Title: Younger and older women's concerns about menopause after breast cancer

Abstract

A number of treatments for breast cancer induce menopause. This study's aim was to explore women's perceptions and beliefs about menopausal symptoms and their management following breast cancer, and to compare younger and older women's experiences. Data were collected via semi-structured focus groups from women who had undergone treatment for breast cancer, and who were currently experiencing menopausal symptoms. Data were interpreted by way of simple inductive thematic analysis. The women experienced a range of menopausal symptoms that they were not prepared for and found difficult to manage. The central themes related to their lack of knowledge of how to manage menopausal symptoms, and the distress and helplessness that arose from this. Women who were diagnosed prior to 40 years of age reported additional menopausal issues than women who were older at diagnosis. The women in this study expressed a thirst for information related to menopause after breast cancer. The women identified that their needs with regard to menopause after breast cancer were not being met, either through their own lack of knowledge or via conflicting or absent support and management. The importance of enabling women to deal with menopausal symptoms was a central theme to emerge from the data.

Key words:

Young breast cancer survivor; menopausal symptoms; qualitative study; focus groups

Breast cancer is the most common invasive cancer diagnosed in women in Australia (Australian Institute of Health and Welfare, 2008). A number of treatments for breast cancer, including chemotherapy, hormonal therapy, radiology and surgery[1], induce temporary or permanent menopause (National Breast and Ovarian Cancer Centre, 2008). Regardless of whether the menopause is temporary or permanent, cessation of menses may be accompanied by menopausal symptoms of varying frequency and severity. Menopausal symptoms include vasomotor events such as hot flushes and night sweats, vaginal dryness, sleep disturbance, fatigue, mood symptoms, loss of libido, memory impairments, bladder problems, bone and joint aches, and weight gain (Nelson et al., 2005).

In 2007, approximately 25% of women diagnosed with breast cancer were under 50 years of age, below the average age for the natural menopause (Australian Institute of Health and Welfare, 2010). Approximately two-thirds of these women will experience menopause as a result of their treatment.

The prevalence and severity of menopausal symptoms amongst women who have received breast cancer treatment has been reported as being higher (McPhail and Smith, 2000) and likely to be experienced for a longer period than women in the general population (Carpenter et al., 1998). Politi et al. (2008) published a review of studies of natural menopause, which revealed that vasomotor symptoms, the most common symptoms of menopause, have a median duration of 4 years. In contrast, 73% of postmenopausal breast cancer patients report hot flushes persisting 6-10 years after their last period (Carpenter et al., 1998). Moreover, women with treatment-induced menopause are more likely to experience more tiredness and lack of energy (McPhail and Smith, 2000); night sweats and hot flushes (Crandall et al., 2004, McPhail and Smith, 2000); higher rates of depression (Conde et al.,

[1] Permanent menopause results from surgery or radiation to the ovaries.

2005); and less sexual activity (Rogers and Kristjanson, 2002) than women of the same age without breast cancer.

Women's experiences of treatment-induced menopause are likely to differ according to a range of socio-demographic, as well as, treatment-related factors. Moreover, at least one study has reported that women who are premenopausal prior to cancer treatment report more frequent and more severe menopausal symptoms after treatment compared to women who are postmenopausal at diagnosis and treatment (Biglia et al., 2003). Younger women may have different or additional concerns about or after their treatment compared with their older counterparts, including concerns about the professional and financial impacts of cancer and cancer treatment, impairment or loss of fertility (Rosendahl et al., 2009), and length of toxicity of treatment and the influence of cancer and cancer treatment on family (Burstein, 2009). Younger women are also more likely to be premenopausal when they are diagnosed with and treated for breast cancer. Experiencing treatment-induced menopause may therefore have differing meanings and present unique stressors for younger women, whose life stage is not normally associated with such symptoms.

While younger women are also more likely to resume menses (although not necessarily fertility) after a treatment-induced menopause, at the time of their menopausal symptoms there is no clinical marker for those women who will regain fertility, resume menses, or continue to be postmenopausal. Therefore, the experience of the younger women with treatment-induced menopause may include uncertainty about fertility and the permanence of their menopause as well as more severe symptoms.

