



## The health of women treated for breast cancer: A challenge in primary care

Moyez Jiwa, Arleen Chan, Jaco Loriet and Shohreh Razmi

The Curtin Health Innovation Research Institute  
Curtin University,  
Perth, Western Australia

### REVIEW

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#### Corresponding Author:

Moyez Jiwa

Curtin Health Innovation Research Institute,  
7 Parker Place, Bentley, Perth WA 6102

Email: [m.jiwa@curtin.edu.au](mailto:m.jiwa@curtin.edu.au)

### Abstract

At least one in a hundred consultations in general practice in Australia involves women being treated for breast cancer. The challenges presented during these consultations test the quality of primary care. Firstly, women are reported to prefer to discuss their breast cancer-related problems with a specialist even though research suggests that patients generally prefer to consult with a general practitioner (GP). The extent to which these patients will have maintained or return to their previous level of functioning will be a reflection on the quality of primary care, as some breast cancer-related health issues may persist beyond the time period when they are undergoing specialist review. Further, psychosocial matters, sexuality and relationships may require repeated review and perhaps consultations involving family members and would therefore be better addressed by a GP. An increasingly urgent need exists to review how best to support people who are successfully treated for life limiting illnesses, such as breast cancer.

#### Key Words

Breast cancer, primary care, cancer morbidity

#### Breast cancer

Breast cancer is the second most common cancer in women. Treatment is generally effective, and most women are still

alive five years from diagnosis. In Australia 143,967 women had been treated for breast cancer between 1981 and 2006.<sup>1</sup>

Since then, another estimated 12,000 cases have been treated annually, suggesting that by 2012 there are likely to be more than 200,000 women living in Australia who have been treated for breast cancer.<sup>2</sup> In this country there

is an estimated one hundred million consultations with GPs every year, 22.4% with women aged 44-74 years.<sup>3</sup>

There are over 22 million residents of Australia, females in the age group 44-74 years represent about 19% of the population or 4,180,000 women. Assuming that women treated with breast cancer consult at least once a year, then at least one in every hundred consultations with a GP involves a woman treated for breast cancer at some point in her life. Treatment for breast cancer is determined by the stage of the disease, and is influenced by patient co-morbidities and personal choice of goals of treatment. However, for most cases treatment will include a combination of surgery, radiotherapy and systemic therapy, including chemotherapy, endocrine or biological therapy.<sup>4</sup>

#### Follow-up practice varies

Following specialist treatment, most women will usually be followed up annually by their specialist-surgeon and/or oncologist for the first five years after treatment.<sup>5</sup> Today, however, some women with early and so-called 'low risk cancers' are likely to be 'discharged' from the specialist clinic as early as one year after treatment.<sup>6</sup> The main focus of this subsequent review for breast cancer is the detection of recurrent disease and the management of potential side effects or complications of breast cancer therapies. In many instances breast cancer recurrence is nevertheless detected not by a doctor, but by the patient. This may be reported to GPs between visits to their treating specialist.<sup>7</sup> Individual follow-up is not standardised, and much depends on treatment, distance to travel for follow-up, place of primary breast cancer care delivery (tertiary referral centre, community institution, public or private setting) and adherence to national and international guidelines.<sup>8</sup> In the light of this



lack of uniform practice, the role of specialists in 'follow-up' appointments have been questioned and some centres now consider curtailing specialist follow-up with shared care arrangements with a GP.<sup>9</sup> The impetus for such a change in approach is the rising incidence of breast cancer and the need for specialists to treat an increasing number of cases. Research furthermore suggests that 'follow-up' in primary care is both acceptable to patients and cost effective.<sup>10,11</sup> Before the issue of follow-up is addressed, the common problems presented following treatment for breast cancer ARE discussed.

### **Treatment**

Following axillary dissection and/or breast radiation therapy, lymphoedema may develop.<sup>12,13</sup> This may be experienced several weeks or months after the surgery, and often manifests as a marked intermittent swelling of the arm. Patients may benefit from exercise or massage therapy and compression garments or pneumatic compression devices to reduce the associated morbidity are advised.<sup>14</sup> Another common experience is shoulder pain and stiffness consequent to neurological damage during surgery.<sup>15</sup> This symptom is sometimes misinterpreted as a sign of recurrence and leads some women to seek investigations for shoulder pain.<sup>16</sup> The involvement of a physiotherapist early in each case may help to reduce distress and speed up recovery, although many women manage without professional assistance. Some patients will undergo mastectomy with or without contralateral prophylactic mastectomy, with some choosing to have breast reconstruction. The latter procedure may be associated with longer post-operative recovery and, occasionally, further surgery is required in the event of haematoma, or flap with significant morbidity as complications can arise ranging from discomfort and inconvenience to further risky surgery.<sup>17</sup>

