

ORIGINAL RESEARCH

Being in suspense: women's experiences awaiting breast cancer surgery

Sigrunn Drageset, Torill Christine Lindstrøm, Tove Giske & Kjell Underlid

Accepted for publication 22 January 2010

Correspondence to S. Drageset:
e-mail: sigrunn.drageset@hib.no

Sigrunn Drageset MSc RN
Assistant Professor
Faculty of Health and Social Sciences,
Bergen University College, Norway

Torill Christine Lindstrøm PhD
Professor
Faculty of Psychology,
University of Bergen, Norway

Tove Giske PhD RN
Associate Professor
Haralds plass Deaconess University College,
Bergen, Norway

Kjell Underlid PhD
Professor
Faculty of Health and Social Sciences,
Bergen University College, Norway

DRAGESET S., LINDSTRØM T.C., GISKE T. & UNDERLID K. (2011) Being in suspense: women's experiences awaiting breast cancer surgery. *Journal of Advanced Nursing* 00(0), 000–000. doi: 10.1111/j.1365-2648.2011.05638.x

Abstract

Aim. This article is a report of a qualitative study of women's experiences after having received a breast cancer diagnosis and awaiting primary surgery.

Background. Breast cancer is experienced as an important stressor and a major challenge. How women appraise the diagnosis affects their postsurgery adaptation. Although studies have documented the presurgery period as stressful, in-depth understanding of women's experiences while awaiting surgery studied *during* this stressful period is still needed.

Method. Twenty-one women with newly diagnosed breast cancer were interviewed individually the day before surgery at a Norwegian university hospital, between February 2006 and February 2007. Interviews were analysed using the qualitative meaning condensation method.

Findings. Feeling healthy, but having to adapt to disease, waiting, uncertainty, having to tell and existential awareness were themes identified. Having to wait was experienced as frightening, painful, long and difficult – but also necessary. Some expressed apprehension because they could not do anything about their situation. Others emphasized that it was good to have some time between diagnosis and surgery to become personally prepared and spend time with loved ones. Informing others about the diagnosis was a great burden for most of them. Social networks could both give and crave support.

Conclusion. Healthcare professionals need to be sensitive to the individual experiences of women awaiting breast cancer surgery to give support to ease their situation. Setting the date for surgery will alleviate anxiety. Follow-up studies about the potential impact of presurgery experiences on later experiences of living with breast cancer and intervention studies are needed.

Keywords: breast cancer, diagnosis, nursing, qualitative interviews, uncertainty, waiting for surgery

Introduction

Breast cancer is the most common cause of cancer death among women worldwide (World Health Organization 2009). One in ten Norwegian women develops breast cancer

during her lifetime (Cancer in Norway 2008). Being diagnosed with breast cancer is experienced as an important stressor cross-culturally. It is perceived as a life-threatening illness associated with suffering, pain and death (Perreault & Bourbonnais 2005, Fu *et al.* 2008, Taleghani *et al.* 2008) and

as a long-term illness (Kralik *et al.* 2001). How women appraise their diagnosis affects both their immediate experiences and postsurgery adaptation (Gallagher *et al.* 2002, Boehmke & Dickerson 2006, Barez *et al.* 2009).

Background

According to several studies, receiving the diagnosis of breast cancer is a traumatic experience (Cordova *et al.* 2007, Mehnert & Koch 2007), and may cause various emotional reactions (Bertero & Chamberlain Wilmoth 2007, Shaha *et al.* 2008, Al-Azri *et al.* 2009), mostly anxiety and depression (Montazeri 2008). The prevalence of anxiety and depression at the time of diagnosis is reported to be significantly related to anxiety (Burgess *et al.* 2005) and depression (Den Oudsten *et al.* 2009), or both (Burgess *et al.* 2005, Vahdaninia *et al.* 2010), 12–18 months after diagnosis, and is even common several years after diagnosis and treatment (Lueboonthavatchai 2007, Montazeri 2008). Some women are reported to have posttraumatic stress disorder symptoms, some even long after treatment (Kornblith *et al.* 2003, Mehnert & Koch 2008).

Several studies report that waiting for health care (Fogarty & Cronin 2008) and preoperative waiting for breast cancer surgery (Oudhoff *et al.* 2004, Schnur *et al.* 2008) are stressful, with the highest level of distress the day before surgery (Ryburn 2003). However, uncertainty remains one of the major stressors that influence women's experiences during the breast cancer trajectory (Shaha *et al.* 2008). They suffer different kinds of uncertainty: before diagnosis (Demir *et al.* 2008, Liao *et al.* 2008, Montgomery 2010), before surgery (Montgomery & Bovbjerg 2004, Schnur *et al.* 2008, Drageset *et al.* 2010), and concerning the future after surgery (Wade *et al.* 2005, Doumit *et al.* 2010). Many patients are afraid of the disease's recurrence and have to live with 'uncertain certainty' (Bertero & Chamberlain Wilmoth 2007). Limited knowledge about cancer and its treatment, and poor understanding of information from the hospital, add to the patients' uncertainty (Gaudine *et al.* 2003, Saares & Suominen 2005, Shaha *et al.* 2008), along with existential concerns (Landmark *et al.* 2001, Logan *et al.* 2006, Bertero & Chamberlain Wilmoth 2007). Anxiety increases in situations of uncertainty and existential threat (Giske *et al.* 2009, Remmers *et al.* 2010).

Uncertainty, stress and anxiety are paramount during diagnosis and treatment of breast cancer (Shaha *et al.* 2008, Vahdaninia *et al.* 2010), and even affect long-term adaptation (Montazeri 2008). To our knowledge, most qualitative studies on presurgery experiences of breast cancer have been conducted postsurgery and, retrospectively. Quantitative

studies, however, have focused on *selected* aspects of the experiences rather than on the *total* experience as subjectively expressed by the women, as qualitative studies can do. Therefore, in-depth understanding of these women's experiences is still needed, with data collected, *during* this particularly stressful period when the stress level peaks (Ryburn 2003).

