

'It's like being pushed into sea on a boat with no oars': Breast cancer survivorship and rehabilitation support in Ireland and the UK

Elizabeth Deery¹  | Katie Johnston¹ | Thomas Butler²

¹Department of Clinical Sciences and Nutrition, University of Chester, Chester, UK

²Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, UK

Correspondence

Elizabeth Deery, Department of Clinical Sciences and Nutrition, University of Chester, Parkgate Rd, Chester CH1 4BJ, UK.

Email: e.deery@chester.ac.uk

Abstract

Background: Cancer survivorship is associated with co-morbidities including anxiety, depression and cardiovascular disease (CVD). Rehabilitative care post-treatment is vital for survivors' psychological and physical well-being. The present study aimed to investigate breast cancer survivors' attitudes towards their health post-treatment; their awareness of co-morbidities associated with treatment; and their awareness of support systems available.

Methods: A qualitative research approach was employed, using semi-structured interviews with breast cancer survivors from the UK and Ireland. Data were analysed using thematic analysis. Eight breast cancer survivors were recruited through purposive sampling.

Results: Two themes emerged from the data: (1) health and rehabilitation post-treatment, which included mental and physical health and a desire to control one's own health in survivorship as well as a discussion around co-morbidities, and (2) access to support services in survivorship, which highlighted both positive and negative experiences of accessing support, as well as reasons for not accessing support in survivorship.

Conclusions: Access to rehabilitation support, including diet, exercise and stress management, is key to survivorship. Rehabilitation and support services need to be more readily available for survivors to aid them in this journey and to educate them on the increased risk of conditions such as CVD with cancer treatment. Utilising current cardiac rehabilitation models could be a solution to provide a holistic cancer rehabilitation, thus providing the lifelong support that cancer survivors both want and need.

KEYWORDS

cancer, cancer-journey, cardio-oncology, rehabilitation, survivorship

Key points

- Access to rehabilitation support, including diet, exercise and stress management, is key to survivorship; however, access to support differed and was lacking for many survivors.
- Longer-term comorbidities of cancer treatment were not fully understood. Therefore, there is a need for rehabilitation and support services to educate survivors on the increased risk of conditions such as cardiovascular disease with cancer treatment. These services must also address long-term risk through lifestyle factors, including diet and physical activity.

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- Utilising current cardiac rehabilitation models could be a solution to provide a holistic cancer rehabilitation, thus providing the lifelong support that cancer survivors both want and need.

INTRODUCTION

Breast cancer is the most common cancer in the UK and Ireland, with more than 150 new UK diagnoses daily between 2016 and 2018.^{1,2} Furthermore survival rates are increasing, with 5-year survival at 82% and 10-year survival rate at 76% in Ireland and the UK, respectively.^{1,2} This increasing survivorship is important to consider because the treatment of cancer has a profound effect on both physical and psychological wellbeing, with acute side effects including nausea, fatigue and loss of physical fitness and chronic side effects including the development of comorbidities such as osteoporosis and cardiovascular disease (CVD).² In an analysis of 2552 breast cancer survivors, 24% had at least one comorbidity at 5-year follow-up, with this increasing to 25% between 6 and 10 years.³ The absolute risk of dying from CVD following breast cancer ranges from 1.6% to 10.4%⁴ and this may be attributed to cardiotoxic effects of treatment such as radiotherapy, particularly if the heart is in the treatment field.⁵ Radiation-associated cardiovascular-toxicity may be progressive, and thus survivors may still deal with the effects of their treatment years after its completion.

The transition from 'patient' to 'survivor', when such chronic conditions can begin to develop, may be a period of uncertainty. The routine of actively receiving treatment has been reported as a coping strategy for some patients that is lost once treatment has been completed.⁶ The need to develop active behavioural strategies specifically for this transition, focusing on health practices, managing stress and coping with physical and psychological effects associated with cancer treatment, has been previously highlighted.⁶ Smith *et al.*⁷ reported that breast cancer survivors have a desire for information on lifestyle, nutrition and exercise support to promote their health and minimise risk of cancer recurrence, as well as access to available resources for ongoing support and counselling. Participants considered the most appropriate time to have this conversation to be toward the end of their treatment. Continuous care post-treatment is therefore vital for survivors' psychological and physical well-being.

Despite this, the after-care for breast cancer survivors varies globally and there is no standardised national approach.⁸ In 2009, Macmillan proposed a system of after-care that would include an end-of treatment assessment and risk stratification of the level of ongoing support likely to be needed by the survivor.⁹ In the UK, there is a nationwide service, Move More, which

encompasses behaviour change and physical activity (PA) interventions and has been shown to increase PA, health-related quality of life (QoL) and fatigue in participants.¹⁰ The need for a multidisciplinary team to offer support from the point of diagnosis throughout the cancer pathway was highlighted, as well as the need for cancer specific training for staff on such programs.