Radiotherapy is offered to more than 70% of all patients with breast cancer.<sup>18</sup> Following radiotherapy, patients may experience superficial damage to the overlying skin and may report blistering. Occasionally, the resulting trauma may lead to infection and pain.<sup>19</sup> Chemotherapy, however, is believed to be the adjuvant therapy associated with the greatest morbidity. Depending on the stage of disease, up to 50% of women are recommended to have chemotherapy.<sup>20</sup> Chemotherapy may be administered pre-operatively, but more commonly following completion of breast and axillary surgery. Most women receiving chemotherapy also in addition to endocrine treatment for breast cancer will experience fatigue and hair loss.<sup>22,23</sup> Fatigue may continue for several months after treatment, may be transiently exacerbated by adjuvant radiation therapy, and can persist for longer despite efforts to increase exercise tolerance and boost

vitality. This may furthermore be exacerbated by concomitant depression which has twice the incidence in women treated for breast cancer compared to the general female population.<sup>24</sup> Hair loss is temporary and initial hair regrowth may be more fine and frequently curlier. For women receiving adjuvant endocrine therapy, a recognised risk of iatrogenic osteopenia exists. This may occur in both premenopausal and postmenopausal women, and there is a need to assess patients for risk of fractures over time.<sup>25</sup> Growing evidence suggests that bisphosphonates may minimise osteoporotic risk, but use of this family of drugs may be associated with adverse effects including acute-phase reactions and, rarely, renal toxicity and osteonecrosis of the jaw (ONJ).<sup>26</sup>

### **Problems after treatment**

Over the past five years, a team in Perth, Western Australia has documented the experience of women who have been followed up in specialist clinics. An overarching observation was that women who are diagnosed with breast cancer experience a major life event which sometimes leaves them with very different ideas, concerns and expectations on a host of issues ranging from employment preferences to their choice of life partner.<sup>27</sup> The average age of women studied was 62 years  $\pm$  10 years. Some women revisited many of their previous life choices and occasionally actively sought to redirect their lives in those areas.<sup>28</sup> The women appeared to benefit from being encouraged to be proactive in dealing with problems that may have a radical impact on their lives and families. They especially benefited from the promotion of self-esteem, as women reported a profound sense of loss through disfiguring breast surgery and in some cases the effects of premature menopause.<sup>27</sup> As an indication of fear of recurrence, many patients reported new lumps or thickening and changes of breast tissue, although the overwhelming majority did not have recurrent cancer.<sup>27</sup> For the medical team supporting the woman with multiple new symptoms, there was indication to screen for depression and, in extreme cases, to rule out suicidal risk.

In addition, these women needed support to 'normalise' their experiences as there is a risk of interpreting the benign symptoms related to their surgery or other co-morbidities as a mark of recurrent breast cancer.<sup>27</sup> The most common symptom reported was new or persistent pain, followed by fatigue, general loss of well being, sexual dysfunction and menopausal symptoms. This was also reflected in the findings of an earlier study involving women with breast cancer in the UK.<sup>29</sup> Such issues call for particular skill in assessing symptoms: On one hand



excellent clinical acumen may reduce the risk of over investigation or iatrogenic harm and, on the other hand, may identify recurrence or treatable iatrogenic conditions sooner rather than later. More challenging still is the promotion of a healthy lifestyle, including maintaining an exercise programme, weight control and a healthy diet. These have a particular relevance in breast cancer where survival has been shown to be improved by avoiding obesity.<sup>30</sup>

### Primary care

A notable observation was that a large proportion of women continue to experience problems even 10 years after treatment.<sup>28</sup> Furthermore, contrary to expectations, 68% of women who are treated for breast cancer treated at one tertiary centre in Western Australia did not visit their GP in the previous year with problems that they believe may be somehow associated with their breast cancer. However, they did present to hospital clinics with these problems.<sup>28</sup> Despite this observation, older patients who were surveyed seemed to express a preference to consult their GP, especially if they were worried about a recurrence or wanted emotional support. Overall, women however preferred a hospital-based breast care nurse if they were worried about a recurrence or required emotional support.<sup>28</sup>

