

**An exploration of the experiences of women treated with radiotherapy for breast cancer: learning from recent and historical cohorts to identify enduring needs.**

Alison Llewellyn<sup>a,b</sup>, Claire Howard<sup>a</sup>, & Candida McCabe<sup>a,b,c</sup>.

<sup>a</sup>Royal United Hospitals Bath NHS Foundation Trust, Combe Park, Bath, BA1 3NG, UK

<sup>b</sup>Department of Nursing and Midwifery, University of the West of England, Glenside Campus, Bristol, BS16 1DD, UK

<sup>c</sup>Florence Nightingale Foundation, 11-13 Cavendish Square, London, UK

Keywords: Breast cancer, radiotherapy, cancer survivorship, cancer late-effects, qualitative

Corresponding author: A Llewellyn

Email: Alison.Llewellyn@uwe.ac.uk

Address: Department of Nursing and Midwifery

University of the West of England

Glenside Campus

Blackberry Hill

Bristol

BS16 1DD

## **Abstract**

### **Purpose**

Recent decades have seen improvements in UK breast cancer services and treatments. Despite this, it is recognised that a range of patients' psychological and emotional needs remain unmet, both at the time of treatment and into survivorship. Using data from two distinct cohorts of women: those treated with radiotherapy for breast cancer historically, and women treated more recently, this study sought to identify and explore those needs and concerns that have continued to persist, despite advances in treatment and care.

### **Method**

Data from N = 13 semi-structured interviews were analysed using Interpretative Phenomenological Analysis. An heuristic framework was applied to extract themes common to both participant cohorts.

### **Results**

Participants' data evidenced an enduring vulnerability amongst cancer patients that has not diminished with new treatment pathways. Themes common to both cohorts highlighted the ongoing importance of personal factors such as resilience, and strategies to help retain a sense of normality. Extrinsic support was important too, especially high quality communication by healthcare professionals and having access to ongoing emotional support from others, particularly when active treatment ends. Participants' suggestions for future service development included the provision of ongoing continuity of care and greater access to emotional support services.

### **Conclusions**

This study highlights the psychological needs and concerns of breast cancer patients that have persisted, despite the many advances in patient-centred care. Findings are of value to nurses and other healthcare professionals in highlighting the ongoing importance of recognising, acknowledging and addressing patients' concerns and needs, even within current cancer care pathways.

## **1. Introduction**

Breast cancer is the most commonly diagnosed cancer in England (Office of National Statistics, 2016) and around 1 in 8 women will be diagnosed with breast cancer during their lifetime (Cancer Research UK, 2018). Whilst, in the 1970s, fewer than 25% of cancer patients survived, this figure has doubled in the last 40 years, with more than half now surviving (Cancer Research UK, 2017). Today, 78% of women with breast cancer will survive for 10 years or more (Cancer Research UK, 2018),

In the context of increasing survivorship, addressing the unmet supportive care needs for women with and after breast cancer becomes a growing concern. Research has drawn attention to the ongoing needs of patients across the breadth of psychosocial, physical, sexual and occupational domains (Capelan et al., 2017; McGarry et al., 2013; Armes et al., 2009). Patients have reported a need for fatigue management, for support in adapting to changes in appearance, and for relationship counselling (Tighe et al. 2011). Existential concerns have also been highlighted as a specific, but common, unmet need (Hodgkinson et al., 2007). The point of transition from the end of active treatment to survivorship has further been identified as a distinct stage in the trajectory of the

cancer experience and one in which patients' needs are focused on personal reflections, restoring "normality" and feelings of loss and isolation (Fenlon et al., 2015).

Evidence suggests the many physical, psychosocial, emotional and cognitive effects of breast cancer persist long into survivorship, and that need levels are not correlated with years since diagnosis (Hodgkinson et al., 2007). Ongoing symptoms include fatigue, sleep problems, anxiety and depression (Cheng et al., 2016). Survivors also have to cope with fear of recurrence, post-traumatic stress disorder, sexual dysfunction and decreased satisfaction with life (Kenyon et al., 2014; Ewertz and Jensen, 2011). Schmid-Buchi et al. (2011) found that many long-term survivors further struggled with weight gain and a changed body image and felt impaired in daily and social activities. Mehnert and Koch (2008) reported that 38% of women had moderate or high anxiety and 22% had moderate or high depression at more than four years post diagnosis.

Over recent decades breast cancer services have been redesigned with a focus on multidisciplinary team management and defined care pathways (Pittathankal and Davidson, 2010). In the UK, the NHS published its Cancer Plan in 2000 (Department of Health, 2000) setting out its ambition to improve cancer services, and then in 2012 launched a stratified pathway of care model, aimed at improving the quality and effectiveness of services for patients (NHS Improvement, 2012). Treatment techniques have similarly advanced, and the wider use of adjuvant chemotherapy, hormonal therapy, and radiotherapy treatments, have led to improved survival (Early Breast Cancer Trialists' Collaborative Group, 2005). Additionally, the knowledge of iatrogenic consequences, such as radiation induced peripheral neuropathy (RIPN) has also developed (Delanian et al., 2012). However, despite policy commitments to UK cancer care reform, and the many wide-ranging advances in care provision, treatment techniques and understandings, it is clear from the literature that patients' needs continue to be unmet.