The Study

Aim

The aim of the study was to describe the women's experiences after having received a breast cancer diagnosis and awaiting primary surgery.

Design

A qualitative descriptive design was used.

Participants

Using convenience sampling, 21 women with newly diagnosed breast cancer were recruited from a day-surgery unit at a Norwegian university hospital. The participants received the invitation to participate together with the information about surgery. The selection criteria were: scheduled for primary surgery, i.e. lumpectomy or mastectomy, over 18 years of age, and able to speak and write Norwegian. All were ethnic Norwegian, with similar culture, and came from the same geographic area. The sample size was determined by data saturation – the point at which no new information is obtained and redundancy is achieved (Polit & Beck 2008, p. 357). Since no new essential information was forthcoming after the 20th interview, we decided that the saturation point had been reached. Data collection was therefore discontinued after the 21st interview. The participants received their cancer diagnosis after core needle biopsy. They had no information about the type of breast cancer, stage of disease, or final treatment plans. This information was received about 3 weeks postsurgery.

Data collection

Data were collected from February 2006 to February 2007. The interviews were conducted in the hospital on the day before surgery, and before preoperative information was given. The interviews lasted from 50 to 120 minutes. A semi-structured interview guide was developed based on our previous research (Drageset & Lindstrøm 2003, 2005) and

focused on the women's experiences, i.e. 'How did you experience receiving the diagnosis?' 'How have you experienced this period before surgery?' During the interviews themes mentioned by the women were probed. The interviewer's impression of atmosphere and non-verbal communication were noted shortly after each interview.

Ethical considerations

The study was approved by the Regional Ethical Board. All participants were given oral and written project information, and gave their written informed consent. The women's needs for emotional protection were respected by not dwelling too deeply on threatening issues, thereby taking into consideration that the day before surgery was extra stressful. The outpatient clinic offered a special follow-up consultation with professionals if needed. None requested it. Contrastingly, most participants reported that the interview had been beneficial for them. Since the interviews took place on days when the women had to come to the hospital anyway, they were not burdened by an extra visit.

Data analysis

Interviews were analysed in three steps using the method of qualitative meaning condensation (Kvale 2006). Three levels were used: self-understanding, common-sense understanding and theoretical understanding. At the first level, the transcribed interviews were read to acquire a sense of the whole. The meaning units were identified, and data condensed. Self-understanding emerged as the researchers condensed the women's personal statements according to the researchers' understanding. At the second level, transcriptions were read several times to achieve a common-sense understanding, providing a broader context of comprehension. The different themes were identified and transformed into meaningful units, then coded into major themes. The third level, theoretical understanding, implied uncovering a deeper meaning, where the mutual relationships between the whole and the parts became clearer. These themes were discussed in the light of earlier research and Mishel's nursing theory of 'Uncertainty in illness' (Mishel 1988, 1990, Bailey & Stewart 2006). The qualitative data-analysis software QRS-NVivo 7 (<http://www.qrsinternational.com>) was used.

Rigour

Trustworthiness was established using the guidelines by Kvale (2006). The criteria of credibility and dependability were applied. The interviews were conducted, audio-taped

and transcribed verbatim by the first author. The authors analysed data independently, and findings were discussed by all authors throughout the analysis process to reach agreement. Memos were written during the analysis to ensure that ideas and reflections were not lost.

Findings

The 21 women's mean age was 54, ranging from 41 to 73. Sixteen women were married or cohabiting, one single, one widowed, and three divorced. Sixteen had children. Seventeen lived with another person (spouse/partner/children). Nineteen were employed, and two had retired. Five women had completed lower secondary school education, nine upper secondary, six had attended university colleges and one had a university degree.

Five themes were identified: feeling healthy but having to adapt to disease, waiting, uncertainty, having to tell and existential awareness.

Feeling healthy but having to adapt to disease

The diagnosis felt unreal for most of the women. They described the experience as earth-shattering and mentioned feelings of stress, crisis, paralysis and chaos. They described a surreal feeling that their world had changed quickly and dramatically. One said: 'It felt so unreal to me. I felt as if it was somehow outside me'. The women were feeling physically well, but had learned that they had a potentially serious disease. They spent a lot of time pondering whether they were healthy or ill: 'I've understood that with this disease you are well and sick at the same time. That's why things are a bit difficult, such as relating to it and understanding it fully'. For most of them the diagnosis was frightening and difficult to understand and accept, because the majority did not notice any lump, pain, or other symptoms. 'It's frightening to be healthy one day and ill the next. I didn't notice the lump. I thought you'd feel ill when you got cancer'. Another said: 'If I'd felt ill, perhaps I could have accepted my illness'.

Waiting

The waiting time between diagnosis and surgery varied from 1 to 3 weeks. The length of time that elapsed from diagnosis to surgery influenced the emotional reactions. Those with considerably death anxiety seemed to react more negatively to the waiting period. Some had lived as normal. One said that the waiting time had passed too fast to comprehend it fully. For most women the waiting period was experienced as

frightening, hopeless, long and hard to endure. They wanted to have the surgery done quickly and get on with their life:

Every morning I wake up and think 'I have cancer'. You have to wait. It's a terribly hopeless feeling. You are in a catastrophe. I'm terribly scared! That has created a great vacuum for me.

To endure the waiting time triggered emotional reactions of different character and intensity. Some suffered quite severe anxiety attacks: 'My cheeks turn red, my pulse rises, it's hard to breathe. I feel there's a shield over my body'. Another said: 'I'm in chaos. It's torture to wait'. Many described how emotions came in waves. They had no control over their feelings, which swamped them when they were least prepared. Several experienced disrupted sleep that impaired their functioning during the day. One could not bring herself to touch the lump, while others were afraid that the cancer spread and grew during the waiting-period.

