



ROYAL COLLEGE OF NURSING, AUSTRALIA

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

1. Introduction

Royal College of Nursing, Australia (RCNA) welcomes the opportunity to provide comment to the Senate Community Affairs References Committee Inquiry into Services and Treatment Options for Persons with Cancer which the Senate referred to the Committee on 10 February 2005.

2. RCNA – Background

RCNA is the peak national professional organisation for Australian nurses. RCNA was established in 1949 and until the early 1990s was a provider of formal ongoing education for nurses who wished to gain higher qualifications in nursing. Following the completion of the transfer of nursing to the higher education sector in 1993, RCNA refocused its functions to encompass continuing professional development and policy analysis and development.

In 1997, RCNA became the Australian representative to the International Council of Nurses (ICN). The ICN is a federation of 125 national nurses' associations representing the millions of nurses worldwide. Operated by nurses for nurses since 1899, ICN is the international voice of nursing and works to ensure quality care for all and sound health policies globally.

RCNA represents nursing across all areas of practice throughout Australia. RCNA has members in all States and Territories of Australia, and internationally. RCNA is a not-for-profit organisation, providing a voice for nursing by speaking out on health issues that affect nurses and the community. With representation on government committees and health advisory bodies, RCNA is recognised as a key centre of influence in the health policy arena in Australia. When health policy decisions are made, RCNA presents a professional nursing perspective, independent of political allegiance.

In addition to the ICN, RCNA is affiliated with several other international organisations and numerous national organisations/associations. RCNA has a memorandum of collaboration with the Australian Nursing Federation. RCNA has well established National Nursing Networks for members, which provide access to a range of expert practitioners. RCNA members and others from within the profession produce regular evidence based papers for *Collegian* – the refereed journal published by RCNA.

3. RCNA Response

RCNA is responding to the Inquiry of Services and Treatment Options for Persons with Cancer being conducted by the Senate Community Affairs References Committee.

The Terms of Reference are:

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(i) the efficacy of a multi-disciplinary approach to cancer treatment,

(ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

(iii) differing models and best practice for addressing psycho/social factors in patient care,

(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and

(v) current barriers to the implementation of best practice in the above fields; and

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

(i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

(iii) the legitimate role of government in the field of less conventional cancer treatment.

3.1 General Comments

At the outset, RCNA believes that it is necessary to develop a comprehensive and complete definition of ‘a multi-disciplinary approach’ in the Australian context.

The international literature is not extensive in regard to the development of a model of multi-disciplinary care for persons with cancer. Therefore, Australia needs to take a progressive approach to this concept.

The model of a multi-disciplinary approach in Australia is generally accepted as a combination of the relevant specialist physicians and surgeons in the care of a person with a diagnosis of cancer. However, in Zorbas et al (2003) “*Multidisciplinary care for women with early breast cancer in the Australian context: what does it mean?*” it states that

the principle of a team approach “identifies the core disciplines integral to providing good care. In addition to specialist providers, the general practitioner is included as a core team member, and may play a number of roles in all stages of the disease process, including diagnosis, referral, treatment, coordination of care, continuity of care, and provision of information and support to the woman and her family. Also included in the core team is a supportive care provider (e.g., a specialist breast nurse, oncology nurse or social worker) who deals with the psychosocial aspects of care.

RCNA makes the following recommendation:

That to ensure the efficacy of a multi-disciplinary approach for a person with cancer, the treating team requires the inclusion of health disciplines other than specialist physicians and surgeons.

Specific comments are provided below against the Inquiry's Terms of Reference.

3.2 Specific comments

(a) *The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:*

(i) *the efficacy of a multi-disciplinary approach to cancer treatment*

As discussed above, it is necessary for the best outcomes for a person diagnosed with cancer that psychological support is provided as well as the appropriate medical care. A clear framework for establishing this model is required to ensure the delivery of high quality care for persons with cancer.

RCNA notes, in particular, the importance of nurses' specific involvement in a multidisciplinary team to care for a person with cancer. The significance of nursing care in regard to an integrated model is expressed in the statement: *Patients speak clearly to the importance of the nurse meeting their treatment needs (instrumental activities) and doing this in a way that protects and enhances the unique identity of the individual Fundamental to the experience of care is the patient's confidence in the ability of the nurse to provide the necessary physical care and treatment. (Christine Webb, 1995).*

Nurses in Australia who work in oncology have specific training and education in this specialised area of nursing care. This gives nurses comprehensive knowledge in regard to the treatment of cancer, including skills in assessment and evaluation of the care required by the person, and also skills in being able to respond to the psychosocial needs of the person.