Despite a clear need for ongoing support, this is not always felt by survivors. A cohort of post-menopausal breast cancer survivors in Ireland raised concerns regarding survivorship care, with participants reporting to feel 'dismissed' when asking healthcare professionals (HCPs) for advice.¹¹ Some women felt that HCPs had not sufficiently informed them of the side effects experienced during survivorship. Additionally, women felt that medical reviews during survivorship were unsatisfactory and impersonal in nature.¹¹ These findings highlight the importance of educating patients of the chronic comorbidities of cancer, and the psycho-social impact of the diagnosis and treatment as well as a survivorship strategy or post-care plan.¹² Little is known however about whether this is the experience of breast cancer survivors.

The present study aimed to investigate breast cancer survivors' attitudes towards their health post-treatment; their awareness of co-morbidities associated with their treatment, including CVD; and their awareness of support systems available.

METHODS

Sampling and recruitment

Participants ($n = 8$) in Ireland and the UK were recruited through Facebook groups for breast cancer survivors, as well as via Twitter and Instagram, between 6 January and 15 February 2021. The recruitment advertisement was shared 71 times; 42% of the shares came from Facebook, 52% from Twitter and 6% from Instagram. Guest *et al.*¹³ reported that theoretical saturation can be achieved within the first six interviews; thus, the target sample size was set between six and 15 participants.

The study's inclusion criteria comprised: female breast cancer survivors; in remission for a minimum of 2 years; 18 years and older; a resident in Ireland or the UK; possessing a phone or computer with web browser access; and being willing to attend a recorded hour long interview at a time that was convenient to both themselves and the lead researcher.

Participants were excluded from the research if they were unable to understand written and spoken English and/or if they had known or diagnosed CVD, type 1 or type 2 diabetes or chronic kidney disease, which was established at the stage of consent. These participants were excluded because of their potential increased awareness of CVD. Seventeen participants expressed an interest in the research; nine of the participants met the exclusion criteria and therefore did not participate in an interview.

Design

The research design was formulated following guidance by Moisey *et al.*¹⁴ and Swift and Tischler.¹⁵ The work followed an inductive and reflexive approach, thus acknowledging a relativist ontology. Participants were interviewed via Microsoft Teams (Microsoft Corp.) at a pre-arranged time. Online interviews were utilised as a result of Covid-19 restrictions and to allow for recruitment to occur from a wider sample of participants. A semi-structured interview guide was developed using open-ended questions and prompts. The interview was broken up into five sections: demographic information; the participants' breast cancer journey; the idea of health to a survivor; knowledge of comorbidities associated with cancer treatment; and knowledge of rehabilitation support for survivors. This allowed the researcher to identify and make connections between knowledge regarding the effects of an individual's treatment, as well as connections between geographical locations and access to services. The participants had 24 h to withdraw from the study once they had completed the interview. Following the interview, participants were directed to support groups including MacMillan and Breast Cancer Now, and information surrounding their health post treatment as well as recommendations surrounding a healthy diet and lifestyle in a follow-up email. Following a 24-h period, data were transcribed verbatim, using an AS-2400 Transcription Kit (Olympus). Ethical approval was granted by the institute's Research Ethics Committee in January 2021 (KT/JB/2021).

Data analysis

Data were thematically analysed using the five-step approach outlined by Braun and Clarke.¹⁶ Thematic analysis aims to identify patterns of meanings and themes within a data set, which may be both implicit and explicit, thus providing the necessary groundwork for establishing models of human thinking, feeling and behaviour. This method of analysis acknowledges the importance of the prevalence of themes without sacrificing depth of analysis.¹⁷ Familiarity of the data began with listening to individual transcripts before reading transcripts and checking for accuracy. Transcripts were then read line-by-line and initial

codes were generated. These codes were then examined, and similar codes were clustered together to form candidate themes. These themes were then reviewed and refined to ensure that they reflected the coded extracts and the entire data set. Extracts to illuminate the themes and sub-themes were then selected. Ongoing reflexivity was practiced through discussions of emerging data, presentation and questioning of the data between the first and second investigator. These were then presented to the third investigator for further interrogation of the themes emerging. This process served to encourage dialogue, reflexivity and critique of interpretation of the data through peer-debriefing, hence ensuring trustworthiness, rigor and accuracy of the data.

