



Follow-up of breast cancer patients: Preliminary findings from nurse-patient consultations and patient surveys

Moyez Jiwa^{1*},

Georgia Halkett²,

Kathleen Deas²,

Moira O'Connor²,

Jody Weir³,

Catherine O'Driscoll³,

Elizabeth O'Brien³,

Lisa Wilson³

Sholeh Boyle³.

¹*Curtin Health Innovation Research Institute, Curtin University of Technology, Perth, Western Australia*

²*WA Centre for Cancer and Palliative Care/Curtin Health Innovation Research Institute, Curtin University of Technology, Perth, Western Australia*

³*Breast Centre, Sir Charles Gairdner Hospital, Perth, Western Australia*

CORRESPONDING AUTHOR

Professor Moyez Jiwa

Email: m.jiwa@curtin.edu.au

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Abstract

BACKGROUND:

Although clinicians in both primary and tertiary care settings are involved in the care of breast cancer patients following the active treatment phase, few studies report how patients interact with health care providers.

METHODS:

Participants in this breast cancer follow-up study were recruited from a hospital based nurse-led follow-up clinic in Western Australia. Methods included audio taped, transcribed consultations with Specialist Breast Nurses (SBNs) and patient self-completed surveys.

RESULTS:

Preliminary data suggest that SBNs play an important role in supporting women to deal with the impact of breast cancer in the years following active treatment. The data suggest that the process of adjustment to a diagnosis of cancer continues for many years after the treatment has ceased. In many cases the women require on-going support to recalibrate their response to normal physical changes that may or may not be a consequence of surgery, radiotherapy and chemotherapy.

CONCLUSIONS:

These preliminary data map the plethora of issues that influence cancer patients in the years following treatment. Women who were attending follow-up appointments for breast cancer experienced similar levels of enablement following SBN consultations as would be expected from consultations with general practitioners.

Keywords: Breast cancer, Follow up, preliminary findings, research



Introduction

The incidence of breast cancer has increased at a steady rate over the past 30 years and is predicted to accelerate further over the next 10 years to reflect the growing number of women over the age of 45. More than 80% of women who are diagnosed with breast cancer will survive the disease for five or more years after diagnosis.¹ In addition, the increasing complexity of protocols for diagnosis and treatment as well as the recognition that women require considerable psychosocial support is contributing to an expanding workload in specialist practice. In most countries breast cancer patients are offered follow-up appointments for some years following active treatment. There is little evidence to support a single model of 'best practice' and arrangements for 'follow-up' vary greatly.²⁻⁴ Traditionally, the goals of breast cancer follow-up include the early detection of local recurrence, screening for new primary breast cancer, monitoring for treatment-related toxicities and provision of psychosocial support.⁴⁻⁶

Jiwa et al. reported that patients attending follow-up clinics discussed and or presented issues that arguably had little or no relationship to a recurrence of breast cancer.⁷ Instead, consultations focused on: anxiety/depression, unrelated medical problems, menopausal symptoms, mastalgia, malaise, lymphoedema, family history concerns and body image concerns. Similarly others have suggested greater involvement of practitioners in primary care during the follow-up phase.⁸

While current opinion favours formal follow-up arrangements, there are no standard protocols in Australia that offer 'benchmarks' for 'best practice'. Locally SBNs are involved in the follow-up of breast cancer patients at a tertiary hospital in Western Australia. In essence, SBNs are experienced Registered Nurses with further training in breast care and counselling (accredited post-graduate training). The SBNs consult patients from first presentation and then annually until they are discharged from the clinic as per local protocols.

During follow-up the patient also have access to their General Practitioner (GP) and may raise issues related to the cancer. Although clinicians in both primary and tertiary care settings are involved in the care of breast



cancer patients in Australia, there is a lack of published information about how these patients interact with hospital based staff and to what extent they consult their GPs about breast cancer related problems in the period after active treatment. Therefore, the aims of this study were to explore the interaction between the nurse and her patient. Here we report our preliminary findings.