Despite having been informed that they had to wait for the date of surgery to be set, one was afraid of being forgotten and called the hospital to ensure she was on the waiting list. All women had been told they could call the hospital any time. However, some were afraid of disturbing the health professionals, while others were afraid to call somebody they had never met: 'You get a diagnosis and feel it very difficult and then you have to call somebody you haven't seen'. Getting the date of surgery alleviated fear and anxiety and gave a sense of security and control: 'I felt I had much more control, because I could say: I'm having surgery'. Another said: 'When I got the date, I felt calmer. That helped me greatly. It was much easier once I knew!' Another said: 'Somebody else is involved in my cancer'.

Some of the women said that a certain time was necessary to build themselves up to be prepared for what they were to go through. They found different ways to prepare themselves both psychologically and physically:

It's been good to have some time before the surgery. I feel rested, strengthened, and I've been outdoors walking a lot. One needs a week; otherwise it would be too fast. I wouldn't have been ready.

Another said:

It has been good for me to have gone through this, to accept that I have cancer and must have a breast removed, to talk to those I love and to rest my body.

Uncertainty

Uncertainty was related to three situations: the future, surgery and losing the breast. How their breast cancer would influence their future was essential for almost all. Considering

the future provoked feelings of uncertainty, fear and exhaustion: 'The fear of how this is going is quite unique. I can't get any answer. These feelings exhaust me'. One woman said that she could not endure imagining a future without being able to live fully. Others tried to reduce feelings of uncertainty by focusing on the present: 'I want to manage things as they are today. If I have to be concerned about the future too, I won't be at ease'. Another said: 'I try to plan as if this does not exist'.

Many of them were nervous about what they would be told by the doctor in the preoperative meeting. Worries and uncertainty were connected to both the surgery itself and their postsurgery conditions: 'I don't know what I'll have to go through, and how extensive it will be. I haven't seen the doctor yet. Everything is in limbo'. Another said: 'The worst thing of all is not knowing'. According to another: 'I only want to know *exactly what it is*'. Most of the women thought about what kind of therapy would follow surgery, and how this would influence their lives: 'I'm in suspense until I'm informed about what type of cancer I have and if I'll need chemotherapy'. Despite having received written information about surgery and anaesthesia, the prospect of having an anaesthetic led to uncertainty and fear of losing control: 'I'm very concerned about the anaesthetic; how will I react? It petrifies me'. Some were afraid of pain and postoperative nausea; others were concerned about the operation scar and afraid of being dependent on others for practical help after surgery. Others were not concerned, only eager to get it done. Standard preoperative diagnostic tests, such as radiography of the thorax, also created uncertainty: 'Is it possible that I also have lung cancer?' The greatest fear for practically all was to receive a message of metastasis: 'The fear is greatest, perhaps, when I'm to be informed what's going to happen next. What will the treatment be? Has it spread? It's so frightening to think about'.

Some women were prepared for mastectomy and were offered reconstruction later, others for lumpectomy, but with a possible mastectomy later. To keep the breast was a relief, but also increased uncertainty: 'Will all the cancer be removed?' Reactions to mastectomy were very varied: for some it was acceptable, for others worrying, and for some terrifying. However, to get rid of the cancer was the overarching goal for all. In this perspective, the loss of a breast could be of minor importance:

I don't mind losing a breast. I don't connect identity and feelings to it. If the doctors had told me that my prognosis would be better by taking *both* breasts, they could!

Others found losing a breast terrifying: 'I'm willing to fight to keep it! My greatest fear is to lose the breast'. The women

were concerned about disfigurement and reduced womanliness. Their partners' reactions were of importance:

You'll be disfigured. You think of that especially when you have a husband who thinks of such things. I worry about how my husband and other people will look at me. Nevertheless, I hope that somebody still loves me. It's a bit difficult when you're married.

Having to tell

Our participants considered their family and close friends to be their best supporters. However, for most of them it was a great burden to have to inform significant others about the diagnosis. They struggled with the questions of what to tell, and were afraid that the news of their cancer diagnosis would scare friends and family: 'My husband was more shocked than I was. I dreaded telling him'. Some said that they were guilty: 'It was hard to tell my parents. I felt that I was inflicting pain on them, that it was my fault that they were sad and sleepless'. Another said: 'I shrank from telling my daughter, in particular. We are very close. I thought she would have problems with her studies afterwards, and that would be my fault'.

Practically all said that they had to be strong and composed when informing others about their diagnosis: 'I felt I had to be strong because of my family: my children have always seen their mother as a strong person'. According to another: 'I feel that I need to cry but I can't break down and not support my children'. Another said: 'I had to forget myself: my children were the ones who needed support'. How the news was broken was important: 'Since I didn't react hysterically and burst into tears, also those around me reacted calmly'. Some did not inform *all* close family members: they wanted to protect them. Others were *ambivalent* about telling the news about their diagnosis: 'I cringed at the prospect of telling them, at the same time I had to do it'. Some of the women became exhausted by constantly having to update others about their situation. In some families, members were scared and the women had to give encouragement and support when informing: 'The first thing I did was to call my daughters and tell them. They started to cry. So I had to console them'. According to another: 'I try to tell and console simultaneously. It's not good for my family and friends to hear about it. I'm afraid of hurting them'.

Existential awareness

Most of the women expressed a new awareness of death. One of them prepared to die by terminating her membership in hobby organizations. Others said about their desperation and

death anxiety: 'I felt that I wouldn't live through this year'. They were afraid of being separated from their family, especially afraid of dying from their children and of not seeing grand-children grow up.

In contrast, some were pondering about a possible 'meaning' in getting cancer: 'Since I got this message, I think there's a meaning. Perhaps I'll learn to appreciate other things'. Another said: 'You live more intensely. That's the positive side'. Others experienced everyday life as becoming more important. Learning to live in the moment was described: 'I'm going to appreciate the good days more'. Materialistic factors reduced their importance, and some became more selective concerning whom they chose to spend their time with. Others were convinced that their breast cancer experience would give them personal mental strength and valuable life experiences: 'I'll come out of this as a wiser person'. One compared her own situation to that of others with cancer and serious health problems. These comparisons gave a new meaning to their situation: 'It isn't a matter of "poor me"'. I have a friend who hasn't got long left. That puts matters into perspective'.

