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Moving forward – developing resources for women with breast cancer at the end of hospital-based treatment

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Background

When women finish hospital-based treatment for breast cancer and become a breast cancer survivor, they experience a distinct 're-entry' point in their lives. For many this is a time of crisis (Allen, 2009). While breast cancer patients have a range of information resources available to them at diagnosis and through treatment, there is a gap in information and support available once treatment has finished (Vivar, 2005). In addition, high levels of distress in the post-treatment phase have been found to lead to poorer long-term adjustment (Cimprich, 2005. Allen, 2009). Women's lives and self identity can be permanently altered as a result of their breast cancer diagnosis (McCann, 2010). Women have reported feeling abandoned and isolated (Smyth) during the shift from frequent interactions with healthcare professionals and a focus on hospital-based treatment to moving forward with their lives after treatment.

In July 2009 Breast Cancer Care commissioned market research with women affected by breast cancer to examine their services portfolio. A key recommendation was a need for a 'life after breast cancer' resource that could be disseminated to all women at the end of their hospital-based treatment.

Aim

To make recommendations on the content and format of a new resource pack for breast cancer survivors post-treatment developed by Breast Cancer Care.

Methods

A qualitative mixed methods approach was used to collect data. This qualitative study consists of two phases. This poster describes phase one only. Phase two, evaluation and feedback on the prototype resource pack, will commence in October 2010.

Phase one (a) Qualitative study to explore fully the experience of women with breast cancer during this transitional period, to identify unmet needs and inform the development of a new Breast Cancer Care resource package. (b) In addition, we sought the views of a range of healthcare professionals and academic experts on the information and support needs of women at the end of hospital-based treatment.

Inclusion criteria (a) Breast cancer patient focus group discussions: women who had finished treatment for breast cancer within the previous three months to five years. (b) Healthcare and academic experts telephone interviews. Interest and expertise in the psychosocial aspects of breast cancer.

Exclusion criteria (a) Breast cancer patients: currently undergoing active hospital-based treatment; individuals diagnosed with metastatic/secondary breast cancer; unable to communicate in English. (b) Healthcare and academic experts: non-English speaking.

Sampling and recruitment A combination of convenience and snowballing sampling approach was adopted. (a) Women were recruited through the voluntary network, Breast Cancer Care Voices, the Breast Cancer Care website forums, contact with Breast Cancer Care regional offices staff and volunteers. (b) A sampling matrix was developed from known contacts to cover a variety of health professionals and academic experts.

Ethical issues The research proposal, invitation letter, information sheet and consent form were first reviewed by Breast Cancer Care Service User Research Participatory group (SURP) of which all members are breast cancer survivors. Second by Breast Cancer Care Research Committee members (which included external experts in the cancer field, healthcare professionals, Breast Cancer Care staff and lay members). Finally ethical approval was obtained from the University of Southampton Ethics committee.

Data collection (a) Two focus group discussions (London and Cardiff based) led by an experienced facilitator (DF) supported by an independent researcher (EB). (b) One-to-one telephone interviews with a range of healthcare professionals and academic experts with knowledge and expertise in breast cancer were conducted by a Breast Cancer Care researcher (LR) and independent researcher (EB).

Data analysis Following the framework approach to analysing the qualitative data, LR conducted the majority of the data analysis with independent scrutiny and development by DF. LR followed several steps systematically to analyse the data, including listening to the original audio recordings alongside reading and re-reading the original verbatim transcripts, identification of an initial thematic framework followed by thematic framework, indexing, charting, mapping and interpretation (Ritchie and Lewis, 2003).

Participants

Twelve women who completed hospital-based treatment took part in focus groups in Cardiff (10) and London (2). A third focus group was cancelled because of adverse weather conditions. Table 1 shows the age range of participants. The youngest woman was in her 30s and the oldest in her 80s, with the majority being in their 50s (5). All were white British. Time since finishing treatment ranged from 1–25 month (mean 9.6).

Using a sampling matrix to ensure a range of views were sought, healthcare professionals and survivorship experts were approached to take part in an interview on the needs of women at the end of hospital-based treatment. Those interviewed included breast care nurses (5), medical oncologists (2), survivorship experts (2), general practitioner (1), breast surgeon (1) and practice nurse (1).

Table 1: age range of participants

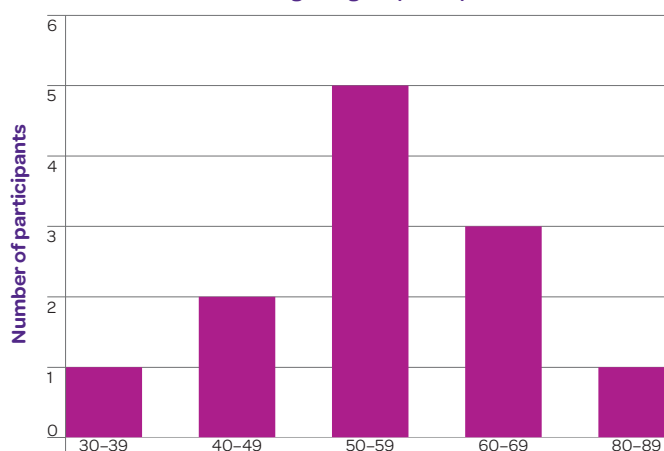
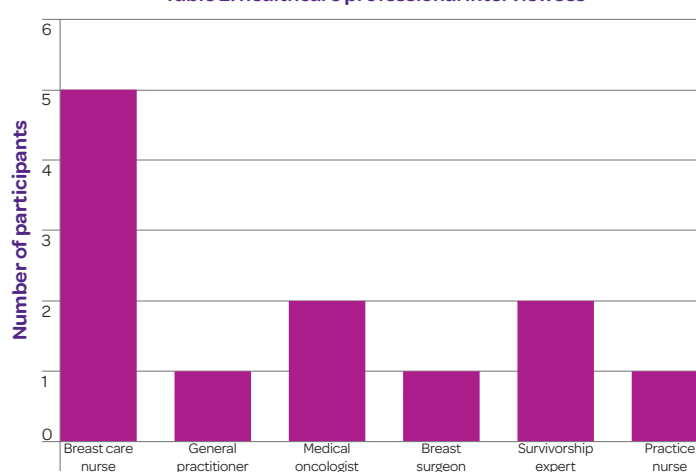


