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Survivorship care after breast cancer

Background

Due to early detection and improving treatment, the number of breast cancer survivors is increasing. It is estimated that there are now over 113 000 women living in Australia who have had a diagnosis of breast cancer in the past 20 years. How to best care for these women in the long term is an issue currently facing oncologists. With workforce shortages affecting cancer professionals and the changing focus of care to a more holistic approach, it is likely that general practitioners will have opportunities to become increasingly involved in the care of breast cancer survivors.

Objective

This article outlines issues to consider when caring for women in the years following their breast cancer treatment, and discusses the role of the GP in current and future models of care.

Discussion

General practitioners are ideally placed and skilled to address the long term issues that affect women who have survived breast cancer.

■ **'After my very last radiation treatment for breast cancer, I lay on a cold steel table, hairless, half dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing... I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship...'**¹

It is estimated that there are now over 113 000 breast cancer survivors in Australia.² With current workforce shortages affecting cancer health professionals and the changing focus of care to a more holistic approach, it is likely that general practitioners will become increasingly involved in the care of breast cancer survivors.

Defining survivorship

Life after breast cancer involves adjusting to a 'new self', adapting to living with the long term effects of cancer and its treatment, as well as living with uncertainty. In the past, the term 'cancer survivor' was used to describe someone who is cured of their cancer. This usually meant someone who was free of disease 5–10 years following treatment. 'Survivorship' now refers to life after a diagnosis of cancer; from the moment of diagnosis and the years thereafter.³ Survivorship, in this context, is the pursuit of optimal health of body and mind for life. Being a survivor means maximising disease free quality of life, but also includes maximising health and wellbeing should recurrence occur and while living with metastatic disease.

Survivorship care

'You are busy in your life juggling several balls – work, kids, home and relationships. Then you get handed an unwelcome extra ball – breast cancer. For a while you put something else down so you can juggle treatment, and at the end, you

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should be able to put down the cancer and go back to your life. Instead, it's like throwing that extra ball up in the air – you never know whether it's going to come back down or not...' (Breast cancer survivor)

As early detection and advances in treatment lead to improved survival, improved care for cancer survivors has become increasingly important. Survivors are telling their health professionals that they want more from their care than just being told there is no sign of recurrence, and doctors are recognising that there are many other areas to be addressed including psychosocial care and the management of long term effects of cancer and its treatment.

Two major American publications have put survivorship care on the oncology agenda. One of these, a 2004 report by Centers for Disease Control and Prevention in collaboration with the Lance Armstrong Foundation, 'A national action plan for cancer survivorship: advancing public health strategies', outlines a plan for improving survivorship care in a number of ways, including raising awareness, educating health professionals, improving infrastructure and supporting research.⁴ Another, published in 2005 by The Institute of Medicine, 'From cancer patient to cancer survivor: lost in transition', stresses the importance of recognising cancer survivorship as a distinct phase of care that deserves ongoing attention from cancer clinicians and other health care providers. It gives recommendations for survivorship care, one of which is the development of a survivorship care plan.¹

Follow up after breast cancer

'They talk about the treatment roundabout as if you get off at the same point you get on. But I found it more like one of those moving walkways at the airport – you get off somewhere completely different, and unless your family come along with you, they will be waiting at another gate for you to 'get back to normal'. Instead, it's a 'new normal' you have to define'. (Breast cancer survivor)

As well as the risk of local and distant recurrence there are many issues that can affect women in the years following treatment for breast cancer. Long term and late effects of breast cancer and its treatment include menopausal symptoms,⁵ weight gain,⁶ sexual and fertility difficulties,⁷⁻⁹ osteoporosis, cognitive dysfunction and fatigue,¹⁰⁻¹⁴ cardiovascular disease, arm oedema,^{15,16} reduced quality of life, relationship and family breakdown, and psychosocial distress.¹⁷⁻²⁰ Many of these effects may be prevented, or their impact minimised, with appropriate assessment and early evidence based intervention.²¹