As seemingly younger and younger women are diagnosed with breast cancer, there is variability in how *young* or *younger* breast cancer patients are defined in the literature, ranging from younger than 35 years of age (Bacchi et al., 2010, Livi et al., 2010) to younger than 50 years of age (Camp-Sorrell, 2009, Ganz et al., 2003). In this study, younger breast

cancer survivors were defined as those who were *40 years of age or younger*. This cut-off was chosen after consideration of the average age of peri-menopause, which is 47-51 years; a cut-off of 40 years of age allowed women who were five or more years from peri-menopause to be classified into the *younger* group. These women could be clearly categorised as being premenopausal prior to their breast cancer treatment.

The aim of this study was to explore the experiences of menopausal symptoms in women who had been treated for breast cancer. The related objectives were to identify and describe women's experience of their menopausal symptoms following breast cancer treatment, to understand how these symptoms affected them, and to compare younger (premenopausal) and older (peri menopausal) women's experiences of these symptoms.

Method

Sample

Participants comprised a convenience sample of women who attended one of two cancer clinics in Brisbane, Australia. Clinic 1 is a not-for-profit organisation run from a private hospital. Clinic 2 is a for-profit private acute treatment facility. Usual care at these clinics includes a phone call at 1 week, 3 months and 7 months post-diagnosis to discuss concerns regarding treatment or treatment side-effects. However, patients do not necessarily receive survivorship planning in a structured way, rather relying on each patient to raise issues of concern with treating staff.

The inclusion criteria comprised currently experiencing at least one target menopausal symptom of moderate to severe intensity assessed using the Greene Climacteric Scale (Greene, 1998); completion of acute treatment for breast cancer (surgery, radiology, chemotherapy) within 2 years of joining the study; and able to speak and read conversational English. Patients with metastatic breast cancer and inoperable or active loco-regional disease were excluded. Women were screened verbally and in writing prior to their participation in

the focus groups. Participants were made aware of the eligibility criteria. Ethical approval for this study was granted by university and hospital Human Research Ethics Committees.

The women were screened by senior registered nurses at these sites, who then provided women with a participant information sheet and consent form to read after inviting them to participate in the study. While women of any age could participate, women were separated into two age groups: those over 40 years old and those younger than 40 years. A total of 16 women participated in three focus groups; two groups comprised women > 40 years of age, n=10 and one group of women ≤ 40 years, n=6. This enabled exploration of experiences that might be unique to women in these different age groups.

[Insert Table 1 here]

As described in Table 1, the participants in this study were mostly in married or de facto relationships and were currently working. The age range for the younger group ranged from 34 to 36 years of age; whereas the age group of the older group ranged from 42 to 53 years of age. All the women had completed acute treatment for breast cancer.

Data collection

Focus groups were used as the primary source of data collection as they encouraged discussion and enabled participants to react and build on other women's responses (Morgan, 1988, Stewart and Shamdasani, 1990). Focus groups were audio recorded and field notes were also taken during the discussion by an associate researcher. Each focus group was conducted for approximately one hour.

The first author, an experienced menopause researcher, moderated the focus groups. The use of a female moderator conversant with the language and science of menopause facilitated open and relaxed participation among the women. She was comfortable discussing

the potentially sensitive aspects of menopause such as sexual symptoms and sexual activity. Two associate researchers participated in the focus groups – one attended two groups, and the other associate researcher attended one group. Both were women, each of whom holds a degree in psychology.

Focus groups were held in a non-clinical space to provide a comfortable, non-threatening setting for the women. The focus groups commenced with the introduction of the research team and the focus group participants. The following introductory questions were asked to elicit participant's experiences. The questions were arrived at after a priori review of the literature; and were reviewed by an expert panel comprising 2 experienced clinicians and 3 specialist academics in the field. The questions were piloted on a small group of women (n=3) from the breast clinic to explore face validity and appropriateness. The aims of these questions were to introduce participants to the general topic of discussion, with a view of promoting connection with and reflection on participant experiences with the topic; and to facilitate interaction and discussion of shared experiences with other group members. Stem questions included:

- *What has been your experience of menopausal symptoms following breast cancer treatment?*
- *Have you found any of these symptoms bothersome?*
- *If so, which symptoms are the most bothersome?*
- *How have these symptoms affected your quality of life?*
- *Is there anything else you would like to tell us about menopausal symptoms and breast cancer?*

Each focus group concluded with a summary from the research team, with the aim to review the discussion and check for the accuracy and completeness of the researchers' understanding of the issues discussed. In this phase of the focus groups the researcher

provided a summary which included: *"Is that an accurate summary of some of your experiences of menopausal symptoms?"* and *"Is there anything you think has been missed?"*

Data analysis

Focus group sessions were audio recorded to ensure that all information collected was available to the researchers. This also ensured that focus group protocol was monitored and adhered to. Recordings were transcribed, for further analysis, by a transcription service.