Discussion

Study limitations

The participants came from the same geographical area, with similar ethnicity and culture. A more varied sample may have yielded different results, and the most anxious patients may have refused to participate.

Feeling healthy but having to adapt to disease

We found that most of the women had difficulties accepting their diagnosis while feeling healthy. Our participants felt their health status had changed overnight and that they had become affected by an uncontrollable and unpredictable disease. They experienced a sudden transition from a state of wellness to a state of illness and disease (Boehmke & Dickerson 2006). According to Mishel and Braden (1988), lack of symptom patterns increases the ambiguity and uncertainty about the illness-wellness state and the inability to determine the meaning of illness-related events. Likewise, our participants reported that their ambiguous situation was difficult to comprehend and adapt to. Consistent with previous studies (Landmark *et al.* 2001, Taleghani *et al.* 2008, Tobin & Begley 2008), our findings revealed that receiving the diagnosis caused emotional reactions that can be characterized as a psychological crisis. The women struggled

to absorb and accept what had happened. Negative unexpected life events create distress (Gurevich *et al.* 2002), which adversely affects psychological adjustment and highlights potential needs for psychosocial counselling and support (Mehnert & Koch 2008). Nurses are resources to assist patients in interpreting and structuring the meaning of illness-events (Mishel 1988), and to assist adaptation to life changes induced by an unexpected, negative life event (Roy 2009).

Waiting

Our findings revealed different emotional reactions such as anxiety, fear and suffering during the waiting time, characterized by intense uncertainty. Uncertainty is appraised as 'danger' in most cases related to serious diseases (Mishel 1988). Some of our participants clearly appraised the diagnosis as a threat, implying unknown but anticipated negative consequences for their identity. Others trusted surgery to alleviate their suffering, but found it hard to endure the indeterminate waiting time. Suffering due to breast cancer has been documented previously (Arman & Rehnsfeldt 2003, Perreault & Bourbonnais 2005). Suffering is defined as 'an individualized, subjective and complex experience that involves the assignment of an intensely negative meaning to an event or a perceived threat' (Rodgers & Cowles 1997, p. 1048), and is apparent when the most crucial aspects of personal integrity are threatened or lost (Roy 2009). According to Morse (2000), suffering must be 'worked through', which implies acknowledging and adapting to negative situations. Nurses may support the person through this experience, thus making the suffering more bearable.

Individuals who experience loss of control over their situation tend to exhibit more stress-related problems than those who believe they can influence their situation (Olff 1991, Mishel 1997, Lazarus 1999). Loss of control is mentioned by many patients with breast cancer (Sharpley & Christie 2007, Barez *et al.* 2009) and has been shown to create helplessness and depression (Seligman 1975). Trust and confidence in credible authorities and expertise decrease uncertainty according to Mishel and Braden (1988). Therefore, to be informed about the date of surgery as soon as possible was essential. It gave a sense of control and the reassurance of belonging to a healthcare system, thus alleviating the unbearable experiences of waiting. Despite being told they could call the hospital nurse for counselling, many women were unfortunately reluctant to use this service despite wanting to talk to somebody.

However, some *positive* experiences related to waiting were also identified in our study. The women claimed they

got time to prepare themselves both physically and psychologically, and to accept the diagnosis gradually. A diagnosis can be shocking, affect cognitive capacity and temporarily reduce comprehension and information-processing (Mishel 1988), which is also a common response to the crisis of cancer (Holland & Gooen-Piels 2000). Acknowledging the diagnosis required time. The importance of time before surgery to become emotionally prepared was also reported by Landmark *et al.* (2008), finding that this time prevented strong negative reactions following surgery.

Uncertainty

According to Mishel (1988), lack of information and unpredictability of disease increases uncertainty. Similarly, our participants' need for knowledge and the unpredictability of their cancer and treatment increased their fear and uncertainty. As reported previously (Taleghani *et al.* 2006, Wonghongkul *et al.* 2006, Al-Azri *et al.* 2009), women with breast cancer use different coping strategies to endure uncertainty. Morse (2000) claimed that people who are enduring adversity focus on the present, as our findings also revealed. Focusing on the present enabled most of the women to 'keep going', thus alleviating fear and anxiety. Women with breast cancer have also reported strong needs for cancer-related information (Liao *et al.* 2007, Landmark *et al.* 2008, Lally 2009) which reduces uncertainty (Loiselle *et al.* 2006). Healthcare providers are credible resources to reduce uncertainty by providing medical-related information (Mishel 1997, Mishel *et al.* 2005). Contrastingly, our findings revealed that *some* general information was welcome, but *too detailed* information was threatening. What most of the women wanted was information on *their own* actual status in the disease process. Unfortunately, at this point of time this information was impossible to obtain.

Anxiety is almost universal in preoperative patients (Pritchard 2009). Our findings also revealed that thoughts about both anaesthesia and surgery itself caused fear, anxiety and loss of control. Preoperative routines and procedures seemed ominous because what they implied was unclear. Giving individual information about procedures as part of preparing patients for surgery may improve patients' sense of control (Hawighorst-Knapstein *et al.* 2006, Schmid-Buchi *et al.* 2008) and reduce uncertainty and unfamiliarity about treatment and the healthcare system (Mishel & Braden 1988). Our participants' greatest fear was connected to the postsurgery information: all feared the possibility of metastases. This finding confirms conclusions by Montgomery *et al.* (2003) and Schnur *et al.* (2008) who also found that worry about the outcome of surgery was more stressful than

aspects of the surgery itself. Our participants were also concerned that the operation and treatment would affect their total physical condition and the time needed to return to everyday life.

Our participants had differing attitudes to losing a breast. Consistent with previous studies (Landmark & Wahl 2002, Taleghani *et al.* 2008), all the women regarded losing the breast as less important if it reduced the risk of dying of breast cancer. However, the main concern for some participants was the anticipated changes in their appearance. Breasts are considered as a symbol of femininity, womanhood, sexuality and self-concept (Yankaskas 2005, Demir *et al.* 2008, Helms *et al.* 2008). Changes in appearance have been reported as the main concern, primarily for young women (Avis *et al.* 2004, 2005), but in our study this was also a major concern for some of the older women. Furthermore, our findings revealed uncertainty about the effect on the opposite sex. Some of our participants connected their breast to their female identity and were afraid of feeling less worth than women with two breasts. The partner's reassurance was important. It was essential to know that they would still be valued and loved as a woman.

