Support Care Cancer (2011) 19:1975–1982
DOI 10.1007/s00520-010-1041-4

ORIGINAL ARTICLE

Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women

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Received: 4 August 2010 / Accepted: 1 November 2010 / Published online: 16 November 2010

Abstract
Purpose This study aims to explore and examine experiences and perceptions of follow-up care (medical and psychosocial) after active treatment for breast cancer among women living outside major Australian cities.
Method Twenty-five semi-structured telephone interviews were conducted. Participants also completed a brief questionnaire to collect demographic, diagnosis, and treatment information. Interviews were audio-recorded, transcribed, independently coded, and then thematically analysed.
Results Themes that emerged from the interviews centred on patient experiences and perceptions of follow-up service provision and provider interactions related to medical, psychosocial, and lifestyle (e.g., diet, physical activity) care. Many women perceived a marked decline in the quality and duration of follow-up consultations with clinicians in comparison to their initial treatment experiences. Several women experienced considerable overlap in follow-up care when multiple providers were involved resulting in 'unnecessary' time and travel costs. Generally, women experienced limited availability of medical providers in rural areas, resulting in a lack of continuity in care, exacerbated by limited communication and coordination between treating health professionals. Lastly, women perceived a lack of available psychosocial support and resources for rural breast cancer survivors in their areas.
Conclusions Breast cancer survivors living outside major Australian cities have limited access to medical follow-up care, and psychosocial and lifestyle support programmes. There is a need for greater co-ordination of care between health professionals to improve communication and reduce patient and medical system burden. Finding solutions (such as eHealth options) could help to alleviate these barriers and improve follow-up care for rural breast cancer survivors.

Keywords Breast cancer survivors · Follow-up care · Rural

Introduction

Approximately 13,000 women in Australia are diagnosed with breast cancer each year [1], yet the number of women dying from the disease is declining, with 5-year survival rates reaching 88% [2]. Such a growing population of breast cancer survivors - approximately 130,000 at the end of 2004 [3]—highlights the need for accessible and quality post-treatment medical and psychosocial care. Addressing this may be particularly difficult for rural women (30% of all women with breast cancer in Australia) with rural health service provision challenged by issues of equity, coverage, and supply [4].

Breast cancer survivors may experience a range of potential ill-effects as a result of their cancer and treatment. The presence of physical and psychosocial symptoms that may be long-lasting following treatment is well established [5–9], yet, not adequately addressed in follow-up care [10, 11]. The transition from active treatment to follow-up care can be difficult for women as they leave the hospital and health professional contact becomes infrequent. Patients

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across the cancer spectrum may experience a downturn in emotional and interpersonal support during the early follow-up period [12–14], and research has identified that many cancer survivors are 'lost in transition' and feel vulnerable and confused with the multiple activities and scope of follow-up care [12].

The vast majority of research on breast cancer survivors residing in rural areas has focused on initial diagnosis and treatment issues (i.e., surgery, chemotherapy, radiation therapy) [4, 15]. Despite a small but growing body of literature examining follow-up care among breast cancer survivors following active treatment, there remains a paucity of studies investigating patient–provider interactions and service provision received during this period. A Canadian study found women were satisfied with their health professionals during active treatment, but this declined during follow-up due to poor availability of local physicians and/or lack of physician understanding about oncology-related care [16]. Wilson et al. [17] identified that rural breast cancer survivors in Washington State (USA) desired greater patient education and more information about what to expect during and after treatment, plus more oncology- and health-related information specific to their rural context. Many rural survivors reported feeling isolated, exacerbated by difficulty in establishing support groups or networks with other breast cancer survivors [16, 17].

The Australian clinical practice guidelines for the management of early breast cancer follow-up care [4] are guided by the principles of early detection of local recurrence, screening for a new primary breast cancer, detection of treatment related toxicities, and provision of psychosocial support. The minimum recommended follow-up consultation schedule is every 3 months for the first year, every six months until 5 years, and then annually thereafter. While these guidelines exist, there has been little investigation of whether follow-up care guidelines filter down to patient lived experiences, particularly for rural women with breast cancer.