Data was analysed using thematic analysis. The themes were reanalysed by the associate researcher to ensure that there was at least 70% agreement. Researcher triangulation was employed to collect and analyse the data to capture the complexity of the area studied and enhance the validity of the findings (Creswell, 1998). An assistant was present to provide supplementary notes on the focus groups and to aid in the validation of themes and conclusions drawn.

Thematic analysis comprised the following discrete steps: simultaneously listening and relistening to the interview tapes, and reading and rereading the transcripts and field notes; ordering the data into manageable forms by sorting them into initial categories, such as levels of distress; quality of life; and symptoms encountered; refining the concepts with further reference to the transcripts and field notes; examining the links between concepts and weaving them together to arrive at an interim interpretation; and verification of these themes by all analysts checking them against the original data and with each other until a consensus interpretation was achieved.

Themes were named and categorised and closely examined to compare for similarities and differences. Connections were then made between the categories and subcategories found with a verification of the statements against the data. The core category was then selected and systematically related to the other categories. This methodology was used to give vigour and precision to the analysis.

Ensuring rigour

Rigour is an important element of qualitative research that enhances the consumer's confidence in the findings and in the interpretation of the study. For the purposes of this study; rigour was considered in terms of dependability, confirmability and data saturation (Emden, 2001). The criterion of dependability asks whether the research findings and conclusions derived from the data, in such circumstances, are plausible (Liamputtong, 2009). To meet this criterion, audit trails were kept amongst analysts to clarify all thematic decision-making. It also entailed constant re-reading of the raw data and continued reflexive discussions amongst the research team about the plausibility of the themes in general and their relationship to the context from which the data were drawn, to ultimately reach a consensual interpretation of the data. Confirmability refers to the ability of the researchers to demonstrate that the findings and interpretations are clearly linked to the data (Liamputtong, 2009). To meet this criterion, this paper provides abundant raw data drawn from the participants and descriptions of the context from which the data were drawn, so that interpretations and conclusions can be followed by the reader. A limitation of this study is related to the criterion of data saturation, which means that the interviews yield no new data or insights to the researchers. Data saturation was reached in one sense during the focus groups, in that after a certain time in each focus group, no new information was forthcoming. This small sample size is typical of focus group research. While it enhances the researchers' in-depth understanding of an issue in context, it does not enable complete saturation in, or understanding of, the menopausal issues of those women who are not able, or not willing, to participate in such studies. Hence, we acknowledge that the findings and interpretation presented here pertain only to the women in question and the context under study.

Results

A greater number of women who were older than 40 years of age (n=10) participated in the study compared to women under 40 years of age (n=6). In summary, the five themes were:

(1) Menopausal symptoms: types and experiences, with the subthemes: a) hot flushes, night sweats, and sleeplessness; b) dry vagina and lack of sex; c) irritability, depression and memory impairment; d) weight gain; and e) positive aspects;

(2) Lack of knowledge and information related to menopause after breast cancer;

(3) Feeling old;

(4) Affects on work life and career;

(5) Health practitioner support and management and supportive strategies.

Quotes are used to illustrate the themes.

Menopausal symptoms: types and experiences

The symptoms that appeared to concern and significantly impact on the women fell into four subthemes, including; 1) hot flushes, night sweats, and sleeplessness; 2) dry vagina and lack of sex; 3) irritability, depression and memory impairment; and 4) weight gain. The cumulative and circular nature of many of these symptoms is illustrated by the following comments:

> *I used to get really dramatic [night] sweats and insomnia, but that's dissipated now. Now I just get periodic hot flushes and really wacky irritability, every now and then, like completely uncontrollable, like there's an alien in my brain...the other thing too, is weight gain (woman ≤40 years).*

> *Because [the symptoms are] a combination. I find that I just don't want to do anything because I'm having the hot flushes and I'm just so exhausted and so hot and so uncomfortable all the time and I can't be bothered … (woman >40 years).*

Hot flushes, night sweats and sleeplessness

When describing the experience of hot flushes and night sweats, the women particularly emphasised its disruptive effect on their sleeping patterns, and the frustration and "embarrassment" of experiencing hot flushes in the workplace.