A new UK service 'The Breast Radiotherapy Injury Rehabilitation Service' (BRIRS) was established in 2012 to address the physical and psychological consequences of complex and severe late-effects arising from treatment for breast cancer. Specifically, BRIRs was designed for those who have longstanding pain and disability arising from radiotherapy induced brachial plexus avulsion in the arm adjacent to the treated breast. By the nature of their treatment, this cohort of patients commonly experience more widespread radiation induced problems such as severe osteoporosis and /or bone loss, severe lymphoedema, heart and lung abnormalities (<http://www.rnhrd.nhs.uk/175>). More recently the scope of this service has been extended to include people living with complex late-effects from any cancer site and any cancer treatments. In the present study we had unique access to a cohort of women treated by the BRIR service (who were treated with radiotherapy for breast cancer in the UK 30-40 years ago), and to a recent cohort of women (treated with radiotherapy 1-3 years ago). Conducting semi-structured interviews with participants from both cohorts allowed us to explore how the women coped psychologically whilst undergoing curative radiotherapy treatment for breast cancer, and how they are currently coping, living beyond cancer treatment. Identifying common themes from both groups provided an heuristic framework in which to provide a contextualised understanding of their experiences of care. It also provided an opportunity to identify any remaining needs and concerns of patients that have continued to persist over the intervening years, despite the advances in cancer care services and improvements in patient-centred care. The study also asked participants for their recommendations for the development of future breast cancer services. Together, these understandings will be of

value to healthcare professionals in providing care to breast cancer patients after radiotherapy and have the potential to inform the development of future cancer services.

## 2. Methods

### 2.1 Method/Design

This study took a qualitative approach, using N=13 semi-structured interviews. The analytical method adhered to the philosophy of phenomenology, selected in order to explore individuals' meanings about their experiences (Bowling, 2014).

### 2.2 Participants

Recruitment was via purposeful sampling and included individuals who had attended the BRIR service at a hospital in the South West of the UK within the past year (the historical cohort), as well as individuals attending an annual mammogram screening at a hospital in the South West of the UK up to three years post treatment (the recent cohort). Eligibility criteria stipulated that participants should be 18 years of age or older, have received radiotherapy treatment for breast cancer, be able to converse and read in English, have capacity to provide written informed consent and be in stable physical and mental health. Full ethical approval was obtained by NRES Committee London - City & East (Ref: 14/ LO/ 1953) and the local NHS Trust Research and Development Department (RD: 01916). Following the guidance of Smith, Jarman and Osborn (1999) we aimed to recruit approximately 10-12 participants as this is considered appropriate for the methodology chosen (see section 2.4).

### 2.3 Procedure

Individuals identified as meeting the criteria (see above) were provided with an invitation letter and study information by clinical staff and asked to return an opt-in form if interested. They were then contacted by telephone to arrange an interview. Participants were given the opportunity to ask further questions face-to-face with a member of the research team before full written informed consent was received. The interviews were semi-structured, based on the self-regulatory model of chronic illness (Leventhal, 1980) with open questions to facilitate discussions about experiences of radiotherapy treatment, emotional adjustment, perceptions and coping with late-effects (Figure 1). The interview schedule had previously been piloted with a small focus group of women attending the BRIR service to ensure acceptability and face and content validity. Interviews were conducted between February and September 2015 (by AL) in a quiet room on hospital premises, or in participants' own homes, depending on their preference. All interviews were audio recorded and transcribed verbatim.

| Interview Schedule   |   |
|--|---|
| The first questions are about when you initially got diagnosed with breast cancer: |   |
| 1)   | Looking back, can you tell me about events leading up to you (first) being told you had breast cancer? (story of breast cancer)   |
|  | <ul style="list-style-type: none"><li>- Initial awareness of symptoms: health beliefs</li><li>- Interactions with health professionals: explanations, understanding</li><li>- Course of treatments: RT, chemo, surgery etc.</li><li>- What things stand out in your memory about this time?</li></ul> |
| 2)   | How did you cope with receiving the diagnosis and undergoing the treatments?  |
|  | <ul style="list-style-type: none"><li>- Most difficult aspects? (psychological/emotional/physical effects)</li><li>- What things were helpful/unhelpful?</li><li>- Understanding of treatments: short/long-term consequences</li></ul>  |
| The next few questions are about when your initial treatment had finished:         |   |
| 3)   | Looking back, what, for you, have been the consequences of going through treatments for breast cancer?  |
|  | <ul style="list-style-type: none"><li>- Main worries/concerns at the time?</li><li>- Side effects from treatments?</li></ul>  |

Figure 1: Interview schedule

#### *2.4 Data analysis*

The interviews were analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al. 1999) which recognises the dynamic nature of analysis and the interpretative process adopted by the researchers. It provides a rich in-depth analysis of illness interpretation as it is idiographic in focus and offers insights into how a person perceives a particular phenomenon within a given context, thereby focusing not only on the illness discourse, but on the underlying cognitions. Each transcript was read intensively several times by the lead researcher (CH) and inductive analysis applied to identify recurring patterns and emerging themes. Recurring themes identified something that mattered to the participant (e.g. determination to cope) and that also conveyed something about its meaning (e.g. not coping is akin to giving up, which will increase risk of not surviving cancer and death). Transcripts were continuously recoded to review the evidence for new emerging themes in a cyclical interactive process and codes categorised under broad themes. Two researchers (AL and CM) independently coded a sample of transcripts. Together with the lead researcher (CH) any discrepancies were discussed, and the final coding structure agreed. The analytic process continued until no further data could be added to the categories and a heuristic framework applied, whereby data were extracted where common themes were identified in both participant cohorts.

### **3. Results**

#### *3.1 Participants*

The study sample consisted of 13 women. Six of these (mean age = 79, range 72 to 81) had been treated with radiotherapy for breast cancer 30-39 years ago (mean number of years since treatment = 34), had a diagnosis of radiotherapy induced brachial plexus avulsion, and formed the historical cohort. Seven women (mean age = 62, range 56 to 68, mean number of years since treatment = 2, range 1-3) formed the recent cohort. All participants were white UK residents. The median interview duration was 46 minutes.

