The Breast Service Psychosocial Model of Care Project

Lauren K Williams and G Bruce Mann

Abstract

Objective: It has been consistently demonstrated that many women with breast disease will experience psychosocial distress at some stage along the patient journey. Psychosocial care has recently gained more prominence and is increasingly recognised as an important aspect of care offered to patients with breast cancer. The purpose of this project was to develop a model that improved the way psychosocial services were provided to patients. The aim of this paper is to describe the process in developing this psychosocial model of care for patients with breast disease.

Methods: Using in-depth semi-structured interviews with a sample of patients and staff, we examined psychosocial concerns experienced by breast patients and the factors associated with the effective assessment and delivery of psychosocial care. The project was approved by the Royal Women's hospital ethics secretariat as a quality assurance project.

Results: An inductive analysis of staff responses indicated that a standardised screening and referral pathway was needed in a context of well defined staff roles and a multidisciplinary team environment. An inductive analysis of patient responses indicated that psychosocial concerns were common, but varied, and a tailored approach to the provision of psychosocial care was warranted.

Discussion: In line with these findings, a standardised assessment and referral pathway was developed for The Breast Service that may be extended for use in other clinical settings and tumour streams.

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OVER 12000 WOMEN are diagnosed with breast cancer in Australia each year. 1 Unsurprisingly, psychosocial distress plays a significant role in the journey experienced by women diagnosed with this disease. Many of the common psychosocial concerns of women with breast cancer include body image disruption, sexual dysfunction, treatment-related anxieties, depression, marital/partner communication and relationship difficulties, and existential concerns regarding mortality.²⁻⁴ Although many women will encounter and manage some degree of psychosocial distress following diagnosis, it is estimated that as many as 30 percent of women will experience episodes of persistent psychosocial distress that will interfere with their ability to cope with cancer treatment and life in general.^{2,4}

Psychosocial interventions such as support from a nurse/breast care nurse, exercise, telephone counselling, computer/online support, psychological and psychiatric care and social supports have all been found to improve the psychosocial status of women diagnosed with breast cancer. 5-7 As a result, the clinical practice guidelines from the National Health and Medical Research Council of Australia for the psychosocial care of adults with cancer³ highlight the need for further research regarding "strategies to improve the detection of psychological difficulties in people with cancer" (p. 136) and "optimal methods for psychosocial referral and practice strategies to improve uptake" (p. 136). Enhanced knowledge about the best way to detect and respond to patients' psychosocial needs is vital in empower-

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ing and equipping health professionals with the necessary skills and resources to help patients with the range of psychosocial issues that arise along the breast cancer treatment continuum.

Setting

Recently, the Royal Women's Hospital and Royal Melbourne Hospital breast services merged to form The Breast Service in an attempt to connect existing resources and provide a more comprehensive breast cancer service. Strategies to detect and respond to patients' psychosocial needs were identified as a key priority area for The Breast Service. Before the merging of services, psychosocial care coordination differed between sites and was largely managed by the breast care nurses. Previous research has highlighted that a range of health professionals is optimal in assessing and managing the psychosocial needs of women diagnosed with breast cancer and to support breast care nurses who, in some cases, are not trained in making psychosocial assessments and referrals for patients. Furthermore, before the merging of services, the screening tool used to detect psychosocial concerns (entitled supportive care tool [SCT]) was an amalgamation of items from instruments utilised in other health care settings. Before the development of the current project, the SCT had not been evaluated since it was implemented into The Breast Service.

A psychosocial working group and steering committee was developed to address challenges and opportunities arising from the merging of the two services, and involved clinicians from the departments of psychology, psychiatry, medicine, nursing, social work, pastoral care, women's services and music therapy. A consumer representative was included and a project worker appointed to coordinate and execute the project objectives.

Objectives

The aim of the psychosocial model of care project was to develop a standardised way of screening for psychosocial distress and referring patients to the most appropriate clinician(s) and supports.

The first objective of the project was to provide a reflection of the strengths and weaknesses of the current model of psychosocial care from relevant clinicians and to generate ideas on the most effective way to merge and coordinate existing services. The second objective was to provide a reflection from consumers regarding their psychosocial needs, the level of psychosocial support they received and their perceptions and opinions on the structure and delivery of the current psychosocial model of care from The Breast Service

Consultation with health professionals

Methods

A total of nineteen staff members who had (or wanted to have) a role in the screening, assessment and treatment of patients were interviewed by the project worker. Staff were recruited from social work, pastoral care, psychology, psychiatry, medicine, nursing and community support services (eg, BreaCan). A semi-structured interview guide was developed which focussed on (a) the method for screening and referring patients, (b) the role of different staff in providing psychosocial care, and (c) issues, barriers or concerns with the provision of psychosocial care. Data were analysed qualitatively using inductive thematic analysis. The project was approved by the Royal Women's hospital ethics secretariat as a quality assurance project.