RESULTS

Participant characteristics are shown in Table 1. Eight participants were recruited to the study. All participants were female, aged 45–64 years, had been diagnosed with

TABLE 1 Participant characteristics

	<i>N</i>
<i>Age (years)</i>	
45–49	1
50–54	1
55–59	2
60–64	4
<i>Place of residence</i>	
Cork, Ireland	1
Donegal, Ireland	1
Dublin, Ireland	1
Kilkenny, Ireland	1
Laois, Ireland	1
Bristol, UK	1
Chester, UK	1
Leeds, UK	1
<i>Treatment course</i>	
Lumpectomy	3
Lumpectomy including lymph node removal	2
Mastectomy	1
Bilateral mastectomy	2
Chemotherapy	4
Radiotherapy	4
Targeted biological therapy	3
Hormone therapy	5

breast cancer and received treatment in the UK or Republic of Ireland. Participants were included from both urban and rural locations. All participants received curative treatment for their breast cancer. The most common treatment pathway used among participants was hormone therapy, including tamoxifen and anastrozole, followed by chemotherapy and radiation. Six out of eight participants had surgery in their treatment pathway, with this ranging from a lumpectomy to bilateral mastectomies and reconstruction. Five of the six participants who had surgery received at least two other forms of treatment. Seven of the eight participants received more than one form of treatment. The treatment received by each participant is shown in Table 2.

The average length of interviews was 30 min, equating to 52 pages of transcript. Two themes (Figure 1) and six sub-themes were generated from the transcripts with illustrative quotes chosen for each (Table 1).

The core concept of holistic health and survivorship

The core concept that emerged was an individualised and holistic approach to health, focussing on mental and physical well-being. Survivors considered access to post-treatment rehabilitation support a core component of their survivorship care pathway, regardless of whether they had a negative or positive experience of accessing support in survivorship. A holistic approach to health involves a range of HCPs. This approach allows a patient to be assessed and treated by the HCP that are required to treat any co-morbidities or side effects of treatment following its completion; for example, a dietitian to treat chemo-induced malnutrition, a physiotherapist to aid movement following a mastectomy and a psychologist to

provide support following the completion of treatment (Table 3).

One participant felt that where ‘*everything had fallen down*’ in terms of the level of care received throughout their cancer journey was the aftercare following the completion of their treatment and at the beginning of their survivorship:

It was like ... being pushed into sea from shore on a boat with no oars ... what now? What do I do? ... I've had to do all this myself, and I don't think that's right

The participant felt that it was her ‘own research’ and ‘determination’ that enabled the investigation and

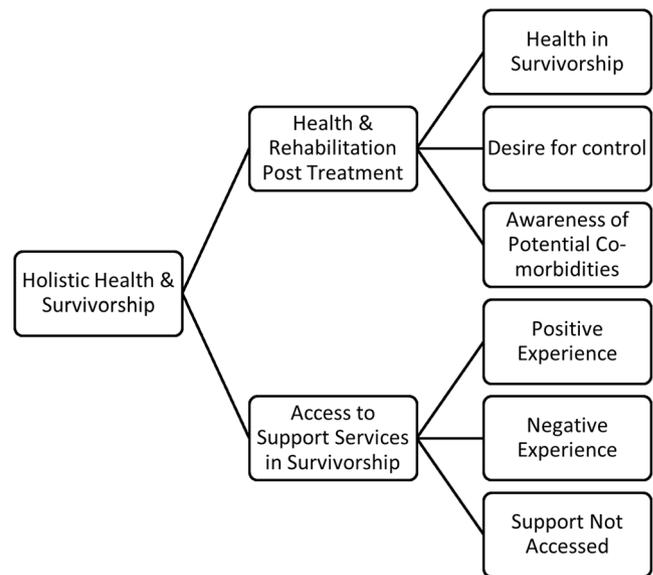


FIGURE 1 Themes generated from the data

Participant	Treatment
1	Lumpectomy with lymph node removal, chemotherapy, radiotherapy, hormone therapy (tamoxifen)
2	Lumpectomy with lymph node removal, chemotherapy, targeted biological therapy (herceptin and pertuzumab) and hormone therapy (anastrozole)
3	Lumpectomy, chemotherapy, targeted biological therapy (herceptin)
4	Bilateral mastectomies and reconstruction
5	Radiotherapy
6	Lumpectomy, radiotherapy, hormone therapy (tamoxifen)
7	Lumpectomy, radiotherapy, hormone therapy (arimidex) full mastectomy and failed reconstruction
8	First diagnosis: chemotherapy, targeted biological therapy (herceptin and trastuzumab) Second diagnosis: double mastectomy, hormone therapy (letrozole and zoladex)

