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**Survivorship care for postmenopausal breast cancer patients in Ireland: what do women want?**

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## **Abstract**

**Purpose:** The aim of this study was to identify the concerns of postmenopausal breast cancer patients in Ireland and inform the development of a survivorship care plan.

**Method:** A qualitative participatory approach was used. Focus group interviews (n=6) with 51 women were undertaken. Following analysis of the focus group discussions, two nominal group technique (NGT) (consensus workshops) involving representatives (n=17) from each of the six focus groups were held.

**Results:** Ten key issues were highlighted by women in the focus groups and these were prioritised at the consensus workshops. The most important issues in survivorship care planning prioritised by the women were as follows: meet the same healthcare professional at each review visit; contact number of a named person that you can contact if you have any concerns between review visits; at each review visit, have a physical examination and blood tests and explanation from HC professional outlining if follow up scans needed and if not, why not; information on signs and symptoms of recurrence; advice on diet, exercise, healthy lifestyle and advice on coping and pacing yourself; information and management of side effects of therapy-long and short term.

### **Conclusion:**

Survivorship care planning for breast cancer is underdeveloped in Ireland. There is a lack of consensus regarding its provision and a lack of structured approach to its implementation. This study demonstrates the role of postmenopausal breast cancer patients' involvement in identifying their needs and reports that continuity of care was their top priority and the need for an adoption of a survivorship care plan was emphasised by participants.

**Key words:** breast, cancer, focus group, nominal group technique, survivorship, care plan.

## **Introduction**

Internationally, breast cancer is the most common non cutaneous malignancy among women. In the US, breast cancer survivors account for 23% of more than 10 million cancer survivors (Cappiello et al., 2007) and long term survival of breast cancer patients is high with 5 year survival rates of almost 90% (Runowicz et al., 2016). In Europe, there are currently 10 million cancer survivors diagnosed from 2000 - 2007 with 280,000 survivors currently in Ireland. Cancer survival has generally been increasing with survival rates in Ireland for female breast cancer patients increasing by 5% between 1995-1999 and 2000-2007 (National Cancer Register (NCR), 2014). These numbers are expected to grow dramatically given the aging population and the expected increased incidence of cancer over the next two decades. The total numbers of new female breast cancer cases is projected to increase by 130% between 2010 and 2040 (NCR, 2014). Improvements in screening and early detection, coupled with successful adjuvant treatments, have led to improved survival rates for breast cancer patients and more women are now living with breast cancer as a chronic condition (Haq et al., 2013). Traditional routine follow up visits were concentrated on detecting recurrent or new primary breast cancers. However many studies highlight the unmet needs of cancer survivors, fuelling the discussions for comprehensive survivorship care (Brennan et al., 2011; Thompson et al., 2014).

Evidence suggests that breast cancer survivors have unmet physical and psychosocial needs (Maher and Fenlon, 2010), and live with a sense of 'permanent treat to the self' (Hubbard and Forbat, 2012 p. 2030). Postmenopausal breast cancer patients experience a variety of symptoms associated with therapies given to prolong survivorship (Chim et al., 2013; Pan et al., 2016). Thus the need for a co-ordinated

approach to their care is required. The use of survivorship care plans provides a comprehensive and coordinated approach to care (Shewbridge et al., 2014; Rushton et al., 2015; Palmer et al., 2015). Over a decade ago the Institute of Medicine (US) (2005) first highlighted the importance of recognising survivorship cancer as a distinct phase of cancer care. Four essential components of survivorship care were outlined and included prevention, surveillance, intervention and coordination of care. The Institute of medicine recommended that cancer patients be provided with a comprehensive care summary and follow-up plan that is clearly explained and reviewed on discharge with an emphasis on addressing health care and quality of life issues facing cancer survivors. The National Comprehensive Cancer Network and the American Society of Clinical Oncology published evidence and consensus based survivorship care guidelines for breast cancer patients in order to help survivors reach optimal health and quality of life (Runowicz et al., 2016).