### 3.2 Themes

Two main themes emerged from the data: 1) using personal resources, and 2) needing support from others. Within the “Using personal resources” theme, four subthemes highlighted the ongoing importance of drawing upon intrinsic psychological resources, and how adaptive personal strategies are crucial in ensuring active coping and making sense of one’s experience. These sub-themes were identified as: being resilient, seeking a sense of normality, talking about cancer and finding meaning, and coping with an uncertain future. Data relating to participants’ need for extrinsic support highlighted the desire for high quality communication by healthcare professionals and the importance of ongoing emotional assistance provided by others within and beyond the healthcare system. Sub-themes were coded as: needing to feel acknowledged and treated sensitively, managing expectations, needing emotional support, needing to have faith in others, and feeling isolated when treatment ends.

Themes and sub-themes are discussed below, with numbers assigned to each participant, with the prefix H for Historical cohort and R for Recent cohort. Figure 2 provides a schematic illustration of the theme hierarchies.

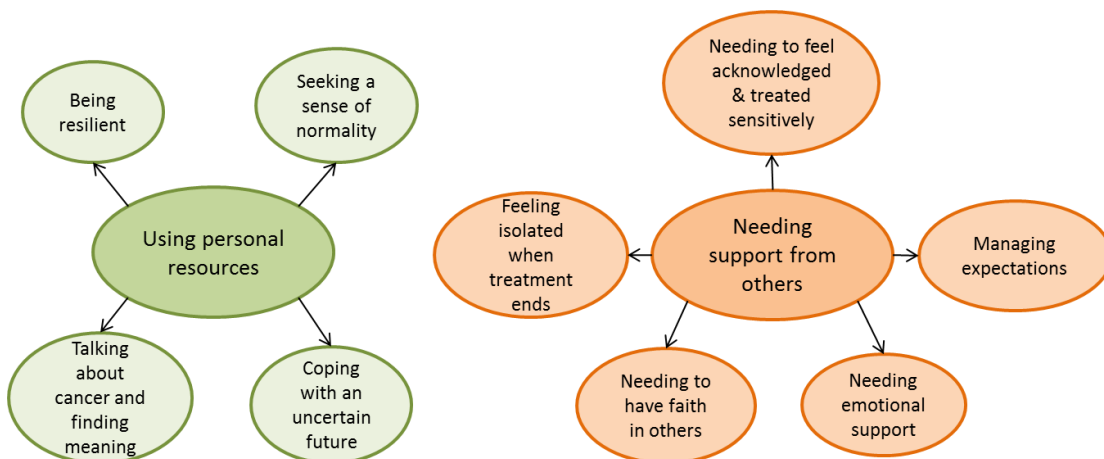


Figure 2: Theme hierarchies

#### **Theme 1: Using personal resources**

##### **Being resilient**

Participants expressed the significant impact of unexpectedly being given a potentially life-threatening diagnosis. Reflections on the experience indicated how their reactions had included shock, disbelief, numbness and a heightened sense of mortality for both cohorts:

*“That’s right, being unsure of the future, really, because you don’t want to die at 48, do you?” (H 02)<sup>1</sup>.*

*“Well, the, the sudden thought of, you know, mortality, really (laughs), you know, how long did I have, you know” (R 13)<sup>2</sup>.*

When faced with adversity, participants described how they coped through resilience, referring to the will to survive, inner-strength, determination and stoicism:

*“I never thought for one minute I wouldn’t get through it” (R 11).*

Participants’ comments therefore reflected the importance of drawing upon intrinsic psychological resources in positive coping. Conversely, their recollections of feelings at the time also revealed the more negative emotions underlying their coping efforts, reporting a fear of death if one gave up and was not stoical:

*“You know there was another woman who had her breast removed at the same time as me, she was slightly older, I think she was in her mid-forties and she sort of gave up and I heard later that she did actually die and I thought that’s not going to happen to me. I’m absolutely determined I’m going to survive” (H 01).*

For both cohorts, emotional suppression and avoidance were also characteristic of their apparent resilience. Some participants omitted to label an emotion when asked questions such as *“How did you feel?”*, substituting emotions with a behaviour, and thereby revealing the challenge in developing and maintaining resilience in the face of threat:

*“Oh, not very sure, no. Erm, I suppose it makes you feel well...[pause]...I’ll just get on with it you know” (H 03).*

*“But I felt...[pause]...oh well, they found it, get it out and get, you know get it all sorted” (R 12).*

### Seeking a sense of normality

Efforts to maintain normality and avoid an unwanted survivorship identity were made by both cohorts, for example, wanting to be treated normally. However, it was clear that this was often a difficult process and one which manifested in concealing their feelings and not accessing support:

*“Yeah. Because the other thing is I, I didn’t want my friends to, to know how awful I felt. Er, er, as well, you know, I, I sort of wanted them, I wanted to be me, I wanted*

---

<sup>1</sup> The prefix H refers to a participant from the historical cohort.

<sup>2</sup> The prefix R refers to a participant from the recent cohort.

