Senate Community Affairs References Committee Inquiry into Services and Treatment Options for Persons with Cancer

NATIONAL BREAST CANCER CENTRE
Incorporating the
Ovarian Cancer Program

Submission by the National Breast Cancer Centre

Overview

Cancer in Australia

In Australia, one in three men and one in four women will be affected by cancer by the time they are 75 years of age.[1] Management of cancer involves a wide range of disciplines and services in both the public and private sectors.

The provision of cancer care in Australia offers some unique challenges. There remain issues around equity of access to some services and discrepancies in care provided to cancer patients across Australia. Resource allocation is a real issue in a country of such vast distances and differing population densities. Specialist services and expertise are often many hundreds of kilometres away from the cancer patient. Yet, for example, we know that for women with ovarian cancer, appropriate initial referral to specialist expertise can significantly impact on patient outcomes.

Many cancer patients use or consider using the growing market of complementary and alternate therapies and 'health products', either in conjunction with or as an alternative to standard medical treatment. Until now, there has been little emphasis on evidence of benefit or safety for patients, especially important for those concurrently taking other treatments.

In response to the Committee's Inquiry, this submission outlines many initiatives that the National Breast Cancer Centre believes would enhance the care and support of cancer patients across Australia.

The National Breast Cancer Centre

The National Breast Cancer Centre (NBCC) was established by the Federal Government in 1995 to improve outcomes for women with breast cancer. Based on the significant work of the NBCC in improving not only clinical care but also psychosocial and supportive care, the NBCC was granted additional funding to implement an ovarian cancer program.

The NBCC aims to improve health outcomes for women with breast and ovarian cancer by ensuring that wherever they live, these women receive the best possible care.

The work of the NBCC is proudly evidence-based and patient-centred. Consumers play a major role in helping to identify needs, define priorities and input into our work in a meaningful way. Our work is based on the best available evidence and developed by multidisciplinary teams of experts and consumers. We believe our model of working has broad applicability.

There are many areas that have been pioneered by the NBCC, including implementing a national demonstration project in multidisciplinary care, developing the world's first psychosocial guidelines for adults with cancer, developing user-friendly evidence-based information for patients based on clinical practice guidelines, raising the profile of the specialist breast nurse in providing information and continuity of care, and addressing cancer patient support needs, particularly in regional Australia.

Further information in response to the committee's particular terms of reference follows. Reference is made to a number of NBCC publications, copies of which are attached separately. Printed copies can be mailed if requested. Copies of some relevant NBCC guidelines and publications have also been requested by and provided to the committee secretariat.

A. Delivery of services and options for treatment for persons diagnosed with cancer

(i) Efficacy of a multidisciplinary approach to cancer treatment

The benefits of multidisciplinary care (MDC) in the management of cancer have been demonstrated in a number of studies both in Australia and overseas. There is evidence that decisions made by a multidisciplinary team are more likely to be in accord with evidence-based guidelines than those made by individual clinicians.[2] Patient satisfaction with treatment and the mental well-being of clinicians has been shown to be improved by a multidisciplinary approach to care.[3]

Despite the growing body of evidence of the benefits of MDC, there is no universally accepted model for its implementation. In Australia, the challenge of implementing multidisciplinary cancer care is complicated by Australia's unique geography and the mix of public and private services In recognition of these difficulties, the NBCC has developed a flexible set of *Principles of Multidisciplinary Care*[4] to guide the development of strategies to implement MDC in Australia, recognising that implementation may vary in different locations. The NBCC has investigated sustainable strategies for implementing MDC based on these *Principles* using breast cancer as a model through a *National Demonstration Project of Multidisciplinary Care*[5,6] funded by the Australian Government Department of Health and Ageing. Outcomes from the project have broader application to all cancers. A copy of the Executive Summary of the National Demonstration Project report is attached separately.

In recognition of the need to implement multidisciplinary cancer care in Australia, the NBCC is currently developing a practical guide to assist health service providers in setting up and running multidisciplinary treatment planning meetings. A series of State- and Territory-based forums to promote the uptake of multidisciplinary cancer care is also being planned.

The NBCC has made a series of recommendations based on outcomes from the National Demonstration Project of Multidisciplinary Care.

Successful implementation of multidisciplinary cancer care will require both national and State/Territory support. Promotion of the benefits of MDC is needed at a national level, through the National Cancer Plan and National Service Improvement Framework. At a State/Territory level and at a service level, adequate resourcing will be required to ensure ongoing sustainability of strategies. Recognition of the need for flexibility in the implementation of locally relevant strategies is also a key factor for consideration.

(ii) Role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers

In Australia, screening, diagnosis, treatment and supportive care for patients with cancer are typically provided by different services, often with little coordination, leading to fragmented care, sub-optimal management and high health care costs.[7-9] During a cancer patient's treatment 'journey', he or she will come into contact with multiple health care providers – an average of 28 doctors (and many other health professionals) in the first year following diagnosis, according to one UK study.[10]

The need to improve the coordination of the patient journey has been highlighted in a number of national reports.[11,12] One option for improving the coordination of care is through a care coordinator role. A number of models exist in cancer care for care coordinators and these have been implemented in several regions of Australia.[13]

The specialist breast nurse (SBN) role is one model in which a specialist nurse acts as a pivotal liaison position for the cancer patient from the time of diagnosis through the treatment phase of their care. In some treatment centres, SBNs also function as the coordinators of multidisciplinary treatment planning meetings. SBNs are uniquely positioned to provide support and practical assistance to patients throughout the various stages of their treatment and have been found to be effective and beneficial in the ongoing care of the patient.