Survivorship care plans comprised a record of diagnosis and stage, treatments and toxicities and side effects as well as recommendations for surveillance testing management of long term treatment related effects, monitoring for potential late effects, prevention and health promotion. It was envisaged that survivorship care plans improved patient knowledge with regard to their cancer history and follow up care, increased patient confidence in obtaining appropriate care post treatment and improved communication with and among providers (Faul et al., 2012; 2014).

Survivorship care planning involving breast cancer patients in its development internationally. Moreover, in the Irish healthcare setting survivorship care plans are not routinely adopted into the follow up care of breast cancer patients, and currently, follow

up care for breast cancer patients is provided by breast surgeons and medical oncologists (National Cancer Control Programme (NCCP), 2010). In Ireland there is lack of consensus regarding the most appropriate model of follow up care and whether it should remain in the acute hospital setting under medical supervision or be carried out by general practitioners in the community setting. Lifelong intensive hospital based follow up is neither sustainable nor beneficial to patients in terms of reducing mortality (NCCP, 2010). The nurse led model of follow up care has been researched with no decrease in the detection of recurrences when compared to medical follow up and high levels of satisfaction with the level of care provided (Lewis et al., 2009). Oncology nurses are ideally placed to provide this care but it is imperative that it is evidence based and of high quality (Bessen et al., 2014; Shewbridge et al., 2014; Rushton et al., 2015).

We chose post menopausal breast cancer patients for this study for a variety of reasons. The median age at diagnosis of breast cancer is 61 years with 43% of patients diagnosed over the age of 65 years (Runowicz et al., 2016). However, from our clinical experience, this older cohort of patients are less vocal regarding their needs compared to younger breast cancer patients. In addition, post-menopausal breast cancer patients with hormone receptor breast cancer will be offered endocrine therapy. The addition of aromatase inhibitors to their treatment regime, while beneficial, can have significant impact on quality of life as it is associated with loss in bone mineral density and arthralgia. The aim of our study was therefore to give this specific cohort of patients a voice and facilitate them to become active in their survivorship care planning.

## **Method**

This was a qualitative study employing nominal group technique as part of focus group interviews. This study aimed to illicit the views of postmenopausal breast cancer patients on what was important for them to include in a survivorship care plan and how survivorship care should be delivered. Participants were recruited through the outpatient clinics of two cancer centres in Ireland. Ethical approval was granted from both centres. Centre A is a rural satellite centre managed by one oncologist, a clinical nurse specialist and a Registered Advanced Nurse Practitioner (RANP). The post-menopausal women in Centre A are reviewed by a nurse led service managed by the RANP in Oncology. Centre B is a supra oncology urban site with a dedicated breast care facility and four consultant oncologists and a team of clinical nurse specialists. The review clinics in Centre B are not nurse-led and women attending this centre are reviewed by the medical team.

The study's inclusion criteria included: postmenopausal women who had completed adjuvant breast cancer treatment and were attending Centres A or B for zoledronic acid every six months.

This was a two phase qualitative study. For phase one, focus group interviews (n=6) with 51 women were undertaken (Table 1). The use of two to six focus groups in qualitative studies is generally recommended by most authors (Jayasekara, 2012). The numbers of women attending the focus groups ranged between 8 and 12. All women attending Centre A (n=81) were invited by letter to attend for a focus group interview, and 22 attended. At centre B, simple random sampling was used to draw up a list of

100 patients from the patient database of one oncologist. These 100 women were then invited by letter to attend a focus group.

All six focus groups were undertaken in two hotel venues convenient to public transport. The focus groups lasted approximately 1.5 hours and were all facilitated by the first and last authors (EM & MD) who both have extensive knowledge of cancer survivorship. EM asked the questions and MD acted as moderator and note taker. The interviews began by asking women to talk about what survivorship meant to them and what follow-up care was important to them. Issues raised by women were then explored further within the groups. Many of the women did not attend support groups and this was their first opportunity to talk about their cancer to other survivors. An interview guide was used for all the focus groups. All focus groups were tape-recorded and transcribed verbatim. The focus group data was analysed independently by the first and last authors guided by Braun and Clarke's (2006) thematic analysis, a process with six distinct phases, starting with reading and re-reading the transcripts to the final phase where extracts are selected as exemplars. Both authors then met and agreed on the identification and labelling of themes.