It is clear that breast cancer treatment may, in the short-term, be associated with considerable morbidity for many women. Supporting women in these circumstances is furthermore associated with particular challenges. The ideal 'follow-up' program to ensure early detection of recurrence, optimise early intervention for treatment-related morbidity, and provide maximal support for breast cancer patients has not been identified. Proposals have been made for the follow-up to be conducted entirely in primary care, but this is fraught with challenges in the context of the Australian healthcare system. Firstly the funding structures in Australia are such that patients often have to pay for attending a GP, whilst many GPs charge 'gap fees' over and above the government funded and Medicare prescribed consultation fee. In addition to these potential consultation charges, patients are also faced with out-of-pocket fees for the investigations or referrals ordered by a GP treating them. These investigations may include X-rays, blood tests, or scans to assess individual symptoms. The patient may furthermore benefit from referral to an allied health practitioner, in which case the GP may authorise a government-funded care plan including six sessions with that provider every year.<sup>31</sup> The implication of this is that, if there are other needs that should be addressed, or if the problems require more than six sessions from an allied health practitioner from one discipline, the patient will directly bear some of the costs for care in the community.

### New models of care

In a recent pilot study, a team from Western Australia evaluated whether women who had been treated for breast cancer could have follow-up care coordinated in the community,<sup>32</sup> working to a model of care coordinated by a nurse similar to one previously proposed in the literature.<sup>33</sup> Women were offered the opportunity to have their needs assessed by a multidisciplinary team of allied health practitioners in the community.<sup>32</sup> Of the 74 women who were invited to participate, 21 were recruited and 19 completed the study. The mean age of participating patients was 55 years (range 38–61 years) and the mean time in follow-up was 23 months (range 16–38 months). The team identified a median of three problems per patient (range 2–7) and made an average of two recommendations per patient for referral to an allied health professional (range 0–5). At three months, 17 women had attended their GP, 11 of whom felt their condition had improved as a result of the intervention. However, three months after deploying this model of care, the team did not document any significant improvement in patients on validated measures.<sup>32</sup>

For the above model of care to work in the absence of a care coordinator, the health provider needs to be aware of the plethora of problems that might be experienced by women in this group, and organise access to treatment that may be available in this context. It is generally accepted that people with serious illness have expressed a preference for continuity of care from a care provider that is available, knowledgeable and skilled.<sup>34</sup> Within the context of the Australian healthcare system the GP has traditionally assumed this role, and indeed this was reflected by patient preferences for choice of practitioner expressed to researchers. The patient who has consulted her GP before or at the time of a diagnosis of breast cancer may be more likely to consult her GP after treatment. However, it also requires that her GP must be proactive in screening the patient for a specific set of problems that are commonly experienced following treatment for breast cancer. Although published consultation guides to assist practitioners in their consultation with patients with breast cancer are available,<sup>35</sup> supporting patients with breast cancer is more than a matter of attention to a list of problems. The ability to detect the most complex issues, to recognise the biographical disruption that may occur following treatment for breast cancer, requires excellent communication skills. For example, it has previously been demonstrated that it cannot be taken for granted that practitioners possess the necessary skills to address psychosexual problems as presented by breast cancer



patients.<sup>36</sup> It has similarly been suggested that practitioners do not necessarily offer evidence-based advice when consulting people who may benefit from specialist cancer care when presenting with recurrent cancer.<sup>37</sup>

### The future

At least one in a hundred consultations in general practice involves women treated for breast cancer in Australia. The challenges presented during these consultations test the quality of primary care. Firstly, women are reported to prefer to discuss their breast cancer related problems with a specialist, even though research suggests that they prefer to consult their GP. This may reflect the increased potential for out-of-pocket expenses in primary care, or it may reflect the feeling that the practitioner is inadequately equipped to respond to the needs of this group of patients. A model of care in which the patients were offered allied healthcare in the community was successful, but required a nurse in the coordinator role. It is clear that the number of patients in the community treated for breast cancer will continue to increase as the population ages. The extent to which these patients will have maintained or return to their previous level of functioning will be a reflection on the quality of primary care, as some breast cancer-related health issues may persist beyond the time period when they are undergoing specialist review. Further, psychosocial matters, sexuality and relationships may require repeated review and perhaps consultations involving family members and would therefore be better addressed by a GP. In the future, as the population becomes more computer literate it may be possible to offer many patients web-based support programmes that would allow them to monitor their own problems and symptoms, effectively coordinating their own care. In the meantime there is an urgent need to review how best to support an increasing number of people who are successfully treated for chronic illnesses, such as breast cancer.