> *I probably get 3 or 4 [hot flushes] a night, and 8 or 9 a day which is okay if you're not at work...but doing what I do, I can't do anything about it, I'm there, and have just sweat from top to toe (woman >40 years)*

> *That's the worst thing I think … it's just not being able to sleep and you wake up and you're tired ...I've got to get some sleep, and nothing works! (woman >40 years)*

Women commonly describe being able to fall asleep but waking up frequently in the night and then not being able to go back to sleep.

> *I can't remember the last time I went to bed and woke up and it's morning time. I go to bed and I must wake up five, six times a night (woman >40 years).*

Interestingly, women under 40 years of age did not mention problematic sleeplessness post-treatment, even though they experienced hot flushes. (One woman reported insomnia and night sweats during chemotherapy only). While another woman mentioned night sweats, this was in the context of explaining that this was a symptom with which she could cope (in comparison with sexual symptoms).

Dry vagina and sex

Difficulty with sex was described as one of the most important symptoms by the women. One woman echoed the sentiments of most of the participants when she described it as *"The most alarming thing was … not being able to have sex."* Most of these difficulties were a result of dry vagina, which the participants described in terms of the pain it caused during intercourse; however they also described a general loss of libido:

It's [your body is] just not responding like you'd expect it to be responding (woman>40 years).

Even during my chemo I felt like doing it [having sex] MORE than I do now (woman >40 years).

Several women spoke about the cumulative effects of surgery and menopausal symptoms influencing their confidence or readiness to engage in sexual activity:

And I said to my husband, 'we won't be able to have sex again, this is just too painful'. It's awful... You've already had to cope with showing your body [with changes from surgery etc.]... and then you know, it [dry vagina] freezes you up a bit sexually (woman >40 years).

It was also noted that if women experienced difficulty with having sex, vaginal intercourse could no longer be spontaneous, with much more time required in foreplay or for premeditated strategies such ensuring adequate lubrication.

It's hard...sometimes you just go 'bang' and want to have sex with each other. That doesn't work anymore (woman >40 years).

Many of the women found these two symptoms very distressing and reported that they had a major impact on their quality of life and on their relationships with their partners.

Irritability, depression and memory impairment

The women in the study reported several symptoms related to irritability, depression and memory impairment, which they attributed to menopause or as a consequence of other menopausal symptoms, such as a lack of sleep (mostly older women) or worry about job performance (younger women):

I was waking up probably every hour and a half and very restless, very restless sleep and yes, and because of the lack of sleep I had the irritability, anxiousness, depression and all of that that comes naturally with the lack of sleep (woman >40 years).

They explained that they experienced unusual irritability (as per the earlier quote on page 11) and feeling quite depressed over things that would not normally cause irritation. Similarly, many of those women who prior to treatment had good memories found that they were now challenged to remember things:

My memory…like that's the thing I'm finding really challenging because I have to write everything down (woman ≤40 years).

Weight gain

Most of the women gained weight after their breast cancer treatment had finished. While participants did not seem sure whether their weight gain was related to their cancer treatment or menopause per se, it was a symptom that they reported 'knowing' was related to ageing and menopause. They reported a perceived lack of control over this weight gain; that the weight now sat on their waists (as opposed to their thighs pre-treatment); that their appetites were hard to control; and that they were able to eat sweeter foods than previously:

[Interviewer: Where are you putting on weight?] It's awful; it's like wearing one of those bum bags, it goes from one hip to the other. Totally different to where it used to be ...and I eat the same as I normally do (woman >40 years).

They also said that they found it hard to exercise due to tiredness.

Positive aspects of the menopause experience

While the majority of the data relating to menopausal symptoms focused on negative experiences, not all characteristics of menopause were perceived as negative by all participants. For example, two younger women spoke about their positive evaluation of their

menopause experience, when comparing their hot flushes with the symptoms they experienced as part of their (previous) menstrual cycle. They regarded the experience of their periods, in terms of feeling hot and bloating, as more distressing than the menopausal symptoms. These women evaluated their change from premenopause to menopause and postmenopause positively:

> *And now it's like, well yeah, the hot flushes suck but I prefer that to having my period (woman ≤40 years).*

> *I actually feel better now that I don't get my period (woman ≤40 years).*

Hence, it is important to note that while the study recruitment procedure aimed to recruit women who were experiencing bothersome menopausal symptoms; these data indicate that not all aspects of menopause are bothersome. Some women may find that compared to the symptoms associated with their pre-treatment menstrual cycle, menopausal symptoms are comparatively welcome.