Having to tell

Having to tell significant others about their diagnosis was a major burden for most of our participants. Some kept their diagnosis to themselves to prevent significant others' distress.

Other studies also report that women feel uncertain about communication with close persons about their diagnosis (Fu *et al.* 2008, Remmers *et al.* 2010). Furthermore, it was remarkable how our participants tried to lighten the burden on their family by choosing their words carefully and by being strong, which implied depriving themselves of expressing their own reactions. Expressing emotions can be associated with decreased distress (Iwamitsu *et al.* 2005). But because emotions reinforce themselves (LeDoux 1996), holding back and controlling emotions can also reduce distress (Bonanno *et al.* 1995, Drageset *et al.* 2010). Our participants gave priority to their family members' emotional needs. This may either have imposed a burden of self-control, or protected them from being overwhelmed.

That women with breast cancer have concerns about their children, primarily younger children, has been reported in several studies (Billhult & Segesten 2003, Semple & McCance 2010). Our findings yielded similar results, although these children were adolescents or adults. The women seemed to be torn between their own and their children's needs for care. Therefore, some chose to suppress their own concerns and needs and put the needs of the

children in focus, trying to maintain their role as a good mother in a normal family life. It is possible that this composed attitude may also have benefited the women (Taleghani *et al.* 2008).

Social interaction may help by giving both information and emotional support (Mishel & Braden 1988, Gagliardi *et al.* 2009, Liao *et al.* 2010) as our findings confirmed. The presence of social networks does not always have positive effects (Drageset & Lindstrøm 2003, Cordova *et al.* 2007). It may be a source of distress (Parrish & Adams 2003), as our findings also revealed. Paradoxically, the women took on the role of comforter towards their family, instead of being comforted. Most even increased their own distress by feeling guilty for imposing distress on others. Therefore, their presumed-to-be social supporters were not experienced unequivocally as resources.

Existential awareness

Death anxiety was clearly apparent among our participants. Their existence, values and basic needs for meaning and purposefulness were threatened. Our participants struggled to find meaning in their crisis-threatening situation. Struggling with uncertainty and existential threats may lead to increased awareness of values in life (Logan *et al.* 2006, Bertero & Chamberlain Wilmoth 2007, Giske & Gjengedal 2007).

However, if the uncertainty of illness is also appraised as an opportunity, it becomes positive and enables patients to see life's possibilities (Mishel 1990). Appreciation of life is stimulated when meaning can be found in situations of great uncertainty (Skaggs & Barron 2006). An important finding was that some of our participants started to reflect on their priorities in life. They discovered that their cancer implied a reminder to live for the moment and appreciate life more. Other studies (Cordova *et al.* 2001, Carver & Antoni 2004, Oxlad *et al.* 2008) confirm this enhanced sense of life purpose and appreciation of life after breast cancer surgery. Our participants' ability to find meaning by giving priority to valuable experiences helped them to cope with uncertainty and death anxiety. The importance of finding meaning in illness that might strengthen coping abilities is described previously (Wallberg *et al.* 2003, Collie & Long 2005, Lally 2010). According to Folkman and Greer (2000), meaning-based coping helps individuals to relinquish problems and enables them to pursue goals and formulate new ones, make sense of what is happening and appraise benefits whenever possible. Some of the women even managed to reflect upon the positive sides of having breast cancer and were convinced that it would increase their personal mental strength, which

What is already known about this topic

- Being diagnosed with breast cancer is experienced as a major challenge and an important stressor in a woman's life.
- How women cognitively and emotionally approach the diagnosis of breast cancer affects their experiences and postsurgery adaptation.
- Uncertainty is one of the major experiences reported by women with breast cancer.

What this paper adds

- While awaiting breast cancer surgery, and experiencing death anxiety, the women directed most energy at handling uncertainty about the future and the severity of their cancer.
- The women experienced the waiting time between breast cancer diagnosis and surgery as long and painful but also as necessary to prepare them physically and psychologically for the surgery.
- For women with newly diagnosed breast cancer, having to inform others (family, friends, colleagues) was experienced as a lonely burden of being obliged to both inform and offer consolation.

Implication for practice and/or policy

- Healthcare professionals could consider women's *individual* needs about preparing themselves physically and psychologically for breast cancer surgery, and acknowledge that setting the date of surgery helps to alleviate anxiety.
- By being attentive and supportive, healthcare professionals may help women with newly diagnosed breast cancer awaiting surgery concerning the task of informing their family and friends about their diagnosis.
- Healthcare professionals could take into account the women's individual existential experiences and offer the women opportunities to talk about their emotions and thoughts while awaiting breast cancer surgery.

reflected appraisal of the opportunity of a positive outcome (Mishel 1988).

Conclusion

From a holistic nursing perspective it is important to understand the individual illness experiences, interpretations and

contextual factors in these women's lives. To improve these patients' degree of adjustment, we tentatively suggest that healthcare professionals should be sensitive to the women's *individual* existential experiences and offer them opportunities to talk about these issues. Similarly, these women's needs about preparing themselves physically and psychologically for breast cancer surgery should be acknowledged. Being sensitive to and supportive of the women's lonely burden of telling significant others about the diagnosis is essential. Finally, early setting of the surgery date helps to alleviate anxiety. Our findings give in-depth knowledge of women's experiences while awaiting breast cancer surgery and may give healthcare professionals a deeper understanding which can be used to develop interventions to ease the women's situation. Future research should be directed at follow-up studies about the potential impact of presurgery experiences on later experiences of living with breast cancer concerning physical, psychological, social and spiritual adaptation and at intervention studies.