*them to, to feel that I was normal me, you know. And not for them to feel too bad for me" (laughs)... "I just sort of wanted to be normal" (R 11).*

Frustrations associated with the impact of appearance on identity were also evident, indicating the significant ramifications that body image can have on emotional wellbeing. Similarly, participants referred to their concerns about role and identity within the family, demonstrating how this deleteriously affected their personal relationships:

*"So I noticed that I ... you know I've got clothes that I'm not so keen on wearing, it's only a silly little thing actually but erm" (R 10).*

*"Oh awful, you know, just ... and really pissed off actually because it was very complicated, shopping was very complicated. I had to buy clothes that had special sleeves, you know, like batwings or things like that" (H 01).*

*"I mean, erm, there are still, I mean being with the grandchildren...and I hate not being able to put my arms out when they run" (H 05).*

#### Talking about cancer and finding meaning

Participants explained the importance of talking about cancer and how this has been facilitated by recent changing societal attitudes towards this illness. The consensus from both cohorts was that society is now more open about discussing cancer:

*"I mean you didn't chat about it [then] like you do these days" (H 06).*

*"...actually the big C isn't as big as it used to be, you know" (R 08).*

It was evident that participants found the social acceptability of talking about cancer helpful, expressing the reassuring and normalising benefits of being able to talk candidly about their illness:

*"Yeah um but the other thing I did find out was the amount of people that had breast cancer that you didn't even know about... And it was like "Oh so, I'm not on my own then"... Um and then you talk to the others, and they said "No that's normal, perfectly normal to feel like that." (R 07).*

Participants in the recent cohort also described existential issues such as gaining a different perspective on life when reflecting on how they coped with breast cancer. This enabled them to find meaning in the face of a difficult situation:

*"... I think it made me a more positive person, erm, and a more erm ... it enabled me to value life more and be grateful." (R 10).*

*"It's made me not worry about silly little things, you know, arguments, why, cos it's trivial, you know, it just, it does give you a whole different outlook on life, you know." (R 07).*



### Coping with an uncertain future

Fears of recurrence were common to both cohorts, although more prominent in the recent cohort, particularly in the year post treatment until the first mammogram.

*"...Em, but that, that's it, really, you know, you're sort of told you'll have another mammogram in a year, but you don't see your, em, oncologist again, basically. And em, and I when the treatment stops, er, it, it's totally illogical but it, it's not rational, but you, you sort of, you're frightened immediately that the cancer's going to come back (R 13).*

Challenges associated with forming a post cancer identity intertwined with the realisation of the consequences of breast cancer were also evident, again particularly for the recent cohort:

*"That's, that's, yeah, because I mean, another thing is, with the exercises, you know, I said, oh, how long do I have to do these, and, you know, the nurse said, "For life", you know, for life, and that makes you realise that, you know, things are never going to be quite the same again, you know" (R 13).*

### **Theme 2: Needing support from others**

#### Needing to feel acknowledged & cared for with sensitivity

The importance of feeling acknowledged, recognised and treated as an individual was conveyed by both cohorts. This included experiences relating to diagnosis (of breast cancer and of late-effects) and to their subsequent treatment. However, despite an increasing emphasis on patient-centred care in healthcare services in the UK, even for the more recent cohort of participants, this was not always their experience.

Some participants described how they felt dismissed, which heightened feelings of fear and which they reflected as a failure in care:

*"I went to my GP, I said, "Look, I've got this lump," and he said, "Oh, it'll go away." But I said, "No, I want it investigated," with the family history the way mine was" (H 02).*

*"... I said I've got symptoms which are er ... a painful erm node under my arm, which is all swollen up and a hard lump here. Er and it seems to me, those are the classic symptoms of breast cancer and she probably ... was a woman doctor, she probably thought oh one of these know-all patients and she said "well you're far too young to have breast cancer" (H 01).*

*"I felt we were treated quite badly...he [the surgeon] was just so erm uncaring I felt and erm...almost hardly even acknowledged my existence other than the fact of you know...let's have a look and this is where it is and I'm going to do this, that and the other and right okay goodbye..."(R 06)*

Among both cohorts there was a wish to have been treated with dignity, sensitivity and empathy when feeling vulnerable:

*“Cos it makes you feel oh, I’m not just a number...I’m being looked at as an overall individual” (R 08).*

Participants felt they could empathise with doctors who attempted to honestly and sensitively communicate with them, even if the doctor appeared to struggle with this. The outward demonstration by a clinician of personal attributes such as honesty and compassion, were highly valued and helped participants to feel they were being cared for as an individual:

*“I felt, I really felt for him [the doctor]. He did not know how to approach it. ....but he went round it and in the end I had to tell him, I said, “Look, you’re telling me I’ve got breast cancer and you’re telling me I probably need a mastectomy, aren’t you?” (R 09).*

*“I went back to him [the hospital consultant] he said, “look I’m, I must apologise because I diagnosed wrongly” and I thought a lot of him for that, because he’d got quite a good reputation” (H 05)*

### Managing expectations

There were clear variances between the two participant populations about the information and support they felt they were provided with. For the historical cohort the data evidenced a lack of information provision:

*“Absolutely nothing [referring to whether told about what to expect after radiotherapy], No, I mean I don’t think they knew in those days did they, I mean they were just doing it and hoping for the best, I thought this is a brand new world, yeah” (H 06).*

The recent cohort, conversely, stated they had been given information about the treatment procedures as well as some potential consequences of radiotherapy such as reddened or sore skin. However, some participants from this cohort reported not being alerted to the possibility of common late effects, such as ongoing fatigue and pain:

*And I was ... I was kind of better at first and then gradually I realised I was really, really tired and ... still swollen... I remember saying well look I wish people had said that it might take this long. Erm A because I could have been clearer with work and B because I ... I would have perhaps sought help a little bit more quickly. Erm I mean yes there were things in the leaflets about oedema and things in the leaflets about ... not a lot about fatigue actually. (R 08)*

*“...it was like “Oh my God, I’ve got a little pain, what’s the pain?” (R 07)*

Moreover, emerging iatrogenic effects of treatment were still met with surprise and disbelief and it was evident that participants remained unprepared for the consequences of cancer treatment:

