

Living the experience of breast cancer treatment: The younger women's perspective

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ABSTRACT

Objective

To explore the experience of breast cancer for young women under fifty years of age and describe their personal experience of coping with breast cancer treatment.

Design

An interpretive qualitative design was used to explore the experience of breast cancer in a young women's life. A purposive sample of six women completed in-depth interviews. A thematic analysis of the transcripts generated several themes relating to their personal journey through breast cancer treatment.

Setting

The setting for this study was an oncology outpatient's setting in a large private hospital in Queensland, Australia.

Subjects

Six women aged between 28 and 45 years of age with a diagnosis of breast cancer in the last 12 months.

Results

Treatment for breast cancer began so quickly following diagnosis leaving little time to adjust to the concept of a life threatening disease. The severity of the effects from treatment influenced the women's sense of person and ability to care for family. Fatigue, nausea and early onset menopausal changes were particularly troubling. Women described a positive resolve to survive.

Conclusions

Treatment concerns for younger women are qualitatively different from those of older women. They consider they are too young to assume 'the sick role' and are not prepared for its sudden onset, neither are their support networks. The right kind of support can assist younger women and their families to cope during the early stages of diagnosis and intervention.

INTRODUCTION

Breast cancer is the most common cancer diagnosis for women worldwide (WHO 2006). The incidence for women under fifty years of age accounts for 25% of all breast cancer cases in Australia (AIHW 2008). However, the amount of research focused on this younger cohort is much less than that of older women only serving to limit understanding of the particular needs of younger women. This is problematic because being younger means women are more likely to be diagnosed with a biologically aggressive cancer and tend to need multimodal treatment, often influencing their physical and psychological adaptation (Sammarco 2001; Dixon and Hortobagyi 2000). Studies show compared to older women these women have a heightened concern with aspects related to body image change, fatigue and nausea (Sammarco 2001). The lack of understanding of this group's particular concerns and needs ultimately affects their health care experience.

An important dynamic relates to the developmental stage of life for these young women, this includes having family responsibilities and being premenopausal (Dunn and Stegina 2000). The combination of breast cancer treatment and demands of family life are noted to have significant physical and psychological sequelae (Parle et al 2001). The provision of information regarding treatment has been noted as particularly important for the younger aged family, especially information that can be discussed and understood later in the family environment (Nikoletti et al 2003). Concerns about understanding information may relate to the fact medical consultations are often attended by women without the support of a person close to them because that person is having to care for the couple's children. Alongside the everyday exigencies associated with this particular phase of life, the treatment regime immediately after diagnosis is noted to cause significant stress (Sammarco 2001). Young women are noted to go through a 'why me' phase early after diagnosis as the realisation of the severity of the illness becomes reality (Dunn and Stegina 2000). Specific concerns relate to

the knowledge treatment will cause premature menopause and associated consequences. For example, loss of fertility, psychosocial problems and a number of menopausal symptoms (Del Mastro et al 2006). Clinically induced menopausal symptoms are recognised to be more severe for this age group (McCarthy et al 2007).

In summary, it is well known breast cancer is a devastating disease affecting women across the adult life span in ever increasing numbers. To date there has been a great deal of emphasis on the disease as it relates to women towards the upper end of the age range. What is less well known is how the disease affects women in earlier stages of life. The limited research that has been conducted points to very different kinds of concerns and on the whole a more difficult treatment course.

The aim of this study was to explore the perceptions of young women with breast cancer in relation to their early treatment trajectory and was designed to generate knowledge to improve health professionals' understanding of that experience.

METHOD

This study used a qualitative approach drawing on an interpretative theoretical perspective to explore breast cancer for the younger woman. Based on insights from feminist inquiry the researcher set out to identify and describe the experience through the telling/interpretation of women's own accounts (Emden 1998). These narratives have been analysed and synthesised into a meaningful (re)construction of the experience from which others can learn (Porter 1998).

The study gathered data through the use of in-depth interviews during which the researcher established rapport with the participants and actively encouraged them to speak without the constraints imposed by a series of set questions (Reinharz 1992). The women were asked to describe their experience/s of breast cancer from initial diagnosis. Descriptions of how they coped with treatment, their concerns about family and personal reflections of their journey were explored. The researcher asked broad ranging questions

such as, 'tell me how you felt when you were first diagnosed, what is it like to be having treatment for breast cancer and tell me about a time when you felt particularly (un)able to cope?' The researcher's intent was to allow the women to control the flow of the interview (Glesne 1999) to gather data 'thick' with insightful description (Todres 2007).

