Follow up after breast cancer

Views of Australian women

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Background
Survivorship care after breast cancer treatment is increasingly complex as it aims to manage the long term effects of cancer and its treatment, including psychosocial needs. While survivorship care is traditionally delivered by surgeons and specialist oncologists in Australia, general practitioners are ideally placed to manage these issues.

Methods
This study explored the attitudes of 20 breast cancer survivors to GP involvement in follow up care through semi-structured telephone interviews, which were analysed using qualitative methods.

Results
Women were reluctant to change from specialist based care but identified many potential benefits of GP involvement in long term cancer care. They expressed an interest in shared care programs between specialists and GPs. Some participants thought that additional training may be required if GPs were to deliver this care.

Conclusion
This study shows cautious interest from breast cancer survivors for increasing GP involvement in follow up care. These views should be considered as alternative models of care are developed.

Keywords: breast neoplasms; survivors; general practitioner; primary health care; patient care

Although the incidence of breast cancer is increasing, survival is improving. While the survival rate from breast cancer is high relative to other cancers (around 88% at 5 years in Australia[1]), women live with the life-long effects of the cancer, and its treatment, and these may adversely impact their quality of life.[2–5]

Follow up care after treatment is generally provided by oncology specialists (surgeons and medical and/or radiation oncologists) in Australia.[6] This care has traditionally focused on the detection of cancer recurrence. 'Survivorship care' has become more complex as it also aims to address many of the long term physical and emotional effects of cancer.

General practitioners are ideally placed to provide this care and an increased role for GPs in follow up care has been proposed both in Australia and internationally.[7–9] Randomised trials in the United Kingdom and Canada have shown that GP care is equivalent to hospital breast clinic care in detection of recurrence, is acceptable to patients, and is more cost effective.[10–15] However, studies have also shown that some women perceive a lack of interest or expertise in follow up care on the part of their GP.[16]

The aim of this study was to explore the experiences of Australian breast cancer survivors in follow up care and their attitudes to an increased role of GPs in their long term care. A further aim was to explore attitudes to survivorship care plans and these results are reported separately.[17]

Methods

Eligible participants were women with a previous diagnosis of breast cancer (any time interval since diagnosis) who were members of Breast Cancer Network Australia (BCNA), a consumer information, support and advocacy organisation which had over 36 000 members Australia wide at the time of the study. Fifty members of BCNA's Review and Survey Group (a group within BCNA with an expressed willingness to participate in research) were invited to undergo a telephone interview. The sampling was purposive to ensure representation of all Australian states, rural and urban settings, and a range of ages and time since diagnosis.

Semistructured telephone interviews were conducted following an informed consent process. After demographic and disease details were elicited, women were asked about their experience with breast cancer follow up care and attitudes to GP involvement. Interviews were audiotaped, transcribed and coded into themes using NVivo 8.[18] Thematic coding was initially constructed by two researchers (MB/PB), and once consensus was reached coding was continued by a single researcher (MB). Each theme was analysed and summarised. Demographic data were analysed using SPSS Version 16.0.[19]

Ethics approval was obtained from the University of Sydney Human Research Ethics Committee.

Results

Demographics and current care

Twenty women were interviewed (*Table 1*). All states and territories were represented and 65% of interviewees lived in metropolitan areas (defined by participants). Most women were 2–5 years from diagnosis and most had been aged 40–59 years at the time of diagnosis.

Three women had experienced recurrence of their cancer.

Patterns of current follow up care are shown in *Table 2*. All women were attending regular follow up visits at least 6 monthly, regardless of time since breast cancer diagnosis. Seventy-five percent were seeing a surgeon regularly, 55% a medical oncologist, and 35% a radiation oncologist. In addition, 35% saw their GP regularly for specific care related to their breast cancer; most of these women were living in regional and rural areas. Four of the seven women who saw their GP for check ups also saw a specialist regularly.

Participants expressed a very high level of satisfaction with their current follow up care. When asked to rate it out of 10, the median score was eight (mean 8.5, range 6–10) and five of 20 participants rated their current care 10 out of 10.

Table 1. Participant characteristics (n=20)

Item	Response	n	%
Age at diagnosis	<40 years	6	30
	40–59 years	12	60
	60+ years	2	10
Time since diagnosis	<2 years	3	15
	2 to <5 years	9	45
	5–10 years	5	25
	>10 years	3	15
Place of residence	Metropolitan area	13	65
	Regional centre	3	15
	Rural area	4	20
State of residence (Australia)	New South Wales	5	25
	Victoria	4	20
	South Australia	4	20
	Queensland	3	15
	Western Australia	1	5
	Tasmania	1	5
	Northern Territory	1	5
	Australian Capital Territory	1	5
Initial treatment for breast cancer			
Surgery (type of operation)	Conservation	11	55
	Mastectomy (unilateral)	7	35
	Mastectomy (bilateral)	2	10
Radiotherapy	No	3	15
	Yes	17	85
Chemotherapy	No	6	30
	Yes	14	70
Endocrine therapy	No	5	25
	Yes	15	75
Experienced recurrence of cancer	No	17	85
	Yes	3	15
Currently having treatment	No treatment	11	55
	Yes (oral endocrine)	8	40
	Yes (chemotherapy)	1	5

GP care

All women reported having a regular GP who provided their general medical care. Women were asked about the potential benefits and disadvantages of increased GP involvement in their breast cancer care. 'Increased GP involvement' was defined as a reduction in specialist contact which could be transferred to follow up care provided fully by the GP or could take the form of a shared care program in which some check ups were done by the GP but the specialist also continued to provide care.