*“...With the radiotherapy, the thing that has, er, to effect, has been a concern is the fact that they did say I’d lose some, er, lung capacity. Now I sing with a choir ...yeah (laughs), I had, I, er, er, I find breath control much more difficult... It’s come as a surprise to find out that actually that genuinely is true (laughs). Because I never think it’s going to happen to me (laughs)” (R 09)*

### Needing emotional support

Participants in the recent cohort described how emotional support is available within the current breast cancer care pathway: However, for both cohorts the data indicated that the emotional impact of their cancer commonly became apparent when active treatment had finished. Participants reported feeling that emotional support was less available in this period post-treatment and that greater access to appropriate services would be beneficial at this time:

*"...I never felt that I didn't have anybody to turn to [during treatment]" (R 11)*

*"I don't think the emotional bit really kicked in until afterwards." (R 08)*

*"...afterwards you got a bit depressed about it all." (H 02)*

*"it would have been quite nice for when you'd finished your treatment to sort of be handed onto the GP more, I suppose more or less for reassurance ...and to sort of say right well you know the hospital bit's finished now but you can always come to me." (R 06)*

It was also evident in the data that participants in both the recent and historical cohorts reported unanticipated reactions from friends and family to their cancer and which led to the withdrawal of emotional support. They attributed this to their friends' inability to cope, this interpretation acting as a protective coping mechanism. Whilst participants described how they found these behaviours isolating, they appeared to be stoical about their impact:

*"...and the other thing was that a lot of my friends sort of withdrew ...you know, I think it's because they couldn't cope...I mean it didn't upset me or anything". (H 01)*

*"I had one really strange experience which my friend who I've known since I was six.... She couldn't come anywhere near me, she couldn't deal with it. Which is really weird". (R 06)*

### Needing to have faith in others

This subtheme describes how participants reported how they psychologically handed over control and found reassurance, by placing their faith in others i.e. the medical system, in order to strengthen their chances of survival. It was apparent for both cohorts:

*"Well I think you just have to take the best advice that you think you've got and go with that, I don't know, I don't think you have much choice really in this" (H 06).*

*"...and I thought right, that's it, go in and have it done and I shall be alright" (R 12)*

Their faith in the efficacy of treatment was reinforced by the advanced equipment and skill of practitioners:

*"...Plus I was fascinated by it as well (laughs). I just erm, when the initial bit where they work out where they're going to do it...And I just thought this is wonderful, you know*

*try watching what they were doing and how they were working out exactly where to get the beam. Erm, I just found fascinating” (R 11).*

### Feeling isolated when treatment ends

Participants in both cohorts spoke about feeling in limbo and emotionally isolated when no longer being contained within the medical system. They expressed surprise and confusion at their feelings and reactions towards treatment ending, at the loss of stable relationships with staff and at the adjustment they needed to make.

*“Yeah, Yeah and I felt so lost for the first few years I tell you” (H 06).*

*“Once they say screening is finished, you know that’s it” (H 11).*

Previously suppressed emotional feelings commonly arose due to the loss of distraction that regular radiotherapy sessions provided, diminishing their sense of resilience:

*“I drove myself in every day. I was determined to be independent, and it was alright when I was doing it, then afterwards you got a bit depressed about it all” (H 02).*

There were unexpected reactions towards treatment seemingly ending abruptly particularly for the recent cohort who had developed valued relationships with staff:

*“Suddenly from all this contact, which kind of accumulates because you’re ... suddenly you’re going in every day. And then suddenly it’s absolutely nothing” (R 08).*

*“I remember my last appointment... and I wasn’t going to go back there and I wasn’t going to see any of them again and there was like no ... no closure of that whole big relationship... it was like oh, alright I’ll go home now. It was kind of shocking really.” (R 08).*

Whilst participants clearly valued being able to develop warm relationships with staff and they appreciated the sense of security that this brought during treatment, it is plausible that the feelings of loss, or even abandonment, at this time may have made the experience of transition from active treatment to post-treatment more difficult.

### *3.3 Reflections and Recommendations*

Participants were also directly asked about their suggestions for ways to improve the experience of health care services in relation to breast cancer treatment and care.

The importance of information provision in both verbal and written format was commonly highlighted by both cohorts, although it was also noted that greater knowledge can be seen as detrimental and serving to heighten anxiety:

*"I just feel there should be more of that at the beginning really [referring to information booklets] because what happened is, I've not used my arm in the right way, so other things have gone..." (H 03).*

*"Erm well it would've been interesting I think [to know about potential late effects] and not helpful though, you would perhaps start worrying more" (H 06).*

Continuity of care, with a named healthcare professional was highly valued in current breast cancer care pathways:

*"So I went back and obviously saw her erm each time [breast care nurse] and I think continuity of seeing the same person is quite important... Erm, and I think maybe that was the thing with the radiotherapy, the continuity that it was the same people ...so you knew you know, oh good morning how are you, you know sort of thing" (R 07).*

*"I think having that named person was really important because I would not have known where to start afterwards. If I hadn't been able to ring her and she got back to me within half an hour" (R 08).*

Both cohorts recommended that secondary care services should communicate well with GP's and that there is a comprehensive handover. In addition, there were recommendations for access to more specialist services or better informed GP services in longer-term survivorship:

*"I suppose what I wish was instead of going back to the GP all the time, that there was a follow up service that was a bit more specialist. I think that's a bit more kind of understanding of what you've been through" (R 10).*

*"...if GP's were able to access easily erm information and progress er that's going on in the case of certain serious illnesses. I don't know if it's possible, they just push a button and on a screen would flash up all the stuff about breast cancer ..." (H 01).*

The provision of emotional support was viewed as a positive coping intervention with recommendations that there be greater availability of psychological support:

*"I think they were really good at explaining what was going to happen and how it all worked but there was still that sort of slight kind of anxiety and not necessarily anywhere to express that well" (R 08).*

However, current non-medical interventions such as the 'Moving On' day or Adult Fatigue Course that a few of the recent participants had attended, were viewed upon very favourably, in terms of normalising feelings and providing emotional support and reassurance, particularly when feeling isolated when discharged from treatment services. Participants recommended that these types of interventions should be available more frequently.

