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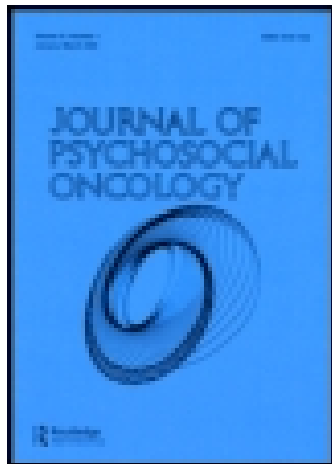
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Moving Forward - a qualitative research inquiry to inform the development of a resource pack for women following primary breast cancer treatment

Deborah Fenlon PhD^a, Elizabeth Reed PhD^b, Emma Blows PhD^c, Karen Scanlon MSc^b, Julie Wray PhD^b & Ann Dewey PhD^d

^a University of Southampton, Macmillan Survivorship Research Group, Southampton, UK

^b Breast Cancer Care, London, UK, , ,

^c School of Nursing, Midwifery and Physiotherapy, University of Nottingham, UK,

^d Portsmouth University, Portsmouth, UK,

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Running title: Moving Forward

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Deborah Fenlon, PhD, Elizabeth Reed, PhD, Emma Blows, PhD, Karen Scanlon, MSc, Julie Wray, PhD, Ann Dewey, PhD

Liz.Reed@breastcancercare.org.uk

Emmablows@gmail.com

karens@breastcancercare.org.uk

ju_jurez@hotmail.com

ann.dewey@port.ac.uk

Breast Cancer Care

5-13 Great Suffolk Street, London, SE1 0NS

Direct line: 020 7960 3418 Switchboard: 0845 092 0800

Author affiliations: University of Southampton, Macmillan Survivorship Research Group, Southampton, UK (Dr Fenlon), Breast Cancer Care, London, UK (E. Reed, K. Scanlon and J. Wray), School of Nursing, Midwifery and Physiotherapy, University of Nottingham, UK (E. Blows) and Portsmouth University, Portsmouth, UK (Dr Dewey)

Corresponding author

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Deborah Fenlon, PhD, University of Southampton, Macmillan Survivorship Research Group,
Highfield, Southampton, SO17 1BJ, UK dfenlon@soton.ac.uk

Abstract

While the UK charity Breast Cancer Care has extensive resources for women with breast cancer, this research partnership developed the first resource driven and informed by primary research with these women; exploring their needs and developing the resource according to need. Data were collected from focus groups with breast cancer survivors and telephone interviews with health professionals and experts, which explored the needs of women after primary cancer treatment and were analysed using thematic analysis. As well as information, these women needed resources to help them regain control over life, adapt to a changed body and restore lost confidence.

Key words:

Breast cancer, survivorship, information needs, resources, charity

Introduction

It has been widely acknowledged, both in the US and worldwide, that there is a growing group of people who are surviving cancer and who are left with a variety of needs that are not met by current health care provision. In the UK a National Cancer Survivorship Initiative (NCSI) was established in 2008 by the Department of Health in conjunction with the UK charity Macmillan Cancer Support, in order to address the needs of this group (Davies and Batehup, 2009).

Evidence reviews from the NCSI have highlighted the existence of unmet information and support needs of cancer patients who are living with cancer. Although breast cancer patients have a range of information resources available to them at the point of diagnosis and during treatment, there is currently a gap in information and support once treatment has finished (Vivar and Mcqueen, 2005). Yet, it is at this time, as people try to regain a sense of normality, think about going back to work and/or cope with the side effects of treatment, that support is often most needed (Vivar and Mcqueen, 2005), with people who have come to the end of regular follow-up appointments reporting feeling abandoned and isolated (Smyth, Mccaughan, & Harrisson, 1995).

The US Institute of Medicine (IOM) have found that cancer survivors may be 'lost in transition' at the interface between primary and secondary care with patients not knowing what to expect with health related follow-up care (Hewitt, Greenfield, & Stovall, 2005). IOM recommendations include the provision of a 'Survivorship Care Plan' outlining the follow up care required for people who reach the end of primary treatment. Current changes in cancer services in the UK are focused on reducing the long term follow term follow up by secondary care and discharging

patients back to the care of their primary care physicians. The consequence of this is to further decrease patient access to specialist sources of information and support. The NCSI are addressing this issue by developing seven work streams to enhance the health and wellbeing of cancer survivors, one of which includes the development of survivorship care plans.

Simultaneously with this work, the UK charity Breast Cancer Care (BCC) commissioned market research to identify the gaps in the provision of information and support provided by BCC to women in the UK with breast cancer and found that a resource for women at the completion of treatment was a priority. In order to ensure that this resource was research driven and based on up to date knowledge and information from the patient perspective, a partnership was set up between BCC and the Macmillan Survivorship Research Group at the University of Southampton to undertake a study to inform the development of this resource. This paper reports on the findings of this study.