The qualitative study reported here examined patient experiences of medical and psychosocial follow-up care after active treatment (e.g., surgery, chemotherapy, and radiation therapy) for breast cancer among Australian rural women. It provides the first in-depth exploration of the experiences and perceptions of service provision and interactions with health professionals in a regional/rural Australian context.

Method

Participants were recruited via an advertisement placed in the October 2007 edition of the Breast Cancer Network Association (BCNA) rural and remote E-bulletin, which was circulated to 154 members residing in a rural or remote location across Australia. An e-mail was also sent in December 2007 and April 2008 on behalf of the researchers by the BCNA to a group of 68 rural women across Australia registered as part of a Review and Survey Group. There may have been duplicate emails across these two lists but that is difficult to ascertain as the invitation was sent on behalf of the researchers. A purposive sampling approach was used to try and include a cross-section of characteristics (rural location, age, breast cancer type, and treatment). Women interested in participating in the study contacted the research team by phone or email, were screened for eligibility and then (if eligible) posted an information sheet, consent form and return envelope. Eligibility criteria were: (1) diagnosed with breast cancer in the previous 5 years, (2) not currently receiving active treatment (excluding hormone therapy), and (3) living in a rural, remote or regional area of Australia according to the 2001 Australian Standard Geographical Classification System [18] at the time of diagnosis and treatment. Interviews were scheduled after written informed consent was obtained from each participant. The study protocol was approved by The University of Queensland, Human Research Ethics Committee in October 2007.

All interviewees were Caucasian, an average of 2.5 years from diagnosis (range, 10 months to 5 years), and a mean age of 49 years at the time of diagnosis (range, 35–69 years). Most women were part of a couple living with no children (68%) at the time of participation. All women interviewed had a previous single diagnosis of breast cancer, had undergone breast cancer surgery (lumpectomy or partial mastectomy 76%, unilateral 28%, or bilateral mastectomy 4%) and had at least one other form of adjuvant treatment including chemotherapy (72%), radiotherapy (84%), hormone therapy (72%), Herceptin (12%), or some other type of treatment (12%). Most of the women (64%) travelled more than 300 km for their treatment, with the remaining women (36%) having travelled between 100 and 300 km.

Data collection procedures

Telephone interviews were conducted in November 2007 to May 2008 at The University of Queensland, Brisbane. A semi-structured interview guide was developed based on existing literature on the experiences of breast cancer patients post-treatment, and breast cancer patients who live in rural, remote, or regional locations [19–22]. Participants were first asked questions pertaining to diagnosis and treatment experiences to help build rapport and understanding between the participant and interviewer. Then, the interviewer prompted the participant to think about their follow-up care (i.e., after they had finished their initial treatment of surgery, radiotherapy, and/or chemotherapy). Then depending on how the interview was flowing, there were prompt questions that could be used, examples of such questions included: What support or follow-up care did you receive after your treatment had ended? Who has been involved in your follow-up care (e.g., your General Practitioner (GP), cancer specialist, surgeon or oncologist, and other health professionals)? What has been involved in your follow-up care? What is your experience in accessing and receiving follow-up care? Do you think the care you received after you finished treatment was impacted by your rural/remote/regional location?

The average interview duration was 62 min (range, 32 min–1 h 46 min). Interviews did not coincide with scheduled follow-up appointments. Interviews were audio-recorded with participant consent and transcribed using word processing software. Participants also completed a brief postal questionnaire prior to interview to collect demographic information and details related to diagnosis and treatment of their breast cancer. Twenty five interviews were conducted in total; thematic saturation was reached at 22 interviews, whereby three more interviews were conducted to ensure validity of our interpretation. No incentives were offered to interviewees however a thank you note was posted at the end of the study.

Data analysis

Constant comparative analysis of interview transcripts was conducted [23]. Members of the research team independently reviewed a selection of transcripts using open coding to generate initial categories. Investigators then revised or confirmed all categories as appropriate. Transcripts were then reviewed and coded using the agreed category structure. Investigators then reviewed quotes that had been coded according to the structure. Through this process, open codes were collapsed into higher-order categories that reflected the emergent themes. Where differing interpretations of themes occurred, transcripts were re-reviewed until consensus was reached. Researcher triangulation was employed to enhance the inter-rater reliability of the analysis. Analytical rigour was also enhanced by searching for negative cases in code and theme development; however, no such cases were identified.