*"But then the course itself, [adult fatigue course] em, em, immediately helped you put some kind of structure back into your life, it was reassuring, em, because again, they went through these things say, you know, saying how long it can take to recover, so the course was, was, was very motivating, very instructive, em, very reassuring and, and again, once again you were back in this sort of safety net of support" (R 13).*

#### 4. Discussion

Despite the significant advances in cancer treatment and care services over recent years, our data evidenced a vulnerability amongst cancer patients which has not diminished with these new treatment pathways. Our findings highlighted the ongoing importance of drawing upon intrinsic resources to help patients cope at this difficult time. In particular, participants made efforts to retain a sense of normality and identity, make sense of their experience, and to find meaning in the face of uncertainty. The importance of receiving extrinsic support was also evidenced including the critical impact of communication by healthcare professionals, and the importance of having ongoing emotional support from others, particularly at the termination of active treatment.

It was notable in our study that participants from both cohorts described how they relied on their resilience to make sense of their experience. Resilience, as a dynamic capacity to maintain emotional stability at times of adversity, has been explored in breast cancer. In general, resilience refers to a cluster of characteristics such as self-efficacy, goal-orientation, adaptability to change, optimism and capacity to create secure attachments (Markovitz et al., 2015). It has been found to be a relatively stable trait, (rather than a state triggered by stressful events), and one which may partially protect against the emotional distress in cancer patients and facilitate better emotional adjustment (Markovitz et al., 2015). Furthermore, it has been suggested that resilience is a multidimensional dynamic and modifiable process that operates temporally before, during and after an adverse event (Pieters, 2016). As such, including interventions to encourage and support resilience throughout treatment and follow-up may be of considerable benefit in reinforcing how patients cope.

Coping with an uncertain future was an enduring subtheme in our study, with feelings of isolation when treatment ended reported by both cohorts. However, this was particularly true for those treated in more recent care pathways. Research has identified that patients need support to prepare for facing the challenges and losses they commonly encounter at this time in order to regain control over their lives, to regain their confidence, and to avoid feelings of abandonment (Williams and Jeanetta, 2014; Fenlon et al., 2015). "Moving Forward" courses, such as those delivered by the charity, Breast Cancer Care, in partnership with NHS hospitals, may be of particular value in facilitating these adjustments along with signposting to services that can provide emotional support beyond this point and into long-term survivorship.

Participants in both our cohorts described the desire to maintain normality and the challenge of re-establishing a sense of identity that incorporates living with the consequences of treatment. Rosedale (2009) coined the term 'survivor loneliness' to describe the psychological challenge of processing an altered sense of self, connection with others, and identity as a breast cancer survivor. Feelings of loss and grief have also been widely reported in the literature (e.g. Tacon, 2011) as people come to terms with the cancer and try to cope with uncertainty and the side-effects of treatment. Similarly, other researchers have found that women describe their surprise to find themselves fatigued and vulnerable with breast cancer treatments behind them and rebounding was found to take longer than expected (Pieters, 2016; Rowland, 2008). Whilst the more recent cohort in our study had evidently been provided with better information about their cancer treatment than those treated many years previously, they nonetheless still reported surprise when late effects occurred and felt ill-prepared for some of the treatment consequences, such as post-mastectomy scarring. It is apparent therefore that there remains a need to manage patients' expectations and

for health professionals to be alert to recognising and addressing patients' heightened emotional distress connected with their identity at the end of treatment.

Fears of recurrence are frequently cited in the literature and similarly emerged as a persistent subtheme over time in our study. Research suggests that clinical interventions which promote anxiety management strategies and continued participation in valued roles and activities may effectively counteract fears of recurrence and minimise its negative psychosocial impact on patients and their families (Dunn et al., 2015; Lebel et al., 2013). In the context of the ongoing patient-reported fear that we identified, these strategies could be usefully implemented in future service models to address this enduring area of need.

Unsurprisingly, our findings indicated that our participants appreciated and needed support from those around them at a number of points in the care pathway, and this need had not lessened over time. The importance of doctor-patient communication resonated throughout the narratives and was significant in forming the basis of a therapeutic relationship with medical professionals and fostering an overall positive experience of care. These findings are consistent with research by Wright et al. (2004) who found that breast cancer patients were not primarily concerned with doctors' communication skills per se, instead placing greater emphasis on person-centred characteristics of doctors, such as those who formed individual relationships with them, acknowledged and respected them, and whom they regarded as attachment figures who would care for them. Both cohorts in our study also highlighted how they found reassurance from having faith in their clinicians, suggesting this may be another area where interventions to foster trust from patients may be beneficial.

Our findings also indicated that there may be value in preparing patients for unanticipated reactions from others at an early stage in their cancer journey. Indeed, negative support has been asserted to worsen the psychological adjustment of breast cancer patients (Shiozaki et al., 2011). It has been proposed that there is value in providing education about unsupportive social interactions to care givers and healthcare providers to enable them to better support patients in such situations (Figueiredo et al. 2004).

Interestingly, the participants in our more recent cohort indicated that their cancer experience had an unexpected positive impact in terms of providing a window of opportunity in which to find meaning at an uncertain time. This is consistent with other studies who have described post-traumatic growth, or profit-finding from breast cancer which has subsequently promoted psychological wellbeing (Bahrami et al., 2015; Pinquart et al., 2007; Schrovers et al., 2011). For healthcare professionals, this suggests that, whilst acknowledging and attending to patients concerns and fears, concurrently supporting patients' awareness of the indirect positive effects of cancer, may be beneficial. However, we recognise the understandable challenges and sensitivities this may evoke for both parties.