SETTING AND PARTICIPANTS

The study drew on participants from a large private metropolitan hospital. The researcher provided information about the study during a young women's breast cancer information session, following which a call was made for potential participants. The study used a purposive sample - the inclusion criteria stipulated participants needed to be women less than

50 years of age and diagnosed with breast cancer in the last 12 months. The six eventual participants were all English speaking; their disease status varied and they experienced a range of different treatments.

DATA COLLECTION

Each participant was interviewed at a time of convenience in their own home. Interviews were tape recorded and later transcribed verbatim. In keeping with an in-depth interview technique the interviews lasted from 60 to 90 minutes depending on the participant. The interviewer was an experienced registered nurse not involved in providing care to the participants. A formal counselling service was available if needed.

Table 1: Demographic snap shot of participants

Age	Marital status	Children	Work Status	Treatment
Dawn 29yrs	Defacto	Nil	Full time	Mastectomy Chemotherapy Tamoxifen
Fay 33yrs	Married	5 years 2 years	Part time	Mastectomy Chemotherapy Radiotherapy Tamoxifen Breast reconstruction
Carrie 34yrs	Married	18 months old Pregnant when diagnosed	Home mother	Lumpectomy Radiotherapy after baby was born
Anne 40yrs	Married	11 years 8 years	Part time	Lumpectomy Mastectomy Chemotherapy Radiotherapy Tamoxifen
Pat 43yrs	Married	13 years 11 years	Part time	Lumpectomy Chemotherapy Radiotherapy Tamoxifen
Joan 43yrs	Married	15 years 13 years	Part time	Lumpectomy Chemotherapy Radiotherapy Tamoxifen

DATA ANALYSIS

The text from the transcribed interviews was analysed using recognised inductive qualitative techniques that comprised a multi-phased process of thematic analysis (Grbich 1999). The transcripts were read

several times in an effort to gain a comprehensive understanding of the participants' experience/s. Each transcript was analysed for similarity/dissimilarity of issues and perceptions by the members of the research team. The data was then grouped into

categories and common themes within each category through a consensus approach across the team. The categories were drawn from the women's words whenever possible as the analysis attempted to place the woman's description within the context of her life journey (Reinharz 1992). The participants viewed and verified their transcripts and the resultant themes to assure rigour (Grbich 1999).

ETHICAL CONSIDERATIONS

Ethical clearance was granted by the Human Research Ethics Committees of the participating University and private hospital. The National Health and Medical Research Council (NHMRC) Ethical Guidelines for Qualitative Research were adhered to throughout the study. To ensure privacy, participants were asked to choose a pseudonym.

FINDINGS

While several themes emerged from the data the themes presented in this paper relate specifically to diagnosis and early treatment:

1. Diagnosis as a state of disbelief and concern

The diagnosis of breast cancer for all the women was a shock; creating a sense of disbelief described as a period of 'why me?' during which participants grieved for life aspirations suddenly lost.

'I wasn't directly told I had cancer ... I was told I had a lot of abnormal cells ... not normal for someone of my age... that to me was the definitive moment - I knew then I had cancer' Dawn

Carrie who was pregnant at the time faced additional challenges as she attempted to cope with the surgery, worry about a forthcoming baby and care for her existing child. In relation to her treatment she said:

'...in 6 weeks I am going to have a brand new baby and I just want to get the treatment over and done with. I'm going to be tired anyway, I can't breast feed, I'm told not to breast feed ... so I just want to power on through it and put it behind me and basically just get on with life. ...I just think get it over and done with.' Carrie

The whirlwind speed at which the participants received treatment made life difficult for the women because five of them had child-rearing responsibilities. The women spoke of the needs of their children having to be considered at each step of the process. This was exacerbated by the lack of a lead-in time to adequately absorb the diagnosis and prepare themselves let alone the family for what was to come.

Another aspect of diagnosis and treatment was the need for clarity of information, the women explained they had trouble 'focusing' after receiving information and of different interpretations about what they had heard.

'...the minute he [specialist] told us the statistics and how little extra protection chemo [therapy] gave you our jaws just dropped. I don't think we heard another word after that. It was like; we are going to go through all that for another 15%? ... At home my interpretation and my husband's of what my treatment was going to be were different. Then we got out the notes the specialist had given us and it was different again' Pat

The women commented that nurses tried to help them understand but it was still difficult.

'They give you a little piece of paper and say "this is your drug and these are the side effects" ...and of course I copped every single one. So I think there's not enough information about what you are going to get from chemotherapy to really understand exactly what the symptoms will be' Fay

In these quickly moving early stages the women described having to deal with multiple stressors and of having no similar life or family experiences, with this degree of severity, from which to draw strength. The women described a sense of loss of control as they became 'caught up' in a system that dictated the terms. They described this time as "having to be intensely strong for the family".