Background

The transition from end of active treatment to survivorship is a distinct point in the cancer trajectory where women with breast cancer have unmet information needs. Cappiello et al. (2007) state 'the transition to breast cancer survivorship has been described as a tumultuous experience in which women try to balance the elation of surviving a life-threatening illness with the demands of persistent physical symptoms, altered life meaning, uncertainty and fears of recurrence' (p279). This period is particularly important as it is a time when regular interaction with healthcare professionals diminishes and individuals may feel 'abandoned' by the

healthcare system (Cimprich et al., 2005; Allen, Savadatti, & Levy, 2009; Devane, 2009). A small number of studies have explored the transition period or 're-entry' phase from end of active treatment for breast cancer to life post-treatment (Cimprich et al., 2005; Mallinger, Griggs, & Shields, 2006; Cappiello et al., 2007; Griggs et al., 2007; Meneses et al., 2007; Oxlad, Wade, Hallsworth, & Koczwara, 2008; Allen et al., 2009; Kantsiper et al., 2009). Cimprich et al. (2005) suggest that whilst much research has focused on diagnosis, treatment and five-year survivorship (long-term), little attention has been paid to the period immediately following treatment completion. Little is known about the information and support needs of those following treatment and the resources needed to promote recovery and self-management (Cimprich et al., 2005; Cappiello et al., 2007; Allen et al., 2009). Women may experience a range of complications and concerns as a result of treatment, and these are just beginning to be uncovered and addressed in the literature. Currently, cancer survivors do not feel that cancer specialists or primary care meet their information needs (Kantsiper et al., 2009). The situation has clearly not improved since Luker, Beaver, Leinster, & Owen's (1996) study identified that 66% of women still had unmet information needs at follow-up. A more recent study found that 45% of women did not receive information about what to expect after treatment had finished (Cappiello et al., 2007). Of those women that do receive information, many feel it is inadequate and would like more detailed information (Cappiello et al., 2007; Oxlad et al., 2008). Unmet needs in the post-treatment period can lead to problems later on in the survivorship trajectory. Several studies have highlighted that high levels of distress in the transition period can result in poorer long-term adjustment (Cimprich et al., 2005; Allen et al., 2009). Persistent high levels of

information needs are associated with higher anxiety and depression (De Bock et al., 2004) and ongoing physical and psychological symptoms can lead to poorer quality of life (Cappiello et al., 2007). Given the current changes taking place in cancer care, coupled with an identified need both for tools for cancer survivors and the lack of research to inform what is needed at this time, it is timely to conduct this research to ask what cancer survivors want from a resource at the end of their active treatment and transition to ongoing survivorship.

Objective and study aims:

The aim of this study was to explore the needs of women following treatment for primary breast cancer and to make recommendations on the content and format of a new resource pack for breast cancer survivors post-treatment by the UK charity Breast Cancer Care

Study design

Qualitative methods were used to address the research aims. Focus groups with breast cancer survivors and telephone interviews with health professionals and experts in breast cancer survivorship were used to explore the needs of women as they complete treatment for primary breast cancer. The findings from the qualitative research were then utilised in the development of a new resource pack by the charity Breast Cancer Care and a preliminary evaluation was conducted. The study consisted of two phases: Phase 1 resource development. Phase 2 pilot testing and preliminary evaluation of the resource.

Phase 1 gathered information about what was currently known about the needs of women as they complete treatment for primary breast cancer in order to inform the development of the resource pack. This was gathered through literature review, focus groups of women at the end

of hospital based treatment and interviews with expert informants. Phase 2 was the development of the resource and feedback on this from both the women and the healthcare professionals. The study was designed in collaboration between the University of Southampton and the charity Breast Cancer Care. The study was peer reviewed and underwent ethics approval through the School of Health Sciences, University of Southampton.

Method

Women who completed hospital based breast cancer treatment within two years were invited to take part in focus groups in England, Scotland and Wales. The definition of the end of hospital based treatment was those who have completed primary surgery and adjuvant radiotherapy and chemotherapy. Following hospital treatment, patients may still be receiving hormone therapy (such as tamoxifen, anastrozole, letrozole, exemestane, goserelin) and Herceptin (trastuzumab).

Phase 1 a) An advertisement was posted on the Breast Cancer Care website and members of Breast Cancer Care's Breast Cancer Voices¹ were approached via a quarterly e-bulletin informing them of the project and requesting their involvement. Women who had completed hospital based treatment for breast cancer within the last 24 months were recruited to take part in focus groups. The focus groups were conducted by two researchers (DF and EB) and took place in the Breast Cancer Care offices. Vignettes were used to stimulate discussion and help informants focus on the needs of others while drawing on their own experience.

¹ This group is a collective identity for all those affected by breast cancers that take part in user involvement at Breast Cancer Care.

Phase 1 b) Using a sampling matrix to ensure a range of views were sought, healthcare professionals were approached to take part in a telephone interview (conducted by EB) about their experience of caring for women with breast cancer at the end of treatment. Views were sought from breast care nurses, oncologists, surgeons, general practitioners, practice nurses and experts in survivorship.

From the findings of phase 1, a new prototype resource was produced by Breast Cancer Care and disseminated to the original participants in phase 1 of the study.

Phase II a) Women who took part in Phase 1 were given an opportunity to read the new resource and then discuss its content in reconvened teleconferenced focus groups to seek their feedback on the prototype resource.