Phase two of the study involved two nominal group technique (NGT) (consensus workshops) held three months after the focus groups and 17 women participated (n=8 at the first NGT and n=9 at the second NGT). At the earlier focus groups, these women expressed their wish to participate in the consensus workshops and provided their contact details. These workshops were held in the same two hotel venues as the focus groups and facilitated by the first and last authors. A consensus workshop embraces a participatory approach (Bruce et al., 2002), and is a very useful approach when the goal



is to identify a list of priorities (de Ruyter., 2010). Similar to the Delphi technique, NGT determines group consensus (Harvey and Holmes, 2012). NGT is also similar to a consensus development method and facilitates efficient determination of ranked responses (Coker et al., 2013).

The consensus workshops lasted approximately 1 hour each. The participants were asked to vote on the ten issues identified across the focus groups listed in Table 2 and rank the issues in terms of perceived priority. Two rounds of (anonymous) voting were undertaken; the first to identify the top 5 and the second to rank the top 5 (i.e. a score of 5 was given to the issue considered 'most important' in the list of five, a score of 4 to the next most important issue, and so on until a final score of 1). The scores from the two consensus group meetings are outlined in tables 2 and 3.

## Participants

All women had undergone breast surgery (n=51). Most (n=39) also had chemotherapy and most (n=43) had radiotherapy. All of the women were on Zometa (n=51). Nine women were taken off Letrozole and changed to Tamoxifen due to arthralgia. (Table 1)

**Table 1 Participant Data**

<b>Participant data</b>	<b>N=51 (%)</b>
<i>Age</i>	
48-49	2 (3.9)
50-59	11 (21.5)
60-69	27 (52.9)
70-79	9 (17.6)
80-85	2 (3.9)

<i>Treatment information</i>	
Had surgery	51 (100)
Had chemotherapy	14 (27.4)
Had radiotherapy	43 (84.3)
On Letrozole	36 (70.5)
On Tamoxifen (following discontinuation of Letrozole)	8 (15.6)
On Anastrozole	3 (5.8)
On Exemestane	1 (1.9)
Not on an aromatase inhibitor	3 (5.8)

## Findings

Six focus groups with 51 women were undertaken, with a median age of 63 (range 48-83). The issues highlighted by the women in these six focus groups were voted on in the two consensus groups (Tables 2 and 3).

**Table 2 Scores from consensus group 1 (Centre A)**

	Mean Score
Meet the same healthcare professional at each review visit	3.6
Contact number of a named person that you can contact if you have any concerns between review visits	3.5
Information on signs and symptoms of recurrence	3.1
A written summary of diagnosis and treatment journey	2.6
Information and management of side effects of therapy-long and short term	2.1

**Table 3 Scores from consensus group 2 (Centre B)**

	Mean Score
Meet the same healthcare professional at each review visit	4.5
At each review visit, have a physical examination & blood tests and explanation from HC professional outlining if follow up scans needed and if not, why not	3.2
A written summary of diagnosis and treatment journey	2.8
Advice on diet, exercise, healthy lifestyle and advice on coping and pacing yourself	2.7
Information and management of side effects of therapy-long and short term	2.4

The seven issues voted as most important in the consensus groups are presented below in three themes, i.e. Review visits (meet the same healthcare professional at each review visit, contact number of a named person that you can contact if you have any concerns between review visits); Fear of recurrence (information on signs and symptoms of recurrence, at each review visit, have a physical examination & blood tests and explanation from HC professional outlining if follow up scans needed and if not, why not); Survivorship care plan (a written summary of diagnosis and treatment journey, Advice on diet, exercise, healthy lifestyle and advice on coping and pacing yourself, Information and management of side effects of therapy-long and short term).

Pseudonyms are used in place of the women's names.

## Review Visits

The highest scoring need identified at the consensus workshop among all the women was to 'meet the same healthcare professional at each review visit'. The women relayed their need to have a relationship with the HC professional undertaking their review. By having a relationship the women felt they could ask questions and explore issues important to them.