While there are no published data documenting patterns of breast cancer care in Australia, anecdotally it appears that in metropolitan areas, most follow up care is provided by specialists (medical

oncologists, radiation oncologists and/or breast surgeons.) This may differ in rural areas, where GPs may be more involved in long term care. Follow up care after breast cancer treatment has traditionally focused on the detection of local and distant recurrence. The majority of research evaluating optimal follow up protocols has focused on the need for routine scans and other medical tests to detect recurrent disease at follow up. A Cochrane review that included randomised controlled trials (RCTs) of over 3000 women showed that there is no difference in overall survival or disease free survival in women who were followed up by clinical assessment and mammography compared to those whose follow up included more investigations such as other radiological tests and blood tests.^{22,23} It is therefore recommended in many guidelines, including Australian,²⁴ that routine follow up includes clinical assessment and mammography but no other investigations unless they are indicated by clinical symptoms or signs. Many guidelines from around the world discuss the importance of providing psychosocial support and addressing lifestyle and sexuality issues, but none provides a recommendation on how this comprehensive care should or could be delivered.²⁴⁻²⁷ As more women who have had breast cancer will die of cardiac disease than breast cancer, attention to cardiovascular risk factors, often gauged to be a low priority in the early phases of treatment, is increasingly important.

The needs of breast cancer survivors in Australia have not been previously explored, however there is evidence from the United States and the United Kingdom that the follow up care provided to many breast cancer survivors is inadequate. Follow up visits tend to focus on the detection of recurrent disease by clinical examination, but little attention is paid to patient education and to meeting psychosocial needs.²⁸ Women want their follow up care to include discussion of lifestyle and psychological issues²⁹ and they also want information on the possible long term effects of treatment and the prevention of recurrent cancer.^{30,31}

Survivorship care plans

The Institute of Medicine (IOM) report recommends that a survivorship care plan be developed at the end of treatment for all people treated for cancer of any type. The survivorship care plan is described as a patient held written record of cancer treatment with a detailed plan for future care. The minimum requirements of the survivorship care plan, as recommended by the IOM, are listed in *Table 1*.¹ While some commentators consider it to be intuitive and 'common sense' that such a plan will improve care, trials have not been done to assess whether the use of a formal survivorship care plans actually improves care.

The role of the GP

There is evidence that women find the concept of GP follow up care an acceptable alternative to specialist follow up. In a study exploring preferences, women said that the most important aspects of follow up care were continuity of care and an 'unrushed' consultation, which they feel their GP can provide. They also said that they value the availability of specialist care when needed.³⁰

Table 1. Survivorship care plan – recommended content¹**Part 1. Record of treatment**

- Diagnostic tests performed and results
- Tumour characteristics (eg. site(s), stage and grade, hormone receptor status, marker information)
- Dates of treatment initiation and completion
- Surgery, chemotherapy, radiotherapy, transplant, hormone therapy, or gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment
- Psychosocial, nutritional and other supportive services provided
- Full contact information on treating institutions and key individual providers
- Identification of a key point of contact and coordinator of continuing care

Part 2. Follow up care plan

- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them)
- Information on possible late and long term effects of treatment and symptoms of such effects
- Information on possible signs of recurrence and second tumours
- Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work and parenting, and the potential future need for psychosocial support
- Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counselling, legal aid and financial assistance
- Specific recommendations for healthy behaviours (eg. diet, exercise, healthy weight, sunscreen use, immunisations, smoking cessation, osteoporosis prevention). When appropriate, recommendation that first degree relatives be informed about increased risk and the need for cancer screening (eg. breast cancer, colorectal cancer, prostate cancer)
- As appropriate, information on genetic counselling and testing to identify high risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention or risk reducing surgery
- As appropriate, information on known effective chemoprevention strategies for secondary prevention (eg. tamoxifen in women at high risk for breast cancer; aspirin for colorectal cancer prevention)
- Referrals to specific follow up care providers (eg. rehabilitation, fertility, psychology), support groups, and/or the patient's primary care provider
- A listing of cancer related resources and information (eg. internet based sources and telephone listings for major cancer support organisations)