Phase II b) The new prototype resource was sent to all healthcare professionals and experts in survivorship who took part in phase 1 and telephone interviews and/or email correspondence was undertaken to gain feedback on the content and format of the resource.

Phase III c) The Moving Forward resource was developed by Breast Cancer Care in response to feedback from both the women and healthcare professionals.

Analysis

The data were analysed using a thematic analytic approach (Braun and Clark, 2006). All data from the women's focus groups and healthcare professional interviews were transcribed verbatim and analysed using the software package NVivo. The written texts which were produced from transcription were read while listening to the tapes in order to verify accuracy.

They were then re-read and significant phrases or comments were marked. Thematic analysis of initial concepts and themes were generated by the data, and a conceptual framework derived from recurrent themes and knowledge of the area of investigation (Ritchie, Hansen, & Elverdam, 2003). The themes and conceptual framework were developed in consultation with principal investigators (ER/DF/EB). The analysis was initially conducted around the focus group transcripts and then compared with the data from the expert informants to look for confirming, conflicting or extra content. The final analysis was returned to one of the patient informants to confirm validity. It was not possible in the focus group analysis to identify individual contributors.

Results

The informants

Sample: Twelve women who had completed active hospital based treatment in the past 25 months took part in focus groups in Wales (n=10) and London (n=2). A third focus group was planned in Scotland but due to adverse weather had to be cancelled. Focus group participant's ages were collected in ranges, ranging from the 30's to the 80's (table 1). All were white British. The time since finishing their treatment ranged from 1 month to 12 months (mean (SD): 7.3 (4.6)). In total 20 healthcare professionals were approached to take part in the study. Five breast care nurses expressed interest and all were interviewed, six GPs expressed interest (1 agreed to take part), two practice nurses were approached (1 took part), four oncologists (2 took part), 2 surgeons (one took part) and 2 cancer survivorship academics. Twelve healthcare

professionals were interviewed once and eleven (the GP failed to respond) fed back on the prototype resource by telephone or email.

The findings

Recommendations to Breast Cancer Care were made about the development and purpose of the resource. These were based on the findings from all sources including the literature review, focus groups and interviews with health professionals. A model was developed around the key issues that arose from the data. The central theme was one of reconciliation where women had gone through a major life upheaval involving loss and isolation before coming back to reconciling themselves with a new self-identity (see figure 1). The key issues that were taking place at this time were: reflection on the cancer experience; loss of self; isolation; and moving forward. The women wanted a resource that would help them to deal with these issues. The findings will be presented in detail through these key issues.

1. Reflection

At the end of hospital based treatment, instead of feeling elated as they had anticipated, most participants felt a need to reflect on the cancer experience and the changes that had taken place in their lives over the last few months of diagnosis and treatment. Many expressed feelings of being scared and isolated. Having endured cancer treatment which had been the focus of their lives, often for many months, they emerged to a new landscape and had to negotiate a changed identity and the next set of concerns.

'I think a lot of it is to do with time.....it's like a bereavement almost where you think you have to live with it and obviously you have to put your life back together. When you go through

chemo and radiotherapy and you've got appointment, after appointment, after appointment. Its all going so quick you've just got to deal with the next thing and the next thing and the next. And then suddenly you stop. And you're like, you've got no more hurdles and its like whoa there, then you do reflect don't you?'

'During the treatment I didn't need it [support]; it was like I had enough. I had my friends, my family, my situation controlled. It was controlled. But afterwards I, I found the end of treatment very, very, very scary.'

Reflection was suggested as a positive way of coping by the women with cancer as they said that they could look back to earlier times and see how much progress they had made. A specific suggestion was that keeping a journal could facilitate this process.

Part of this reflection was noting that their needs for support and information changed considerably over time and that they would need a different kind of input depending on a wide variety of factors. It was therefore recognised that this time would be very variable and each cancer survivor would have different needs; what suited one would not necessarily be appropriate for another. Variability might be about targeted information needs or those with different coping styles. For example, some people need a lot of information in advance and others prefer to have information as and when it is needed.

Generally there was a feeling that the actual end of treatment was not the best time to impart large amounts of information as this is a stressful, emotionally charged time with feelings both of anxiety and elation, resulting in a decreased ability to retain information. The first follow up appointment after the end of treatment was generally considered the most appropriate event

to spend time receiving the information and guidance women needed. However, there was a suggestion that they needed guidance prior to this on what questions they should ask and some form of preparation for the first follow up meeting

'I had a post radiotherapy appointment six weeks after it [treatment] finished which was quite a nice time gap so you are over one phase and into the next so to speak. That six week later appointment was crucial for me as it was a time when I got all my on going information.....that was just the right moment. I had been tired for so long and was worried.....she said 'you are expecting too much of yourself.'

While the face to face meeting between the specialist and the patient was a very important means of information giving the women expressed a need to receive written information in the form of a pack which could be added to over time and tailored to need. There was a suggestion from the participants that this appointment could be a *'wellness check'* considering their holistic wellbeing, which incorporated an individualised plan devised in partnership between the patient and healthcare professionals. This concept was supported by the professionals, that a formalised appointment using appropriate validated assessment tools, perhaps within a health promotion model, would allow healthcare professionals to monitor the women's health and wellbeing after treatment.