*"It does matter [to see the same person at clinic]...I saw some lad [Junior Doctor] that was in a hurry. He was tired, he was fed up, he said to me 'Oh God you are looking well. You skipped in the door there today not a bother on you". And before I knew it I was skipping back out the door. I didn't get a chance. I said now there were things I wanted to ask him". (Cathy, FG6. Centre B)*

*"...but I find when I you go for the check-ups they just say 'well how are you doing', you know, there's no kind of prompt questions, and I say 'fine' and that's it like...there is no word of conversation other than 'how are you doing', you know....I'm in and out and I'm saying, you know, you have your mammogram so you get, you know, a breast examination but there is no word of conversation other than 'how are you doing' you know. I feel there is never a two way thing and I'm sitting there and I don't know enough, I feel, to know what questions to ask, kind of what relevant questions to ask, you know" (Jackie, FG5. Centre B).*

*"I would like if the nurses were doing it [review clinic], it would be consistent. In the clinic they [doctors] are on six monthly rotations. You don't know who you are going to have, and don't know if the last person you saw previously is going to be there" (Evelyn FG6. Centre B)*

*"...you have a profile of the person you're working with, you also build up a relationship because if you're going in to somebody new every time it's starting to build that relationship again, your time and energy is going on that again, so you're not going to feel the same comfort..." (Rebecca FG5. Centre B)*

Many women found the review visit unsatisfactory and impersonal in nature. This was especially evident in the focus groups from Centre B where the women were attending the centre without a nurse-led review service.

*“...when you have a check-up you meet a different doctor every time...I don't like that...you know when you go in that they haven't even looked at your chart until you arrive...I meant it's great having regular follow-ups, but as I said I come away after three minutes in there with him [doctor] and all I feel I've done is, at least that is, but I kind of think when I come out... every day [at review clinic] it's someone different...so he [doctor] examined my, and then he said to me, he said, where I had the node removed, what's that scar and I said to myself 'Oh Sweet Lord' was this the cleaner passing the door that just ran in here?” (Eva, FG5. Centre B)*

The second highest priority for the women was the need to have a contact number of a named person should they need assistance between the review visits. This theme was considered to be integral to the first priority 'meet the same health care professional at each visit' above.

*“Somebody that we can ring or phone or follow up...” (Betty FG2. Centre A)*

*“But do you mind me asking you there now, you're saying yes come in and talk about [what the problem is], who do you actually contact in that case? If you've a new pain and that's lasting and going on, who do you contact then?” (Brona FG4. Centre B)*

*“I had a terrible, I had a bad year last year because I got infections and whatever, but I found that it's just maybe, as you said, the gap, you don't know who to go to...when I started the Femara, I didn't know who to turn to and I went to my GP and she couldn't do anything” (Laura FG5. Centre B)*

The women expressed the view that ideally the person who reviewed them on their clinical visits should be the HC professional they contact between review visits if they were worried about a symptom. While many of the women found their GP supportive

they also found that GPs generally advised them to share their specific concerns with the oncology team when at the review clinic where breast cancer expertise and knowledge is available. Many of the women felt that GPs do not want to follow up on issues related to their breast cancer or were not skilled enough to do so.

## **Fear of Recurrence**

Women's need for a physical examination and blood testing was considered important. They wanted to have a physical examination and blood testing at each review visit. Many women also expressed the wish to have scans undertaken on their review visits, especially among the women attending Centre B. This need was fuelled by a fear of cancer recurrence.

*"Well they'll tell you there's no need for them. I've asked several times for a bone scan or an all over body scan, how do we know sitting here that we don't still have cancer in our bodies. With the tiredness that we have, with the symptoms that we still have from treatment"* (Mary FG4. Centre B)

*"Well I suppose I need to be reassured that I suppose by having tests done, whatever tests, that I have no further cancer in my body, going forward. Does that make sense?"* (Aoife FG4. Centre B)

*"...you'd be waiting and waiting for scans and things and they won't do it until you're nearly walking lame or using two sticks, they won't call you and do it [scans]... I think we should get a scan occasionally to see if we're Okay"* (Emily FG5. Centre B)

*"I just recalled when I was diagnosed too, the one thing I wanted them to do for me to give me a PET scan. And every time I'd go on, I'd say I need a PET scan, I need a PET scan, but they wouldn't give me a PET scan because I was thinking if I had cancer everywhere else it would have show up"* (Anne FG4. Centre B).

