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The experience of providing support about menopausal symptoms to women with breast cancer

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A B S T R A C T

Purpose: The purpose of this study was to describe the experiences and expectations of both women with breast cancer and the health professionals who care for them, in relation to the management of menopausal symptoms.
Method: A qualitative, exploratory study using a combination of focus groups and in depth individual interviews was carried out to collect data from women with breast cancer (14) and Health Professionals (15).
Key results: A number of categories arose including breast cancer experience, menopausal symptoms, seeking support, taking control; with a number of contributory factors.
Conclusion: The findings illustrated the complexity of supporting women experiencing menopausal symptoms following their breast cancer diagnosis. They also captured the difficulty women have in isolating these symptoms from their experiences of breast cancer and associated management from diagnosis and beyond. The results indicate that health professionals are working and reacting to individual requests for support in isolation of the team. There is a need to assess and manage women both individually and within a multidisciplinary context. This would allow complex issues that span across the pre, peri, or post-menopausal stages, to be identified and resolved effectively.

Introduction

Breast cancer survival has improved considerably within Scotland and the wider European Union (Information and Statistics Division Scotland, 2011; Jemal et al., 2011). Improved outcomes are largely attributable to early detection through mammography, improved treatments and better co-ordination of care. While this reflects success, it also presents a new set of challenges, namely survivorship and how to refocus services and respond to issues that are of concern to cancer survivors (Department of Health et al., 2010). The use of chemotherapy and endocrine therapies in both pre and post-menopausal women has contributed to favourable survival outcomes (Early Breast Cancer Trialists' Collaborative Group, 2005), but has left many survivors of breast cancer experiencing menopausal symptoms which have a significant impact on their recovery and quality of life (Loibl et al., 2011; Schultz et al., 2005; Stricker, 2007). Cancer treatment is gonodotoxic, particularly chemotherapy drugs; the regimen, the drug dose, duration of therapy and current menopausal status appear to influence the incidence and severity of symptoms, and the experiences of women with breast cancer across different age groups (Anderson et al., 2011; Biglia et al., 2003; Cardoso et al., 2012; Harris et al., 2002; Ganz et al., 2000; Pinto and de Azambuja, 2011; Walshe et al., 2006). Despite this knowledge, little is known about the practices of different clinicians as they move from the intensive management of breast cancer to the on-going advice and support of symptoms associated with the menopause, and how women perceive this care. The purpose of this paper is to provide an overview of a study undertaken and some of the findings.

Background

The menopause is generally described as occurring following 12 months of amenorrhoea resulting from the permanent cessation of ovarian function (Greendale et al., 1999). When the term is used in breast cancer management a profound and permanent decrease in ovarian oestrogen synthesis also occurs (National Comprehensive Cancer Network (NCCN), 2013). The NCCN (2013) suggest that amenorrhea alone is not a good indicator when chemotherapy has been used in pre-menopausal women because ovarian function

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may recover. The median age that menopause occurs in Europe ranges from 50.1 to 52.8 years (Palacios et al., 2010), with the decline of ovarian function beginning gradually at around 35 (Goodman, 1999). It is often this gradual decline and the final menses that marks the beginning of a transition period that is often associated with symptoms such as hot flushes, vaginal dryness and mood disturbances, which may disrupt sleep. Carpenter et al. (2004) reported that breast cancer survivors experienced hot flushes that were more frequent, distressing, and of greater duration than healthy age matched women. Gupta et al. (2006) also concluded that an abrupt chemotherapy-induced menopause results in more severe vasomotor instability (hot flashes) than occur with a more gradual normal menopause. UK Age-specific incidence of breast cancer rates rise sharply between 35 and 39, with 48% of cancers occurring among women 50–65 and around the time of the menopause (Cancer Research UK, 2012). Breast cancer therefore coincides with a time of natural aging, women who may be currently taking hormone replacement therapy and those who experience a premature therapy-induced menopause (Carpenter et al., 2004; Cancer Research UK, 2012; Hickey et al., 2005). Studies which have explored the experiences of premature menopause in women have indicated, certainly among younger women, that this is a complex experience which can be very distressing. Knobf (2002) interviewed 27 women (mean age 40.8 years) with early breast cancer following chemotherapy. They reported women described a cluster of symptoms similar to a natural menopause; however it was the abruptness of the menopausal change within the context of a women's life which created additional distress. Thewes et al. (2003) also interviewed 24 women (26–45 years) about their fertility and menopause related information needs and also identified specific issues associated with this group. They reported many women found the information about fertility and early menopause was insufficient or lacking. What comes through from both these studies is that one size does not fit all in this particular context.