The content of information to be given at this time was discussed and again the dilemma was of giving enough information without overload. Basic minimum information was to be given details of a point of contact for on-going information and support. Key content agreed by all parties were: knowing what signs and symptoms might indicate concern about recurrent

disease; possible side effects from new therapy such as hormonal therapy; long term side effects and what to expect from follow up. The health professionals had particular concerns around informing women adequately about signs of recurrence without adding to fear of recurrence.

Some professionals expressed concern that current follow up focuses on a biomedical model of follow up and the psychological and social concerns and problems are not adequately addressed. The women also identified that psychosocial concerns, such as body image and sexuality, were often a problem for them and that this was inadequately addressed.

'And the sex word and sexuality has never been mentioned, to this day, by anybody.'

It was discussed that a diversity of family life should be acknowledged as some women have partners, children, parents and friends, or only some of these, while others may be facing breast cancer on their own. Other targeted needs might include language, socioeconomic, educational or cultural differences. This meant that a resource pack would need to be flexible and open to individualisation by adding resources according to need. This need for flexibility suggested that there would be a core of information that could be given to everyone and that other pieces of information could be added as appropriate.

'You're an individual and as an individual I guess your needs are slightly different and sometimes it's when you get to different points that you need something.....so we could benefit from a sort of "keep you going" pack.....you might almost have a pack at an appointment before your last appointment and have the opportunity to come back and say, actually now I want this and on top of what you gave me before.'

While all agreed that breast cancer survivors need some kind of long term health monitoring there was no clear preference for how this should be delivered. The health professionals agreed that long term care needs to be in the primary care setting, although some felt the initial holistic assessment should be in acute care and others in primary care. The women themselves focused more on the relationship with the health professional and how a key factor for them was trust. The women's preferred criterion for deciding who should provide follow up care was that they had the choice.

'I think yes, you're absolutely right, that you're... assigning a key worker is useless, frankly. You... you've got... you've got to choose the person who you best work with and the other... the other issue with assigning a key worker is; while there are some people who get on better with certain types of people than others, there are also going to be some in the team who are frankly lacking.'

All agreed that a point of contact is important for on-going information and support and to be confident that this is available. The healthcare professionals reinforced the need for women to know who to turn to and how to access support:

'Because when I discharge people they think – I can see it in their faces – that's it then, right, that's it, and then the next sentence is, 'but, you know, you can always ring us if you're ever worried'. And it's sort of like different sort of... their facial expression changes so I think you've definitely got to give expressed permission to do that.' (Breast Care Nurse).

2. Loss of self

Part of the process of reflection was that women began to strive towards regaining the life they had before cancer. With that came the realisation of many losses, including the realisation that they had changed and so the loss of the old self became apparent.

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

'Well, I liked my life, I love my husband and I adore my children, I have a fantastic career. I have a, I have a.....I didn't want to change. I didn't need a life affirming event for me to suddenly appreciate what I had around me.'

The women described a shift from the person before a breast cancer diagnosis to the person after. This was an unexpected loss and they underwent a process of grieving their old self before breast cancer. They felt it would have been helpful to understand this process and that this was a natural part of the trajectory through treatment and recovery.

'I would like some information on the natural process of grief because I remember the following day sitting down and crying my eyes out and banging my hand on the floor saying you know 'why me?'

'... I want the old me back.'

A major concern for the women was the loss of the body that they had before their treatment. There were many issues for a changed body, including surgical scars, wearing prostheses, hot flushes, fatigue, hair loss, fertility and weight gain. Body image changes resulted in existential challenges where women questioned who they were and whether they were still the same

person they had been before. This resulted in a lack of confidence and difficulty in engaging in the normal social activities previously undertaken.

'... you got issues then with your whole identity, the blueprint of who you are. I can honestly say I meant to go out last Saturday night, I put my makeup on, got to the clothes, I went, don't look like me in front of my friends, I'm not going out, I'm too upset, um, how I look...'

'... I'd lost all my long blonde hair, I had very tiny curls that were grey, I was a totally different me and I didn't know who the hell I was.'

As well as visual changes the body often had functional changes which needed to be incorporated into life and these were not always anticipated.

'And one thing I wanted to do because I was a late starter at swimming, was to get into my swimming costume, go down to my club, I was terrified. I'd put on weight...'

[Group laughter and nods of agreement]... 'So I thought, instead of going swimming, I'll go to yoga which I also adore, and this day, I thought, I'm feeling good, I'm, I will go today, and they fitted me into the class. I thought, this is lovely, I'm with my buddies, I'm going to do yoga. I started stretching exercises; I couldn't get my arms up. And I wept and sobbed through that, I couldn't believe how stupid I'd been.'

These changes in the body meant that confidence was lost as they discovered their inability to do the things they had done before. A further consequence of this was loss of desirability and feeling feminine.

'I really struggle with my desirability to the opposite sex, really big time for me.'

The women wanted acknowledgement that they were not alone in these losses, a recognition that they were different and ways of finding confidence in the body again. They also found that body image issues and sexuality were never discussed and that they would have liked them to be raised.

