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Survivorship care for postmenopausal breast cancer patients in Ireland: What do women want?

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ABSTRACT

Purpose: The aim of this study was to identify the concerns of postmenopausal breast cancer patients in Ireland and inform the development of a survivorship care plan.
Method: A qualitative participatory approach was used. Focus group interviews ($n = 6$) with 51 women were undertaken. Following analysis of the focus group discussions, two nominal group technique (NGT) (consensus workshops) involving representatives ($n = 17$) from each of the six focus groups were held.
Results: Ten key issues were highlighted by women in the focus groups and these were prioritised at the consensus workshops. The most important issues in survivorship care planning prioritised by the women were as follows: meet the same healthcare professional at each review visit; contact number of a named person that you can contact if you have any concerns between review visits; at each review visit, have a physical examination and blood tests and explanation from health care professional outlining if follow up scans needed and if not, why not; information on signs and symptoms of recurrence; advice on diet, exercise, healthy lifestyle and advice on coping and pacing yourself; information and management of side effects of therapy-long and short term.
Conclusion: Survivorship care planning for breast cancer is underdeveloped in Ireland. There is a lack of consensus regarding its provision and a lack of structured approach to its implementation. This study demonstrates the role of postmenopausal breast cancer patients' involvement in identifying their needs and reports that continuity of care was their top priority and the need for an adoption of a survivorship care plan was emphasised by participants.

1. Introduction

Internationally, breast cancer is the most common non cutaneous malignancy among women. In the US, breast cancer survivors account for 23% of more than 10 million cancer survivors (Cappiello et al., 2007) and long term survival of breast cancer patients is high with 5-year survival rates of almost 90% (Runowicz et al., 2016). In Europe, there are currently 10 million cancer survivors diagnosed from 2000 to 2007 with 280,000 survivors currently in Ireland. Cancer survival has generally been increasing with survival rates in Ireland for female breast cancer patients increasing by 5% between 1995-1999 and 2000–2007 (National Cancer Register (NCR), 2014). These numbers are expected to grow dramatically given the aging population and the expected increased incidence of cancer over the next two decades. The total number of new female breast cancer cases is projected to increase by 130% between 2010 and 2040 (NCR, 2014). Improvements in screening and early detection, coupled with successful adjuvant treatments, have led to improved survival rates for breast cancer patients and more women are now living with breast cancer as a

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chronic condition (Haq et al., 2013). Traditionally routine follow up visits were concentrated on detecting recurrent or new primary breast cancers. However, many studies highlight the unmet needs of cancer survivors, fuelling the discussions for comprehensive survivorship care (Institute of Medicine (US), 2005, Brennan et al., 2011; Thompson et al., 2014). In the last decade, many countries have developed survivorship care programs in an effort to improve the provision of care for cancer survivors (Jefford et al., 2013).

Evidence suggests that breast cancer survivors have unmet physical and psychosocial needs (Maher and Fenlon, 2010), and live with a sense of 'permanent threat to the self' (Hubbard and Forbat, 2012 p. 2030). Postmenopausal breast cancer patients experience a variety of symptoms associated with therapies given to prolong survivorship (Chim et al., 2013; Pan et al., 2016). Thus, the need for a co-ordinated approach to their care is required. The use of survivorship care plans provides a comprehensive and coordinated approach to care (Shewbridge et al., 2014; Rushton et al., 2015; Palmer et al., 2015). Over a decade ago the Institute of Medicine (US) (2005) first highlighted the importance of recognising survivorship cancer as a distinct phase of cancer care. Four essential components of survivorship care were outlined and included prevention, surveillance, intervention and coordination of care. The Institute of Medicine recommended that cancer patients be provided with a comprehensive care summary and follow-up plan that is clearly explained and reviewed on discharge with an emphasis on addressing health care and quality of life issues facing cancer survivors. The National Comprehensive Cancer Network and the American Society of Clinical Oncology published evidence and consensus based survivorship care guidelines for breast cancer patients in order to help survivors reach optimal health and quality of life (Runowicz et al., 2016).

Survivorship care plans comprised a record of diagnosis and stage, treatments and toxicities and side effects as well as recommendations for surveillance testing management of long term treatment related effects, monitoring for potential late effects, prevention and health promotion. It was envisaged that survivorship care plans would improve survivorship care planning and patient knowledge with regard to their cancer history and follow up care and increase patient confidence in obtaining appropriate care post treatment as well as improved communication with and among providers (Faul et al., 2012, 2014).