*"Well I suppose I need to be reassured that I suppose by having tests done, whatever tests, that I have no further cancer in my body, going forward. Does that make sense?"* (Aoife FG4. Centre B).

The wish for scans to be undertaken was very evident among the focus groups from women in Centre B, where the medical model of breast care follow up was utilised.

The fear of recurrence was related to their need for tests at each review visit and the need to have a named person to contact if they had a worrisome pain or discomfort that they feared was a recurrence.

*“Everything that happens to you, you think it’s it [recurrence] somewhere else growing back at you.” (Betty FG2. Centre A).*

*“It [cancer] is always just there and it is just waiting for to pounce again, cos the fear doesn’t go away from me...So sometimes you think, does it always come back, or you hear other people who had cancer ten years ago, five years ago and it comes back. I’m kind of worried to say, am I really cured. Or can anybody ever say you’re really cured, you know” ” (Collette FG3. Centre A).*

*“People who have cancer, we have all here, we worry a lot, do people out there realise that we worry so much? You know what I mean. As I said I only had my bloods done a week ago and I had pain just here and I thought Oh God, it’s gone to my liver...” (Marie FG4. Centre B).*

*“You are nervous that it would come back you know, and if you get a pain you think ‘Oh My God, is it coming back again’, you know” (Martha FG 5. Centre B).*

## **Survivorship care plan**

Across all the focus groups, women expressed the view that in survivorship they wanted to know their personal disease history, through the provision of a written summary of their diagnosis and treatment journey. Many recalled being told this information when being treated but they could not accurately remember what they were told. Moreover, some expressed the view that this information was something they were not ready to hear during treatment.

*"I was told [how many nodes were removed] but I can't remember what he [doctor] told me, I was so stressed" (Cora FG4. Centre B).*

The women wanted their personal disease trajectory in written form and they wanted a full account of their type of cancer, node involvement, treatment given and so on.

*"If you were told....And you were sat down and it was said to you, well now Marie, I was quite happy up until now as I said, Marie you have, it was breast check that picked me up, I didn't have a lump, I had no lump but yet I had surgery, I had chemo and I had radiotherapy. And now I'm on Femara, do you know what I mean? And to be told well you know it's not gone anywhere else, you had chemo. Do you know what I'm saying...That [information] should be [written], I like documentation. It's there in front of you" (Marie FG4. Centre B).*

Some women also wanted to know their risk status for recurrence which was related to information about their diagnosis and how that impacts on their risk long term.

*"...at least if you said well yours is this type [of breast cancer] and it's, I don't know, on the scale of one to ten it's this serious or that serious, you know...I know it was about the size of a bean, but that's about all I know"....at the time [of diagnosis] maybe I didn't want to know. But I think now I would like to know..." (Edwina FG1. Centre A).*

*"Even getting the glands removed, that wasn't explained to me until I came [for follow-up care]...sometimes if you know too much beforehand, it's just too much worry for no advantage" (Noelle FG1. Centre A)*

*"Women should be educated more about it [breast cancer]. I educated myself when I got it. There are several types of breast cancer so we shouldn't compare ourselves..." (Collette FG3. Centre A)*

The women's need for advice on what to eat and what exercise they do in survivorship was discussed at length across the focus groups. Within the groups, women who felt



they were coping well shared their stories of their activities (such as yoga) with others. However, there was much confusion on what diet was the 'best' in survivorship.

