



Gynaecological Cancer in Australia

Submission to the Senate Inquiry

The Cancer Nurses Society of Australia

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Introduction

The Cancer Nurses Society of Australia (CNSA) is committed to achieving and promoting excellence in cancer care. CNSA achieves this by providing leadership to the nursing profession by advocating for effective cancer control policy and supporting the delivery of quality cancer nursing care.

The CNSA has a membership of approximately 700 nurses and is governed by a nationally elected Executive Committee which comprises representatives from each State and Territory in Australia. Committees and project teams are appointed by the National Executive to lead activities that assist with achieving the Society's mission of excellence in cancer care. CNSA Regional Groups and Special Interest Groups provide further opportunities for meeting the professional needs of nurses.

As the peak body representing cancer nurses in Australia, CNSA is actively working with other peak organisations to achieve improvements in cancer care nationally. The Society is a member body of the National Nursing Organisations and the International Society of Nurses in Cancer Care. CNSA is also the nursing group of the Clinical Oncological Society of Australia.

CNSA is also the nursing group of the Clinical Oncological Society of Australia (COSA). As the nursing group of COSA, CNSA endorses the joint submission to the Senate Inquiry submitted by the Clinical Oncological Society of Australia, the Cancer Council Australia, National Cancer Control Initiative, and the National Aboriginal Community Controlled Health Organisation. The recommendations outlined in the Joint Submission from these organisations address important areas that require action.

This submission is presented on behalf of the CNSA. The submission presents issues and recommendations which focus primarily on nursing related issues and perspectives, and the nursing contribution to achieve optimal services and outcomes for women with gynaecological cancer in Australia.

Recommendations

This submission includes recommendations focused specifically on issues concerning nursing services for women with gynaecological cancer. The recommendations are focused on areas that CNSA consider require action if optimal cancer services and treatment for women with gynaecological cancer are to be achieved.

Background

Gynaecological cancer represents a diverse group of diseases with differing presentations, clinical features, treatment and prognoses, affecting a wide age group of women. Women being treated for gynaecological cancer and living with the sequelae of their disease are cared for by nurses from a diverse range of practice settings. These include community and primary health settings, tertiary cancer centres, general medical and surgical units, regional, rural and remote settings, palliative care settings and support agencies.

Multidisciplinary approach to care

Recent reports emphasise the benefits of multidisciplinary care to people with cancer (National Breast Cancer Centre 2004). Such benefits are likely to result from many factors such as:

- opportunity to achieve best practice in management, as gynaecological cancers today require multi-modal treatments to achieve optimal outcomes. Planning and delivery of these multiple treatments requires a team approach to achieve best clinical outcomes
- provision of improved patient experiences in terms of continuity of care, enhanced confidence, and satisfaction with health care professionals.
- consideration of patient issues and concerns from multiple perspectives, providing a better opportunity for health professionals to understand an individual's needs, social context, preferences and wishes.

Traditionally, definitions of multidisciplinary care have emphasised the contribution of the various medical disciplines involved in cancer management, for example, medical oncologist, surgeon, radiation oncologist). Less attention has been given to the contribution of nursing and other allied health professionals to patient and team outcomes, or to the consumer's role in the multidisciplinary team.

Recent evidence highlights the important role cancer nurses play in the multidisciplinary care. The National Breast Cancer Centre (NBCC) Specialist Breast Nurse Project identified that the presence of a specialist breast nurse contributed to a range of improvements, including: improved team functioning and appropriate utilization of each professional's skills and resources; care being delivered more smoothly, including referrals; other health professionals having improved information about patients and breast cancer issues; and women being prepared for each treatment stage (National Breast Cancer Centre Specialist Breast Nurse Project Team 2003). While the evidence that specialist nurses contribute to improve patient outcomes comes from the field of breast cancer, it is likely that the same outcomes could be achieved if specialist nurses roles are supported for women with gynaecological cancers.

Preparation of nurses caring for women with gynaecological cancer

Because of the intimate nature of nursing care provided for women with gynaecological cancer, nurses are well placed to:

- assess a woman's understanding of her disease and treatment
- address knowledge deficits
- provide supportive interventions for her and her family

Frequently nurses caring for women with gynaecological cancer report a lack of confidence in their ability to manage commonly experienced issues, in particular infertility, genetic susceptibility, menopause, lymphoedema and psychosexual dysfunction. A survey in 2004 of 150 nurses who care for women with gynaecological cancer from a variety of practice settings in NSW found that despite considerable experience and formal qualifications, only 12% felt very confident in discussing the management of gynaecological cancers, while 5% felt very confident in addressing genetic susceptibility, 8% for fertility issues, 12% for lymphoedema prevention and 15% for sexuality and body image (Maidens et al. 2004). Reports suggest that health care professionals require development of skills in psychosocial assessment and care. Nurses, like other health professionals require development of competency in this area (Victorian Centre for Nursing Practice Research 2001).