Survivorship care planning involving breast cancer patients is in its development internationally. Moreover, in the Irish healthcare setting survivorship care plans are not routinely adopted into the follow up care of breast cancer patients, and currently, follow up care for breast cancer patients is provided by breast surgeons and medical oncologists (National Cancer Control Programme (NCCP), 2010). In Ireland, there is lack of consensus regarding the most appropriate model of follow up care and whether it should remain in the acute hospital setting under medical supervision or be carried out by general practitioners in the community setting. Lifelong intensive hospital based follow up is neither sustainable nor beneficial to patients in terms of reducing mortality (NCCP, 2010). The nurse-led model of follow up care has been researched with no decrease in the detection of recurrences when compared to medical follow up and high levels of satisfaction with the level of care provided (Lewis et al., 2009). Oncology nurses are ideally placed to provide this care but it is imperative that it is evidence based and of high quality (Bessen et al., 2014; Shewbridge et al., 2014; Rushton et al., 2015).

This study aimed to illicit the views of postmenopausal breast cancer patients on what was important for them to include in a survivorship care plan and how survivorship care should be delivered. We chose post-menopausal breast cancer patients for this study for a variety of reasons. The median age at diagnosis of breast cancer is 61 years with 43% of patients diagnosed over the age of 65 years (Runowicz et al., 2016). However, from our clinical experience, this older cohort of patients is less vocal regarding their needs compared to younger breast cancer patients. In addition, post-menopausal breast cancer patients with hormone receptor breast cancer will be offered endocrine therapy. The addition of aromatase inhibitors to their treatment regime, while beneficial, can have significant impact on quality of life as it is associated with loss in bone mineral density and arthralgia. It was also hoped that this study would give this specific cohort of patients a voice and facilitate them to become active in their survivorship care planning.

2. Method

This was a qualitative study employing nominal group technique as part of focus group interviews. This study aimed to illicit the views of postmenopausal breast cancer patients on what was important for them to include in a survivorship care plan and how survivorship care should be delivered. Participants were recruited through the outpatient clinics of two cancer centres in Ireland. Ethical approval was granted from both centres. Centre A is a rural satellite centre managed by one oncologist, a clinical nurse specialist and a Registered Advanced Nurse Practitioner (RANP). The post-menopausal women in Centre A are reviewed by a nurse-led service managed by the RANP in Oncology. Centre B is a supra oncology urban site with a dedicated breast care facility and four consultant oncologists and a team of clinical nurse specialists. The review clinics in Centre B are not nurse-led and women attending this centre are reviewed by the medical oncology team.

The study's inclusion criteria included: postmenopausal women who had completed adjuvant breast cancer treatment and were attending Centres A or B for zoledronic acid every six months.

This was a two-phase qualitative study. For phase one, focus group interviews (n = 6) with 51 women were undertaken (Table 1). The use of two to six focus groups in qualitative studies is generally recommended by most authors (Jayasekara, 2012). The numbers of women attending the focus groups ranged between 8 and 12. All women attending Centre A (n = 81) were invited by letter to attend for a focus group interview, and 22 attended. At centre B, simple random sampling was used to draw up a list of 100 patients from the patient database of one oncologist. These 100 women were then invited by letter to attend a focus group.

All six focus groups were undertaken in two hotel venues convenient to public transport. The focus groups lasted approximately 1.5 h and were all facilitated by the first and last authors (EM & MD) who both have extensive knowledge of cancer survivorship. EM asked the questions and MD acted as moderator and note taker.

Table 1
Participant data.

Participant data	N = 51 (%)
Age	
48–49	2 (3.9)
50–59	11 (21.5)
60–69	27 (52.9)
70–79	9 (17.6)
80–85	2 (3.9)
Treatment information	
Had surgery	51 (100)
Had chemotherapy	14 (27.4)
Had radiotherapy	43 (84.3)
On Letrozole	36 (70.5)
On Tamoxifen (following discontinuation of Letrozole)	8 (15.6)
On Anastrozole	3 (5.8)
On Exemestane	1 (1.9)
Not on an aromatase inhibitor	3 (5.8)