*"Oestrogen, mine is supposed to be oestrogen fed and I was talking to a girl and she was telling me, I used to use soya mild because I try to eat healthy, porridge and stuff, and she says there's oestrogen in soya milk...but my daughter looked it up, so I stopped using soya milk but I don't know, should I have done that, I just stopped using it then."* (Jenny FG4. Centre B)

*"I can read all sorts of different sources but some of them will be too scientific for me to understand and others I don't know whether to trust them or not"* (Ruth FG6. Centre B)

*"I was wondering about the diet because I was saying, you know, how can you leave out all the diary stuff and end up with osteoporosis and you know, and all the problems we're having, and still you're reading saying oh dairy products feed cancer...do we need to be eating dairy and yoghurt and milk, you know, for our bones...and yet on the other hand I've an article here that says oh you know, dairy products feed cancer"* (Eva FG5. Centre B)

There was also some frustration among the women that advice on diet was not being provided by HC professionals at clinic visits:

*"Who do I go to ask these things or if someone would talk to you about diet, or, you know, to forget about it...without making you, dismissing it as if you're some sort of-you should be grateful to be alive, will you stop this nonsense about diet, you know, get on with your normal life"* (Eva FG5. Centre B)

*"Nobody in the clinic wants to give you advice [on diet or exercise]. I don't know, I get the impression that either they are not convinced themselves that diet makes any difference or it's not conclusively researched so they are not sure...but it's [diet] probably one of the things when I do come off the treatment, it's one of things I'd like advice on. If I don't have the oestrogen suppressants and I won't in another two years then maybe I'll use my diet to keep my oestrogen down"* (Ruth FG6. Centre B),

The side effects from endocrine treatment dominated much of the discussions across all focus groups. Many women were very surprised about the side effects they were experiencing in survivorship and felt that HC professionals had not warned them sufficiently of what to expect.

*“When that’s over [treatment], it’s like you’re bringing home your first baby because you don’t know what to expect. You’re terrified.” (Dawn FG2. Centre A)*

*“I was put on these anti-cancer tablets, I wasn’t told they could have any effects on me whatsoever except that they were the thing to do, you had to go on these for five years to keep it [cancer] away...and then as time went on like I was in unbearable pain, every night I got into bed and my shins were painning me, I , I don’t think I got a night’s sleep for I don’t know how long... and he [doctor] said, well I have to tell you, he said, that this anti-cancer treatment can exacerbate arthritis and osteoporosis and he said unfortunately that is what’s happening to you and I’m three years on them at this stage and suffering all this and deterioration all the time, so I said well, I mean, what has taken you so long to inform me? Nobody has ever said to me this could happen and if you have any predisposition for these things it could happen and they’re going to get worse...but what I have to worry about now is arthritis and osteoporosis accruing from the Letrozole that I was taking for three years. So I must say I just said I was horrified, I am really truly horrified.” (Emily FG5. Centre B).*

*“The hormone tablet I’m on, they said there’s so many side effects, and if I say it any of my doctors they sort of say well there’s a list of side effects, there’s loads, and the headaches have got worse and I can’t get rid of the bit around the middle and the knees ache when you’re climbing up stairs. You just feel older” (Edwina FG1. Centre A)*

*“I expected at the end of twelve months that it [fatigue] would have lifted but it hasn’t” (Norma FG2. Centre A)*

*“You don’t know if it’s depression or physical or what. It’s like the menopause again for the second time” (Betty FG2. Centre A)*

*“The Femera we’re taking. I’m taking at the moment, how will that affect me in the long term? Will it affect your kidney and your liver if you’re on it, I don’t know.” (Mary FG4. Centre B)*

*“You go out [from clinic] as ignorant as when you went in” (Martha FG5. Centre B)*

*“...when you finish all your treatment...and you go on the, the medication [Letrozole] for five years of whatever...if you want something you have to go out there and get it yourself, there’s no follow-up ...” (Tara FG5. Centre B)*

For many women, arthralgia limited their mobility:

*“...since I’m on that five year tablet [Letrozole] I have put up about I’d say two stone, but that’s because I’m not able to walk...” (Margaret FG1. Centre A).*

*“No matter how hard I try now I can’t exercise because my knees have completely seized up. And my mobility is nil. Now I know I had arthritis starting off at the beginning but it’s really bad now. Definitely that tablet [Letrozole].” (Norma FG2. Centre A)*

