



Living into old age with the consequences of breast cancer

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A B S T R A C T

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Purpose of the research: Breast cancer survival rates are improving with over 60% likely to live 20 years. As 30% diagnoses occur in women over 70 the prevalence of breast cancer survivors living into older age is increasing. The specific needs and experiences of this group have rarely been addressed. This study aimed to explore older women's experience of living with breast cancer alongside other health conditions, and to identify their information and support needs and preferences.

Methods and sample: Data were collected from 28 semi-structured qualitative interviews and 2 focus groups ($n = 14$), with breast cancer survivors aged 70–90, and were analysed using thematic analysis. *Key results:* These older breast cancer survivors experienced a range of long-term physical problems resulting from treatment, including poor cosmetic results and poor shoulder movements, and bras and prostheses were often unsuitable. Many were keen to preserve their body image ideal irrespective of age. Reconstruction was rarely discussed, but all would have liked this option. Older women wanted to be treated as individuals rather than uniformly as older people, with their personal physical and social needs (including co-morbidities) taken into account. They expressed a preference for information direct from health professionals.

Conclusions: Many breast cancer survivors will live into advanced old age with permanent physical and emotional consequences of their treatment. Holistic and personalized assessment of needs becomes increasingly important with age, particularly with comorbidity. Effective rehabilitative care is important to reduce the impact of breast cancer into old age.

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Introduction

Worldwide, over 1.1 million women are diagnosed with breast cancer each year (Cancer Research UK, 2012). Contrary to popular images, incidence of breast cancer rises with age, with most diagnoses occurring in women over 60 years of age, and one third in the over 70s. Furthermore, with the five year survival rate from breast cancer in Europe and North America higher than 80% (Cancer Research UK, 2011) and the 20 year survival rate at over 60%, there are increasing numbers of women who are breast cancer survivors. As a consequence the number of older women in the population living with the long-term consequences of breast cancer is also increasing as women survive longer and as the population continues

to age. Although there is a growing body of research into living with breast cancer (Crooks, 2001; Liang et al., 2002; Ballantyne, 2004; Maly et al., 2004) the experiences of older women have been relatively neglected. Not only does cancer become more common with age, but general health may decline and the incidence of other chronic ill health conditions increases (Office of National Statistics, 2006a,b). Deimling et al. (2005) report that older people with cancer have an average of 3.7 chronic health conditions, for example arthritis which affects 23% women over 65 (Office of National Statistics, 2006a,b) and that the number of co-morbidities is the best predictor of functional difficulties (Deimling et al., 2005). Vacek et al. (2003) suggest that women who have had breast cancer are more likely to have concurrent chronic health conditions than people with other cancers and this is associated with significantly lower levels of quality of life. Reduced quality of life may be because chronic disease is associated with a variety of common non-specific symptoms such as pain, fatigue, loss of appetite, depression, anxiety and functional decline (Vacek et al., 2003; Walke et al., 2004).

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Despite this, a study of older women with breast cancer found that few had their physical needs or physical function assessed or had been asked how they were managing at home (Crooks, 2001). Furthermore, Perkins et al. (2007) reports considerable variability in the well-being of older breast cancer survivors.

Older women have also been shown to have poor knowledge about breast cancer (Grunfeld et al., 2002), and low levels of cancer knowledge are associated with higher rates of recurrence and higher mortality amongst older women (Goodwin et al., 1996). Older women may have different information needs than younger women although there has been no specific research to investigate these needs. Women with breast cancer aged over 70 years are also less likely to use existing avenues for information and support than younger women (Grunfeld et al., 2002), although the reasons for this are poorly understood.

The relationship between patient and physician is an important component of support in breast cancer. Physicians have been reported to spend less time with older women, and provide better information and support and more choice to younger patients (Cawley et al., 1990; Crooks, 2001; Liang et al., 2002). Studies have shown that an increase in communication between doctors and older women resulted in increased knowledge about breast cancer, increased patient satisfaction, a reduction in treatment delay, an increase in the ability to make decisions, and the uptake of optimal treatment (Maly et al., 2004), especially in those aged over 80 (Liang et al., 2002).