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### References

1. Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre\* 2009. Breast cancer in Australia: an overview, 2009. Cancer series no. 50. Cat. no. CAN 46. Canberra: AIHW.
2. Breast cancer in Australia: an overview, 2009. Available from: <http://aihw.gov.au/publication-detail/?id=6442468297> (Accessed 26/03/2012).
3. Britt H, Miller GC, Charles J, Henderson J, Bayram C, Harrison C, Valenti L, Fahridin S, Pan Y, O'Halloran J 2008. General practice activity in Australia 2007-08. General practice series no. 22. Cat. no. GEP 22. Canberra: Australian Institute of Health and Welfare.
4. Treatment options by breast cancer type. Available from: [\[cancer/treatment/treatment-options-by-breast-cancer-type\]\(#\) \(Accessed 26/03/2012\).](http://canceraustralia.nbocc.org.au/breast-</a></li></ol></div><div data-bbox=)

5. Follow-up of breast cancer survivors. Available from <http://www.petermac.org/cancersurvivorship/Followupofbreastcancersurvivors> (Accessed 26/03/2012).
6. C Davis, P Williams, S Redman Early discharge following breast surgery: assessing care, support, and informational needs of women with early breast cancer in Australia. *Aust N Z J Surg.* 2000; 70: 569-72.
7. Beaver K, Luker KA. Follow-up in breast cancer clinics: Reassuring for patients rather than detecting recurrence *Psycho-Oncology* 2005: 14; 94-101.
8. Khatcheressian JL, Wolff AC, Smith TJ, Grunfeld E, Muss HB, Vogel VG, Halberg F, Somerfield MR, Davidson NE. American Society of Clinical Oncology American Society of Clinical Oncology 2006 update of the breast cancer follow-up and management guidelines in the adjuvant setting. *J Clin Oncol.* 2006;24: 5091-7. Epub 2006 Oct 10.
9. NBOCC Shared Care Demonstration Project. Available from <http://www.smics.org.au/breast/nbocc-shared-care-demonstration-project.html> (Accessed 26/03/2012).
10. Grunfeld E, Levine MN, Julian JA, Coyle D, Szechtman B, Mirsky D, Verma S, Dent S, Sawka C, Pritchard KI, Ginsburg D, Wood M, Whelan T. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol.* 2006 Feb 20;24(6):848-55. Epub 2006 Jan 17.
11. Grunfeld E, Gray A, Mant D, Yudkin P, Adewuyi-Dalton R, Coyle D, Cole D, Stewart J, Fitzpatrick R, Vessey M. Follow-up of breast cancer in primary care vs specialist care: results of an economic evaluation. *Br J Cancer.* 1999 Mar;79(7-8):1227-33.
12. Treatment Option Overview. National Cancer institute. Available from <http://www.cancer.gov/cancertopics/pdq/treatment/breast/Patient/page5> (Accessed 26/03/2012).
13. Hayes SC, Janda M, Cornish B, Battistutta D, Newman B. Lymphedema after breast cancer: incidence, risk factors, and effect on upper body function. *J Clin Oncol.* 2008 Jul 20;26(21):3536-42.