*“I found when I was put on my tablet my arthritis went very, very bad and my weight started to go on. I have 4 stone on now at the minute which I don’t want because it’s bad, my knees are gone, my back, I have problems with my back and I’m trying to lose get this weight off now. I got on alright, I got through the chemo and radium and everything else but it was afterwards that everything started to set in.” (Brona FG4. Centre B)*

Having to take the endocrine therapy was a source of extreme distress to some women and their quality of life was profoundly affected:

*“I managed one year [on Femara] and the joint pain was so horrific, and I’m someone who’s twenty years of yoga behind me...I did a year and I said no. I can’t do it. So they agreed to just let me go onto Tamoxifen...” (Ruth FG6. Centre B).*

*“Like everyone else [in focus group], it’s the hormone treatment that is more of the problem than anything else. And I definitely wasn’t prepared for that...the hormone treatment Tamoxifen, I got a clot from it so I came off that, I went on the Letrozole then and Oh my God the bone pain on that is unreal! And now I’m on Letrozole and I’ve neuropathy which nobody explained that was going to happen” (Claire FG6. Centre B).*

*“My feet, I hadn’t driven since I because my feet are like lumps of ice, my fingers are all the same, I can’t sew, I can’t text on the mobile because the figures are too small, so they’re all stiff now, you know, the tops of my fingers, all the time. But they’ve [HC professionals] never, anytime I’ve gone back [to clinic] they’ve never given me any encouragement that they’ll, you know, all this will clear up in twelve months or six months or whatever” (Martha FG5. Centre B).*

## **Discussion**

This study has shown the importance of seeking the views of postmenopausal breast cancer survivors on what they want in a survivorship care plan. Cancer survivors should be provided with the space to articulate their challenges without them feeling dismissed (Hubbard and Forbat, 2012).

The study highlights the main issues that should be addressed in a survivorship care plan for postmenopausal women. Women want to see the same named HC professional at each review visit and be provided with a contact number between visits. Women want to feel reassurance at each visit with a physical examination and an explanation regarding follow up investigations. They also want their survivorship care plan to outline their disease and treatment history, what side effects they should expect from endocrine therapy and what exercise and diet regime to follow. The findings here reflect those reported recently in the US by the American Cancer Society’s study of long term cancer survivors (Playdon et al., 2016). This survey with 3138 long term cancer survivors (n=870 of which had breast cancer) revealed that one of the survivors’ greatest need was for information on long-term treatment side effects (Playdon et al., 2016).

Women in our study wanted a written summary of their cancer journey from diagnosis to treatment. A need for information on cancer diagnosis has also been identified as

important in survivorship care plans among Australian women survivors (Brennan et al., 2011). Furthermore, a high prevalence of unmet health information needs have been reported among survivors in the US who did not receive a written treatment summary (Kent et al., 2014; Playdon et al., 2016).

The women in this study generally experienced reluctance among GPs to assume their care in follow-up, this finding has also been reported among Australian breast cancer survivors (Brennan et al., 2011). However, cancer-related outcomes for women reviewed by a primary care clinician are reported to be similar with those reviewed by an oncology specialist clinician (Grunfeld et al., 2006). Moreover, a recent Irish study reports that most of the women surveyed were satisfied with GP led care following discharge from the Oncology service (Naidoo et al., 2013). Nevertheless, non-adherence of adjuvant endocrine therapy remains an issue (Patridge et al., 2008) and has been reported to be greater among women being followed up by their GP than among women followed up in a oncology unit (Güth et al., 2008). In Ireland the majority of breast cancer patients are reviewed in medical oncology and surgical clinics without universal consensus on the duration of this follow up. Current recommendations from the National Cancer Control Programme (NCCP) advise that patients should be followed up by their primary care physician 5 years post operatively or when their endocrine therapy is completed (NCCP, 2010). However, this recommendation has not been implemented to date due to cost and resource implications for general practice.