Results

Twenty-five in-depth, semi-structured interviews were conducted. Themes that emerged from the interviews centred on patient experiences and perceptions of follow-up service provision and provider interactions related to medical care, psychosocial, and lifestyle support. This encompassed issues relating to transitioning from active treatment to follow-up care, follow-up care regime and structure, accessibility and coordination, and availability of follow-up care in the residing region, and relationships and interactions with health providers. The themes of follow-up care regime and structure, and accessibility reflect content of interview prompt questions, while other themes are those that were offered voluntarily by the interviewee.

Transition in care

Returning home after active treatment was described as a difficult time by several women, (particularly one women who had been away from home for 14 weeks) exemplified by feelings of isolation and vulnerability after having been in constant contact with health professionals during the diagnosis and treatment phases. Women talked about being focused on ‘just getting through treatment’ that there was often not a lot of time to mentally process the experience until treatment was finished.

> What I found was that the cotton-wool-type situation that you find yourself in when you’re under the treatment regime...As soon as that was removed from my life, I really felt extremely isolated and vulnerable because it just sort of ended there. ...I really felt that I was set a cast on a very big ocean, with lots of things to contemplate because you really don’t have time to think (participant 5).

Clinical regime and structure of follow-up care

Many women reported consultation with a provider every 3 months during the initial follow-up period, which reduced to six monthly visits after 2 years and then yearly visits thereafter. However, there was variation in the structure and timing of care received, and this was typically related to the grade of breast cancer diagnosed, the type of treatment received, area of residence and whether the individual was participating in a clinical trial. For example, those women who were participating in a clinical trial had regular and consistent follow-up, and access to numerous health professionals, although all women still travelled to major metropolitan areas to be involved in these trials.

Several women thought that an appointment every 3–6 months was a good timeframe for follow-up especially in the first couple of years post-diagnosis. Most women expressed the importance of follow-up care being continued for at least 5 years.

> Well I think…that you should go and see your oncologist every three months—I think that’s very important. I

> think that in that three month period that you must write down if you're having problems because three months you forget and I think it's very important that you manage yourself…I think for five years especially when you're taking medication…. (participant 17).

Often, women perceived there were too many health professionals involved in the delivery of follow-up care and in some instances unnecessary overlap occurred during consultations. It was expressed that one or two providers would be sufficient, as long as the team of doctors (including GPs) were made aware of the content of follow-up appointments and kept informed about any concerns or problems that arise. As some women felt communication between their doctors was often lacking.

> I'd happily only see one doctor now, once a year rather than the two or the three. I know the gynaecologist he's sort of looking after more of the side-effects of the drugs (Tamoxifen) that I'm on than the cancer at the time……But, um, yeah like I said for me I feel it's a waste of time seeing both the radiation (sic, radiologist) and the surgeon. I think one would be sufficient for follow-up (participant 8).

Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as psychologists, dieticians, and physiotherapists, to assist with making lifestyle changes (e.g., diet, exercise, complementary, or alternative medicine), addressing other health issues (e.g., lymphoedema) and improving emotional well-being.

> I had to ask to see a dietician cause I had put on a lot of weight. Um, and that was concerning me and causing me stress...but that was all instigated by me… (participant 5).

> Probably everyone who has had cancer and gone through treatment should really be seeing a psychologist (participant 20).

Accessing and coordinating follow-up care

According to some participants, scheduling regular follow-up appointments with individual health professionals was not difficult. However, appointments to see multiple health professionals during one visit were often logistically harder to arrange. In several instances, it was suggested better access to health professionals and organisation of appointments was needed, especially for rural women who often had to travel long distances.

> I believe if the public hospitals have the capacity and the power to identify the rural patients, and therefore understand that you know they have made a significant journey to be here, they have to make a significant journey to get back, you know, can they not be seen in priority, particularly when it's just a review-type situation (participant 5).

> The other way is to bring the specialists out into the rural areas but that doesn't always work either because people's… appointment times aren't always coordinated and then if there's any issues in between, … who do the women go to? (participant 12).