The nature of the journey for women with gynaecological cancers is that they will be cared for by nurses in a range of settings (e.g., surgical, radiation oncology, medical oncology, general practice, palliative care). Some women will receive some or most of their care in specialist cancer centres, while others may receive the majority of their care in non-specialist settings and in rural/regional communities. Nurses caring for women outside of specialist cancer centres indicate that despite wishing to provide quality supportive care for their patients, inadequate education hinders their efforts to do so (Mohan et al. 2005). To ensure a coordinated approach to care, and ensure that women receive access to services with the appropriate level of nursing expertise to ensure optimal outcomes, models of care are needed which allow linkages between specialist and non-specialist nurses and which facilitate communication between nurses within these various settings. Appropriate education is also required to ensure nurses have skills required to work within such a system, including knowledge of appropriate referral and communication pathways. Nurses caring for women with gynaecological cancer need to be adequately prepared to assess psychosocial needs and thus able to collaborate with other members of the multidisciplinary team to ensure that appropriate psychosocial interventions are implemented.

However, there are challenges in providing a skilled nursing workforce to care for these women including: the poor link between education and career pathways; the costs of higher education; high workloads and competing demands that impact on nurses' ability to undertake courses (Yates 2001). Furthermore, there are no nursing education programs relating specifically to gynaecological cancer in Australia to enable the development of nurses with specialist skills who can provide the leadership in development more patient centred models of care.

Role of specialist nurses

Research reveals that by focusing on broader aspects of the health care experience, specialist nursing improves quality of cancer care (Ambler et al. 1999; Campbell et al. 2000; Faithful et al. 2001; Corner et al. 2002). Specialist nurses are well positioned to identify and address issues related to gynaecological cancer treatment, especially with regard to long-term sequelae such as menopausal symptoms, psychosexual dysfunction, lymphoedema and bladder and bowel dysfunction. Recent evidence suggests a positive impact on quality of cancer care when it is nurse led, particularly in the areas of information provision, side effect management and psychosocial assessment and support (Corner, 2003).

In general, women with a diagnosis of cancer have a more troublesome experience with menopause than do other women. About 40% of women who have been diagnosed with cancer experience a physical or emotional problem related to menopause (Couzi et al. 1995). Women who experience treatment-related menopause report a higher incidence and greater severity of tiredness, hot flushes and night sweats (McPhail & Smith 2000). These symptoms can persist for three or more years following diagnosis (Carpenter et al. 2002).

Rates of sexual dysfunction after treatment for gynaecological cancer range from 20% to 100% (Lutgendorf et al. 2000). Despite its obvious importance, sexuality within the context of gynaecological cancer is under-recognised and professional knowledge and communication about this aspect of care is inadequate (Stead et al. 2001). Because nurses are frequently in contact with patients and because they are often involved in personal care and emotional support they are the most appropriate health care provider to address issues such as sexuality (Gamel, Hengeveld & Davis 2000). Women with gynaecological cancer who receive support from a specialist nurse experience reduced psychosexual dysfunction and a clinically significant reduction in their level of psychological distress (Maughan & Clarke 2001; Booth et al. 2005).

Lymphoedema is a chronic and irreversible condition. The incidence of lower-limb lymphoedema in women who have been treated for gynaecological cancer ranges from 18% to 41% (Werngren-Elgstrom & Lidman 1994; Ryan et al. 2003). Lower-limb lymphoedema causes problems with mobility, clothing and footwear and can significantly affect occupational and social activities (Carter 1997). Many health professionals are unaware of the extent of this problem in gynaecological cancer and this can result in delay in diagnosis, delay in referral to a lymphoedema practitioner, inappropriate treatments and significant physical and psychological sequelae. Specialist nurses are ideally placed to provide information and support about preventative measures, early recognition and referral for treatment.

Nursing research

Nursing research in cancer care provides evidence to inform practitioners about the impact of cancer and its management on the patient and family, and the efficacy of interventions to alleviate disease or treatment induced problems and needs. Collaborative research, with other health care practitioners could illustrate the benefits of the multidisciplinary team approach and also identify the unique perspective that nursing can bring to multidisciplinary research.

It is acknowledged that there continues to be gaps between research and practice in cancer nursing and currently there are clinical practices for which there is limited evidence, for example, the management of mucositis and fatigue. As nurses often have an ongoing and supportive relationship with women with gynaecological cancer that encompasses all aspects of their illness journey, there would be opportunities to undertake research that relates directly to clinical practice.

The appointment of joint academic and clinical positions would promote nursing research, practice, and education and build evidence, developing nurses to enhance the quality of care for women with gynaecological cancer.

Recommendations

To enhance the care of women with gynaecological cancer the CNSA recommends:

1. That a multidisciplinary approach to care including medical nursing and allied health care practitioners appropriate to the needs of women with gynaecological cancer is implemented
2. That validated and rigorous assessment tools for treatment related sequelae be developed and implemented.
3. That research is undertaken to develop and evaluate innovative models of care involving specialist gynaecological cancer nurses.
4. That there is recognition that women with gynaecological cancer are cared for outside of specialist centres and that appropriate supports and educational opportunities are implemented to support nurses in all settings.
5. That appropriate methods for providing professional support and clinical networks for nurses who care for women with gynaecological cancer be identified, developed and supported.
6. That appropriate educational opportunities are implemented to support nurses in all settings.
7. That financial support is provided to enable nurses to pursue further studies.
8. That more joint academic-clinical appointments in cancer nursing are established to foster critical thinking and research to guide clinical practice.

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