In a RCT, 296 women in England were randomised to follow up by the hospital clinic and follow up with their GP. There was no difference in recurrence or time from treatment diagnosis of recurrence and no difference in anxiety levels.³² Women participating in the trial reported greater satisfaction with care in all areas assessed which included service delivery, the consultation itself, and continuity of care. Women being cared for by their GP were more likely to feel that things were explained to them, they could talk to the doctor about problems, and they felt less rushed than women attending hospital clinics for follow up.³³ Follow up by the GP also incurred less cost to the patient and the health system than hospital based follow up.³⁴

A RCT with similar methodology comparing follow up by family physicians and specialist clinics was conducted in Canada by the same researchers. The trial included 968 women and it showed no difference in recurrence, serious clinical events, or death, or in health related quality of life between the two groups.³⁵

General practitioner follow up is not the preference for all women. Of those invited to participate in the trial 55–67% took

up the offer.^{34,35} There is also some evidence that some GPs do not wish to provide follow up care to breast cancer survivors; in the Canadian trial, 83% of GPs were willing to participate³⁴ although it is acknowledged that there may have been reasons other than GP preference why others declined.

Other models of follow up care have been explored including nurse led clinics and shared care programs between specialists and GPs. In Australia, shared care models exist for the management of other conditions and it may be that care after breast cancer is suited to this style of care. Breast physicians, GPs with additional training in breast medicine, are part of breast cancer treatment teams in some parts of Australia, and also represent a possible alternative to hospital or specialist care.^{36,37}

Australian guidelines

The National Breast and Ovarian Cancer Centre (NBOCC, formally NBCC) has produced guidelines for follow up after breast cancer.²⁴ These are summarised in *Table 2*. As well as outlining how follow up should be performed, the guidelines briefly touch on the question

Table 2. Summary of current NBOCC follow up recommendations*²⁴**Goals of follow up**

- the early detection of local recurrence
- screening for a new primary breast cancer
- detection of treatment related toxicities
- provision of psychosocial support
- identification of family history

Recommended follow up schedule

- History and examination
 - 1–2 years, every 3 months
 - 3–5 years, every 6 months
 - After 5 years, every year
- Mammography (+/- ultrasound)
 - 1–2 years, 6–12 months after radiotherapy
 - 3–5 years, every year
 - after 5 years, every year
- Chest X-ray, bone scan, blood count and biochemistry, only if clinically indicated
- Evidence based guideline

A minimal follow up schedule is recommended as there is no evidence that frequent intensive follow up confers any survival benefit or increase in quality of life

- General comments
 - individual treatment teams should develop their own protocols for follow up within the team
 - follow up by a GP may be appropriate for some women as long as the GP is aware of follow up guidelines
 - not every clinician involved in the care of a woman will be closely involved in her follow up
 - symptoms should be assessed as they arise
 - communication between treating practitioners (specialists and GPs) is essential

* These recommendations are currently being updated. New guidelines are due for release in 2008

of who should provide follow up care. These evidence based guidelines are currently being updated, with new guidelines due for release in 2008.

Australian research

The authors are currently conducting research into the attitudes of consumers, GPs and specialist oncologists to follow up care. The content of a possible survivorship care plan and the feasibility of its use in the Australian health system is being investigated. It is hypothesised that breast cancer survivors, as well as their families and treating doctors, will benefit from this style of coordinated care.

Conclusion

Survivorship is now recognised as a phase of cancer that requires ongoing specialised care. Current models of delivering follow up care

after breast cancer may be failing to address all of a woman's needs. Specialist and hospital based care is facing sustainability challenges with workforce shortages in oncology. There is good evidence that GPs are capable of detecting recurrent cancer and providing follow up care with a high level of patient satisfaction. Current guidelines for the follow up of breast cancer survivors in Australia state that GP rather than specialist follow up is an acceptable alternative. Survivorship care must be capable of addressing all of the long term issues following treatment, including psychosocial, relationship and menopause issues. As GPs are highly experienced and skilled in providing continuity of care in a holistic way, as they do routinely for many other chronic conditions, they are ideally placed to provide survivorship care.

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