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Abstract: 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 comorbidities) 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.

Suggested Reviewers: Amanda Shewbridge MSc
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Dear Alex,

We would be grateful if you would consider publishing this paper which presents the findings of original research in elderly survivors of breast cancer. While it is known that women can experience many long term consequences of their breast cancer treatment, this paper highlights that women may continue to suffer physical and emotional consequences, not only in the long term, but into their advanced old age and which have not been addressed or resolved. This is having a permanent impact on their lives and ability to function into old age. Furthermore, their preferred form of receiving information in the form of professional communication is lacking and so elderly breast cancer survivors are not getting the support they need.

Many thanks
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Potential conflicts of interest

In the last five years Dr Peter Simmonds has received honoraria from Novartis for several presentations on management of GI stromal tumours; honoraria from Novartis, Pfizer and Roche for attending advisory boards on letrozole, sunitinib and trastuzumab and has been supported to attend a number of conferences funded by Novartis and Pfizer.

Dr Deborah Fenlon has received an honorarium from Roche to present on hormone treatment in breast cancer.

All other authors have no conflicts of interest.

Living into old age with the consequences of breast cancer

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Abstract

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Living into old age with the consequences of breast cancer

Background

Worldwide, over 1.1 million women are diagnosed with breast cancer each year (CancerResearchUK 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% (CancerResearchUK 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, Burnett et al. 2002; Ballantyne 2004; Maly, Leake 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 (OfficeofNationalStatistics 2006). Deimling et al (Deimling, Sterns 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 (OfficeofNationalStatistics 2006) and that the number of comorbidities is the best predictor of functional difficulties (Deimling, Sterns et al. 2005). Vacek et al (Vacek, Winstead-Fry 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, Winstead-Fry et al. 2003; Walke, Gallo et al. 2004). 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(Perkins, Small et al. 2007) report 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, Ramirez et al. 2002), and low levels of cancer knowledge are associated with higher rates of recurrence and higher mortality amongst older women(Goodwin, Samet 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, Ramirez 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, Kostic et al. 1990; Crooks 2001; Liang, Burnett 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, Leake et al. 2004), especially in those aged over 80(Liang, Burnett 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, Dukes 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(Maly, Leake 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 Figuerido et al (Figueiredo, Cullen 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 co-morbid 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 co-morbidity 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 focusing exercises, rather than direct questioning, the purpose of which is to generate discussion between group members (Bloor, Frankland 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 hours 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 identified where possible. Interviews and focus groups were analysed separately, although there was clearly overlap in themes. Initial codes were identified. These related to the aims of the study, but also to emergent themes within those aims. Codes were identified independently by two of the authors and agreement of any discrepancy reached. Codes were also discussed and agreed at regular meetings with the steering group. Data were labelled manually through line by line coding. Coding was added to the interview/focus group transcript and then data falling under each particular code were collated together in separate files. A description of each code was then developed by comparison of the data across the interviews/focus groups, to provide a thorough description, ensuring that both confirming and deviant cases were included. The analysis was discussed with the study steering group.

Results

Sample

Following advertisement of the study, 63 recruitment packs were sent out and 51 women indicated that they would like to participate in the study. Thirty women were selected to take part in individual interviews (28 interviews were included in the analysis because of recording difficulties in two cases). All the women who took part in the interviews were aged over 70 at the time the study was conducted. However, the table shows that the year of diagnosis ranged from 1977 to 2008, when the women were aged from late 40s to late 80s at diagnosis. For the purposes of the study, it is assumed that

women diagnosed from 2003 onwards (N=13) were treated according to more recent medical practice, which may vary from earlier clinical practice in areas such as information giving and participation of the patient in treatment choices. Thirteen women had three or more co-morbidities, such as cardiac conditions, arthritis, hypertension, diabetes, hearing and sight difficulties, and the remaining 15 had less than three. Fourteen lived in areas of moderate socio-economic deprivation (according to postcode), ten in areas of low deprivation and four in areas of high deprivation. Ten lived alone and 18 with others .

Fifty-one invitations to attend the focus groups were sent to those women who had indicated interest in the original recruitment process, and 15 women attended one of two groups (FG1:8, FG2:7). Ten of the women who participated in focus groups had also given an individual interview.

Findings

The findings are presented in two main areas that address the aims of the study. These are first the experiences of living with cancer, which draws on the individual interviews, and then the identification of information and support needs and preferences, which draws on the focus groups. Despite the fact that many years may have passed since diagnosis the women still talked as much about their primary treatment phase as the experiences since treatment; so the results for experiences of living with cancer are presented according to the primary treatment phase and as life after primary treatment. Where quotations are given, 'I' indicates that the interviewer is speaking and 'R' the respondent.