Table 2: healthcare professional interviewees



Results

The conceptual framework derived from the women's narrative was one of reconciliation. Through the life-changing experience of breast cancer, the women underwent a process of loss and isolation moving through to a process of reconciliation. The themes which made up the framework were reflection, loss of self, isolation and restoration.

Reflection 'afterwards'

When the hospital-based treatment ended, the women experienced a mixture of elation and fear. Having endured the diagnosis and treatment of breast cancer they emerged to a life after breast cancer and a new landscape. This was a time of adjustment and assimilation to reflect on what they had experienced and to build their lives after breast cancer. The women had a need for information immediately after treatment: what signs and symptoms indicated recurrent disease, the next step of follow up, side effects of medication and whom to contact if they had a problem, as well as written resources and a 'wellness' assessment after around 3–6 months.

Loss of self – 'I'm not the same person'

The women described a loss of self before a diagnosis of breast cancer, so when they emerged at the end of their treatment they underwent a process of grieving the old self image and felt it would be useful to have understood this process and that it may occur. To compound the sense of loss, women had to adjust to a changed body due to things such as surgical scars, hair loss, wearing prostheses, hot flushes, fatigue, fertility and weight gain. A heightened sensitivity to the behaviour of others. For some this meant a lack of self confidence and withdrawal from social activity. They also recognised the challenge of adjustment experienced by partners, family and friends, and expressed that those around them across their wider social network would benefit from a resource addressing their needs too.

Isolation – 'lost and lonely'

At the end of their treatment the women felt that as others celebrated this time there was an expectation that they return to their lives and present an image of coping and wellness to the outside world. For many this heightened a sense of isolation. In addition, the women acknowledged that family members may also experience a parallel sense of loss and grief. One survivorship expert suggested a family approach to the development of resources and services was key so that a shared responsibility for recovery after treatment was not solely that of the women.

Restoration – 'new normal'

The process of restoration took place over time with challenges to navigate along the way. Women expressed a sense that their bodies had been dominated by the healthcare system and treatment but now it was their responsibility. Women expressed the need to develop self management strategies. There was a need to be informed and supported through this transition but many felt inadequately prepared to cope and move forward with their lives. Self management strategies identified were diet and nutrition, exercise and complementary therapies. Other items women felt would be useful were a journal-style resource to keep a record of their development, DVD of other women's experiences, coaching skills and advice on returning to work.

Sampling matrix of healthcare professionals and academics showing the range of topics

Healthcare professionals and academics	Information post treatment	Diversity	Type and timing of follow up	Long term side effects of treatment	Body image	Self efficacy strategies	Format/language and graphics
F/group 1	✓	✓	✓	✓	✓	✓	✓
F/group 2	✓		✓	✓		✓	✓
BCN	✓		✓	✓		✓	✓
BCN	✓		✓	✓	✓	✓	✓
BCN	✓		✓	✓	✓	✓	✓
BCN	✓	✓	✓	✓		✓	✓
GP	✓		✓			✓	✓
Practice nurse	✓		✓		✓		✓
Oncologist	✓		✓	✓			
Oncologist	✓		✓				
Surgeon	✓		✓				✓
Survivorship expert	✓		✓	✓		✓	✓
Survivorship expert	✓		✓	✓	✓	✓	

Framework of reconciliation

Reflection

'During the treatment I didn't need support, it was like I had enough, but afterwards, I found the end of treatment very, very, very scary.'

Loss of self

'You're not...I'm not the same person. Not necessarily a bad thing... getting to know the new me is not always easy. That's something I wasn't prepared for.'

Reconciliation

Isolation

'I wept. I didn't really know why except that I felt lost and lonely. I lost my breast, I was a different shape and I was a different person and I needed help.'

Restoration

'It's a new normal now and that's how I describe it to people. It's the new normal. It's still great, it's just getting better and every day, every month and hopefully this time next year I'll be two years past.'

Conclusion and recommendations

At the end of hospital-based treatment women want resources that reflect what they have experienced in this transition to survivorship. In order to move forward the women need information and support around their fears of recurrence, how to cope with the social pressures to return to life as it was before and where to access resources in the absence of the hospital support network they have been accustomed to. Such support would help to facilitate the restoration of the 'new normal' life after treatment and assist them to take control, restore confidence and sense of self. Our research has led to the following recommendations:

- The pack needs to be a resource that can be individualised, capable of being added to as needed by the women, and developed over time
- The inclusion of a personal diary or journal-style resource could provide space for the women to document their thoughts and experience, then later use these notes to reflect back on how they were coping. The journal could also be used as a means of jotting down questions for healthcare professionals
- There is a need for information at the end of treatment on, what is normal, the signs and symptoms of recurrence and where to turn for support
- A 'holistic wellness' check at 3–6 months post treatment by a healthcare professional needs to see the whole person to meet all unmet needs
- A care plan is required – drawn up between the women and the healthcare professionals.

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