Acknowledgements

The authors thank those who participated in the study, without whom this study would not have been possible. We also thank Haukeland University Hospital, Breast Clinic Department, Surgical Outpatient Clinic for valuable support and cooperation.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors declare no conflict of interest.

Author contributions

SD and TCL were responsible for the study conception and design. SD performed the data collection. SD, TCL, TG and KU performed the data analysis. SD, TCL, TG and KU were responsible for the drafting of the manuscript. SD, TCL, TG and KU made critical revisions to the paper for important intellectual content. TCL and KU supervised the study.

References

- Al-Azri M., Al-Awisi H. & Al-Moundhri M. (2009) Coping with a diagnosis of breast cancer – literature review and implications for developing countries. *The Breast Journal* 15(6), 615–622.

- Arman M. & Rehnsfeldt A. (2003) The hidden suffering among breast cancer patients: a qualitative metasynthesis. *Qualitative Health Research* 13(4), 510–527.
- Avis N.E., Crawford S. & Manuel J. (2004) Psychosocial problems among younger women with breast cancer. *Psycho-Oncology* 13(5), 295–308.
- Avis N.E., Crawford S. & Manuel J. (2005) Quality of life among younger women with breast cancer. *Journal of Clinical Oncology* 23(15), 3322–3330.
- Bailey D. & Stewart J. (2006) Uncertainty in illness theory, Sixth edition. In *Nursing Theorists and Their Work* (Tomey A.M. & Alligood M.R., eds), Mosby Elsevier, St. Louis, Missouri, pp. 623–643.
- Barez M., Blasco T., Fernandez-Castro J. & Viladrich C. (2009) Perceived control and psychological distress in women with breast cancer: a longitudinal study. *Journal of Behavioral Medicine* 32(2), 187–196.
- Bertero C. & Chamberlain Wilmoth M. (2007) Breast cancer diagnosis and its treatment affecting the self: a meta-synthesis. *Cancer Nursing* 30(3), 194–202.
- Billhult A. & Segesten K. (2003) Strength of motherhood: nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences* 17(2), 122–128.
- Boehmke M.M. & Dickerson S.S. (2006) The diagnosis of breast cancer: transition from health to illness. *Oncology Nursing Forum* 33(6), 1121–1127.
- Bonanno G.A., Keltner D., Holen A. & Horowitz M.J. (1995) When avoiding unpleasant emotion might not be such a bad thing: verbal-autonomic response dissociation and midlife conjugal bereavement. *Journal of Personality and Social Psychology* 68, 975–989.
- Burgess C., Cornelius V., Love S., Graham J., Richards M. & Ramirez A. (2005) Depression and anxiety in women with early breast cancer: five year observational cohort study. *British Medical Journal* 26, 702–705.
- Cancer in Norway (2008) *Cancer Incidence, Mortality, Survival and Prevalence in Norway*. Retrieved from <http://www.krefregisteret.no/en/Cancer-prevention/Breast-Cancer-Screening-Programme/> on 18 February 2009.
- Carver C.S. & Antoni M.H. (2004) Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology* 23(6), 595–598.
- Collie K. & Long B.C. (2005) Considering 'meaning' in the context of breast cancer. *Journal Health Psychology* 10(6), 843–853.
- Cordova M.J., Cunningham L.L., Carlson C.R. & Andrykowski M.A. (2001) Posttraumatic growth following breast cancer: a controlled comparison study. *Health Psychology* 20(3), 176–185.
- Cordova M.J., Giese-Davis J., Golant M., Kronenwetter C., Vickie C. & Spiegel D. (2007) Breast cancer as trauma: posttraumatic stress and posttraumatic growth. *Journal of Clinical Psychology in Medical Settings* 14(4), 308–319.
- Demir F., Donmez Y.C., Ozsaker E. & Diramali A. (2008) Patients' lived experiences of excisional breast biopsy: a phenomenological study. *Journal of Clinical Nursing* 17(6), 744–751.
- Den Oudsten B.L., Van Heck G.L., Van der Steeg A.F., Roukema J.A. & De Vries J. (2009) Predictors of depressive symptoms 12 months after surgical treatment of early-stage breast cancer. *Psycho-Oncology* 18(11), 1230–1237.
- Doumit M.A., El Saghir N., Abu-Saad Huijer H., Kelley J.H. & Nassar N. (2010) Living with breast cancer, a Lebanese experience. *European Journal of Oncology Nursing* 14(1), 42–48.
- Drageset S. & Lindstrøm T.C. (2003) The mental health of women with suspected breast cancer: the relationship between social support, anxiety, coping and defence in maintaining mental health. *Journal of Psychiatric and Mental Health Nursing* 10(4), 401–409.
- Drageset S. & Lindstrøm T.C. (2005) Coping with a possible breast cancer diagnosis: demographic factors and social support. *Journal of Advanced Nursing* 51(3), 217–226.
- Drageset S., Lindstrøm T.C. & Underlid K. (2010) Coping with breast cancer: between diagnosis and surgery. *Journal of Advanced Nursing* 66(1), 149–158.
- Fogarty C. & Cronin P. (2008) Waiting for healthcare: a concept analysis. *Journal of Advanced Nursing* 61(4), 463–471.
- Folkman S. & Greer S. (2000) Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-Oncology* 9(1), 11–19.
- Fu M.R., Xu B., Liu Y. & Haber J. (2008) 'Making the best of it': Chinese women's experiences of adjusting to breast cancer diagnosis and treatment. *Journal of Advanced Nursing* 63(2), 155–165.
- Gagliardi C., Vespa A., Papa R., Mariotti C., Cascinu S., Rossini S., Gagliardi C., Vespa A., Papa R., Mariotti C., Cascinu S. & Rossini S. (2009) Social support networks and depression of women suffering from early-stage breast cancer: a case control study. *Journal of Psychosocial Oncology* 27(2), 216–229.
- Gallagher J., Parle M. & Cairns D. (2002) Appraisal and psychological distress six months after diagnosis of breast cancer. *British Journal Health Psychology* 7(Part 3), 365–376.
- Gaudine A., Sturge-Jacobs M. & Kennedy M. (2003) The experience of waiting and life during breast cancer follow-up. *Research and Theory for Nursing Practice* 17(2), 153–168.
- Giske T. & Gjengedal E. (2007) 'Preparative waiting' and coping theory with patients going through gastric diagnosis. *Journal of Advanced Nursing* 57(1), 87–94.
- Giske T., Gjengedal E. & Artinian B. (2009) The silent demand in the diagnostic phase. *Scandinavian Journal of Caring Sciences* 23(1), 100–106.
- Gurevich M., Devins G.M. & Rodin G.M. (2002) Stress response syndromes and cancer: conceptual and assessment issues. *Psychosomatics* 43(4), 259–281.
- Hawighorst-Knapstein S., Brueckner D.O., Schoenefuss G., Knapstein P.G. & Koelbl H. (2006) Breast cancer care: patient information and communication as a preventive educational process. *Breast Care* 1(6), 375–378.
- Helms R.L., O'Hea E.L. & Corso M. (2008) Body image issues in women with breast cancer. *Psychology, Health & Medicine* 13(3), 313–325.
- Holland J.C. & Gooen-Piels J. (2000) Principles of psycho-oncology. In *Cancer Medicine*, 5th edn (Holland J.C. & Frei E., eds), B.C. Decker Inc, Hamilton, ON, pp. 943–958.
- Iwamitsu Y., Shimoda K., Abe H., Tani T., Okawa M. & Buck R. (2005) Anxiety, emotional suppression, and psychological distress before and after breast cancer diagnosis. *Psychosomatics* 46(1), 19–24.
- Kornblith A.B., Herndon J.E. II, Weiss R.B., Zhang C., Zuckerman E.L., Rosenberg S., Mertz M., Payne D., Massie M.J., Holland J.F., Wingate P., Norton L. & Holland J.C. (2003) Long-term

- adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy. *Cancer* 98(4), 679–689.
- Kralik D., Brown M. & Koch T. (2001) Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing* 33(5), 594–602.
- Kvale S. (2006) *InterViews: An Introduction to Qualitative Research Interviewing*. Sage Publications, London.
- Lally R.M. (2009) In the moment: women speak about surgical treatment decision making days after a breast cancer diagnosis. *Oncology Nursing Forum* 36(5), E257–E265.
- Lally R.M. (2010) Acclimating to breast cancer: a process of maintaining self-integrity in the pretreatment period. *Cancer Nursing* 33(4), 268–279.
- Landmark B.T. & Wahl A. (2002) Living with newly diagnosed breast cancer: a qualitative study of 10 women with newly diagnosed breast cancer. *Journal of Advanced Nursing* 40(1), 112–121.
- Landmark B.T., Strandmark M. & Wahl A.K. (2001) Living with newly diagnosed breast cancer – the meaning of existential issues. A qualitative study of 10 women with newly diagnosed breast cancer, based on grounded theory. *Cancer Nursing* 24(3), 220–226.
- Landmark B.T., Bohler A., Loberg K. & Wahl A.K. (2008) Women with newly diagnosed breast cancer and their perceptions of needs in a health-care context. *Journal of Clinical Nursing* 17(7B), 192–200.
- Lazarus R.S. (1999) *Stress and Emotion: A new Synthesis*. Springer Publishing Co., London.
- LeDoux J. (1996) *The Emotional Brain: The Mysterious Underpinnings of Emotional Life*. Simon & Schuster, New York.
- Liao M.N., Chen M.F., Chen S.C. & Chen P.L. (2007) Healthcare and support needs of women with suspected breast cancer. *Journal of Advanced Nursing* 60(3), 289–298.
- Liao M., Chen M., Chen S. & Chen P. (2008) Uncertainty and anxiety during the diagnostic period for women with suspected breast cancer. *Cancer Nursing* 31(4), 274–283.
- Liao M.-N., Chen P.-L., Chen M.-F. & Chen S.-C. (2010) Effect of supportive care on the anxiety of women with suspected breast cancer. *Journal of Advanced Nursing* 66(1), 49–59.
- Logan J., Hackbusch-Pinto R. & De Grasse C.E. (2006) Women undergoing breast diagnostics: the lived experience of spirituality. *Oncology Nursing Forum* 33(1), 121–126.
- Loiselle C.G., Lambert S.D. & Cooke A. (2006) The searching, processing, and sharing of breast cancer information by women diagnosed with the illness. *Canadian Journal of Nursing Research* 38(3), 82–104.
- Lueboonthavatchai P. (2007) Prevalence and psychosocial factors of anxiety and depression in breast cancer patients. *Journal of the Medical Association of Thailand* 90(10), 2164–2173.
- Mehnert A. & Koch U. (2007) Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary cancer care: a prospective study. *Psycho-Oncology* 16(3), 181–188.
- Mehnert A. & Koch U. (2008) Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research* 64(4), 383–391.
- Mishel M. (1988) Uncertainty in illness. *Image: The Journal of Nursing Scholarship* 20, 225–232.
- Mishel M.H. (1990) Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship* 22, 256–262.
- Mishel M.H. (1997) Uncertainty in acute illness. *Annual Review of Nursing Research* 15, 57–80.
- Mishel M.H. & Braden C.J. (1988) Finding meaning: antecedents of uncertainty. *Nursing Research* 37, 98–103.
- Mishel M.H., Germino B.B., Gil K.M., Belyea M., Laney I.C., Stewart J., Porter L. & Clayton M. (2005) Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology* 14(11), 962–978.
- Montazeri A. (2008) Health-related quality of life in breast cancer patients: a bibliographic review of the literature from 1974 to 2007. *Journal of Experimental & Clinical Cancer Research* 27(32), 1–31.
- Montgomery M. (2010) Uncertainty during breast diagnostic evaluation: state of the science. *Oncology Nursing Forum*, 37(1), 77–83.
- Montgomery G.H. & Bovbjerg D.H. (2004) Presurgery distress and specific response expectancies predict postsurgery outcomes in surgery patients confronting breast cancer. *Health Psychology* 23(4), 381–387.
- Montgomery G.H., David D., Goldfarb A.B., Silverstein J.H., Weltz C.R., Birk J.S. & Bovbjerg D.H. (2003) Sources of anticipatory distress among breast surgery patients. *Journal of Behavioral Medicine* 26(2), 153–164.
- Morse J.M. (2000) Responding to the cues of suffering. *Health Care for Women International* 21(1), 1–9.
- Oloff M. (1991) *Defence and Coping: Self-reported Health and Psychobiological Correlates*. Dissertation, University of Utrecht, Utrecht, The Netherlands.
- Oudhoff J.P., Timmermans D.R., Bijnen A.B. & van der Wal G. (2004) Waiting for elective general surgery: physical, psychological and social consequences. *ANZ Journal of Surgery* 74(5), 361–367.
- Oxlad M., Wade T.D., Hallsworth L. & Koczwara B. (2008) 'I'm living with a chronic illness, not dying with cancer': a qualitative study of Australian women's self-identified concerns and needs following primary treatment for breast cancer. *European Journal of Cancer Care* 17(2), 157–166.
- Parrish M.M. & Adams S. (2003) An exploratory qualitative analysis of the emotional impact of breast cancer and caregiving among older women. *Care Management Journals* 4(4), 191–197.
- Perreault A. & Bourbonnais F.F. (2005) The experience of suffering as lived by women with breast cancer. *International Journal of Palliative Nursing* 11(10), 512–519.
- Polit D.F. & Beck C.T. (2008) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*, 8th edn. Lippincott Williams & Wilkins, USA.
- Pritchard M.J. (2009) Managing anxiety in the elective surgical patient. *British Journal of Nursing* 18(7), 416–419.
- Remmers H., Holtgrawe M. & Pinkert C. (2010) Stress and nursing care needs of women with breast cancer during primary treatment: a qualitative study. *European Journal of Oncology Nursing* 14(1), 11–16.
- Rodgers B.L. & Cowles K.V. (1997) A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing* 25(5), 1048–1053.