Results

It was found that the existing method of screening for psychosocial needs of patients with breast cancer relied heavily on the breast care nurses. Completion of a screening tool by patients at the time of initial diagnosis and surgical treatment was viewed as beneficial for identifying and recording psychosocial concerns, however the screening process relied on breast care nurses to administer the tool, evaluate the results and generate referrals at their discretion. In addition, The Breast Service staff identified several issues

I Issues with the psychosocial screening tool identified by staff and patients

Issues identified by The Breast Service staff

- Staff not accessing the completed supportive care tool (SCT) in patient's medical file
- More specialised tools needed for specific areas of concern
- Not specific to breast cancer/some questions not relevant
- Only used once. Supplement testing/brief version needed at different stages of the disease
- Some questions not included to screen for identified psychosocial concern (eg, body image)
- Absence of criteria for referral (eg, if patient answers "yes" to certain questions what is the process for referral? Criteria needed to facilitate consistency between clinicians)
- Questions regarding patient strengths to use for possible referral/support
- Section needed for patient comments
- Dichotomous responses (eg, yes/no) create limitations
- Area needed to record referral details/outcome. Possibly useful to combine details from referral form to SCT. Expansion of referral options
- Unclear psychometric validity
- Does not assess all risk factors

Issues identified by The Breast Service patients

- Include questions that ask women whether they wanted to be linked in with a group
- Tailor SCT to patient's individual situation given that some questions are not relevant
- Administer the SCT later given that concerns are greater after surgery (it is generally administered at preadmission clinic [PAC])
- Administer the SCT twice, rather than once at PAC. Some experience concerns at later stages than before surgery and others don't recognise their issues until later stages of the disease
- Include body image questions

with the SCT (Box 1). Although the role of breast care nurses in screening psychosocial needs was viewed by most as valuable, it was commonly agreed that psychosocial assessment from additional health professionals would enhance the validity of the screening procedure. In addition, it was suggested that periodic rescreening was required to identify those with particular psychosocial needs that emerge subsequent to initial diagnosis and surgery.

Consultations with patients attending The Breast Service

The second step of the project was to consult patients about their psychosocial concerns and supports they received from The Breast Service staff

Methods

A total of thirteen women diagnosed with breast cancer attending The Breast Service participated

in either a focus group or individual interview. The age of participants ranged from 33 to 87 years and four women were from non-English speaking backgrounds. A semi-structured interview guide which contained open-ended questions that assessed patients' psychosocial concerns and their experience with The Breast Service (psychosocial screening and referral procedures) was developed.

Patients were recruited from a list of all patients that had attended/were attending The Breast Service for the last 6 months. Interviews were conducted at The Royal Women's Hospital in a private room and were later transcribed to facilitate coding and analysis. Data were analysed qualitatively using inductive thematic analysis.

Results

The most commonly reported psychological concerns were anxiety and depression. Anxiety was reportedly heightened at diagnosis, between appointments while waiting for results, before

chemotherapy and in social situations for those with visual signs of cancer, such as hair loss. Patients reported feeling depressed during treatment, particularly those patients having chemotherapy. Other reported psychosocial concerns included body image concerns, relationship issues with their partners, family and friends, and concerns with mortality, survival and recurrence. Eight of 13 women interviewed (61.5%) had completed the screening tool, with most reporting no issues or distress in answering the questions. Specific comments are shown in Box 1.

Psychosocial support accessed by patients varied. Some women reported accessing counsellors, psychologists and social workers. These services were offered through The Royal Melbourne Hospital or privately. Other women reported that they felt comfortable knowing that these supports were available, however were not ready or did not feel they would be able to assist them with their concerns. These women relied on community, family, peer and individual supports. Some women felt uneasy or awkward about attending group settings with strangers and would prefer alternative supports such as email, telephone or a casual unstructured group setting. These results suggest the individuality of women's support needs and the need for a wide range or services that can address different concerns at different stages of the disease.

The Breast Service Model of psychosocial care

Based on the outcomes of this project, a revised model for the assessment and delivery of psychosocial care was developed and is currently being implemented. As highlighted in Box 2, and consistent with the previous pathway, at the first suitable visit (preferably soon after diagnosis), the breast care nurse uses a screening tool to identify patients who are potentially in need of more extensive assessment and intervention. The new screening tool combines a risk factor checklist,* a distress thermometer (0–10 ranking of distress) and a "yes/no" checklist of items/concerns; which differs from the original screening tool that relied

solely on the latter. The patient is then discussed at a newly developed multidisciplinary psychosocial team meeting where a referral is made if appropriate. Review of patients and subsequent referrals also occurs in this forum. Given that some patients reported experiencing psychological concerns such as anxiety and depression and body image issues, referral options were extended to include a clinical psychologist, psychiatrist and a sexual counsellor. A music therapist is also available to assist patients.