There is some evidence to suggest that older women neither find written information as helpful as younger women, nor do they seek it (Silliman et al., 1998). Furthermore, being offered written information without adequate verbal explanation is suggested to indicate a lack of interest in them as people (Crooks, 2001). Sources of information and support through the Internet are less likely to be accessed by older people, particularly the very old. Support groups and information centres may also be inaccessible to older women due to difficulties of transport, lack of social support and frailty. Maly et al. (2004) found that tangible information, such as booklets and videotapes, had no positive relationship with cancer knowledge, treatment delay or receipt of breast-conserving surgery amongst older women.

There is little research about the experiences of older women of breast cancer treatment or of longer-term issues and concerns. Some authors have stated that older women find body image to be less important in treatment decisions than younger women, yet a study by Figueiredo et al. (2004) showed that 31% of older women said that body image was an important factor in treatment decisions and that older women who underwent mastectomy had more body image concerns than women who received conservation treatment.

Current sources of information and support, based on research conducted in younger age groups, may not be suitable for older women. Research needs to be conducted to identify the experiences and needs of older women with breast cancer alongside other health conditions, in order to inform the development of integrated health and social care services. This paper reports on a study which explored first, older women's experience of living with breast cancer, with particular emphasis on living with breast cancer alongside other health conditions and second, their information and support needs and preferences.

Methods

Design

Qualitative methods were used to address the research aims. Interviews were used to investigate the women's experiences of

living with breast cancer alongside other health conditions. Focus groups were used to explore the women's information and support needs. A User Reference Group of older women with breast cancer and comorbid conditions was established to help shape and inform the method and conduct of the research to ensure that it was compatible with the needs of this group and that their voice would be heard accurately. Research ethics approval was obtained from the University of Southampton School of Nursing and Midwifery Ethics Committee.

Recruitment

Women were recruited to the study via advertising in local media and through relevant organisations, such as Age Concern, the Women's Institute and local libraries. Advertising took place in two cities in the South of England; one in an inner city area with a diverse socio-demographic and ethnic population and the other with a high density of older people. Women interested in the study contacted the study team. Those eligible were sent a recruitment pack, containing an information sheet, and were asked to return a reply slip if interested in participating in the study.

Data collection

Women were selected for interview from those who returned a positive response slip, using maximum variation sampling. Factors considered in sampling were age; socio-demographic deprivation (based on postcode); year of diagnosis and presence of comorbid conditions.

All interviews took place in the participant's home. The interviews followed a broad interview guide which covered: the women's breast cancer experience, including diagnosis, treatment, follow up and survivorship; their perception of the impact of their age and co-morbidities on their experience of breast cancer; views on specific issues for older women with comorbidity on the experience of breast cancer; and socio-demographic details. Interviews were conducted in 2008. All interviews were audio recorded, with participants' permission.

Once the individual interviews had been completed, letters of invitation to the focus groups were sent to all women who had expressed an initial interest in the study. Those women who returned a reply slip were invited to one of two groups. The focus groups were held at central locations, easily accessible by public transport. The groups were conducted in December 2008 and January 2009. Women were offered transport to and from the group if needed.

The focus groups were moderated by one of the authors, with assistance from a second author. Focus groups often engage group members in joint focussing exercises, rather than direct questioning, the purpose of which is to generate discussion between group members (Bloor et al., 2001). In this case, group members undertook two activities: they were first asked to comment on a vignette which described the experience of an older woman with breast cancer and other co-morbidities who had recently been told she needed a mastectomy; they were also presented with two ranking exercises, the first to explore information preferences, and the second preferences for support. The focus groups lasted for 2 h and were audio recorded. Written consent was received from all participants.

Analysis

The data were analysed using a thematic analytic approach (Braun and Clark, 2006). The focus groups and interviews were transcribed verbatim. In focus group transcripts, the speaker was

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