Experiences of living with cancer: primary treatment phase

In order to reflect more recent medical practice, the analysis of experiences of primary treatment has been limited to the experiences of the 13 women who were diagnosed since 2002. Most of the women talked about how their diagnosis and treatment had been high quality, although there were some specific incidents of poor communication described. Most believed that being an older woman had made no difference to their

care and treatment, while others wondered whether they would have been treated the same way if they had been younger. One woman expressed how she felt that there was insufficient attention paid to the potential impact of the cancer and its treatment on her situation.

"I thought I was given less consideration for the trauma really that it caused. I can understand, I felt quite guilty because I had young girls in there with me who were in far worse situations than I am, and I just feel they could have still, they could still pay attention, a little more attention ...to the fact that you are older and have got a life and responsibilities." (G400; diagnosed 2003)

On the whole, the comorbidities experienced by women at the time of diagnosis did not seem to have been an issue for the women in their breast cancer treatment or recovery. A couple of women were concerned about their pre-existing skeletal problems when facing their operation, and one, despite being unable to do the exercises she had been given, was offered no support by any rehabilitation therapists. Few had been involved in discussion with their doctors about any implications of their other conditions on their breast cancer treatment, as the women made the assumption that their doctors must have taken the conditions into account.

Several of the women felt that age had had an impact on their approach to their illness and their subsequent coping, making them more philosophical about their illness.

"You think well you've reached this age, which I never expected to, and I cannot believe I'm 78 now, and I just, and I'm very pleased I'm here but... I never thought I would reach this age, so ... I haven't got much to lose like a younger person have I?" (F500)

While the majority of these older women had been aware of the availability of counselling and of support groups, few had taken up any of these opportunities, including one to one support.

"The ones that come in and offer support and that, and she was on about this wanting to come to the house...and I thought, 'I don't want that, I can cope with it on my own.'"
(B100; diagnosed 2006)

The reasons for this are not entirely clear, but could be due to the values of this generation or to generally reduced mobility.

Experiences of living with breast cancer: life after primary treatment

This section will look at the women's experiences of living as an older woman with the consequences of breast cancer. The analysis of information about this stage encompasses interviews with all 28 women.

A number of women suffered long term physical and emotional problems as a result of their breast cancer treatment, such as poor cosmetic results post-surgery resulting in lumps which caused some discomfort. Others talked of having decreased shoulder movement following surgery and radiotherapy. This caused ongoing problems with simple daily activities, such as heavy lifting and even getting dressed. One woman felt she had suffered worsened joint problems when taking drug therapy and had difficulty separating joint pain caused by drugs from her arthritis. Another woman found that the demands of caring for her husband had aggravated her lymphoedema. A number of the women described distress at scars and their changed body as a result of their surgery. For some, these changes had been in the recent past, but for others had surgery many years before.

"It really is grotesque when you get undressed, well I don't do it now, I don't look; it looks absolutely grotesque." (B300; diagnosed 1990)

Only two of the women had had reconstructive surgery and one had had a reduction. Of those who had undergone mastectomy, the majority used prostheses. Reconstruction had not always been raised as a possibility for the women, nor had they raised the issue themselves. While the majority did not mind, all would have liked to discuss the options and one woman described how she regretted not having the opportunity for reconstruction:

"Because he was aware of my back condition, no question of reconstruction came up, I have bitterly regretted that every day... I still haven't coped with it. (G400; diagnosed 2003)

Reasons for not wanting a reconstruction included not being worried by the new body, not wanting more surgery and hearing stories of women for whom reconstruction had gone wrong. In addition, there was a feeling among a couple of women that the lack of discussion of reconstruction was to do with their age. Reasons for not wanting a reconstruction included not being worried by the new body, not wanting more surgery and hearing stories of women for whom reconstruction had gone wrong.

There were some women who were not interested in wearing prostheses and had a relaxed attitude towards their clothing and projected body image.

R. I don't have anything there and I am flatter on one side than the other but I think that doesn't worry me because I am not a beautiful shape and I never have been really.

I. Soyou have never worn a prosthesis then?

R. No, I never have. (H100; diagnosed 2001)

Equally, many women were keen to preserve their ideal body image irrespective of their age.

