Survivorship care after breast cancer treatment: Experiences and preferences of Australian women

A collaborative research project between BCNA and researchers from The Mater Hospital (Sydney) and The University of Sydney

Background

Follow-up care after breast cancer treatment is increasingly complex and addresses the long-term needs of survivors. This study explores survivors’ experiences with follow-up care and their attitudes to alternative models including a tailored survivorship care plan either (a written, patient-held booklet containing a personalised plan for care) and involvement of general practitioners (GPs) and breast care nurses BCN’s.

Fifty members from Breast Cancer Network Australia’s Review & Survey Group were invited to participate in a semi-structured telephone interview, with twenty members agreeing to participate. Women were asked about their experience of follow-up care, their comments on survivorship care plans and shared care programs between specialist oncologists, GPs and BCN’s.

The majority of women who participated were 2-5 years post diagnosis with some women being 10 years post diagnosis. All women involved were attending regular follow-up visits with the majority having check-ups at least every six months, regardless of time since their diagnosis. The majority of women were regularly seeing their surgeon and medical oncologist for routine visits, with few seeing their radiation oncologist and GP and none regularly seeing a BCN.

Satisfaction with current follow-up care

Women expressed that they had a high level of satisfaction with their current follow-up care and the average score for women rating their care was 8.5 out of 10. Five women rated their current care a perfect ten.

Reactions to the terms ‘survivor’ and ‘survivorship’

Women were uncertain about the terms ‘survivor’ and ‘survivorship’. Some women took inspiration from the concept of being a cancer survivor, but many did not feel comfortable or identify with the term “survivor”. Those participating in the study highlighted the dislike of labels and the feeling that having breast cancer should not define who they are.
“I considered myself to be a survivor from the day I was diagnosed because that’s what I intended to do and that’s what I’m doing. I am surviving this. Breast cancer is still part of my life.”

“Well, you’ve had an illness and you’ve dealt with it the best way you could and you just move on.”

“I’m surviving, not a survivor”

Follow up consultations – strengths and areas for improvement

Women felt that the most important reason for follow-up care was to address the issues of ongoing treatment and the detection of cancer recurrence and felt that their current follow up care addressed this very well. Despite high satisfaction with follow-up care, women highlighted that psychological well-being and menopausal symptoms should be discussed and acknowledged more often during these visits.

“I think the thing that’s been missing has been the psychological care There aren’t people who have time to say ‘How are you feeling?’ And I mean, there may be a brochure saying ‘Go and see a counsellor’ or something. But it’s more about wanting the people you’re dealing with to recognise that it’s a stressful – psychologically stressful thing, and that it’s okay if you burst into tears. To have a bit more compassion and understanding of the emotional impact of breast cancer; and that continues for a long time afterwards.”

“I wasn’t aware of the menopause issues and what they could be like. I mean you hear about hot flushes but that is really about all that you hear and it is not until you go right into it there are a lot more others happening in areas. Nobody talked to me about that.”

Importance of coordinated follow-up care and attitudes to a survivorship care plan

Women discussed the importance of a continuous and coordinated approach to follow-up care, as many though the communication between team members was poor and that the GP was often excluded. Women also raised the need for consistent advice from different members of their multidisciplinary team as there was a feeling of confusion with different recommendations from different members. This confusion was also related to poor communication between team members. There was enthusiasm for a survivorship care plan (SCP) that could assist communication among team members as well as providing a plan for the frequency of their visits.
“I think for the patient to be aware of what is expected medically for the next five years, how many visits they are expected to have, and what sort of testing they are likely to have.”

Attitudes to increased GP and nurse involvement in follow-up care

Women clearly described the key characteristics of a follow-up care provider being someone who:

- had time for consultation
- knew the history of the cancer well and
- they had developed a long-term relationship throughout their journey.

The relationship with treating cancer specialists was highly valued by women and in many cases this was the reason for reluctance, to consider other models of follow-up care such as shared care with a GP or BCN.

Women saw several potential benefits of increased involvement in care by their GP and shared care with an oncologist. Some of the benefits discussed included; convenience as there would be less travel involved, and already having an established trustful relationship with their GP. Several women highlighted that their GP may not have the specialised knowledge required to provide cancer follow-up care and this may require more training. Some women had the perception that their GP may be reluctant to take on the responsibility of this care.

“My GP doesn’t like to make decisions, she just thinks that that’s the decision that the oncologist should make and not her because she’s not in the position where she’s done the studies to see it.”

Women also saw possible benefits with a BCN providing follow-up care in a shared care program with a specialist as most participants had previously seen a BCN and valued this support. The only hesitation expressed, was the need for reassurance that BCN’s had adequate training, if they were to have an increased role in follow-up care.

“I think that the nurses sometimes have a little bit more time for you and may spend a bit more time with you just discussing general things. And but again you’d want to be happy that they were up to date and that their skills were up to date.”
Results

The results of the research found that:

1. Women expressed a high level of satisfaction with their current care.
2. Management of menopausal symptoms and emotional support were identified as areas of ongoing need.
3. There was a high level of trust and dependence on their relationship with individual clinicians in their specialist team and a preference to continue this specialist-based model of care.
4. There was considerable concern about the ability of GPs or BCN’s to provide the required level of long-term cancer care. There was a perceived need for additional training for these health professionals if they were to have an increased role in follow-up care.
5. The idea of a written care plan was appealing.
6. Model of shared care between GPs and specialists rather than a full hand-over of care may be an acceptable way to support specialists with the increasing follow-up load in their practice while increasing the role of GPs as women gain confidence in this model of care. Training for GPs would be needed in order to help this confidence and women would need reassurance that their specialist would be available and remain involved in their care.

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