Women described a very strong and trusting relationship with their cancer specialists and an initial reluctance to consider models that would involve them moving away from the specialist who had supported them throughout the cancer journey. There was a much stronger level of support for the idea of shared care (such as alternating visits) rather than a move completely away from the specialist. Most of the participants who were seeing their GP for visits were also seeing specialists so were already in shared care.

Women described many potential benefits for a greater GP role in their care (see *Table 3* and *4* for a list of perceived advantages and disadvantages of GP involvement in follow up care and participant quotes). The main advantages were that the GP is convenient geographically and also convenient because breast checks could be combined with other health checks in the same visit. Women commented:

'Well, your local GP is handy, for a start; you don't have to drive far.'

'You can just fit it [your cancer check up] in when you've got other things or you're in there because you've got bad sinus or, you know, something else and they'll just do a quick check.

The same way as I get my blood pressure checked fairly often, my breast gets checked as well. Part of the whole health check that happens for me now that I'm a cancer patient. A huge relief to get it done.'

The trusting, long term relationship already developed with the GP from their general healthcare was also identified as an advantage. The women already seeing their GP for follow up care reinforced these advantages:

'My GP was good through it all. I had to go and see her a few times. And she would always fit me in because she knew about the problem [the cancer].'

'I know the GP I've now got is very understanding and has discussed and talked about my experience and what I've gone through. So I trust him.'

Several disadvantages were identified. Women felt that they required a high level of specialised care and they expressed concern that GPs may not have the knowledge to provide this care:

'They [the specialists] are doing it all the time. Whereas a GP, I don't think has the experience that the oncologist and the surgeon would in the area of examination and trying to pick up nodules.'

Women said that if more training was provided for GPs and there was an efficient referral pathway back to the specialist if problems developed then they might feel more confident in their GP's ability to provide the required level of care. Another disadvantage was a perception that GPs would not be interested in follow up care. Some women believed that their GP was relieved to have a specialist do follow up visits and that their GP would not feel confident making decisions and performing breast examination.

'My doctor… doesn't really want to sort of get himself too involved, so what he does is send you off to specialists.'

'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.'

The women already seeing their GP for cancer care did not describe any disadvantages.

Table 2. Current follow up care: participants' reported pattern and satisfaction (n=20)

Item	Response	n	%
Frequency of follow up visits	<6 months	17	85
(interval between visits)	6–12 months	0	0
	12 months (annual)	3	15
	>12 months	0	0
Regular visits with surgeon	Yes	15	75
	No	5	25
Regular visits with medical oncologist	Yes	11	55
	No	9	45
Regular visits with radiation oncologist	Yes	7	35
	No	13	65
Regular visits with GP	Yes	7	35
	No	13	65
Regular visits with breast care nurse	Yes	0	0
	No	20	100
Satisfaction with current care	<5 (out of 10)	0	0
(1 = unsatisfied, 10 = very satisfied)	6 (out of 10)	1	5
	7 (out of 10)	2	10
	8 (out of 10)	8	40
	9 (out of 10)	4	20
	10 (out of 10)	5	25

Table 3. Potential advantages and disadvantages of GP follow up care identified by breast cancer survivors

Advantages	Disadvantages
'Geographical convenience – GP is closer to home'	'GP would need more training'
'Long term relationship and trust already established'	'GP would not be interested in breast cancer care, sends me to a specialist for everything'
'GP has a good links to specialist and would know how to get help if needed'	'GP wouldn't know what to do if there was a problem'
'Convenience – saves time as breast cancer checks can be done at same visit as other health checks'	'I would miss my specialist's input as he has been there for me through the journey'
'GP knows my history'	'Can't get in to see GP for weeks'
'GP costs less'	'I just prefer the specialist, more knowledge'
'GP is very understanding and supportive'	'GP doesn't go to international breast meetings'
'Good to take pressure off specialists'	
'Always fits me in quickly'	
'Less threatening than specialist visits'	

Discussion

As well as detection of recurrent disease, survivorship care has the aims of managing the long term physical effects of cancer and its treatment, emotional needs and ongoing needs for information. General practitioners are ideally placed to address many of these issues.

Participants in this study were all having regular visits with their cancer specialists, with most attending consultations every 6 months, even many years after treatment. This is more frequent than recommended in Australian national guidelines[22] and more frequent than recommended by Australian cancer specialists in a previous study.[6] It is also possible that follow up visits are more common than previously recognised, increasing the burden on the health system. These women are gaining benefit from their follow up visits and their frequent consultations are likely to influence the views they express in the study.