Reflecting back on their experiences, the participants in our study offered a number of recommendations or advice for breast cancer services. It was evident that ensuring provision of appropriate verbal and written information was considered helpful in supporting patients' understanding of treatment processes and side effects. Participants stated that they wanted

healthcare professionals to be aware of how access to this information is an important aspect of care. Participants also valued the relationship they had developed with their healthcare professionals. They suggested that, in the future, when the design of acute oncology services is being considered, it would be helpful to provide each person with a named healthcare professional as a point of contact, to help ensure continuity of care. Our study participants thought that nurses may not be aware of the importance placed by patients on these relationships and this knowledge may be of value in their interactions with their patients. Our participants also suggested that ensuring a comprehensive handover from secondary to primary care services, but with ongoing access to specialist or extended services if needed, might serve to alleviate the feelings of isolation they experienced at the end of treatment. They also suggested that there should be increased availability of emotional and psychological support services, including the provision of non-medical interventions for ongoing side effects or feelings of isolation post-treatment. They considered that these additional services would support their transition into survivorship. Further work would be required to explore and evaluate how these recommendations could be translated into clinical practice.

#### *4.1 Limitations*

The authors acknowledge the limitations in our study were that it was small in size, retrospective in nature and the sample was self-selecting, which potentially limits the transferability of the findings. Furthermore, participants were all of white UK ethnic background so it is difficult to determine whether a more diverse participant sample would have generated different issues and concerns. The contribution of the researchers' role within the analysis must also be acknowledged as having a potential influence on information gathered and interpretation of meanings.

#### *4.2 Significance*

It is plausible that the many advances in cancer treatment and services over recent decades have led to the generalised assumption that patients' psychological and emotional needs are now met in the current care pathways. In this study we were permitted access to a distinct and rare historical cohort with severe and persistent long-term effects, and to a more recently-treated cohort. This afforded us a unique opportunity to identify those aspects of psychological and emotional need that have proved to be especially intractable, despite interventions and improvements in service design. Discussion of our findings highlights the ongoing importance for nurses and other healthcare professionals to recognise, acknowledge, and address these concerns within current cancer care pathways.

### **5. Conclusion**

Whilst there have undoubtedly been positive improvements in the experience of breast cancer care over the past few decades, the data from our sample of patients treated with radiotherapy for breast cancer suggests there remains a range of psychological and emotional needs and concerns that continue to endure. New initiatives in aftercare, such as the National Cancer Survivorship Initiative (Department of Health, Macmillan Cancer Support, NHS Improvement, 2010) and the Patient Guide on Survivorship (European Society for Medical Oncology, European Cancer Patient Coalition, and International Psycho-Oncology Society, 2018), are potentially helpful in addressing many of these on-going needs. These initiatives aim to promote supported self-management and



provide more comprehensive information provision, education, and signposting to relevant support services.

Our findings have highlighted the enduring concerns that patients have about their diagnosis and care. This is of value to nurses and other healthcare professionals at all stages along and beyond the acute breast cancer care pathway and to those involved in service design, underlining the ongoing need for recognising and acknowledging these concerns, even within the current cancer care pathway.

### **Acknowledgements**

We thank all participants for their willingness to take part in this study. We also thank the staff at the Breast Radiotherapy Injury Rehabilitation Service in the Royal National Hospital for Rheumatic Diseases (part of the Royal United Hospitals Bath NHS Foundation Trust) and the staff of the Breast Clinic in the Royal United Hospitals Bath NHS Foundation Trust for their assistance with participant recruitment. This study was funded by the Royal National Hospital for Rheumatic Diseases Donated Research Fund, Bath, UK.

### **References**

Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A., Richardson, A., 2009. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J. Clin. Oncol.* 27(36), 6172-6179.

Bahrami, M., Taleghani, F., Loripoor, M., Yousefy, A., 2015. Positive changes after breast cancer: A qualitative study. *J. Educ. Health Promot.* 4, 55.

Bowling, A., 2014. *Research methods in health: investigating health and health services.* McGraw-Hill Education, Buckingham, UK.

Cancer Research UK, 2017. Annual Report and Accounts.

[http://www.cancerresearchuk.org/sites/default/files/cruk\\_annual\\_report\\_2016-17.pdf](http://www.cancerresearchuk.org/sites/default/files/cruk_annual_report_2016-17.pdf) (accessed 22 May 2018).

Cancer Research UK, 2018. Breast Cancer Statistics.

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/survival#ref-0> (accessed 22 May 2018).

Capelan, M., Battisti, N.M.L., McLoughlin, A., Maidens, V., Snuggs, N., Slyk, P., Peckitt, C., Ring, A., 2017. The prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer. *Br. J. Cancer.* 117(8), 1113-1120.

Cheng, H., Sit, J.W., So, W.K., 2016. The Symptom Burden in Breast Cancer Survivors. *Current breast cancer reports.* 8(1), 40-46.

Delanian, S., Lefaix, J.L., Pradat, P.F., 2012. Radiation-induced neuropathy in cancer survivors. *Radiother. Oncol.* 105(3), 273-282.