Unlike previously, where the screening tool was only administered once at initial presentation, the distress thermometer and checklist is administered again during and after definitive treatment. Re-presentation of the same patient occurs if significant distress or psychosocial need subsequently appears. Accurate execution of the revised pathway is overseen by the director of The Breast Service and staff attending the multidisciplinary meeting. Furthermore, patient results (completed screening tool, referrals forms, and related progress notes) are now inserted into the patient's medical file to ensure accessibility by all relevant health professionals.

Limitations and discussion

One of the main challenges of this project was to build a team of clinicians with adequate time and resources committed to assisting with the project. The development of a working group, steering committee and mutually agreed project plan was the fundamental key to initiating this process. Staff provided the project worker with background information, details of current psychosocial practice and feasibility of new ideas.

Another challenge was delegating and executing tasks, both in the development and implementation stages of the project. Clarification was particularly needed around "who is doing what and how". These decisions are best made in the

^{*}National Breast and Ovarian Cancer Centre and National Health and Medical Research Council guidelines for the psychosocial care of patients with cancer recommends assessing these risk factors to alert practitioners about certain sub-groups of potentially "at-risk" patients.

2 The Breast Service Psychosocial Model of Care

Step 1 First suitable visit

Identify high risk factors. (The Is/has the patient: revised assessment tool will allow breast care nurses [BCNs] to document patient risk factors

Risk factor check-list

- Younger
- Single, separated, divorced, widowed
- Living alone
- Children younger than 21 years
- Experiencing economic adversity
- A real or perceived lack of social support
- Poor marital or family functioning
- Had a history of psychiatric problems
- Had stressful life events.
- Had a history of alcohol and/or substance abuse
- Been diagnosed with cancer
- In the advanced stages of the disease
- Received a poor prognosis
- Having/had treatment side effects greater than most
- Experiencing lymphoedema
- Experiencing chronic pain and/or having difficulties managing pain
- Significantly fatigued

Step 2 Assess level of distress

Does the patient appear or is the patient highly distressed/anxious? BCNs to distribute "distress thermometer" whereby patients will rank their perceived level of distress from 0 (no distress) to 10 (extreme distress)

Step 3 Assess specific psychosocial concerns

BCNs will distribute psychosocial checklist to patients where they can indicate (yes/no) whether they have experienced psychosocial distress on a range of dimensions (eg., depression, anxiety, body image, sexual health etc)

Step 4 Psychosocial Assessment/ interview with BCN, BCN expands on relevant areas identified by patient in the screening process (distress thermometer and checklist) and records outcome on the screening forms.

Patient is not considered high risk considered high and is not distressed risk and is

Patient is distressed and requires action (not immediate)

Patient is considered high risk and is distressed and requires urgent/immediate action

Patient completes the A referral is made Clinician pages mental health distress thermometer and the patient is service, social work or pastoral and checklist at next discussed at the care for urgent referral. A visit or as appropriate next Psychosocial referral is made using the Multidisciplinary

referral form and the patient is meeting (PMDM) discussed at the next PMDM

Step 5 PMDM

Discuss patient's risk factors, assessment of distress, BCN evaluation and checklist responses. Multidisciplinary referrals are made where applicable, referral outcomes are discussed

- Step 6 Psychosocial screening may be conducted at:
 - 1. Notification of diagnosis
 - 2. Post-surgery check-up
 - 3. During chemotherapy
 - 4. At the end of treatment
 - 5. 12-month follow-up

Go to step 2

working group meetings, using existing staff and therefore reducing the need for additional resources. Furthermore, it proved pivotal to the cohesion and sustainability of the working/steering group that after each fundamental stage of the project (eg, focus groups) the execution of the findings was communicated to all relevant staff in an interactive forum (eg, email reports, meetings, in-services or workshops).

Conclusion

In summary, the psychosocial model of care project has transformed the way psychosocial care is provided to patients attending The Breast Service. We have implemented a standardised screening, assessment and referral process and a multidisciplinary team to provide a service of psychosocial care to all patients. Decisions about assessment, referrals and treatment no longer rely solely on the breast care nurse. Instead, collaborative recommendations are made for the patient in a forum that can ensure adequate follow-up and execution of accurate and targeted referrals. An evaluation of the revised process is planned.

It is envisaged that these findings could assist researchers and clinicians with the process of developing a psychosocial assessment and referral pathway. The psychosocial model of care can also be adapted and utilised in other clinical settings where psychosocial distress and morbidity is likely. The psychosocial model of care is already being implemented in the gynaecological service and ward nurses are being trained in administering the screening tool. As the results from this quality assurance project suggest, strategies for detecting and responding to the psychosocial needs of patients is a vital and achievable component to the provision of health care.

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Competing interests

The authors declare that they have no competing interests.

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