"I mean if I was the sort of person who just sat around and wore high neck sweaters I really wouldn't worry about clothes and things, but I do, and I'm not giving up yet...I mean really, I'm 80 but ...this is me and my life and the way we live it. I didn't want it to change." (G400; diagnosed 2003)

Although the women generally felt they were given good advice about prostheses, a number of the women who had been diagnosed years earlier had received less adequate advice. There was also lack of knowledge, such as about how and when to obtain replacement prostheses and whether these would be paid for.

A number of women found their bra and/or prosthesis difficult to live with: bras and prostheses were uncomfortable; bras rubbed or needed to be worn tight to hold the

prosthesis; prostheses were heavy; and problems were made worse by physical problems, such as soreness and lumps, resulting from surgery.

"The problem is my bra, you have to have it pretty tight and so that it holds it, I haven't got it tight enough, it's loose up here. But the problem is, I'm so swollen down here in these odd bits of flesh." (G100; diagnosed 2008)

There was a feeling that there was a lack of choice of suitable prostheses, and a particular concern with ageing was the need for front fastening bras as shoulder mobility reduced in older age:

"I can't reach round the back. I've got them with the back fastening but I just can't wear them." (B400; diagnosed 1982).

Information and support needs and preferences

A thread that recurred throughout the focus group discussions was older women's need to be treated as individuals rather than uniformly as older people. The women expressed differing desires for amount and type of information and support. Within this context of individuality of need, the women highlighted a number of areas where they would have liked more information during their breast cancer experience. This included issues such as causes of breast cancer, information on knowing how to recognize recurrence and support on checking for change in their scar, and risk of breast cancer for their daughters. The women felt that available information was relevant to older women as well as younger, with no need to have specific information targeted specifically to them. They felt that older women's needs should be assessed individually and holistically:

"Because there are specifically things like, you know, arthritis and so on, but younger people may also have conditions that interact with breast cancer, so it's quite hard to classify us all as a kind of person isn't it, because we are all individuals." Focus group 1

Information from health professionals was considered the primary source, with the specialist breast nurses having a key role. Written information from official health sources was considered useful as a back up to oral information, though some admitted

to never looking at the information they were given. There was little support in either focus group for information from media sources – magazines and television – which was seen as untrustworthy:

"Magazines are so absolutely hopeless for anything that I wouldn't believe anything I read in them anyway." Focus group 1

Very few of the women attending the groups had access to a computer, nor envisaged using a computer in the future:

"It could be on the internet but, by all means put it on the internet, but for us older people, which I am speaking for all of us, we haven't got internet." Focus group 2

Sources of support identified as trusted and useful were professional support through the specialist breast nurse, and social support in the form of friends and family. Peer support was seen as very important; having swapped a few stories of difficulties with prostheses, the women in the second focus group acknowledged the value of such discussion with women in a similar situation. They felt that they would like more support within the community but didn't know how to access this.

Information that they felt should be shared through public media were the general representation of older women as being at risk of breast cancer and that this was not currently the case.

"It was a discovery that, you know, old girls like us get it! (laughs) It was quite a new one to me." Focus group 1

The group also identified a lack of public representation of women who have had a mastectomy. This meant that women who were facing treatment had a lack of knowledge about how they would look post-surgery:

"The scary thing about when you, as soon as ever you are told about the operation, mine was 'whatever am I going to look like when it's been done?' Because none of us has ever seen anybody else and know what it looks like." Focus group 1

There was a feeling that there should be more images of mastectomy in the public domain so that expectations were more easily managed. This was not only an issue of expectation for the individual having surgery, but also for those around them, such as spouses and other family members.

Discussion

The use of advertising to recruit women to the study was a pragmatic decision prompted by the User Reference Group but resulted in a diverse sample, particularly in terms of time since diagnosis. The method recruited few women who had been treated recently for their breast cancer, and the resultant sample is one of older breast cancer survivors. A weakness of the study may therefore be that the reports reflect care given some time ago and does not reflect current practice. Furthermore, memories of what took place many years ago may not be accurate. A strength of this was the unexpected finding that women who had been treated many years ago are still affected not only by their diagnosis and treatment of breast cancer, but also by the long term consequences of this treatment. Further weaknesses of the method are that no ethnic minority participants were recruited and that the method of recruitment led to a self-selected group whose views may not be representative of the whole.