Hormone replacement therapy (HRT) provides considerable relief from menopausal symptoms and is widely used for the medical management of the menopause in the non-breast cancer population (Crosignani et al., 1997). Its use however has been revisited following results by the Million Women Study Collaborators (2003), which identified increased cardiovascular and breast cancer risks associated with it use long-term use. It remains contraindicated in the breast cancer population due to the close relationship between oestrogen and breast cancer development and the concern that it may increase the risk of recurrence (Pritchard et al., 2002). Current evidence regarding what is best practice pharmacologically has improved in recent years (National Institute for Clinical Guidelines 2009; NCCN, 2013) however recommended medications such as clonidine, venlafaxine and gabapentin to treat hot flushes also have side effects and women need to be fully informed if they are to be prescribed. There is some promising evidence building to support non-pharmacological approaches including homeopathic treatments, cognitive behavioural therapy and relaxation (NICE, 2009;Fenlon et al., 2009; Hickey et al., 2008; Hunter et al., 2009; Mann et al. 2012) The exploratory study by Hunter et al. (2009) offered women a series (6) of structured cognitive behavioural therapy sessions and reported significant improvements in frequency and problem ratings for hot flushes and night sweats, sustained at 3 months. This has been further validated by a randomised controlled trial by Mann et al. (2012) who confirmed that CBT can reduce the effects of hot flushes and night sweats, with these reductions sustained over time. Fenlon et al. (2009) also reported that relaxation training had a beneficial effect in reducing the incidence and severity of hot flashes in a group of women post treatment. Although the benefits did not appear sustainable at 3 months for all women, for those who saw a reduction, the benefit cannot be underestimated.

The studies to date clearly inform clinicians that certain treatments predispose women to the development and severity of menopausal symptoms; younger women have different needs to older women and there is increased data to support non-pharmacological approaches. However, it is unclear whether this evidence is translated into practice and informs day to day management. To encourage rehabilitation among breast cancer patients effectively and appropriately, it is important to understand what their experiences and expectations are of the service provision for menopausal symptoms. Conversely, do the health professionals have the same expectations? Thus, the purpose of this study was to describe the experiences and expectations of both women with breast cancer and the health professionals (HP) who care for them, in relation to the management of menopausal symptoms.

The specific research questions were to: 1. Explore how health professionals perceive their role in managing menopausal symptoms among breast cancer patients? 2. Identify how individual practitioners provide the best possible advice and support? 3. Explore the experiences and expectations of women in the management of their menopausal symptoms? 4. Understand how women perceive the support given to them to manage their menopausal symptoms?

Method

A qualitative phenomenological approach informed by Heideggerian hermeneutic philosophy was used (Morse and Field, 1996). Using a combination of focused group interviews and individual in-depth interviews, it was possible to use complementary methods of enquiry to answer the research question. Webb and Kevern (2001) question the suitability of focus groups within phenomenological research and even suggest incompatibility. However, in this study they opened up opportunities for dynamic interaction, which stimulated discussion and generated ideas, assisting in maximising the collection of relevant, high quality data (Freeman, 2006). The advantages of this method in terms of data collected included; social interaction, an economical means of gaining the views of a number of people and the provision of a safe forum to express views (Sim, 1998). The individual interviews were offered to those whose preference was to be interviewed individually among both health professionals and women with breast cancer. No participant attended both.

Participants

Participants with breast cancer were all recruited through the outpatient department of a large cancer centre in the United Kingdom, with Health Professionals recruited from the same centre. The inclusion criteria included: over 18 years of age, female, diagnosed with primary breast cancer, described experiencing menopausal symptoms to the clinician and able to give informed consent.

Initial contact was made by the Breast Care Nurse Specialist who introduced the study and provided them with the information pack, containing the aims of the study, what we were asking them to participate in and details of the researcher and independent contact. The patient was telephoned by the researcher within seven days to determine if they wished to participate. At this stage we intended to undertake focus groups although it soon became apparent that for a number of these women, individual interviews were both more convenient but also preferable. Times and venue was agreed at this time. A purposive sampling framework was used. Of the 26 patients approached, 14 took part. Seven patients were not interested in