Lack of knowledge and information related to menopause after breast cancer

The majority of women in the older group reported that they were unaware that they would experience menopause as a result of their breast cancer treatment. In comparison, the younger women seemed more aware that menopausal symptoms may result has part of their treatment:

> *Well my treatment plan has included a drug called [medication name] from chemotherapy onwards which induces menopause ... so that's what I'm looking at for the next three years as well (woman ≤40 years).*

However, most women in all groups did not appear to understand which of their menopausal symptoms were attributable to the temporary hormonal blockade induced by maintenance treatment such as Tamoxifen, and which were attributable to the permanent

effects of acute breast cancer treatments such as cytotoxic therapy or surgical ovarian ablation. For this reason, many participants were unsure how long their menopause would last, and whether their periods would return after their maintenance treatment for breast cancer was complete. The following comments typify this confusion:

> *You know there are so many confusing conflicting messages (woman >40 years)*

> *I went on the internet and tried to look at, you know, what was a side effect of the medication and what's normal for menopause (woman >40 years)*

As a result, many of the participants expressed a desire for more information about menopause, preferably material which is straightforward and non-conflicting:

> *But when you can't have any topical oestrogen or any artificial oestrogen or anything like that; it's actually really hard to find out what to do (woman ≤40 years)*

> *Conflicting information, that's what I find the most annoying because I just haven't got the mental energy to drag things from everywhere like I used to (woman >40 years).*

Feeling old

Many of the women associated menopause and menopausal symptoms with ageing and feeling old. This was true for both age groups. Even for women who were over 40 years of age, and were more likely to be peri menopausal, menopause was still a life phase that was unanticipated in the near future. The following comment is typical of these perceptions:

> *Yeah, I wasn't menopausal at all and women in my family don't usually have menopause till there in their late fifties for my family across the board. So it's something that's very shocking to me (woman > 40 years)*

Those women who were under 40 years felt that the pre-conceived notions of menopause applied to them, including feeling and looking old, and they expressed negative body images. They also identified a number of additional issues in their experience of treatment-induced menopausal symptoms that were more characteristic of this age group. None of the younger participants had anticipated menopause for some time and its suddenness and severity clearly had a significant physical and psychological impact. Many participants felt isolated by their experience of menopause because their peers were not undergoing menopause at the same time and did not understand their experiences post cancer treatment. They also felt that most of the literature and marketing on breast cancer did not cater for the younger age group, tending to target older women in language, images and examples. The following quotes illustrate some of these issues well:

> *No one is going through menopause at our age (woman ≤40 years)*
>
> *For the older women, they have had friends and so on who have gone through menopause, so they know what to talk about and they know what the symptoms are...But we don't know anyone our age who is going through it...(woman ≤40 years).*
>
> *It's the language that's used, for me...I think isn't relevant...all of the marketing that's set up around menopause, and breast cancer in general is targeted ...at people over 50, I think that's a bit of an issue.... I feel that younger women have substantially different issues, not that they're any more important or any less important, but very different issues to someone who is older, and that's not represented very well through the menopause discussions (woman ≤40 years).*

A number of the younger women expressed a sense of loss regarding their future life goals and plans because of their menopause. For example, issues of fertility and family planning emerged as significant, particularly for those women for whom menopause was now

permanent. As articulated by one woman in the following extract, it was also a matter of limiting life choices before they were ready to do so:

> *Also issues of fertility, because your decision is taken from you, whereas a woman of 60 has probably had children, or has decided not to have children. Whereas for all of us, that's not on the cards (woman ≤40 years)*

Affects on Work Life and Career

One theme that was only raised by the younger women was the influence of cancer treatment and treatment-induced symptoms on their work life. The women in the younger focus group also believed that this issue was one that was of greater importance to women their age.