While the reality is that older people often have more than one long term health condition (Office of National Statistics 2006), it would seem that this is rarely taken into consideration in treatment for breast cancer. The women in this study reported a number of physical problems which pre-existed their breast cancer but, in common with the study by Crooks (Crooks 2001), there seemed to be little discussion of these with the women prior to surgery or through rehabilitation. The findings also suggest that older women may sometimes have difficulty distinguishing between the effects of breast cancer or breast cancer treatment and the effects of other co-morbidities, particularly arthritis, which may have implications for the detection of recurrent disease. This suggests an ongoing need for communication with this group to ensure that they understand the implications of any symptoms they may experience. There is a need for

further research into breast cancer and arthritis in older age, including epidemiology, impact on quality of life, joint functioning and development of interventions for rehabilitation and self-management.

Women reported enduring physical problems resulting from surgery, including scarring, problems with lymphoedema and reduced functional ability of their arms. While it had not been anticipated that so many women who had been treated many years, even decades, before would come forward for the study, the participation of these women highlighted the fact that breast cancer experiences may have an impact on women for many years to come. This emphasizes the need to consider whether and how best to address the needs of older women living for many years with the physical consequences of breast cancer treatment which they may have accepted as the 'status quo'.

Few of the women in this group had had reconstruction. In the UK women over 70 are much more likely to be offered mastectomy without reconstruction. 35% mastectomies are carried out in the over 70s and only 5% reconstructions (Jeevan, Cromwell et al. 2010). Although many had not wanted reconstruction, there was a perception for a few that this treatment had not been offered or made available to them because of their age. There is a need to investigate further the extent of ageism in reconstructive surgery for breast cancer patients, as well as attitudes of both older women and breast cancer professionals to breast reconstruction for older women, reasons for these attitudes, surgery outcomes and impact on quality of life.

The women in the study also had a number of difficulties with prostheses and bras. While some of these problems are likely to be experienced by women of all ages, there were issues which were more likely to be a problem for older women, such as the difficulty with rear fastening bras for women with restricted shoulder mobility. There is a need to consider provision of and access to prostheses and bras which are easier and more comfortable for older women to use.

It has been questioned whether post mastectomy body image is a concern for older women. In this study, there were a number of women who were experiencing major difficulties in looking at their bodies many years after mastectomy. It is important to

remember that older women are also concerned with body image and to address the psychological impact for them of mastectomy and of resultant scarring.

Older women have been shown to have poor knowledge of breast cancer and to be less likely to use offered sources of support (Grunfeld, Ramirez et al. 2002). Our informants were unlikely to use sources of information available to them, such as the Internet, support groups and public media, preferring to gain information from their health professionals who they trusted, both as a source of accurate information and to know what was important for them as individuals. This is in keeping with research by Mills and Davidson (Mills and Davidson 2002) who also identify the specialist nurse as a key informant. This reliance on oral communication suggests that it is important for health professionals to spend more time with older people rather than less. Although the women in this study did not think that they had vastly different support and information needs than younger women, or that current leaflets and booklets were inappropriate for them, they did feel that they should be given more consideration and attention to address their individual needs, which may be more complex in older age due to their physical and social circumstances. Given the evidence that physicians spend less time with older people (Liang, Burnett et al. 2002) this may require a change in practice. In addition, it is suggested that older women may not be aware of their breast cancer risk, a result of the usual media portrayal of younger women with breast cancer. It is therefore vital for early detection of breast cancer among this group to convey the message of older women at risk and to present media representation as such. It is also important to recognize the particular difficulties that older women may have in accessing support groups.

Implications for practice

Women who are treated for breast cancer may have emotional and physical consequences that are long lasting and have an impact on their functioning in old age. Health professionals involved in their care at diagnosis and treatment need to be aware of the long lasting implications of treatment and ensure appropriate advice and support for effective rehabilitation. As older women are more dependent than younger women on

communication with their health professionals, and they may have more complex needs due to their physical and social circumstances, more time needs to be spent assessing their needs in a holistic and comprehensive fashion. The ongoing and late effects of their treatment suggest that ongoing communication with health professionals is important for this group.

Finally, as well as a need for further studies into the specific needs of older women with breast cancer, it is important to ensure all cancer survivorship cohort studies which include breast cancer patients include the full age range of women living with breast cancer.

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List of tables:

Table. Age of Interview Participants at Time of Diagnosis

	Age at Diagnosis					
	40-49	50-59	60-69	70-79	80-89	Total
Diagnosis Post 2002			1	10	2	13
Diagnosis 2002 or Earlier	2	7	5	2		16*

*Total of 16 as one woman had had two separate incidents of breast cancer

Table. Age of Interview Participants at Time of Diagnosis