The NBCC's *Clinical guidelines for the Psychosocial Care of adults with cancer* identifies the major role played by specialist oncology nurses in ensuring continuity of care in both inpatient and outpatient settings by coordinating the patient's path through treatment, liaising with different members of the treatment team, and monitoring and providing support to the patient.[14] The NBCC has investigated and reported on a model for and benefits of the SBN role.[15] The model identifies the key stages at which consultation with an SBN should be held and provides a flexible structure for the conduct of consultations, providing both practical and emotional support. The model was trialled at four treatment centres across Australia, including rural/urban and private/public settings. While the focus of the project was not entirely on care coordination, it demonstrated a number of benefits, including smoother referrals and improved team functioning. The benefits of the SBN role in facilitating care coordination for women with breast cancer have subsequently been demonstrated in the NBCC's *National Demonstration Project of Multidisciplinary Care*.[5]

Among women with breast cancer involved in the demonstration project, 80% of respondents believed SBNs made a significant contribution to their care and 99% reported they would recommend seeking treatment at a centre that provides a breast nurse

Another example of a case liaison role was recently implemented in South Australia under the Australian Government-funded initiative *Strengthening Support for Women with Breast Cancer.*[16] Cancer contact worker positions were implemented to act as a focal point for cancer patients as they moved through different phases of their cancer journey and to particularly assist patients moving between rural and urban areas for treatment.

Because of the demonstrated success of SBNs in the area of breast cancer there is a growing interest in the benefits of specialist nurses and care coordinators for other cancer types. In order for these positions to be implemented successfully, there is a need for national evidence-based frameworks that support a multidisciplinary approach to care and identify the scope and minimum competencies for the role. The NBCC is currently developing professional competencies for the SBN role. These competencies may be used as a basis for developing competencies with broader application to other cancer types.

(iii) Models and best practice for addressing psychosocial factors in patient care

Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. These psychosocial needs are significant, and frequently go undetected and unmet. Up to 66% of people with cancer experience long term psychological distress;[17] up to 30% experience clinically significant anxiety problems;[18] and prevalence rates for depression range from 20%-35%.[17,19,20]

The significant psychological impact of a diagnosis of cancer highlights the need to recognise that psychosocial care is as important as clinical care. Significant high level evidence exists about best practice in the psychosocial care of cancer patients. The NBCC, in collaboration with the National Cancer Control Initiative, has developed and disseminated the world's first *Clinical practice guidelines for the psychosocial care of adults with cancer*.[14] This document is based on previous best practice guidelines that the NBCC developed for the psychosocial care of women with breast cancer.[21]

A National Steering Committee has been established to undertake the implementation of the psychosocial guidelines. Activities to date have included a national seminar series for health professionals to promote the recommendations and the development of summary cards for health professionals highlighting strategies for improving psychosocial care. The development of information for consumers, based on the guidelines, is also planned.

The implementation of the guidelines has the potential to improve healthcare outcomes, including a reduction in psychosocial morbidity and emotional distress, improved wellbeing and satisfaction with care. Many of the guideline recommendations require no new service delivery infrastructure or additional resources.

(iv) Models and best practice in delivering services and treatment options to regional Australia and indigenous Australians

Models for best practice in delivering cancer services and treatment in Australia must recognise that care is delivered in both the public and private systems, and in rural, regional and remote locations.

The NBCC has developed an interactive workshop model to provide education in a rural setting about the provision of chemotherapy to women with breast cancer including management of side effects, the safe administration and handling of cytotoxic drugs and legal implications for health professionals. The workshops also covered aspects of psychosocial support for women with breast cancer.

The NBCC worked with the Rural Health Support, Education and Training (RHSET) program to implement the program to encourage best practice in the area of chemotherapy treatment for women in rural Australia. A kit, based on the workshops, has been used by organisations to conduct their own workshops for health professionals caring for women receiving systemic adjuvant treatment. The model has been replicated and incorporated into training initiatives and workshops about colorectal cancer.

The NBCC recognises the role of indigenous health workers as primary health care providers in many situations. In particular, indigenous health workers have an important role in ensuring that information about early detection of breast cancer and best practice in treatment is available to indigenous women across Australia. Specific and appropriate training, including the development of relevant resources, is essential to support the work of indigenous health workers in their communities. The NBCC is seeking input from experts in the area of indigenous health to develop national resource kit to improve training about early detection of breast cancer for indigenous health workers

B. Assessment of less conventional and complementary cancer treatments

To date, evidence-based information and guidelines about the management of cancer have largely focused on traditional treatments such as surgery, radiotherapy and chemotherapy. Evidence to support the development of this information comes from randomised controlled clinical trials. The majority of complementary therapies – therapies outside the mainstream treatments that are used in addition to traditional treatments – have not been tested in controlled trials and therefore evidence of their effectiveness and safety is difficult to determine.

There is Level 1 evidence from randomised trials that therapies such as relaxation and meditation can be beneficial for patients alongside conventional treatments. The benefits of these therapies are promoted in the NBCC and NCCI *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*[14] and in other NBCC clinical practice guidelines for the management of breast and ovarian cancer.[22-24]

Where evidence exists about the benefits of a complementary therapy, recommendations about the uptake of these therapies should be adopted alongside clinical recommendations. However, there are a large number of complementary therapies for which the evidence base is low.

The NBCC is currently undertaking a survey of women with breast cancer to identify commonly used complementary therapies. Outcomes from the survey will inform the development of information for clinicians and women about complementary therapies. It is acknowledged that for some of these therapies there may be insufficient evidence to inform a recommendation. Priority should be given to conducting controlled trials of the more common therapies to facilitate the development of evidence-based information to facilitate informed decision-making about the use of these therapies.

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