Given the demographic of this well-educated and relatively affluent group of younger women, interruptions to career progression caused by the breast cancer diagnosis were problematic. On their return to work they felt their work performance was not as good as it should be. They described how their work roles were now compromised by severe menopausal symptoms such as impaired cognition, irritability and the physical discomfort and embarrassment caused by vasomotor symptoms. The following quote is typical in this respect:

> *The career and financial stuff...that I think is different for women in their sixties...when you're in your prime [in your 30s] and you have that ripped away from you (woman ≤40 years).*

Health Practitioner Support and Management

Many of the women were not interested in further medical or hormonal treatments for their symptoms. Participants discussed how each medication led to more symptoms, which in turn required more medications. After treatment with a battery of drugs, it was clear that some women had simply had enough:

> *[My doctor] offered me [antidepressant medication], if I wanted to, which apparently helps with hot flushes but I don't want to because I take enough stuff as it is, without more tablets (woman >40 years).*

> *…but you go to a doctor and they'll fix a symptom with a drug and then four weeks later we're back there because that drug has given you another symptom. They'll give you another drug to counteract the symptom of the first drug and you just get a bit tired of running around (woman >40 years).*

Some of the women expressed a frustration with discussing the menopausal symptoms with male health professionals who some felt could not understand these uniquely female symptoms.

> *The hot flushes haven't abated one little scrap…the doctor's keep saying, MEN doctors you've got to love them, "oh they'll go away, they'll go away one day you'll notice you haven't got them"…this comes from a MAN who has never had a hot flush in his life…(woman >40 years)*

> *They go to male doctors and you know it's like speaking a foreign language and it's like he looks at me confused like… (woman >40 years).*

Supportive Interventions

In response to being asked what interventions they believe would assist or support them during the post-treatment phase, most women felt additional group support with other women would assist them to cope with and share information and strategies about managing menopausal symptoms. Not all of the women believed that face-to-face contact with other women in the post-treatment phase was necessary; however, they would like the option of attending such a group or believed that internet contact would be adequate and would suit

their busy lifestyles, particularly in the younger women's group. These attitudes are reflected in the following quotes:

> *I think the group session would be okay, things would come out of it you know and then you could compare to each other how you're going (woman >40 years).*

> *I prefer a group; at least you hear what everyone's been going through (woman ≤40 years).*

> *The web based thing would work best for people with time constraints of going back to work that couldn't commit to coming to...if you wanted to just monitor ...do it like that and you could even have a bit of a chat thing so that people can chat too when it's not taking up so much of their time (woman ≤40 years).*

Discussion

For women recovering from treatment for breast cancer, the experience of menopause can be unexpected, and difficult to manage. The qualitative methodology used in this study enabled an in-depth exploration of women's perceptions, concerns and perceived needs regarding menopause and in particular the impact of the experiences of younger women going through this process.

The women in this study expressed a lack of knowledge and a thirst for information related to menopause after breast cancer. The women seemed unsure about where to find information and how to weigh conflicting information. Similarly, an American sample reported received conflicting advice from varying specialists, which they found difficult to reconcile (Knobf, 2002). Many women spoke about the absence of support from health practitioners. In other qualitative studies from countries other than Australia, women have also reported receiving little or no information about the possibility of treatment-induced

menopause (e.g., Karaöz et al., 2010), what menopausal symptoms are, or how to manage such symptoms (e.g., Wilmoth, 2001).

In two of the focus groups, the women openly asked what symptoms were menopausal symptoms before being able to respond to the initial stem question, *what has been your experience of menopausal symptoms following breast cancer*? During the discussion, women seemed confused about what symptoms were related to chemotherapy or treatment-induced menopause (due to anti-hormone treatments or damage sustained to their ovaries). The symptoms that seemed to be associated with the most confusion were hot flushes and dry mouth. Similarly, Turkish women (Karaöz et al., 2010) and American women (Knobf, 2002) treated for breast cancer reported not knowing whether the symptoms they experienced were a result of menopause or chemotherapy.

Women did experience a range of menopausal symptoms that seemed to be persistent and of real concern, impacting on both their quality of life and that of their partners. The most common symptoms reported included hot flushes, impairments in memory or concentration, vaginal dryness and decreased libido. Likewise, in an American study, women reported hot flushes, vaginal dryness and loss of libido as their primary concerns (Wilmoth, 2001). Women in this study also frequently reported symptoms of irritability, depression, sleeplessness, and weight gain. While, the purpose of the current study was to explore the experience of both older and younger breast cancer survivors and not to quantify the common symptoms of each group, it was evident that different symptoms emerged as priorities for the younger and older women. This has also been seen in quantitative surveys of women after breast cancer treatment (Biglia et al., 2003).