'...close family members, including my mother, found it very difficult to accept [the diagnosis] and I found I was counselling them. ... that was really interesting because it really made you distance yourself a bit

more from it, to be able to cope with other people's grief' Dawn

2. Surrounded by family yet 'going it alone'

Even though they were surrounded by family, for much of the early treatment the women described an overwhelming sense of having to 'go it alone'. This was because of the desire to keep the family routine as 'normal' as possible during the treatment process.

'So here I am with ice packs taped all over me, again heading up to the hill (hospital), again by myself ... because John was home with the kids. God knows how it was for him' Pat

Pat talked of chemotherapy as a period of time when she existed by taking each day at a time suffering from mouth ulcers and becoming neutropenic and yet at the same time 'having to keep the family going'.

'We all thought I was going to die from the chemo[therapy] not from the cancer. I had such horrific, horrific mouth ulcers....Here was I a few months down the track going bald and I was starting to get that horrible chemo[therapy] emaciated look and all I could think of was that this wasn't really good for them to be seeing me like this.' Pat

The women talked of their hardship in trying to work out what each member of the family needed in order to help them cope while at the same time trying to cope themselves.

'...I got really angry ...because I thought, "damn it, this is a big deal for me, I need support too". But I didn't know what support I needed, I didn't actually know what I needed.' Dawn

Dealing with the actual treatment at the same time as having to help the family to cope, increased the difficulty in adjusting to the diagnosis and treatment. A mother of young girls talked of her distress when one child reacted to the breast cancer by stating she was afraid to 'grow' breasts and asked her mother 'because you've got it, will I get it too'? (Anne).

3. 'Ups and Downs', the treatment effect

Younger women are noted to experience greater physical and psychological difficulties resulting

from the effects of aggressive treatment schedules (Partridge and Ruddy 2007). In this study the women's experience could be likened to an 'emotional rollercoaster' requiring enormous adjustment to the breast cancer treatment trajectory. The women described the effects of chemotherapy as something totally unexpected and frightening.

'I don't know whether more information would have helped or not or would just have made it more frightening. Even the terminology of "putting it [the chemotherapy] in" just made my stomach turn. ...I was not expecting the volume and I wasn't expecting the sensations of it going into my arm, into the muscle. I'm sure I could feel it going into my heart.' Pat

For the youngest woman the mastectomy scar on her body was perceived as an 'attack' on her femininity and the potential long term effects of the breast cancer treatment had life changing ramifications.

'...in one fell swoop I was told everything that was feminine about me was gone, I was losing my breast, I possibly couldn't have children. ... all of a sudden choices for the life I had planned were being taken away from me. When you see your mastectomy scars, they start under your arm and go right across your chest. There's no way you can hide that, it's there. ...every time you look in the mirror you are reminded you've had breast cancer.' Dawn

For Carrie the staff reinforced how young she was to have breast cancer.

'I wasn't treated differently in any other way. It was noted I was pregnant and that was it ...they'd have to send someone up from maternity to come and monitor the baby and it was always, "oh gosh so young!"' Carrie

Another aspect of the treatment period was accepting help; some of the women had their mother's help to keep the family going, also friends and neighbours provided support. Women often received unsolicited support:

'I got sick [after my chemotherapy] and all these people started seeing me looking ill and were asking questions; so we made the decision that we would

actually tell them. ... We were quite open about it and we received the most amazing support ... whether it was fruit and vegetables or cooked meals they had rosters done up it was just amazing and that was the biggest support we ever had and you would never have realised there were people like that out there.' Fay

Although it was not always easy for the women to accept help;

'It was especially hard for my husband he couldn't handle it at first and I just said to him we have to because if we don't we won't cope. I was totally bed ridden with my chemotherapy so we had to accept help' Fay

Although they were careful to point out it took a few months to feel 'normal' again, once the treatment was finished and the women began to feel better they described some positives in their lives. One of the underlying themes from all of the participants was that even though it was devastating to be diagnosed with breast cancer this was not the end of their lives and they were going to recover. While the breast cancer journey had become a very real part of their lives they tried not to let it take over. Pat said, '...the first time I stood on the beach after it was all over I just cried and cried. I definitely don't take anything for granted anymore'. Another said: 'It's great not to be sick anymore.... To get your hair back - It feels so good' (Anne).

DISCUSSION

The findings from this study substantiate the limited available research related to this particular research problem (Bloom et al 2004). A major issue for the women was the lack of preparatory time afforded before treatment began and this created a number of difficulties. Although on the one hand it could be seen as a move in the right direction it did leave little time for psychological adjustment and making arrangements for family.