TABLE 2 Treatment received by each participant

TABLE 3 Themes, sub-themes and illustrating quotes

Theme	Subtheme	Illustrating quote
1. Health and rehabilitation post-treatment	Health in survivorship	<i>'I was lucky that physically my rehabilitation was easy ... but I suppose psychologically that's the area that is harder ... It's a more complicated rehabilitation [the psychological] because it's about you know how you think and how you get back into your life and you know your attitudes to some things change ... I suppose the counselling was the biggest part of my rehabilitation' (P4)</i>
		<i>'Rehabilitation for me means physical and psychological ... going back to my full potential for my abilities in those areas ... psychological one is a bit more difficult because everyone is different ... it means going back to my physical abilities and my psychological wellbeing ...' (P1)</i>
	Desire for control	<i>'I am determined to get back, but I mean whether I ever get back to what I was I don't know' (P2)</i>
		<i>'I am back in Pilates and I've changed from mat classes to reformer classes because its more on the muscle, its's more intense ... I still don't drink and I don't smoke and we are very careful about the majority of foods' (P3)</i>
	Awareness of potential co-morbidities	<i>'... it was the fact that my fertility would be impacted ... with the chemotherapy ... and that was quite traumatic for me' (P1)</i>
		<i>'I'd read about what could happen, but you are in that situation, and I still think it ... it's better than cancer ... I was given a leaflet that listed what might happen and two of them did' (P6)</i>
		<i>'I was conscious that I could be restricted in my kind of movement and strength in my shoulders because the surgery involved ... its muscles contract in an unusual way and I suppose it took me a while to adjust to that' (P4)</i>
		<i>'I had been diagnosed with osteoporosis before my first diagnosis ... I was very worried at the time I was going onto the Arimidex about what that would to my bone health' (P7)</i>
2. Access to support services in survivorship	Positive experience	<i>'You met a lot of other people [at a support group] who were able to tell you things that they found useful or didn't find useful ... So that interaction with other people who had been in the same position I thought was very beneficial' (P6)</i>
	Negative experience	<i>'I felt where everything has fallen down for me is the follow-up care ... I've had to do this all myself, and I don't think that's right ... it was like being pushed into sea from shore on a boat with no oars ... like what now? What do I do?' (P3)</i>
	Support not accessed	<i>'... if I had needed it [support], I didn't have anywhere to access it' (P4)</i>
		<i>'Well, there was a support group there ... I didn't think I needed it ... I suppose if my cancer had been farther advanced, I probably would have needed it more' (P5)</i>
		<i>'I didn't avail of any of the psychological services afterwards [failed reconstruction] ... I did have advice obviously from the nurse specialists ... so I would have dropped in to see them a couple of times ... but I haven't engaged much with the services this time around as I feel there's not much they can do for me' (P7)</i>

treatment of chemotherapy induced Achilles tendonitis and plantar fasciitis. They spoke of having to source their *'own physio ... own MRIs ... [and] own X-rays ...'* to investigate a co-morbidity of her cancer treatment. This participant felt that they *'... should have been able to go back in where [they] had [their] treatment and have somebody take you seriously.'*

Three two themes formed around this core concept and will be reported individually in sub-sections as the

following: (1) health and rehabilitation post-treatment and (2) access to support services.

Health and rehabilitation post-treatment

Participants discussed what rehabilitation meant to them and all participants discussed a multi-faceted and holistic rehabilitation process. This included support groups,

information and both physical and psychological well-being. For the survivors who were interviewed, an important aspect of rehabilitation appeared to be returning to some form of normality:

I suppose the word rehabilitation to me is about getting from a place where something has stopped you doing what you would normally do to get back to where you want to be, or as close to that as possible. So, in terms of my journey, it's about getting back to ... my life in the best way that I can (P8)

I suppose it's going back into a normal life ... you're in a sort of bubble but it's quite a secure bubble ... So, I suppose rehabilitation is what life is going to be from now on (P6)

This theme generated sub-themes, which will be explored in turn, including mental and physical health, control and potential co-morbidities.

Health in survivorship

All participants discussed both physical and mental wellbeing in survivorship and reflected on the role of rehabilitation in rebuilding their health:

Rehabilitation means I'm good enough to try to increase my stamina and do more exercise ... because ... I don't seem to have the stamina to do things. I think I can do them and then I'm absolutely wiped out (P2)

Another participant highlighted the importance of taking control of their health in survivorship:

It [the cancer diagnosis] made me very conscious of the control I had of my health after the treatment had finished ... I was very conscious of what I could do to make sure I stayed healthy (P6)

All participants discussed their exercise in survivorship, with differing experiences of returning to exercise in survivorship. One participant explained:

Oh it [my exercise routine] is still the same, ... I try and get out, I'm back working, I try and get out for a walk every day, I'm not quite up to my 5K but I'm getting there ... slowly, slowly, steady, steady wins the race. I do my Pilates online (P3)

Another highlighted the different experiences they had between physical and psychological rehabilitation:

I was lucky that physically my rehabilitation was easy ... but I suppose psychologically that's the area that is harder ... it's a more complicated rehabilitation because it's about, you know, how you think and behave and how you get back into your life, and you know, your attitudes to some things change ... (P4)