'... that you may find perhaps going on, a personal development course, um, something that will look at, you know, for ladies who have breast cancer, would address the issues of just looking at makeup, at fashion, at what's out there.'

Another major loss was the loss of certainty, the loss in a belief that the world is a predictable place, that events will carry on as normal and that plans can be made for the future. This loss was also grieved.

'I think, speaking about loss, there's that loss of certainty.'

The end of treatment was a time when they also reflected on relationships with those around them. The women appeared sensitive to the behaviour of others towards them, although they acknowledge it is difficult for others to know how to behave and what to say. Some spoke of losing friends who could not cope with their diagnosis.

'The big thing I would like to have in there is the way it can change relationships. Sometimes for the better, sometimes not. That was something I wasn't prepared for.'

Relationships with partners appeared to change for some women and this was a surprising consequence for them. They recognised that there was a need to guide and inform partners, relatives and others and a resource would be useful for them as a way of explaining about the treatment but also the emotional coping and adjustment the women do, while acknowledging

the emotional adjustment of the partners, family and friends, and how to communicate with them while seeking support for themselves.

'My sisters can't understand. They have an idea, they can maybe, I don't want sympathy, we just want understanding but we have in some way to meet them half way and this is where I feel a pack needs to be addressing the family. You can go home and sort of say 'oh look, it says such and such here, I may be up one minute and down the next'. They tend to brush it under the carpet because all they want you know is you functioning normally because that's the only indicator they have that things are normal.'

'You see my husband could have done with it [the pack] really. Because there was a time when I wouldn't talk about it either.....but he was really worried about it you see, so a carer or loved one might want the pack.'

For some family members there could be a parallel sense of loss and bereavement and this was even more difficult to acknowledge as they were not the focus of the cancer experience.

'...when the treatment finished, that's when he... I don't want to say broke down, but that's when he started to talk about... Because up until then, he'd said; well it wasn't about me, it was about you. But afterwards, it was like he'd had... like a grieving I think.'

3. Isolation

At the same time as grieving the loss of self the women felt isolated. Not only had they lost their contact with the hospital where they were being provided with help and support, but they also had to present an image of coping and wellness to the outside world, which heightened

their sense of isolation. Those around them celebrated the end of treatment and assumed they would automatically return to their lives with little adaptation.

'... she said, we'll send for you in a year, you know? You've had your, your mammogram and will have another one in a year. And I felt it was a bit like being sent out in a rowing boat without, without oars, you know?

'I wept. I didn't really know why except that I felt lost and lonely.'

'My life was sort of no man's land.'

This sense of isolation was enhanced as the individuals were trying to regain their normality and present a normal exterior to the world, while recognising that in themselves, things were not normal.

'... because, you know, I had this, my sparkly face on all the time, and, but inside, I was like, bleurgh.'

One way suggested to address this isolation was for health professionals to take a family based approach. Having a member of the family in medical consultations and specifically in the end of treatment assessment, could benefit both the woman and the family by having a second listener and having a family member involved in the process of transition to survivorship.

Suggesting this as a way of coping needs to be done sensitively as not all people have someone to fulfil this role and this could enhance their sense of isolation.

'So every time I read on the forum, 'oh, take someone, you must take someone with you'. I thought, 'oh shut up!' You know, and no you don't need to take someone with you, um, although it would be nice. So the trouble with putting something very obviously for carers and

loved ones in the pack is; it highlights to those people who would have like that, that there isn't anyone.'

When considering the media of information, as well as written information the use of a DVD of individual experiences of how women who had breast cancer felt at the end of treatment was highlighted as a powerful means of sharing experience and reducing the sense of isolation.

4. Moving Forward

While the women felt they needed to reflect on what had happened and to grieve their losses, they did not want this to dominate their lives and felt that moving forward into the rest of their lives was ultimately their priority. This was a process which took place over a period of time and there were a number of challenges to face on the way.

'There is ait'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 it. I think speaking of loss, there's that loss of certainty I struggle with as well and that is kind of assumed that I was, you know, good to go.'

'No, I think it's so that women, sort of, can read somewhere or watch a DVD to say that even though you're off that scary rollercoaster, your journey doesn't end and you're disorientated for a while and you've got to find a new normal, and it will come, and there is hope and you will have maybe, you know, it may highlight different areas of your life and whatever. And you will grow and move forward.'

There was a sense that their bodies and lives had been dominated by the healthcare system and treatment and the responsibility for their wellbeing was now theirs. They needed adequate

information and support to move on and begin to rebuild their lives. They also needed reassurance that they would be able to restore their lives.

'... you will feel differently about yourself and you'll need to regain your confidence in the way you look and, and your desirability, uh, but these things will return.