A diagnosis of breast cancer is usually unexpected and 'unbelievable' however the women described 'having to be strong' in support of the family to

maintain a sense of normality and calm. Mellon and Northouse (2001) discuss similar factors in their research exploring family survivorship following cancer diagnosis. The stress of needing to be supportive of others particularly children, at a time of needing support oneself, is heightened for younger women. At this stage in their lives many women have had limited experience of being so sick and as the mainstayers of family life cannot afford to be (Walsh et al 2005).

This study also found women experienced disempowerment or loss of control of self during their breast cancer treatment. Health professionals were perceived to focus squarely on the disease rather than the whole person; this phenomenon is well documented (Mellon et al 2006). It was especially true for the youngest participants who found it particularly hard to come to terms with the 'why me' factor.

Research has shown having multiple stressors add to a woman's overall psychological and physical suffering at this time (Coyne and Borbasi 2006). The women in this study reported similar stressors as those that occurred during diagnosis and treatment. Open discussions about how to cope with the symptoms of treatment would be helpful for younger women, who as stated often have difficulty assuming the sick role and asking for help (Manne et al 2005). The provision of incremental information in a variety of forms (such as oral taped or written) regarding treatment options was noted as helpful by the women in this study and facilitated much needed discussion with their partner and family members on a range of issues. This has been noted in previous research (Nikoletti et al 2003).

All of the participants commented on the unexpected length of time it took them to recover after each treatment phase, both physically and emotionally. This was associated with the severity of side effects including nausea, fatigue and specific concerns such as mouth ulcers. Yet, staying 'on top of the treatment' was a major goal for these women. The women stated they were not prepared for the emotional toll the treatment took on them but were certainly

aware that how they responded to their medical treatment influenced the family's mental health. They noted the importance of the family in spurring their recovery. These findings are consistent with previous research identifying that the availability of both physical and psychological support produces better mental and physical wellbeing in women (Northouse et al 2007).

In terms of recovery many of the women spoke of coming out of the treatment phase with a positive outlook. While the period of diagnosis and chemotherapy constituted a rollercoaster of physical and psychological concern, as the treatment came to an end a strong sense of survivorship ensued together with an attitude of no longer taking life for granted. The participants' descriptions affirm previous research identifying a positive attitude in younger women to survive and get back to 'normal' (Walsh et al 2005; Sammarco 2001) and young women often show great resilience and discover positive meaning in having breast cancer (Albaugh 2003). It would be useful for health professionals to validate and support women when they identify positive aspects of their experience and adjustment thus reinforcing their adaptation in the longer term. This could be achieved by understanding the need for women to adjust to each phase of treatment and by maintaining open communication with both the woman and her family as she seeks to cope with each new treatment concern (Mellon et al 2006). The women in this study suggested several strategies that helped them maintain some control over their lives; journal writing and scrap booking helped them to appreciate each day and focus on aspects other than the disease.

While it is inevitable individuals will draw on differing coping strategies during the treatment regime and beyond it is important for health professionals to consider and respond to individual and family needs (Hutchinson et al 2006; Coyne 2004; NBCC 2001). Previous research identifies the importance of the family working together to overcome the problems associated with treatment schedules (Clark 2002). Researchers note the importance of understanding

family strengths and networks to ensure the caregiver support network does not become stressed and unable to provide vital support (Northouse et al 2005; Clark 2002). An increased understanding of the young woman's perspective and taking time to question how she is adjusting and maintaining her role in the family is important. A multidisciplinary team approach is essential to ensure young women and their family members can access counsellors, social workers and other support health professionals as this age group tend not to identify the need for or ask for assistance because of their reluctance to adopt a sick role. Breast care nurses are especially important at this time.

CONCLUSION AND RECOMMENDATIONS

In conclusion, it is important for health professionals to understand that the experience of breast cancer diagnosis and treatment for younger women is made more difficult because of their biological status and the complexity of the roles traditionally associated with this time of life. The aggressive nature of the breast cancer, unyielding treatment schedules and physical side effects compound the distress. Specific recommendations for nursing staff would be the provision of taped doctors' visits and written notes explaining treatment schedules; the organisation of a special time to discuss how the family is coping with the breast cancer treatment; and the encouragement of the woman and her family to use the resources provided by health professionals. As younger women with breast cancer move into longer term survival there is a need for research exploring on-going care and concerns.

LIMITATIONS

In keeping with the nature of interpretative inquiry there is no intent to generalise the findings of this study rather the intent is to produce credible findings (Sandelowski 1993). While the number of participants in this study was small it is feasible that young women with breast cancer in matching settings will experience similar issues.

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