Some participants discussed prioritising themselves more, spending less time worrying about the 'mundane', and employing mindfulness and meditation techniques to help manage stress. A breast cancer diagnosis and subsequent treatment appeared to put life into perspective for the survivors, whether it was actively looking after their health through eating well and exercising more or managing stress within their lives:

I mean the most important thing for me in terms of staying well is to avoid stress, try not to let myself get stressed out. I try not to let myself get burnt out (P7)

As discussed in a later theme, not all participants felt they had access to adequate support during survivorship. One participant recognised this as having a negative impact on her mental wellbeing during survivorship:

That's [psychological support] quite important actually and maybe this is something that I missed a bit ... I felt that I was on my own ... (P1)

Desire for control

Survivors stated that they wanted to actively be in control over their health during their survivorship with some explaining it was something they felt they had taken for granted before their diagnosis:

'I've always wanted to be healthy ... everybody wants to be healthy. But when you get the [cancer] diagnosis, you do realise, you realise that this isn't in your control anymore (P6, view of health after diagnosis)

But it [a breast cancer diagnosis] made me very conscious of the control I had over my health after the treatment had finished. And I was very aware that both exercise and diet were going to have a lot to do with the future for me (P6, view of health as a survivor)

Some participants explained they were determined to maximise their rehabilitation, taking all measures they felt they could:

I am determined to get back, but I mean whether I ever get back to what I was, I don't know (P2)

I am back in Pilates, and I've changed from mat classes to reformer classes because its more on the muscle, its more intense ... I still don't drink and I don't smoke and we are very careful about the majority of foods (P3)

Diet is critical really, I think, exercise is critical, maintaining a healthy weight and a maintaining a healthy mindset ... (P7)

However, that sense of control was not experienced by all survivors, with one participant describing survivorship and recovery as a 'lottery', illustrating a sense of a lack of control:

I knew people who had died from breast cancer, and I knew people who had recovered well, and it just seemed like a lottery in some ways ... I think it [a second diagnosis] just had reinforced for me that it is kind of a lottery once you have cancer ... (P7)

Awareness of potential co-morbidities

Each survivor had a different experience of chronic conditions following their cancer treatment, including plantar fasciitis and tendonitis, tenderness of the breast, infertility, restriction of physical movement, pneumonitis and nose bleeds. An awareness of potential co-morbidities arose when discussing the diagnosis and early treatment journey with participants. The source of this knowledge was not always discussed, but some participants explained they'd received leaflets from their medical team. One participant explained:

I'd read about what could happen, but you are in that situation, and I still think it ... it's better than cancer ... I was given a leaflet that listed what might happen and two of them did (P6)

Two survivors identified the potential risk to their cardiovascular health because of the treatment that they had:

I knew that there might be side effects in relation to that [radiation treatment], so I'd be mindful of that, I've had my heart checked a couple of times ... (P7)

I asked 'why?' [they were receiving an echocardiograph]. And I was told it was because of the treatment, but I said 'why? ... Like what's in the treatment that you're doing this [echocardiograph]?' and then eventually I wangled the information out of them (P3)

Although these two survivors recognised the risk to their cardiovascular health and employed measures to continue to look after it, other survivors did not appear to be aware of this risk. This included survivors who were receiving cardiovascular tests as part of their aftercare. One survivor who had received 3-monthly scheduled echocardiograms following their treatment could not recall why she was receiving aftercare specific to her cardiovascular health:

Is that [the risk of CVD] why I had a ... an echocardiogram? ... They didn't explain that really, I don't think. Mind you, it's all a bit of a blur to be honest (P2)

When introduced to this risk, one survivor expressed an interest to learn more about it and its association with cancer treatment:

What is the link [between CVD and breast cancer]? What is the mechanism of that? (P1)

Access to support services in survivorship

Survivors reported one of three experiences when accessing support during their survivorship. Positive experiences of support and support services that provided tools to aid them during their survivorship; negative experiences of accessing support that left survivors feeling alone in their survivorship journey; or survivors felt that they did not need support in their survivorship journey.

Positive experience

Survivors discussed accessing support through several different pathways, including psycho-oncology services provided by their hospital, Facebook Support Groups, independent charities such as Penny Brohn and Macmillan, and Health Service Executive (Ireland) programs curated specifically for breast cancer survivors. Survivors reported the benefits of support and engaging with women who had been through similar journeys:

I can't sing their [a UK based charity] praises enough. I mean, I know, I'm probably

slightly biased, [due to family links to the charity] but ... they've been phenomenal and invaluable (P8, positive experience of accessing support]

Survivors who had positive experiences of support recognised the disparities of geographical location and access to support that other survivors may face. This was something which is covered in the negative experience sub-theme:

I'm very aware that had I lived somewhere else, I wouldn't have had access to the support I had, and my, my outcomes could have been different, you know (P8)

Negative experience

Some survivors felt alone during their survivorship journey, feeling they had no means to access support after their treatment had finished. These survivors either accessed support through independent charities or online groups on platforms such as Facebook.

