainly fight for it".
>
> "I may be dead tomorrow."
>
> "I said to my daughter the other day that my house has to be tidy the day I am not here anymore."

These concerns about death were again raised by women. In addition, the worries also lead to actions and decisions. For example, some tried to enjoy their daily life and family or bought new furniture, because:

> "You have to remember doing this stuff [spend time with family]".

Participants attempted to cope with concerns about the future in different ways. A common coping strategy was to compare their own situation with others who may be worse off. They expressed positive thoughts such as:

> "I am lucky. Others are worse than me."

Others used their work to relieve and to distract them from their illness to gain a sense of normality. Despite these strategies, women are still worried about the future. Furthermore, the women stated self-contradictions as:

> "I am fully recovered–right?"
>
> "The cancer is in control all the time. But as you know, I am not sick."

3.5 Fortunate only having radiotherapy

Interestingly, the comparative strategy became evident between the women in chemotherapy treatment and radiation therapy. The women who only received radiation treatment felt luckier than the women who received chemotherapy. They expressed that they were not that sick of the cancer when they only needed radiation therapy. These women mention that they felt "lucky" because they did not need chemotherapy.

> "I am lucky. Others are worse than me. I only need radiotherapy."

Another woman said it in this way:

> "I think that I belong to the lucky group [implied only radiotherapy]. Yes."

Another woman mentioned:

> "I only needed radiotherapy. Actually, (groan) I am slightly relieved in a way. I am terrified by chemo".

They really felt that they are lucky, in 'the good group'. However, that does not mean that they not felt unsafe and worried about the future. One of the woman said this:

> "Thoughts are running in my head of course and also [about] my job. I'm only there in the morning, so I have to plan my day a little differently".

Even if the women felt they are in 'the good group', they still had the feeling of uncertainty, sense of powerlessness and were worried about their future.

4. DISCUSSION

The findings regarding uncertainty and powerlessness can be perceived in the context of transition from health to illness, when women attempted to cope with the cancer and treatment. Meleis transition model consists of three general dimensions of transitions: Nature of transitions, transition conditions, and patterns of responses.[17] The nature of transitions includes the types, patterns, and properties of transitions. Transition conditions play an important role in mediating between transition properties and the indicators of healthy transition and include personal, community, and/or societal factors that could facilitate or inhibit the cancer health-illness transition. Patterns of responses to the transition include process and outcome indicators. Health professionals interconnects all three dimensions of the transition model and consists of interventions that can occur at each of the three dimensions within the transition process.[17] These interventions can facilitate or diminish barriers affecting the transition outcome to promote healthy responses to transition at many points during the health-illness transition process.

4.1 Transitions through no-mans land

Two of the main findings in the current study were that the women's experienced uncertainty and sense of powerlessness. These experiences were major for the woman, and can perceived as a dimension of the transition when diagnosed with breast cancer. Meleis describes change and difference as essential properties of transitions. When women are talking about "I felt like a 'non-mans-land', and I really needed a lifeline" they were trying to adapt to a new role and situation. During the treatment, they seem to go through a period of instability, confusion and distress, before they can start with a new beginning.[17] According to Dragsett et al.[29] women diagnosed with breast cancer experience uncertainty about their future. They also struggle to find the meaning with the life changing, which are essential properties of transitions during the time when your life changes radically by a cancer diagnosis. Meleis et al. argue that personal contact to other people in their social network is essential to meet the need of feeling connected.[17] Another major aspect of the transitional experience is swift from feeling in control to feeling the powerless. Boehme and Dickersons[14] study of transition from health-to-illness in breast cancer concurs with these feelings as their study indicates that the women could not do what they have done before in their life because of the side effects of the treatment. Our study pointed out that the powerlessness was particularly related to the lack of planning in their everyday lives. The nature of transition also contains the powerlessness of the everyday life, and not only the side effect of the treatment.