Oncology specialists have concerns about the sustainability of specialist based follow up care due to the increasing number and complexity of breast cancer cases they are managing.[6] It is therefore important to consider alternative models of care as 'shared care' programs and transition to GP-led care. Australian breast oncologists are supportive of this concept,[6] and there is international research to show it is safe and cost effective,[10–13] but there is currently no research assessing the level of consumer support for this concept in Australia.

Table 4. Participants' quotes about GP follow up care
Possible advantages of GP care
'The GP is only 5 minutes away from me'
'My doctor wouldn't need training, she's pretty much right. And anything that she actually was worried about, she's rung the specialist clinic. So she's got sort of connections that she can find out what she doesn't know herself'
'You can just fit it [your cancer check up] in when you've got other things or you're in there because you've got bad sinus or, you know, something else and they'll just do a quick check. The same way as I get my blood pressure checked fairly often, my breast gets checked as well. Part of the whole health check that happens for me now that I'm a cancer patient. A huge relief to get it done'
'It's more everyday and it's less threatening [to see the GP]. I don't feel at all threatened by my specialists, but for things when I was a bit worried the GP is just easier and you feel more able just to go and see him. Oh yeah, I need a script for this or I need this and while I'm there I'll just get my boob checked. It's just on the little shopping list of things to do and it's easy'
'Anything that takes the pressure of specialists is probably a good idea'
Possible disadvantages of GP care
'A couple of the GPs have actually said they don't feel like they have the knowledge, understanding. And like doing physical examinations, because my breast is so lumpy, the GP says, "I want you to go and see the breast surgeon because I don't know what's going on." So I think GPs would need more training'
'You need to feel confident that that person is competent to do it. I mean, you know, my experience with the – with the cancer was that as soon as the breast surgeon felt the lump he knew what it was, whereas the GP hadn't, and I don't know if a breast care nurse would. So I think it's – for me, personally, it's about the competence of the person doing it. You have to feel confident that they're not going to miss something'
'You've got to be able to get in to see the GP. If I was to ring up today, I'd probably wait 3 weeks. Unless it was urgent, I'd probably wait 3 weeks'
'I would just prefer to stay with the specialist'
'The specialist has a lot more knowledge than the GP – that is her specialty... my GP... no she wouldn't know as much. My GP never does a chest examination or checks the nodes'
Note: Further quotes are in the text

This study has highlighted the importance of the relationship the patient develops with her oncologist(s) during treatment and has shown reluctance by some women to move away from care by the specialist. The feeling of 'abandonment' that can occur at the end of hospital based cancer treatment is well documented[23] and the present study suggests that similar feelings may develop when specialist based follow up care is completed. These issues may indicate that shared care programs will be more successful than a transition of full responsibility for follow up care by the GP. In addition, clear pathways of referral back to the specialist in a timely manner would be an important component of any shared care program.

One explanation for the dependence of cancer patients on specialists may be that GPs often lose touch with the patient during treatment. This may be perceived by the patient as a lack of interest or expertise on the part of the GP but may actually reflect poor communication between the specialist and GP. Efficient communication from the specialist and regular appointments with the GP during treatment may provide better support to the patient and the specialist team. This may also reduce the patient's anxiety about a return to the care of the GP at the completion of cancer treatment.

This study has also identified the importance of training programs for GPs involved in cancer care. This is consistent with previous research showing that patients considered their GPs to be unwilling or to have insufficient time and expertise to provide follow up.[16] This highlights the importance of informing women of the additional training their GP has undertaken to provide this care if training programs are developed. This may increase women's confidence in their GP's ability to deliver high quality care and the GP's attendance at training workshops or other educational activities would be a clear indication of interest. In fact, a high level of expert knowledge is not generally required to provide follow up care. However patients in this study did not express this view.

The use of patient-held written (or electronic) survivorship care plans has

been recommended in the United States of America[23,24] and proposed in Australia.[7,8] Care plans have the potential to improve communication between GPs and specialists (and other health professionals). They may also increase patient and GP confidence as it would provide a checklist of things to discuss at each visit and outline a pathway for referral to the appropriate person if problems develop. Whether care plans improve treatment requires further evaluation and this is the subject of a trial being conducted by the authors. A national project exploring models of shared care is also underway in Australia.[25] Exploration of GP views and preferences is an important component to complete the picture and further research in this area is needed to evaluate this.

Conclusion

This study is the first to describe the attitudes and preferences for GP involvement follow up care in Australian breast cancer survivors. Interviewees reported a high level of satisfaction with their current specialist based care arrangements and a reluctance to consider other models of care. However, they identified many potential benefits of GP involvement and identified possible barriers. Some patients were in a shared care arrangement and this may be more acceptable to women than transfer to GP-led care. Training programs and referral pathways have been identified as important components of a shared care program from the patient perspective. In addition, efficient communication between specialists and GPs, and regular appointments for the patient with her GP during treatment, are likely to reduce the patient's anxiety in transitioning to a shared care or GP-led model of follow up care. Exploration of GP views and preferences would inform further progress in this area.

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