Weight gain is common in women without breast cancer after menopause. The women in this study also identified weight gain as a significant factor. Like naturally postmenopausal women, women in this study reported that they had increased abdominal

weight gain. The women also reported that it was increasingly difficult to exercise due to tiredness. Previously, research has found that while dietary intake did not change after cancer treatment, women's activity levels noticeably decreased, which resulted in weight gain (Demark-Wahnefried et al., 2001).

The sexual symptoms were described by the women in this study as the most problematic. This is consistent with other literature; for example, a recent review revealed that the sexual symptoms described by the participants in this study are not uncommon and may be the most problematic treatment side-effect (Emilee et al., 2010, see also Archibald et al., 2006, Karaöz et al., 2010, Wilmoth, 2001). Unfortunately, such symptoms can persist for many years (Emilee et al., 2010).

In our study the majority of women demonstrated a lack of knowledge about menopause after breast cancer, the symptoms and their management. Confusion about how to deal with menopausal symptoms was a central theme to emerge from the data. In addition, women understood the risk of and were concerned about using products that may contain oestrogen. Women seemed reluctant to try other therapies or supplements to manage their menopausal symptoms.

A key difference between the older and younger women was that the younger women seemed to know to expect some changes related to their altered hormone state after chemotherapy and during anti-hormone therapy. However, all of the women were unsure how to manage their menopausal symptoms and many women reported that they perceived that their symptoms were downplayed by chiefly male health practitioners. Indeed, in some studies, support provided to breast cancer patients around fertility, contraception or sexual problems from oncology clinic or nursing staff is reported as being limited (Karaöz et al., 2010). In Italy, one out of five breast cancer patients reported having their menopausal

complaints deemed as irrelevant; 50% were warned not to use hormone replacement therapies and only 20% were offered alternative therapies (Biglia et al., 2003).

The distress associated with the experiences of menopause for younger women in this study (i.e., women who did not expect to go through menopause for some time) was especially profound. Younger women, in particular, noted that their experience of menopausal symptoms was isolating, and had a significant impact upon them both physically and psychologically. These women felt the literature available on the topic was targeted at older women, and also, that they knew no one in their age group with whom to discuss their experiences. Thewes et al. (2004) reported a comparable issue in another Australian sample of breast cancer survivors. In this study, women also reported feeling alienated in support groups where they were the youngest attendee. Additionally, the interference of menopausal symptoms on issues of fertility and family planning were endorsed by the women in the younger group as an issue that was of great personal significance.

Although this study has identified concerns and self perceived needs of women experiencing menopause after breast cancer, it is important to recognise some limitations when interpreting these findings. The women who participated in the study were volunteers, and attended a private health facility, and may not represent women with breast cancer who attend public health facilities. Clinical data were not obtained about the permanence of participants' menopause, their chemotherapy treatment regimen or whether they continued to receive hormone treatment, and therefore, a comparison of the experience of these women based on such factors cannot be made. However, the goal of this study was to explore the experiences of these women, in particular the effect menopausal symptoms had on their lives, rather than to quantify the relationships between treatment regimens and symptoms. In addition the sensitivity of the topic may have been underestimated. During the focus groups, women expressed negative feelings about menopausal symptoms after breast cancer and the

younger women in particular described how it was an issue which they could not generally discuss openly. The women who participated in the focus groups did, however, exhibit a willingness to talk within the group and share openly experiences of a sensitive nature including personal sexual issues.

Several implications can be drawn from this research. First, women need more information, particularly about their areas of concern. The women in this study would have liked more information about sexual symptoms and how to manage these, and about the management of hot flushes. Conversely, although younger women reported greater isolation and additional side-effects of treatment (e.g. loss of fertility) than older women, they seemed better informed about the likelihood of menopausal symptoms as a result of cancer treatment. Second, the women reported wanting to do more to manage their menopausal symptoms (and also their health after breast cancer treatment). However, they reported needing information and strategies to be broken down for them and provided in simple discrete steps. They were looking to health professionals and other breast cancer survivors for ideas for how to manage these experiences. Implementing strategies that enable women to re-focus their lives to deal with new health concerns following their cancer treatment are required. Future research needs to address the information needs of women with breast cancer on menopause as well as the timing of such information. Interventions which target self management strategies based on the latest evidence to enable women to manage their menopausal symptoms and their health needs associated with menopause after breast cancer may support the experience for women with breast cancer.

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