Methods

The project was reviewed by the Curtin University of Technology and Sir Charles Gairdner Hospital Human Ethics Committees.

PARTICIPANTS

Participants were eligible for the study if they were able to give informed consent and attending a nurse-led follow up appointment having completed treatment for breast cancer in the previous two to five years.

Participants were recruited from consecutive cases listed at the clinic.

NURSE-PATIENT CONSULTS

Consecutive nurse-led consultations with the patients were audio recorded and transcribed verbatim. The transcripts were independently reviewed by four researchers (MJ, GH, MO, KD). Recordings ceased when the team reached consensus on the 'saturation' of themes. This occurred at 21 consultations.

PATIENT SURVEYS

Patients attending the nurse-led clinic were surveyed about physical signs and symptoms including changes in the breast, a new and persistent pain in any part of the body; unexplained weight loss; unexplained tiredness or loss of well being; a cough, shortness of breath, or chest pain; abdominal pain, a change in bowel habit, or other abdominal symptoms; signs of lymphoedema; problems with shoulder mobility; hot flushes; insomnia



and sexual dysfunction. Participants were also asked about anxiety or depression. The same checklist was used as a prompt in the subsequent consultation with the nurse.

Following the nurse consultation patients were invited to complete the Patient Enablement Instrument (PEI). This PEI contains items relating to their ability to cope and keep themselves healthy as a measure of the impact of the consultation. The PEI has established reliability and validity in the context of General Practice.⁹

DATA ANALYSIS

All quantitative data were entered into SPSS Version 17 and presented as descriptive statistics. Tape recordings of the nurse-led consultations were transcribed verbatim and entered into QSR NIVO Version 7. The transcripts were analysed with reference to 'biographical disruption'.^{10,11} This theoretical framework predicts that the experience of breast cancer has emotional, physical, social, cultural, financial and medical meanings and can affect a woman's sense of self, her goals and her relationships.¹² Bury viewed chronic illness as a 'critical situation or transition' in which taken for granted features of life shift.¹¹ This framework guided the examination of the transcripts for evidence of how women re-construct their identity after treatment for breast cancer and how health care professionals impact on the process.

Results

In the surveys, one in fifteen women reported that they were having trouble coping with everyday life 'most of the time' and a similar number reported that they were also feeling anxious or worried 'most of the time'. Many women described making choices which could be framed within the context of a 'rebirth' following their treatment. For many patients the cancer had opened a new vista on opportunities and choices. Some claimed a different perspective on what was now possible, acceptable or desirable in a host of domains in life ranging from self development to sexual partners.



The nurses played a significant role in facilitating these adjustments to the woman's new self image and bodily functioning. The patient sought validation for her choices at a time of profound physical and emotional change. Many consultations included 'teaching' the woman to become familiar with the new contours and texture of her body. One in 25 women reported a new lump or thickening in a breast and a similar number reported changes in the appearance of a nipple. The nurses moderated the women's reactions to 'normal' pain and lumps or bumps as experiences of ageing or degeneration rather than as a sign of recurrent cancer. In most cases these changes were found to be benign. One in 25 survey participants also reported unexplained weight loss and in all cases the causes were benign.

The nurses were also involved in adjusting expectations about the health care system on which patients were now dependent for reassurance. One in three survey participants reported that they had a new or persistent pain. One in five reported a cough, shortness of breath or chest pain. One in six reported abdominal pain, a change in bowel habit or swelling of the abdomen. One in fifteen women reported a new lump under the arm or in the neck. In most cases these were features of either normal ageing or some process unrelated to cancer. Nurses frequently reassured patients and or facilitated access to diagnostic and supportive services.

Finally, SBNs played a role in encouraging the women to develop strategies for preventing a recurrence of the cancer as well as managing the side effects of treatment. The SBNs emphasised the importance of maintaining a regular exercise regime, healthy diet and making positive lifestyle choices to promote healthy survivorship. One in five reported new unexplained tiredness or general loss of well being; and one in five also reported sexual dysfunction. One in seven reported signs of lymphoedema. One in eleven women reported hot flushes. One in nine women reported that they felt depressed, hopeless or 'flat' most of the time. In 70% of cases women had not consulted their



medical practitioner about these symptoms or problems, choosing instead to present them at the clinic.