... the majority of support I've found, and I know it's an awful thing to say, but it's actually been support groups on Facebook (P3, negative experience of success to support)

One survivor explained that HCPs '*have to hear what's being said*' when it comes to rehabilitation and survivors seeking support for both physical and psychological health. This survivor described feeling that she wasn't being listened to by her care team during her survivor journey, and felt she had to seek follow-up care alone. Locality, particularly amongst the survivors based in Ireland, was discussed in relation to access to support services. The concept of access to support services in rural versus urban areas emerged among all survivors who were in the Republic of Ireland (62.5%). Several survivors who lived in rural areas had to travel to their cancer treatment, with one survivor travelling 300 km to receive radiotherapy weekly. By contrast, a survivor who lived the urban area of Dublin travelled 3 km to receive the same treatment. This had a clear impact on how and if they accessed support services during their survivorship:

... [I'd be told] well you know you've got to go to your local area [for support]. Well, I'm like there's no one in my area (P3, County Cork, ROI)

So, I availed of a local support group rather than one near the hospital ... the hospital was in Dublin, so it was a bit of a distance (P4, County Laois, ROI)

... you just built up on the community of people yourself, it was just our own little network, there was nothing formal after that and that's probably to do with, you know, the way we're located (P6, County Donegal, ROI)

For context, the Irish Cancer Society provided a list of cancer support services in the four provinces (26 counties) of the Republic of Ireland (ROI). Figure 2 illustrates the disparity in cancer support across the ROI; seven counties have no cancer support services, whereas one county has seven cancer support services. The map highlights how services are limited in rural areas of the country, compared to those in urban areas as reflected by participants of this study.

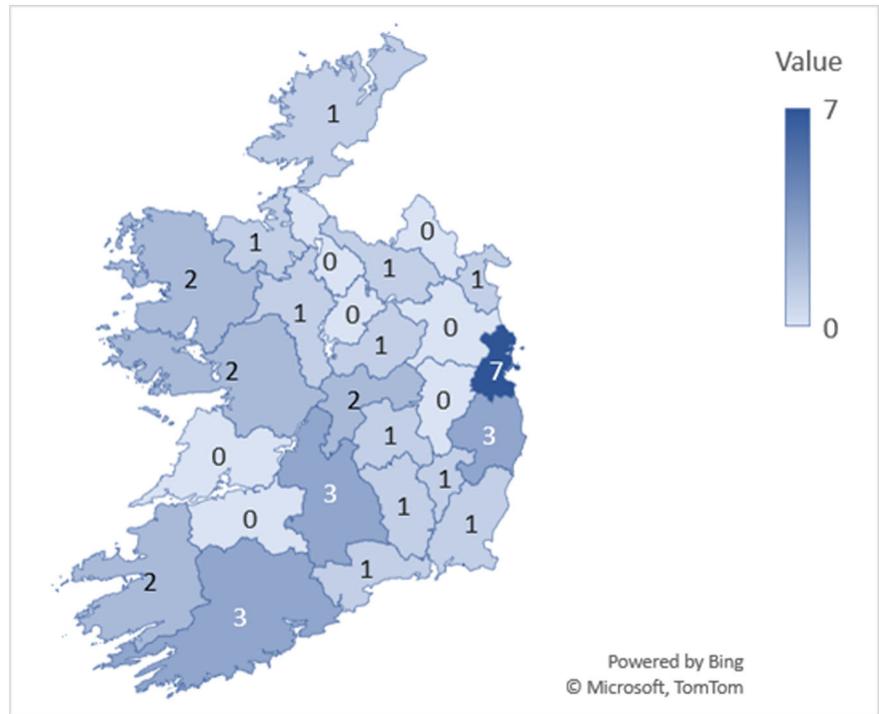
Support not accessed

Some survivors did not access support during their survivorship for one of two reasons: they felt that they did not think they needed it, or they felt that the support services could not do anything for them in their survivorship journey. One survivor explained that they 'just get on with it' and used their family as a support system. Another added:

I know there are places that you can ring if you need to talk to them. And there are groups there to help you through it but I ... I found that I didn't need that support (P5)

Another felt that they didn't want to play the 'victim' role of a cancer survivor and therefore did not access support groups. This survivor reported a feeling of guilt after receiving her second diagnosis. They explained how they felt that their 'drinking to excess' may have contributed to the recurrence of cancer, as a result of the 'one in eight' health promotion campaign in the Republic of Ireland that relates one in eight breast cancers to alcohol consumption. Therefore, they felt that seeking treatment for alcohol abuse was a 'more important journey' than seeking psychological support specifically for their cancer: '*I actually sought treatment for alcohol abuse subsequently the following year and I'm now sober, I don't drink at all. And I kind of felt that that shifted things completely for me*'. This participant also explained how the support accessed in this group helped with their cancer survivorship journey:

FIGURE 2 Location of cancer support services



I suppose in terms of the breast cancer, I would deal with it in terms of my recovery programme, really it would be part of that in terms of a 12-step programme. You know, things that happen in life (P7)

This experience further reiterates the uniqueness of each cancer survivors' journey and the varied range of support systems that are accessed and required.