Another major finding was that women described a loss or change of identity, which was also reported by McCann et al.[30] as they explored the experiences of people with cancer within the first year following diagnosis.[30] They found that the transition between health and illness impacted on women's identity and way of managing the life immediately after a breast cancer diagnosis and increased a need for interventions that supported women to both manage the experience of cancer diagnosis as well as the treatment. The women needed to equip themselves with the necessary techniques to negotiate transitions towards the future with living with cancer.[29] In addition, after a breast cancer diagnosis and treatment that occurred from six months to a year, many women discovered that their final treatment did not signify an end but rather underlined a different and often traumatic beginning.[29] The women in our study tried to maintain their identity through the normality. Being employed or voluntary during the treatment was very important, even if it only was for a few days or a few hours a week. Employment or voluntariness helped them to sustain their identity. Unlike other studies,[29,31] which reported about normality after reconstructing surgery after mastectomy, our study pointed out the importance of being employed or voluntary as a part of going through a transition.

4.2 Vulnerability in transitions

Women in our study expressed concerns and insecurity reporting they may not survive the treatment. Uncertainty about the future was a fundamental situation, but the uncertainty also meant that there may be hope for survival. This current study reveals that experience of uncertainty underpinned the whole transition experience as Meleis[17,18] indicates the sense of vulnerability exists across developmental, situational, organizational, and health-illness. Therefore integral in care that health professionals support women to stay in employment, plan continuity in their care and ensure that they understand step-by-step what the treatment and care involved.

According to Penrod,[32] the experience of uncertainty is dynamic, is pervasive in human existence, and is a discomforting state that is mediated by feelings of control and confidence.[32] With this in mind, it is particularly relevant to focus on an important area as sustaining normality. Living as normally as possible during transitions is important, for example being active participants in the workforce, is an important aspect of achieving a sense of autonomy and living a normal adult life.[32] Strategies towards uncertainty may focus on the existential aspect or a more cognitive processing of available information.[32] Furthermore, the women participating in this study had no earlier experiences of cancer diagnoses. Other research indicates that women had neither enough knowledge nor experience regarding breast cancer treatment and the effects of the treatment, which increased uncertainty.[33] These findings underpin the diagnostic phase of breast cancer as a stressful time affecting all aspects of the women's life. Health professionals can help patients adjust their identity by being genuine, offering time, being an active listener and, where possible, supporting search for information.[34] Therefore, understanding the transition process from health to illness is important to assist health professionals plan and implement interventions to support women through this process. In another article, the author describes her experience of being diagnosed with breast cancer as a riptide experience.[35] Within this riptide experience following areas are identified: a shattered sense of well-being; feelings of anxiety, fear and uncertainty; learning to live one day at a time; the loving attention of family and friends; and, swimming with the turbulent sea.[35] In accordance with our findings, being diagnosed with breast cancer is like a riptide experience; it pulls you out of your daily swimming with the current and presents you with the challenge of surviving.[35]

Despite the fact that the women who received radiation therapy felt "lucky", they still worried about the future and also experienced sense of powerlessness. The comparative strategy has been identified as being a useful coping strategy for people with chronic illnesses.[36] This comparison made the women feel they were in a better situation than others and helped them stay positive. By imagining a worse scenario the women were able to put things in perspective and thereby overcome their sense of being in the grip of breast cancer. Health professionals need to be mindful that this group of women need targeted and individualized support from health professionals when going through transition into living with a cancer diagnosis.

4.3 Limitations

In the critical interpretation, the findings of this study were discussed using other international research and generally accepted theory, and our findings were partly or fully comparable to the findings of other studies. Since it is a qualitative study with twelve participants it is not generalizable, however, our interpretation is strengthened by partly or fully comparable findings in other international studies. Therefore, these qualitative findings may have a degree of transferability to similar contexts.

5. CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Understanding women's needs in a health–illness transition process from early treatment to recovery is important in order to assist health professionals to support the women. Women need re-assurance that their sense of uncertainty and powerlessness are parts of the transition into living with a cancer diagnosis. The emotional responses in this crucial period as indicated in the current study can potentially be minimized by provision of personalized and holistic care to help them adjust to the new situation. Health professionals need to understand and support women to stay in employment, plan continuity in their care and ensure that they understand step-by-step what the treatment and care entails. Thus, the women were worried about being stigmatized by the social environment; the received social support alleviated the devastating effects of the breast cancer diagnosis. Therefore, health professionals can endorse the social support to women during the diagnostic and treatment phase to help the women establishing a supportive social environment which is essential for their well-being. Health professionals play an integral role during this specific transition period by providing information and support that maintains routine activities to potentially assist them onto a positive life trajectory.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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