PATIENT ENABLEMENT INSTRUMENT

To date, 50 patients have participated in completing the surveys after the nurse-led clinics. The overall PEI scores were skewed towards 0 with a mean score of 4, median score of 2 and mode score of 0 (Figure 1). These scores are similar to those reported in General Practice.¹³

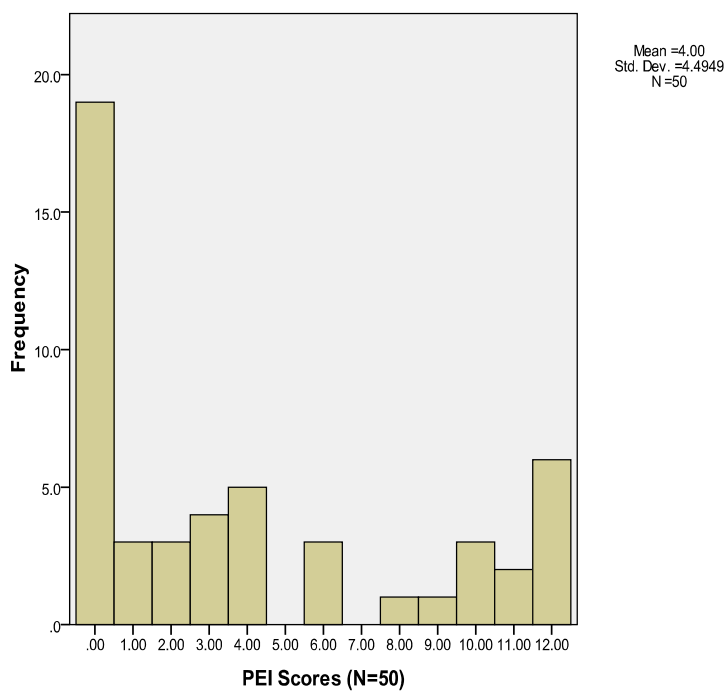


Figure 1: Distribution of PEI scores.

Preliminary conclusions

In these preliminary data we present evidence that SBNs play an important role in supporting women to deal with the impact of breast cancer. Their roles include reassurance and mobilising support services. The study also lists the issues that concern patients in the years following treatment. The



data suggest that the process of adjustment continues for many years after 'active' the treatment has ceased. The fear of recurrence persists for many years. In many cases the women require on-going support from someone involved at diagnosis to recalibrate their response to symptoms that in most cases are not a consequence of surgery, radiotherapy and or chemotherapy. Remarkably women who were attending follow-up appointments for breast cancer experienced similar levels of enablement following SBN consultations as would be expected from consultations with general practitioners.

Competing Interests

The authors declare that they have no competing interests.

Authors' Contributions

Professor Moyez Jiwa developed the research question and research methodology. Kathleen Deas undertook the research. Georgia Halkett and Moira O'Connor supervised the research, and assisted in the production and review of the research manuscript. Jody Weir, Catherine O'Driscoll, Elizabeth O'Brien, Lisa Wilson and Sholeh Boyle participated in the research, and reflected on the findings. All authors contributed to drafting and review of the research manuscript.

Authors' Information

Professor Moyez Jiwa (MD, MA, MRCP, FRACGP) is Professor of Health Innovation, Curtin University of Technology. He is also a practising general practitioner. Kathleen Deas is a nurse and research assistant at the



WA Centre for Cancer and Palliative care, Curtin University of Technology. Dr Georgia Halkett is a radiation therapist and Dr Moira O'Connor is a psychologist. Both are researchers at the WA Centre for Cancer and Palliative care. Jody Weir is a breast care physician, Catherine O'Driscoll, Elizabeth O'Brien, Lisa Wilson, Sholeh Boyle are specialist breast care nurses.

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