14. Harris SR, Hugi MR, Olivotto IA, Levine M; Steering Committee for Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. Clinical practice guidelines for the care and treatment of breast cancer: 11. Lymphedema. *CMAJ*. 2001 Jan 23;164(2):191-9.
15. Caffo O, Amichetti M, Ferro A, Lucenti A, Valduga F, Galligioni E. Pain and quality of life after surgery for breast cancer. *Breast Cancer Res Treat*. 2003 Jul;80(1):39-48.
16. Kuehn T, Klauss W, Darsow M, Regele S, Flock F, Maiterth C, Dahlbender R, Wendt I, Kreienberg R. Long-term morbidity following axillary dissection in breast cancer patients—clinical assessment, significance for life quality and the impact of demographic, oncologic and therapeutic factors. *Breast Cancer Res Treat*. 2000 Dec;64(3):275-86
17. Ascherman JA, Hanasono MM, Newman MI, Hughes DB. Implant reconstruction in breast cancer patients treated with radiation therapy. *Plast Reconstr Surg*. 2006 Feb;117(2):359-65.
18. Early Breast Cancer Trialists' Collaborative Group (EBCTCG). Effect of radiotherapy after breast-conserving surgery on 10-year recurrence and 15-year breast cancer death: meta-analysis of individual patient data for 10 801 women in 17 randomised trials. *The Lancet*, 2011; 378: 1707 – 1716.
19. Kirova YM, Fromantin I, De Rycke Y, Fourquet A, Morvan E, Padiglione S, Falcou MC, Campana F, Bollet MA. Can we decrease the skin reaction in breast cancer patients using hyaluronic acid during radiation therapy? Results of phase III randomised trial. *Radiother Oncol*. 2011 Aug;100(2):205-9. Epub 2011 May 31.
20. Cancer Australia. Types of chemotherapy. Available from <http://canceraustralia.nbocc.org.au/breast-cancer/treatment/types-of-chemotherapy> ( Accessed 26/03/2012).
21. Shimizu C, Ando M, Kouno T, Katsumata N, Fujiwara Y. Current trends and controversies over pre-operative chemotherapy for women with operable breast cancer. *J Clin Oncol*. 2007 Jan;37(1):1-8.
22. Shapiro CL, Recht A. Side effects of adjuvant treatment of breast cancer *N Engl J Med* 2001; 344:1997-2008.
23. Lemieux J, Maunsell E, Provencher L. Chemotherapy-induced alopecia and effects on quality of life among women with breast cancer: a literature review. *Psycho-Oncology*.2008. 17: 317–328. doi: 10.1002/pon.1245
24. Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. *BMJ*. 2005 Mar 26;330(7493):702. Epub 2005 Feb 4.
25. Pavlakis N, Schmidt R, Stockler M. Bisphosphonates for breast cancer. *Cochrane Database Syst Rev*. 2005 Jul 20;(3):CD003474. Review.
26. Diel IJ, Bergner R, Grötz KA Adverse effects of bisphosphonates: current issues. *The Journal of Supportive Oncology*. 2007, 5(10):475-82.
27. Jiwa M, Halkett G, Deas K, Ward P, O'Connor M, O'Driscoll C, O'Brien E, Wilson L, Boyle S, Weir J. How do specialist breast nurses help breast cancer patients at follow-up? *Collegian*. 2010;17(3):143-9.
28. Jiwa M, Halkett G, Deas K, Meng X Women with breast cancers' preferences for surveillance follow-up. *Collegian*. 2011;18(2):81-6
29. Jiwa M, Thompson J, Coleman R, Reed M. Breast cancer follow-up: could primary care be the right venue? *Curr Med Res Opin*. 2006 Apr;22(4):625-30.
30. Carmichael AR Obesity and prognosis of breast cancer. *Obesity Reviews* 2006; 7; 333–40.
31. The Royal Australian College of General Practitioners. Medicare Benefits Schedule fee summary. 2012.
32. Jiwa M, Longman G, Sriram D, Sherriff J, Briffa K, Musiello T. Cancer care coordinator: promoting multidisciplinary care: a pilot study in Australian general practice. *Collegian* (in press) Available from: <http://www.sciencedirect.com/science/article/pii/S1322769612000352>.
33. Jiwa M, Saunders CM, Thompson SC, Rosenwax LK, Sargant S, Khong EL, Halkett GK, Sutherland G, Ee HC, Packer TL, Merriman G, Arnet HR. Timely cancer diagnosis and management as a chronic condition: opportunities for primary care. *Med J Aust*. 2008 Jul 21;189(2):78-82.
34. Curtis JR, Wenrich MD, Carline JD Shannon SE, Ambrozy DM, Ramsey PG. Patient's perspectives on physician skill in end of life care: differences between patients with COPD, cancer and AIDS. *Chest* 2002; 78:701-702
35. Jiwa M, Ping-Delfos WC, Briffa K, Sherriff J, Merriman G, Nockolds J, Jardine L, Musiello T, Longman G Developing a self-administered questionnaire as a guide to consultations with women treated for breast cancer. *Int J Family Med*. 2011;2011:390692. Epub 2011 May 23.



36. Jiwa M, O'Shea C, Merriman G, Halkett G, Spilsbury K. Psychosexual problems in general practice: measuring consultation competence using two different measures. *Qual Prim Care*. 2010;18(4):243-50.
37. Halkett GK, Jiwa M, O'Shea C, Smith M, Leong E, Jackson M, Meng X, Spry N. Management of cases that might benefit from radiotherapy: a standardised patient study in primary care. *Eur J Cancer Care (Engl)*. 2012 Mar;21(2):259-65. doi: 10.1111/j.1365-2354.2011.01314.x. Epub 2011 Dec 6

### **PEER REVIEW**

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### **CONFLICTS OF INTEREST**

The authors declare that they have no competing interests