Seven women spoke of having direct contact with a breast care nurse (BCN) since completing their initial treatment, while the majority of women spoke of having at least some contact during initial treatment and six interviewees did not mention a BCN. This contact during the follow-up period varied from only one follow-up phone call to regular monthly calls. Some women spoke that they would like more contact with their BCN, but there was no funding for this type of health care provision. Three women had negative experiences with a BCN during treatment despite this two still felt that a BCN should be involved in follow-up care. While most women reported seeing the same breast care nurse during treatment and follow-up, there were a couple of women who had seen four or more BCNs.

> One of the breast care nurses from the area health group was very, very good. In fact she pops around occasionally. But like everything else she doesn't have the funding to provide full support for, you know, rural people who need it (participant 2).

> The Breast Care Nurse I really do utilise her. If there is anything I'm worried about, I have such a good relationship with her, I just ring her (participant 20).

> She (sic, BCN) never came again … I have met her since and I said "don't ever bother coming again because you've got no idea what you did to me"… no compassion or anything and to think that I needed a back up (participant 17).

Several women, who did not mention any personal direct contact with a BCN indicated that having access to a BCN or a liaison person central to co-ordinating their follow-up care and acting as a patient advocate would be ideal. It was also suggested that this person could be their primary contact person to help address ongoing questions or concerns.

> …the ideal thing would be to have your own breast care nurse that's involved from day one. I mean you don't need to see them every week or even every month but if you know that there's someone who knows you (participant 2).

Availability of follow-up care

Limited availability of cancer-related health professionals in rural regions was another emergent theme. Some women acknowledged that smaller regions did not have the population density to support a specialist, let alone a wide range of specialists, and accepted the need to travel for follow-up appointments. Some women intimated they would be better off travelling to major towns or cities to access what they perceived to be the 'best' specialists and care available. For several women who were consulting a specialist visiting locally, one drawback perceived was the lack of alternative options if they were dissatisfied with this current provider (for one women this was an issue, however, she could not afford to travel to see another provider).

> I understand that (my town) doesn't have enough people that you're not going to get specialists to come here, and I've always been of the opinion that I would much rather go to where good specialists are even if it costs me money, um to know that I'm getting the best possible care and expertise (participant 9).

Relationship/interactions with health professionals

Communication and rapport with health professionals emerged as prominent themes. While most women stated they were happy with communication style and rapport, a few suggested their health professionals lacked understanding of ongoing concerns or problems. Acknowledgement and validation of concerns was important to the women, with several reporting they were not listened to or (in one case) believed when communicating side-effects of treatments during follow-up consultations. Other women however, did feel that their doctor acknowledged their concerns, and took action to address these concerns by making referrals or carrying out tests.

> … he said 'but you're not going off the drug'. I'm not telling you that I want to go off the drug. I don't want to go off the drug in fact I'm happy to take the drug forever, but what I want is acknowledgment that this is what it is doing. He finally did acknowledge that okay I agree with you it does have these issues, but you're not going off it. … He couldn't see that it was just validation I was after (participant 26).

Women commonly expressed the importance of being remembered and seen by the same health professional at subsequent appointments. This was emphasised by differences in private and public health care. Some women receiving private health care explained they had a continued and satisfying relationship with the same doctor(s), while some women receiving public health care experienced a lack of continuity with their health professionals, and had to retrace their clinical history with a different provider at every follow-up appointment.

> And I guess because I was private I always saw my specialists. Whereas if you go public, you don't necessarily see the same person at all. You may see different people every time you go (participant 9).

> …cause I'm with a public hospital… you're on a team and you just get whoever you see that day… Yes, I think I've seen the whole team.... …they'd come in and sit down and say 'hello how are you, I don't think we've met before have we?' and you'd say 'yep'. You know, you don't remember who I am and therefore you're just a number (participant 2).

Many women acknowledged health professionals' large workloads and suggested this impacted on the length and quality of consultations. Some women perceived their consultations as rushed and their provider as not always taking the time to enquire about their wellbeing on a more personal level.

> I feel the consultations are rushed. You get in, check your blood pressure, write out the request for a mammogram, write out the pathology request, write out your script, everything OK. Good, off you go. I don't feel that you are invited to just sit and chat with how you're doing (participant 26).