The underlying theme throughout was the need for information and support to facilitate self management strategies to allow the women at the end of their hospital based treatment to adapt, cope and move on with their lives. In using strategies to do this, they hoped this would reduce the risk of recurrence, minimise the side effects of treatment and maximise their health and wellbeing. Strategies for self management identified were diet and nutrition, complementary therapies, exercise, particularly exercise advice following breast surgery such as arm exercises which improve the range of arm movement without increasing the risk of lymphoedema. It was suggested that these strategies could be offered as positive tips, rather than a discussion about what side effects and symptoms might be experienced. For example, one woman described how her memory was impaired following treatment and she used post-it notes all around the house as aide-memoires. She suggested the addition of the post-it notes to the Breast Cancer Care resource, with a suggestion as to how some people find them helpful. In addition, a need for a supportive self management approach using coaching skills was identified as a means to help women to move on in their lives and become self managing with confidence (Figure 1). For some this might be part of a course that could be accessed, while others felt able to set their own goals.

'I wanted to take some control back, but I really wanted sort of good and sound advice about diet. I know about keeping your BMI right and all the rest of it but you know, just sensible advice around healthy lifestyle.'

'Moving forward, setting goals. I did a lot of goal setting and I gave myself little prizes. It's about a reality check of saying: look, you're going to be on your own with this to manage it. You know, you'll have these little ad hoc appointments. More self help, more coaching if you like so that we're not always going back and thinking...this is just me but, not going back and thinking about when it was horrible you know?'

'because there's something about...it's been fairly normal to worry that you would get it back again and these are self care things, this is how you can self care and these are the pathways. A course that I'd be going every week, I'll be going every fortnight, I'll be you know, just... because we've got...

'I have found that actually doing something for myself makes me feel more in control. I'm doing something for myself which...well, it probably won't stop the cancer recurring but at least I will feel I've done my bit to live healthily. It does make you feel more in control.'

Ways of doing things that increased control were important as were being reminded that it is reasonable to ask for help and not to expect too much of oneself.

Anxiety about returning to employment was associated with the reactions of colleagues as well as a loss of confidence. Most had positive experiences with employers and colleagues (but not all) but felt there should be some guidance for employers into how to manage people with breast cancer and their return to work after treatment. In addition, the women felt they should

be informed of their rights on returning to work, and to be aware of legislation which informs them of employment rights such as the Disability Act and that there may be options for a supported, phased return to work.

'I returned to work the other day to see my boss.....I was like, I can't remember how to do it, I can't remember how to do all the, all the systems that I used to work on and I'm just like petrified because I 'm going to have to be retrained. And this is a job I've been able to do standing on my head with my eyes closed, hands behind my back.'

Development of the Moving Forward resource

The conceptual model was used to inform the development of the resource. Specific findings and the items included in the resource are outlined in table 2. An important finding from the women was that information alone was insufficient for the reconciliation process that they were undergoing, but rather that they want resources to help them drive their own agenda and increase their confidence to take back control into their lives after the cancer experience. The women in the focus group were keen to have a single resource which could bring together a variety of tools into one place in a format which could be added to and used over time. There was a wide range of possible additions discussed which could be incorporated into this resource. These included checklists, blank care plans to be completed, lists of questions to ask health professionals, lists of information available, DVDs of other peoples' experiences, a diary, post-it notes to use as reminders, space to store doctors' letters and test results, information about lingerie, staff contact details, schedules of tests, and a flow diagram overview of their treatment plan.

The naming of the Breast Cancer Care resource pack was discussed by participants. One group strongly disliked 'living with' as it is: *'a constant reminder. You've got that every day anyway.'*

The phrase 'moving on' was considered more acceptable as it was both positive and descriptive: *'...clear; its fine isn't it?'* and 'moving forward' was liked by all participants. The women in the focus groups were asked if they would like gifts in the pack. There was a general agreement that they would not want this, but that gifts that were about increasing their body image, feeling of wellbeing, or sense of confidence, could be beneficial. Suggestions included vouchers for lingerie, body products, or herbal teas.

There was discussion about moving away from everything being pink and purple which have been used extensively in the US and UK to represent breast cancer. The women were keen to be represented by colours that were not associated with cancer but with new life and vigour. They were keen to see greens and yellows used which were associated with happiness, or the liveliness of clashing colours. The women did not want to be patronised, by use of *'cutesy'* or *'chirpy'* images, or by patronising terms, such as a key contacts page referring to *'MY contact details'* or *'MY specialist team'*.

Discussion

Survivorship from breast cancer has been identified to be a life-long process far beyond the end of treatment (Thomas-Maclean, 2005). For participants in this study the end of hospital based treatment marked the transition from the challenges of breast cancer diagnosis and treatment to facing the rest of their lives as breast cancer survivors. While the participants felt some

elation they were now faced with a new set of challenges to their health and identity. Charmaz (1983) described the loss of self in long term illness saying that ‘the loss of formerly sustaining self images without new ones results in a diminished self concept’. (p168) The participants in this study describe an altered self image and had to find ways to learn to adapt and live with their new identity. To do this they needed to have adequate support and information which provides a “whole person” approach to survivorship.