DISCUSSION

The present study aimed to investigate health during breast cancer survivorship and survivors' access to and awareness of rehabilitation support in survivorship. It emerged that, although survivorship is a unique experience and the pathways that each survivor takes may differ, a holistic approach to health appeared to be a key aspect of survivorship, including diet, exercise and stress reduction. Unanimously, access to rehabilitation support was considered a to be a vital component of survivorship care; however, access to support differed and was lacking for many.

Health was considered a principal aspect of survivorship for every participant. Breast cancer survivors expressed a lack of control over their health after they received their diagnosis, which, for most, resulted in them prioritising areas they could control in survivorship such as diet, exercise and stress reduction. Although all participants discussed their diet prior to diagnosis, suggesting they understood it to be important to general

good health, only one raised diet in relation to their survivorship, perhaps highlighting a gap in the knowledge of nutrition in survivorship. This is pertinent because females undergoing chemotherapy have been reported to be at a high risk of malnutrition¹⁸ and breast cancer patients have been reported to experience changes in weight including weight gain.¹⁹ Our findings are perhaps reflective of a lack of patient education regarding nutrition in cancer recovery. A 2020 study reported that only 15% of healthcare organisations, cancer charities and support groups provided nutrition guidance for cancer patients, whereas just 9.3% provided guidance for cancer survivors.²⁰ This is echoed by the findings of de Kruijff *et al.*¹⁹ who reported that breast cancer patients undergoing chemotherapy experienced little dietary support from HCPs during treatment despite this treatment often negatively impacting dietary intake, with those reporting poorer intake experiencing more fatigue and perceiving less opportunities to be physically active. Research shows that cancer diagnosis alone is not sufficient to bring about changes to dietary intake, therefore highlighting the role of intervention to facilitate change.²¹ Taken together, this evidence suggests there is a lack of education regarding nutritional guidance for cancer patients and survivors. This is clearly an area where dietitians could make a significant contribution to improving patient outcomes and future work should explore the role of the dietitian in cancer survivorship.

There also appeared to be a lack of understanding regarding longer term co-morbidities of cancer-treatment. Only two participants raised the risk of

CVD with treatment despite this being a primary cause of death among cancer survivors.²² It appears that more must be done to provide survivors with an awareness of this risk. Clinicians treating breast cancer must be comfortable with addressing the longer-term impacts of treatment, including cardiotoxicity, so that survivors can be educated toward appropriate health-behaviour change and screening.¹² This might include dietary guidance as previously explored within this work. Within our study, some participants expressed a desire to understand all possible co-morbidities of treatment, whereas others felt that discussing the 'mights' may have contributed to feelings of stress and being overwhelmed. Some participants found that receiving information leaflets was helpful because they could take the information in at their own pace, whilst others found the process to be a 'bit of a blur'. This reaffirms the need for survivors to have access to rehabilitation support that individualises their needs and provides a care plan accordingly, as well as identifying and educating survivors about co-morbidities that they may not be aware of.

Psychological support in survivorship was considered important by participants within this study. Survivors who had access to support (e.g., psycho-oncology services or counselling) reported that they continued to use the tools that these services had provided them with throughout their survivorship journey. One participant explained how strategies learnt during their alcohol-support group helped in navigating their cancer-recovery, highlighting that support looks different for all survivors. A recent consensus view from Macmillian, the Royal College of Anaesthetists and the National Institute for Health Research reported that, despite the area being in its infancy, psychological intervention shows promising psychosocial outcomes including anxiety and depression albeit in the perioperative and not the survivorship period.²³ Many of the survivors in our research felt that psychological rehabilitation was more challenging than physical rehabilitation, and also reported feeling unsupported during their survivorship journey. This resonates with findings of similar literature.^{11,24} These findings suggest that there is an urgent need to progress the support that patients and survivors have access to in the period from diagnosis, through treatment, and into survivorship.