Department of Health, 2000. The NHS Cancer plan: a plan for investment, a plan for reform [http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4009609](http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609) (accessed 2 January 2018)

Department of Health, Macmillan Cancer Support, NHS Improvement, 2010. The National Cancer Survivorship Initiative Vision. [http://webarchive.nationalarchives.gov.uk/20130123201114/http://www.dh.gov.uk/en/Publicationandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111230](http://webarchive.nationalarchives.gov.uk/20130123201114/http://www.dh.gov.uk/en/Publicationandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230) (accessed 22 May 2018)

Dunn, L.B., Langford, D.J., Paul, S.M., Berman, M.B., Shumay, D.M., Kober, K., Merriman, J.D., West, C., Neuhaus, J.M., Miaskowski, C., 2015. Trajectories of fear of recurrence in women with breast cancer. *Support. Care Cancer.* 23(7), 2033-2043.

Early Breast Cancer Trialists' Collaborative Group, 2005. Effects of chemotherapy and hormonal therapy for early breast cancer on recurrence and 15-year survival: an overview of the randomised trials. *Lancet.* 365(9472), 1687-1717.

European Society for Medical Oncology, European Cancer Patients Coalition and International Psycho-Oncology Society, 2018. Patient Guide on Survivorship. <https://www.esmo.org/Patients/Patient-Guides/Patient-Guide-on-Survivorship> (accessed 16 November 2018)

Ewertz, M., Jensen, A.B., 2011. Late effects of breast cancer treatment and potentials for rehabilitation. *Acta Oncol.* 50(2), 187-193.

Fenlon, D., Reed, E., Blows, E., Scanlon, K., Wray, J., Dewey, A., 2015. Moving forward: a qualitative research inquiry to inform the development of a resource pack for women following primary breast cancer treatment. *J. Psychosoc. Oncol.* 33(1), 85-105.

Figueiredo, M.I., Fries, E., Ingram, K.M., 2004. The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psychooncology.* 13(2), 96-105.

Hodgkinson, K., Butow, P., Hunt, G.E., Pendlebury, S., Hobbs, K.M., Wain, G., 2007. Breast cancer survivors' supportive care needs 2–10 years after diagnosis. *Support. Care Cancer.* 15(5), 515-523.

Kenyon, M., Mayer, D.K., Owens, A.K., 2014. Late and long-term effects of breast cancer treatment and surveillance management for the general practitioner. *J. Obstet. Gynecol. Neonatal Nurs.* 43(3), 382-398.

Lebel, S., Beattie, S., Arès, I., Bielajew, C., 2013. Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychol.* 32(6), 695.

Leventhal, H., Meyer, D., Nerenz, D., 1980. The common-sense representations of illness danger, in Rachman S. (Ed.), *Contributions to medical psychology* (Vol. 2). Pergamon, New York, pp. 17-30.

McGarry, S., Ward, C. Garrod, R., Marsden, J., 2013. An exploratory study into the unmet supportive needs of breast cancer patients. *Eur. J. Cancer Care.* 22, 673–683.

Markovitz, S.E., Schrooten, W., Arntz, A., Peters, M.L., 2015. Resilience as a predictor for emotional response to the diagnosis and surgery in breast cancer patients. *Psychooncol.* 24(12), 1639-1645.

Mehnert, A., Koch, U., 2008. Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *J. Psychosom. Res.* 64(4), 383-391.

NHS Improvement, 2012. <https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf> (accessed 6 January 2018)

Office of National Statistics, 2016. *Statistical bulletin: Cancer registration statistics, England: first release, 2016.*

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2016> (accessed 1 June 2018).

Pieters, H.C., 2016. "I'm Still Here": Resilience Among Older Survivors of Breast Cancer. *Cancer Nurs.* 39(1), E20-E28.

Pinquart, M., Fröhlich, C., Silbereisen, R.K., 2007. Cancer patients' perceptions of positive and negative illness-related changes. *J. Health Psychol.* 12(6), 907-921.

Pittathankal, A., Davidson, T., 2010. Care pathways for patients with breast cancer. *Trends in Urol. Gynecol. & Sexual Health* 15(2), 10-13.

Rosedale, M., 2009. Survivor loneliness of women following breast cancer. In *Oncol. Nurs. Forum.* 36 (2), 175-83.

Rowland, J.H., 2008. What are cancer survivors telling us? *Cancer J.* 14(6), 361-368.

Schmid-Büchi, S., Halfens, R.J., Dassen, T., van den Borne, B., 2011. Psychosocial problems and needs of posttreatment patients with breast cancer and their relatives. *Eur. J. Oncol. Nurs.* 15(3), 260-266.

Schroevers, M.J., Kraaij, V., Garnefski, N., 2011. Cancer patients' experience of positive and negative changes due to the illness: relationships with psychological well-being, coping, and goal reengagement. *Psychooncol.* 20(2), 165-172.

Shiozaki, M., Hirai, K., Koyama, A., Inui, H., Yoshida, R. and Tokoro, A., 2011. Negative support of significant others affects psychological adjustment in breast cancer patients. *Psychol. Health*. 26(11), 1540-1551.

Smith, J.A., Jarman, M. Osborn, M., 1999. Doing interpretative phenomenological analysis. In Murray, M., Chamberlain, K. (Eds.), *Qualitative health psychology: theories and methods*, Sage Publications Limited, London, pp. 218-240.

Tacón, A.M., 2011. Mindfulness: existential, loss, and grief factors in women with breast cancer. *J. Psychosoc. Oncol.* 29(6), 643-656.

Tighe, M., Molassiotis, A., Morris, J., Richardson, J., 2011. Coping, meaning and symptom experience: A narrative approach to the overwhelming impacts of breast cancer in the first year following diagnosis. *Eur. J. Oncol. Nurs.* 15(3), 226-232.

Williams, F., Jeanetta, S.C., 2016. Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study. *Health Expect.* 19(3), 631-642.

Wright, E.B., Holcombe, C. and Salmon, P., 2004. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ*, 328(7444), 864.