Community support, resources and facilities

Lack of community-based support programmes was a key concern for many women. Some women described being given information about support programmes but these were not available in their region.

Most women desired contact with other cancer survivors, and some had taken it upon themselves to source support in their local area, and often using the telephone and internet to gain access to support networks.

> I'm a resourceful person in myself, so I explored opportunities…I tapped into a women's health service that had received a grant… that was, you know, going to pay for a telephone call every 6 weeks to hook up for an hour and a half, women in remote areas. And that was a really nice opportunity to, just to be on the end of the phone …it's not confrontational, you're not looking at somebody, and that was really good but that was another thing that I had to go and get (participant 5).

> I know it's very difficult when you're as isolated as I was out there and, well probably not alone, there's

> probably other women in very small towns, but to find… get some sort of a group going of ladies who are close by who you could talk to.... Cause you have nothing…(participant 10).

Discussion

Our thematic analysis shows women living outside major cities in Australia experienced feelings of isolation and vulnerability when moving from active breast cancer treatment to follow-up care. Difficulties in transitioning to follow-up care were further heightened for these rural women by limited access to not only medical health professionals, but also to allied health professionals (e.g., psychologists, dieticians, physiotherapists) that could offer psychosocial and lifestyle support programmes. These findings converge with other published findings from other parts of the world [15, 17] and highlight a significant need for the provision of information and support to assist rural women in adjusting to this new phase in their lives and to ameliorate potential physical or psychosocial symptoms that may be experienced in the months and even years after active breast cancer treatment has ceased [24–26]. Developing effective programmes and interventions to address these limitations for rural breast cancer survivors is imperative. Mediated interventions via the Internet, computer or telephone have the potential to deliver such programmes, and can easily be adopted and delivered as part of routine care of many cancer support organisations.

Women in this study were largely satisfied with the follow-up regimes they were receiving. There were variations depending on severity of cancer and type of treatment received. Importantly, most follow-up schedules described were consistent with the Australian Clinical Practice Guidelines for the Management of Early Breast Cancer Follow-up Care [4]. Many women felt too many health professionals (e.g., oncologists, surgeons, GPs, and radiologists) were involved in their follow-up care, resulting in overlap of content covered at appointments. Having one or two cancer-specific health professionals was often considered to be sufficient, as long as outcomes of appointments were communicated to the entire team of health professionals. Patient experiences reported in this study do not appear to be consistent with the national guideline which stipulates: “with the involvement of various specialists as well as the GP in the treatment of the individual woman, it is important that follow-up care be co-ordinated to ensure patients are not subjected to an excessive number of visits”[p100, 4]. This finding adds to the current literature on follow-up care experiences; however, this study did not set out to systematically investigate whether follow-up care received by women was concordant with the guidelines, further investigation is needed to determine whether women would feel comfortable seeing one health professional for follow-up care as was suggested by women in this study, as this could allow for improved service provision efficiencies.

In some parts of Australia, responsibility is placed on GPs to be involved in provision of follow-up care for cancer patients. This requires GPs to be familiar with requirements and schedules of follow-up care, for communication channels between GPs, clinicians, and other health service providers involved to be free-flowing and consistent, in order for delivery of follow-up care to be integrated, well coordinated, and comprehensive. [4] According to patient accounts given in this study, communication from oncology health professionals to GPs was insufficient. A recent literature review identified poor communication between local rural physicians and cancer specialists [15] as an issue that needs addressing in order to optimise the quality of follow-up care for rural women. Moreover, lack of coordination and inadequate communication between health professionals may result in inefficient use of health care resources, and more importantly, missed opportunities to identify and intervene to avert or reduce consequences of cancer and its treatment for patients. Survivorship care plans are one tool that could help meet the needs of the survivors (such as improved coordination and communication, information about lifestyle, and potential late side effects), but also relieve the ever growing follow-up care load on health professionals, as it would allow integration of primary care and specialist care, as well as some of the care to be delivered by a breast care nurse or breast physician [27]. While the concept of a survivorship care plan has been supported since it was recommended by the Institute of Medicine [10], their utility still needs to be evaluated.