There were mixed experiences regarding access to support in survivorship. Notably, survivors located in Ireland raised disparities in accessing support services in rural and urban locations. The Irish Cancer Society provides a list of support services available to allow for comparison. Urban areas, such as Dublin, have three or more support centres listed, whereas more rural counties, such as Donegal, only have one support centre listed. This had a clear impact on how and whether survivors accessed support services. This is in agreement with findings by Haigh *et al.*²⁵ who reported the physical isolation rural cancer survivors may experience in

comparison to more urban counterparts. In addition to physical barriers to support, one survivor in this study felt that she was not listened to when she raised concerns during her survivorship. This survivor described her transition from 'patient' to 'survivor' as being pushed into sea on a boat with no oars. This experience has been noted in the literature, with Meade *et al.*¹¹ reporting that some breast cancer survivors feel 'dismissed' by HCPs when they raise concerns. Clearly, the transition from active treatment to survivorship care needs to be considered as continuous as the transition is from diagnosis to active treatment for patients.

Participants stated that they would like access to a rehabilitation or support centre that focussed on the 'whole' person. Despite this, many participants had no awareness of rehabilitation or cancer support centres available to them. The Independent Cancer Taskforce²⁶ recommended a national review of the cancer rehabilitation workforce and promoted the role of allied health professionals in multi-disciplinary teams, as a result of inconsistencies in access across the cancer pathway. Despite advances in the field, clearly more must be carried out to improve access to rehabilitation and support in survivorship; however, it will also be important to do this in a streamlined and efficient manner drawing upon proven successful models. The British Association for Cardiovascular Prevention & Rehabilitation (BACPR) provides specific standards and core components for cardiac rehabilitation. The core components are long-term strategies for disease management, promoting lifestyle and risk factor management, psychological health, supporting health behaviour change and education, addressing medical risk management, and encouraging audit and evaluation of practice.²⁷ These core components are clearly transferable to a cancer rehabilitation model and embedded within them is the importance of a multidisciplinary team with respect to providing patient care, including dietitians. This is very much in line with the components of the Move More service.²⁷ It may be that, given the increased survival rates from cancer and the potential for latent cardiotoxic effects, cardiac rehabilitation services are required to accommodate cancer survivors in future. Current investigations provide an argument that such cardiac rehabilitation models are feasible and can improve cardiorespiratory fitness and QoL in cancer survivors.²⁸ More recently Zvinovski *et al.*²⁹ have shown this model to be feasible in breast cancer patients ($n = 18$). In a 14-week cardiac rehabilitation intervention, there were significant improvements in patient reported PA, fatigue and QoL. This occurred without any significant improvement in CVD risk factors; however, this is likely a result of overall adherence to the study being too low to bring about physiological improvements (60%). This is in agreement with findings by Turner *et al.*³⁰ who reported that only 57% of interventions had targets that meet government PA guidelines, with only

62% of those reporting adherence of > 75%. Despite this, however, improvements in aerobic fitness were seen at 2, 3 and 6 months. These findings suggest that early implementation of a rehabilitation program could be considered for cancer patients and survivors.

The limitations of the present study are acknowledged. Although the study employed a relatively small sample, the methods employed to ensure rigor and trustworthiness of the data enhance the credibility of findings.

CONCLUSIONS

Our findings in conjunction with the extant literature highlight that rehabilitation and support services need to be more readily available for to cancer survivors. Furthermore, there needs to be education regarding the increased risk of CVD with cancer treatment, as well as risk-reducing strategies to manage this. Cardiac rehabilitation models may be a feasible means of delivering cardio-oncology care to cancer survivors. This could provide a holistic approach to survivorship care and a seamless transition from 'patient' to 'survivor', giving the lifelong support that cancer survivors both want and need.

AUTHOR CONTRIBUTIONS

Elizabeth Deery: Methodology, Analysis, Writing – original draft, Visualisation, Administration, Supervision. **Katie Johnston:** Conceptualisation, Investigation, Analysis, Writing original draft. **Thomas Butler:** Conceptualisation, Methodology, Writing – review & editing, Visualisation, Supervision.

ACKNOWLEDGEMENTS

We thank each of the participants of this research for sharing their experiences of survivorship for this work.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

ORCID

Elizabeth Deery  <http://orcid.org/0000-0002-2492-8001>

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jhn.13086>

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people living with and beyond cancer. *Cochrane Database Syst Rev.* 2018;9(9):CD010192.

AUTHOR BIOGRAPHIES

Elizabeth Deery, Doctor, is a senior lecturer in Exercise Physiology at University of Chester, and member of the BACPR, with a particular interest in the prevention, treatment and management of lifestyle-related conditions.

Katie Johnston is a registered dietitian and is currently completing a PhD at University College Cork focussing on cancer survivorship and the accessibility to services and support that patients have throughout and beyond treatment.

Thomas Butler, Doctor, is a registered dietitian and senior lecturer in Nutrition and Health at Edge Hill University, and a Scientific Officer for the BACPR.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Deery E, Johnston K, Butler T. 'It's like being pushed into sea on a boat with no oars': Breast cancer survivorship and rehabilitation support in Ireland and the UK. *J Hum Nutr Diet.* 2022;1–12. <https://doi.org/10.1111/jhn.13086>