Fear of recurrence is a consistent theme for women who have had a breast cancer (Cimprich et al., 2005; Capiello et al., 2007; Griggs et al., 2007) and our findings support this. In addition, active information seeking has been found to improve physical quality of life (Ransom, Jacobsen, Schmidt, & Andrykowski, 2005) and as survival issues continue to be a problem for women after breast cancer treatment the need for on-going formalised information and support services to assist in their transition and promote active coping is important. Specifically participants wanted to understand the risk of recurrence, follow up procedure, long term effects and what symptoms of recurrent disease to look for. Participants wished to be treated as individuals and any resources developed should reflect this. To achieve this, there was a desire to formalise the follow up process beginning with a wellness appointment which assessed the holistic needs of each woman and a care plan drawn up from which both the woman and those involved in her care can follow.

The participants talked of grieving their lives before breast cancer and a loss of self associated with the biographical disruption of cancer (Bury, 1982). This loss of self included the difficulties associated with a changed body and the way they looked before as well as loss of certainty in

the old self. There was a need to understand the process of grieving these losses and many would have liked this to be aware of this process and what to expect in order to prepare themselves for after treatment. The planning of care for women with breast cancer should include the preparation of the patients for the next stage of their lives.

Social interaction was a key concern for our participants. As with the work of Rasmussen et al. (2010) the changed body was a representation of cancer and so brought cancer to the forefront in their dealings with others. Furthermore, our findings support the work of others that the transition at the end of treatment has been found to be particularly difficult as regular interaction with healthcare professionals are diminished and there is a feeling of abandonment by the healthcare system (Cimprich et al., 2005; Allen et al., 2009; Devane, 2009). At the same time relationships with others can be problematic with the need to balance their needs with that of the wider social network as others assume they will return to their lives with little adaptation (Cimprich et al., 2005). The experience of a diagnosis can cause problems communicating with others and emphasise the change of self and isolation (Allen et al., 2009). Participants in this study felt pressure from those around them to return to their lives with little adaptation and felt their partners, family and friends also needed resources to help them to understand and cope with the women as they navigated their way through lives after breast cancer treatment.

Evidence suggests that the use of self efficacy behaviours can improve health outcomes, increase self care behaviours and decrease physical and psychological problems (Fenlon and Foster, 2009). The participants in our study sought self management strategies and made

suggestions for services which promote goal setting and life coaching to help women at the end of treatment to adapt and move forward with their lives.

Strengths and Limitations

While many information and support resources have been developed for women with cancer, these have traditionally been developed through a medical and information professionals. This process of developing a resource by taking the affected women as a starting point is a clear strength of this work. A limitation is the small numbers of informants, although there is much in the literature to support our findings and the interviews with the health professionals were largely confirming of our findings from the women. The breast cancer informants were identified through the Breast Cancer Care website and BCC Cancer Voices database, which suggests that these women may not be representative of all UK women with breast cancer and may represent a younger, more educated group with access to the internet. There were also a large percentage of the focus group attendees from a Moving Forward programme offered by Breast Cancer Care, which may have influenced the attitudes and values of this group. No women from black or minority ethnic groups volunteered for this research and so their voices are not heard.

Working with the charity Breast Cancer Care meant that the research team had tight timescales and were required to respond rapidly to present findings to inform the development of the resource. Having many years' experience of providing information and support to people affected by breast cancer, the charity was also able to utilise and adapt some of their existing

material for the resource. While the resultant resource was new and radically different from previous materials, there may need to be on-going work to fully implement some of the concepts that arose from the research. Further work should not only evaluate the resource pack for its acceptability and utility, but research evidence should be sought to support its use as a tool to aid women in their recovery post breast cancer.

Conclusions and implications for practice

Our findings suggested that following breast cancer women want more from a resource pack at the end of active treatment than a collection of information. Their needs are focused around reflection on what has happened to them, feelings of loss and isolation and seeking restoration of a 'normal' way of life through reconciling the changes that have taken place in their bodies and their lives. Fear of recurrence is a common theme, while being subject to social pressure to return to life as it was before. Women need recognition of these problems as well as sensitively and appropriately delivered information. They want help to take control back into their lives, support to adapt to a changed body, and to restore lost confidence. Information provided should emphasise partnerships with health care professionals and support women to obtain appropriate assessment of need and access to on-going support across a wide range of issues. The resource could do much to prepare people for the changes and losses they face, while providing support to take back control over their lives, to drive the agenda around their own health and to help increase their confidence.

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Table 1: Age ranges of participants

| Age | n/% | % |
|-------|-----|------|
| 30-39 | 1 | 8.3 |
| 40-49 | 2 | 16.7 |
| 50-59 | 5 | 41.7 |
| 60-69 | 3 | 25.0 |
| 70-79 | 0 | 0 |
| 80-89 | 1 | 8.3 |

Table 2: Specific items to include in resource pack for end of breast cancer treatment.

| Theme | Item |
|--------------|--|
| Reflection | Providing space for own notes |
| Reflection | A diary with suggestions for how it might be used to reflect on key points of cancer journey |
| Reflection | Space for doctors notes, care plans, schedule of visits, schedule of investigations |
| Reflection | Information on key symptoms and their management, such as fatigue, menopausal issues |
| Reflection | Acknowledging fear of recurrence |
| Reflection | Help to identify key contacts, ways to get specialist advice and referral to specialist when needed. |
| Reflection | Questions to ask health professionals |
| Reflection | A blank care plan template to help lead an assessment of needs |
| Reflection | A list of information leaflets available and where to get them |
| Reflection | Information on what to look for as a sign of recurrence (although not all wanted this, so could be signposting towards this information) |
| Loss of self | Acknowledgement and preparation for change and loss |
| Loss of self | Information about normal grieving |
| Loss of self | Information targeted at family around how people adjust after cancer |
| Loss of self | Preparation for loss of confidence |
| Loss of self | Preparation for loss of desirability |
| Isolation | Details of support organisations, plus space for local contacts |