Some women in this study perceived significant differences in the care breast cancer patients receive through public and private health care systems. Most women reported satisfaction and good continuity of care with private health care, whereas women receiving public health care had to re-iterate their histories due to seeing different healthcare providers at each appointment. This finding warrants further investigation in order to establish if the patterns of follow-up care experienced by rural women in public or private health care systems relates to differing levels of satisfaction and health outcomes. Continuity of care with health care providers is important in establishing rapport and developing a relationship, whereby, women can feel comfortable to openly raise concerns and issues [28]. Interestingly, the majority of women perceived follow-up consultations to be rushed and lacking personal quality, which contrasted markedly with women’s experience during active treatment. Women were aware of time and resource constraints but still felt that extra effort could make the consultation more personable. Breast care nurses are health professionals that could offer continuity in care. The value of BCNs in follow-up care should not be underestimated especially in providing not only medical but psychosocial and lifestyle support that women need. However, the experiences of the women in this study with a BCN after initial treatment was varied, and further work is needed to not only establish whether it is feasible for BCNs to be so intimately involved in follow-up care, but also whether this is what breast cancer survivors desire. An evaluation study of BCN services conducted in Queensland highlighted that BCNs provide an invaluable service during diagnosis and treatment [29], yet information regarding their role in follow-up care was not collected.

Psychosocial and lifestyle support was perceived as lacking for rural women with the information and resources received during active treatment not specific to rural areas (albeit such resources may in fact not exist). Many women in this study described avenues they pursued to access psychosocial and lifestyle support (most commonly via Internet). The need for women to search and source their own support networks confirms previous findings [15], and highlights that modalities women utilise to access cancer-related information may differ between urban and rural contexts. A study of breast cancer survivors living in urban areas found that women were less likely to engage formal services or the Internet for information or support [26], yet findings from our study suggest that these, and a range of other modalities (e.g., telephone) are important avenues for rural women.

This study provides the first in-depth examination of patient experiences and perceptions of follow-up care service provision and interactions with health professionals among women diagnosed with breast cancer residing outside of major Australian cities. This study has highlighted a number of important areas requiring attention. First, better coordination of care is needed to reduce unnecessary burden on women and health services. Second, consistent and systematic communication between rural physicians and oncology health professionals is needed to ensure women are receiving optimal follow-up care. Finally, women transitioning from active treatment to follow-up care require and request support that is accessible from rural areas, such as the telephone, Internet, or email (e.g., informational or supportive emails).

Given the increasing numbers of breast cancer survivors and the ensuing demand on rural health services, other methods and models for delivering follow-up care need to be considered such as GP care models or nurse-led care models, that can be delivered in partnership with oncology specialists, allied health professionals and survivorship care plans [4, 27, 30, 31]. The findings from this study demonstrate that the traditional biomedical model of care does not fulfil the needs of breast cancer survivors in promoting optimal health and well-being, and other models of care need to be implemented and evaluated. Follow-up may not necessarily need to be conducted in person; particularly for patients living in remote areas where telephone-based or other eHealth options such as video linkage may assist to bridge the service provision gap. These methods and models of care could also improve coordination of care, dissemination of resources and information, and thus quality of life for all cancer survivors. The present study draws upon only a small number of rural women's experiences and perceptions, and there needs to be further research on follow-up care from the perspectives of all stakeholders. Large-scale studies are needed to systematically examine the follow-up care received by Australian women living outside major cities and to what extent other models of care might be more appropriate and efficient for this group. Contributions of patient accounts and recommendations for improving follow-up care should not be underestimated in establishing an evidence base.

Acknowledgements Dr. S Lawler had full access to all data in the study and takes responsibility for the integrity of the data and accuracy of the data analysis. This study was funded a Queensland Health Core Research Infrastructure Grant and NHMRC Program Grant funding (#301200). E Eakin is funded by a NHMRC Senior Research Fellowship (#511001). J Adams is funded by a PHCRED Research Fellowship, Department of Health and Ageing. The project funding body had no role in the design and conduct of the study, data extraction or analyses, in the writing of the manuscript, or the review and approval of the manuscript for publication. We thank the participants from across Australia, the Breast Cancer Network of Australia in supporting this study, and the entire project team. There are no conflicts of interest.

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