Many of the women expressed severe side effects of endocrine treatment and a need for more information on what to expect when taking endocrine therapy. It is reported that up to two thirds of breast cancer survivors experience ongoing effects from

endocrine therapy such as osteopenia and osteoporosis (Hill et al., 2014). Arthralgia in particular, was also a troublesome symptom for many of the women in this study. A number of studies have highlighted the prevalence and risks factors with aromatase-inhibitors (AI) related arthralgia among postmenopausal breast cancer survivors (Crew et al., 2007; Sestak et al., 2008; Mao et al., 2009).

The women in this study expressed a wish for advice on a healthy diet and what exercise to do as part of their survivorship care plan. The American Cancer Society advise breast cancer survivors to eat a diet high in vegetables, fruits, whole grains and legumes and low in saturated fats with limited alcohol consumption (Runowicz et al., 2016). It is also recommended by the American Cancer Society that breast cancer survivors should avoid inactivity and engage in at least 150 minutes of moderate or 75 minutes of vigorous exercise per week. In addition, women treated with hormone therapy should include strength training exercises as part of their exercise regime (Runowicz et al., 2016).

Cancer survivorship presents a paradigm shift from a life-threatening to chronic illness, which fits with Mishel's theory of uncertainty in illness (Hebdon et al., 2015). Women in this study continued to experience many troublesome symptoms. Managing these symptoms is an aspect of the illness-related work cancer survivors must undertake on their survivorship journey (Klimmek and Wenzel., 2012). As part of survivorship care planning, oncology nurses may find the transitional survivorship work framework helpful in organising discussions with breast cancer survivors and guiding patients on their journey from active treatment towards a 'new normal' (Klimmek and Wenzel., 2012).

Currently in Ireland the provision of survivorship care is under debate. It is recognised that survivorship care is an essential component in the treatment of breast cancer and is now part of strategic policy (Mullen, 2016) and internationally there is heterogeneity in the provision and extent of survivorship care (McCabe et al., 2013). This study informs current debate in Ireland. The patients in our study (at Centre B, a large oncology centre) were clearly not satisfied with the traditional medical model of follow up and wanted a more holistic, consistent and individual management of their care. However, while we acknowledge that it is reasonable to question if this is feasible in an era where limited workforce capacity exists, we argue that there is scope to provide this type of care in smaller community centres as well as in large academic centres, and this has been demonstrated in the USA (McCabe et al., 2013). Moreover, a shared care provision between the specialist centre and primary care is also now being adopted in many countries which may alleviate capacity issues (McCabe et al., 2013). We need to examine different modules of survivorship care internationally and see which model fits Ireland best. Finally, we believe that nurses are ideally placed to drive the provision of survivorship care programs and be the key providers of survivorship care programs in Ireland. However more education and resources need to be allocated for this to become a reality.

## Limitations

While the study has a number of strengths, i.e. the first and last authors facilitated all of the interviews and consensus workshops, attendance numbers at each group was good, and voting at the consensus workshops was anonymous, the study has a number of limitations. Only one ethnic group was represented (i.e. white Irish) and women from only two centres were interviewed. Moreover, the focus groups were held during the daytime which may have prevented some women in employment attending.

## Conclusion

In this study, we used a participatory approach to identify what post-menopausal breast cancer patients want to be included in survivorship care planning. This current study contributes to the emerging body of knowledge on survivorship care planning by including post-menopausal patients in Ireland. Specifically we examined the experiences and needs of this cohort of survivors with a view to implementing a comprehensive care plan, currently lacking in routine oncology follow up care in Ireland. By consulting women using a participatory approach, we have highlighted what they view as their priority needs in survivorship care planning. This participatory approach was a mutually positive experience, reflecting the experiences of other researchers who have worked with cancer survivors to increase the relevance of study findings to the population under study (Chiu et al., 2013).



Numerous publications and international guidelines emphasise the importance of addressing health, wellness and quality of life for breast cancer survivors. They also clearly identify continuity of care and the utilisation of written care plans as priorities for their care going forward. Comprehensive survivorship care plans aim to improve patients' knowledge and quality of survivorship care and every effort should be made to incorporate them into current oncology working practices.

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### **Conflict of interest**

None

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