- Roy C. (2009) *The Roy Adaptation Model*, 3rd edn. Pearson, Upper Saddle River, NJ.
- Ryburn N.E. (2003) *Daily Assessment of Psychological Distress in Breast Surgery Patients*. Dissertation, Yeshiva University, New York, USA.
- Saares P. & Suominen T. (2005) Experiences and resources of breast cancer patients in short-stay surgery. *European Journal of Cancer Care* 14(1), 43–52.
- Schmid-Buchi S., Halfens R.J., Dassen T. & van den Borne B. (2008) A review of psychosocial needs of breast-cancer patients and their relatives. *Journal of Clinical Nursing* 17(21), 2895–2909.
- Schnur J.B., Montgomery G.H., Hallquist M.N., Goldfarb A.B., Silverstein J.H., Weltz C.R., Kowalski A.V. & Bovbjerg D.H. (2008) Anticipatory psychological distress in women scheduled for diagnostic and curative breast cancer surgery. *International Journal of Behavioral Medicine* 15(1), 21–28.
- Seligman M.E.P. (1975) *Helplessness: On Depression, Development, and Death*. W.H. Freeman, San Francisco. ISBN 0-7167-2328.
- Semple C.J. & McCance T. (2010) Parents' experience of cancer who have young children: a literature review. *Cancer Nursing* 33(2), 110–118.
- Shaha M., Cox C.L., Talman K. & Kelly D. (2008) Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship* 40(1), 60–67.
- Sharpley C.F. & Christie D.R. (2007) 'How I was then and how I am now': current and retrospective self-reports of anxiety and depression in Australian women with breast cancer. *Psycho-Oncology* 16(8), 752–762.
- Skaggs B.G. & Barron C.R. (2006) Searching for meaning in negative events: concept analysis. *Journal of Advanced Nursing* 53(5), 559–570.
- Taleghani F., Yekta Z.P. & Nasrabadi A.N. (2006) Coping with breast cancer in newly diagnosed Iranian women. *Journal of Advanced Nursing* 54(3), 265–272.
- Taleghani F., Yekta Z.P., Nasrabadi A.N. & Kappeli S. (2008) Adjustment process in Iranian women with breast cancer. *Cancer Nursing* 31(3), E32–E41.
- Tobin G.A. & Begley C. (2008) Receiving bad news: a phenomenological exploration of the lived experience of receiving a cancer diagnosis. *Cancer Nursing* 31(5), E31–E39.
- Vahdaninia M., Omidvari S. & Montazeri A. (2010) What do predict anxiety and depression in breast cancer patients? A follow-up study. *Social Psychiatry and Psychiatric Epidemiology* 45, 355–361.
- Wade T.D., Nehmy T. & Koczwara B. (2005) Predicting worries about health after breast cancer surgery. *Psycho-Oncology* 14(6), 503–509.
- Wallberg B., Michelson H., Nystedt M., Bolund C., Degner L. & Wilking N. (2003) The meaning of breast cancer. *Acta Oncology* 42(1), 30–35.
- Wonghongkul T., Dechprom N., Phumivichuvate L. & Losawatkul S. (2006) Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing* 29(3), 250–257.
- World Health Organization (2009) *Cancer. Screening for Breast Cancer*. Retrieved from <https://www.who.int/mediacentre/factsheets/fs297/en/index.html> on 18 February 2009.
- Yankaskas B.C. (2005) Epidemiology of breast cancer in young women. *Breast Disease* 23, 3–8.

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in *JAN*:

- **High-impact forum:** the world's most cited nursing journal and with an Impact Factor of 1.518 – ranked 9th of 70 in the 2010 Thomson Reuters Journal Citation Report (Social Science – Nursing). *JAN* has been in the top ten every year for a decade.
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 7,000 libraries worldwide (including over 4,000 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at <http://mc.manuscriptcentral.com/jan>.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Early View:** rapid *online* publication (with doi for referencing) for accepted articles in final form, and fully citable.
- **Faster print publication than most competitor journals:** as quickly as four months after acceptance, rarely longer than seven months.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).