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| | |
|----------------|---|
| Isolation | Suggestions and tips for coping from other patients |
| Isolation | Personal stories, perhaps audiovisual recordings. |
| Moving forward | Ways to rebuild confidence. |
| Moving forward | Information regarding healthy lifestyle e.g. healthy eating, exercise and complementary therapies |
| Moving forward | Information on beauty and fashion or where to get it |
| Moving forward | Information on Life Coaching or where to get it |
| Moving forward | Information on finance/ employment rights and return to work |
| Moving forward | Not being patronising |
| Moving forward | Making resources user friendly – use of diagrams etc |
| Moving forward | 'post it' notes to use as 'aide-memoires' |

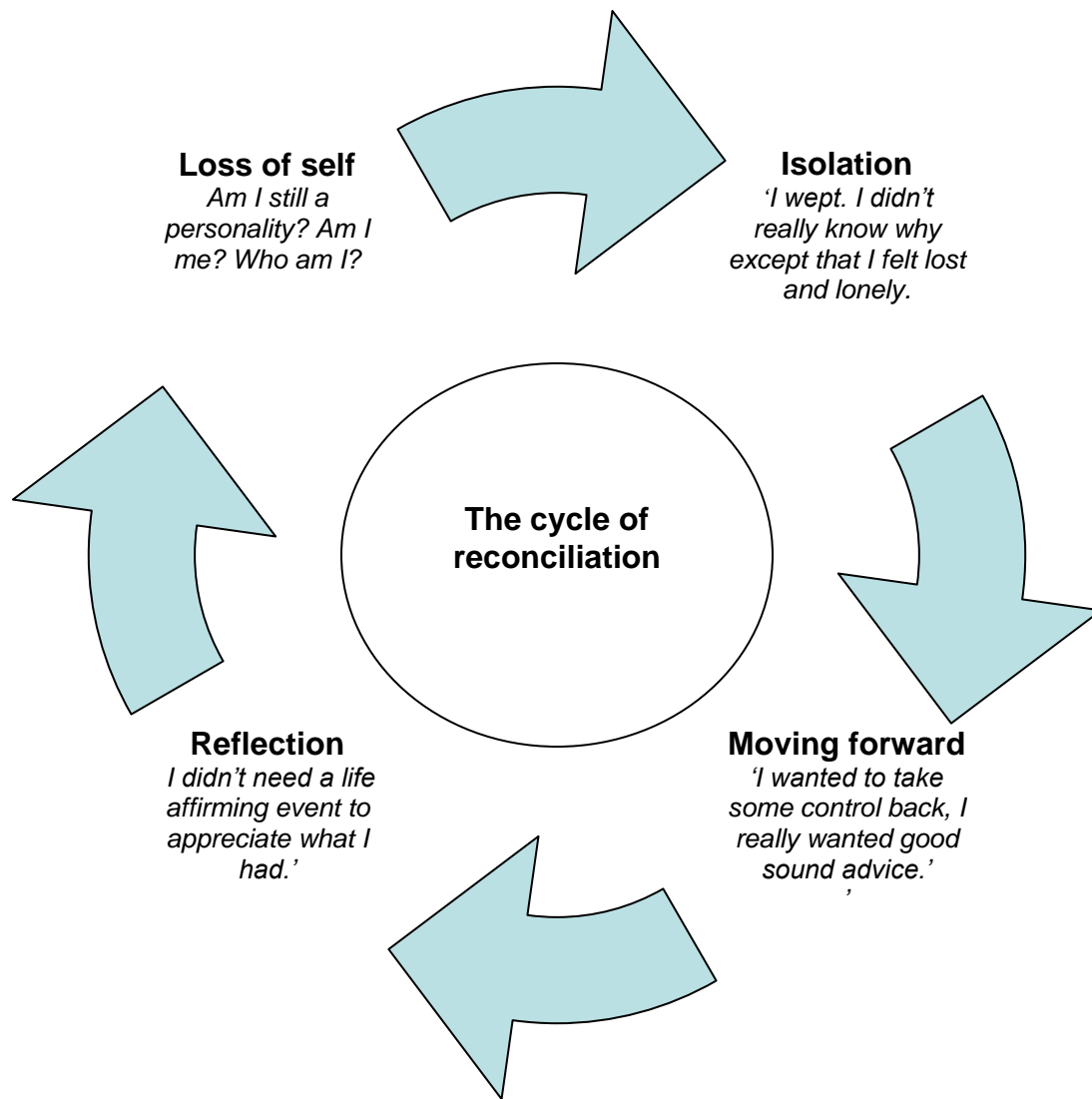


Figure 1: The cycle of reconciliation