RCNA therefore recommends the establishment of a model of a multidisciplinary team to treat and support persons with cancer. It is acknowledged that the multiplicity of healthcare settings in Australia may mean that a single model of multidisciplinary care may not always be feasible. This should not however exclude the innovation of a framework for a multidisciplinary approach for the treatment of a person with cancer as an ideal treatment approach.

RCNA makes the following recommendation:

That a model/s of a multidisciplinary team be established to treat and support persons with cancer, which takes into account the context of that care.

- (ii) *the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers*

Case managers and case coordinators are of primary significance in multidisciplinary teams for the treatment and care of persons with cancer. However, at this time nurses regularly coordinate the care of the patient as the nurse is continually involved with the person with cancer.

As support of care givers is very limited in Australia, nurses frequently provide psychological support to this demographic group. Therefore, a multidisciplinary team would also assist in the essential support for care givers on a long term basis.

RCNA thus proposes that care managers/case coordinators are an intrinsic component for routine assistance of patients and/or primary care givers.

- (iii) *differing models and best practice for addressing psycho/social factors in patient care*

RCNA expresses the principle that as nursing care is an interactive process that requires a nurse to be responsive to the patient on each occasion of the need for care, psycho/social factors are difficult issues for specific measurement. The assessment of best practice for addressing the psycho/social factors in patient care is measurably complex as a result of the ethical and moral aspects of health care. The National Breast Cancer Centre has established best practice psychosocial guidelines, which are appropriate for nurses and other health professionals. However, there is a place for continued professional development in the areas of ethics and decision-making processes.

RCNA considers that best practice guidelines for addressing psycho/social factors in the care of patients with cancer are an important aspect of treatment and care, and consideration needs to be given to the distinct role that nurses provide in regard to patient care and treatment. Therefore, a range of models and best practice guidelines developed for the treatment and care of person with cancer should also take account of the ethical aspects of care.

RCNA makes the following recommendation:

That best practice guidelines be developed for addressing psycho/social factors in the care of patients with cancer as an important aspect of treatment and care, which include the distinct role that nurses provide in regard to patient care and treatment, and the ethical aspects of care.

- (iv) *differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians*

RCNA is strongly supportive of a specific model for best practice in regard to delivering services and treatment options to both regional areas of Australia and to Indigenous Australians. RCNA believes that it is these situations that would greatly benefit from having a case manager and/or case coordinator.

The role of case manager and/or case coordinator in regional Australia would be able to facilitate the overall care of patients with cancer. This is particularly important when treatment is being delivered a considerable distance from the patient's home and results in severe dislocation from cancer patients' families. The role would include ensuring that appointments that need to be made in a major city were coordinated, that all subsequent reports were distributed to the appropriate medical professionals, that appropriate support was delivered to both the patient and their primary care givers, and most importantly ensuring that all areas of treatment are coordinated and communicated to all relevant medical professionals.

The role of the nurse in delivering services to regional areas, both with and without large Indigenous populations, is an important aspect in regard to best practice in regional Australia. As stated previously, nurses often have the role of coordinating treatment and support for cancer patients as there has not been an officially designated position in this regard.

RCNA supports the implementation of models of nurse-led care in the cancer context. There is emerging evidence that indicates that nurse-led services are most effective when the role is focused on delivering clinical and specialised care rather than more generic coordination responsibilities (Jessica Corner 2003). A range of studies evaluating nurse-led care in cancer services indicate effectiveness in relation to high levels of satisfaction with services (Garvican, Grimsey Littlejohn et al 1998; Corner, Moore, Haviland et al 2002; Moore, Corner, Fuller 1999; Faithfull, Corner, Meyer et al 2001), lower costs of care (Addington-Hall, MacDonald, Anderson et al 1992; Rafferty, Addington-Hall, and MacDonald et al 1996; Faithfull, Corner, Meyer et al 2001), reduced hospital admissions (McCorkle, Benoiel, Donaldson et al 1989), lower anxiety (Weintrobe, Hagopian 1990) and shorter waiting times (Campbell, German, Lane, Dodwell 2000).

The role of Nurse Practitioner is currently being developed throughout Australia and will be significant in best practice models throughout regional areas of Australia. NSW Health Department states that: *The Nurse Practitioner qualification requires both postgraduate qualifications and a regulated quantity of experience. Authorised nurse practitioners may prescribe medications, order diagnostic tests and make referrals only when operating within approved guidelines. They provide expert nursing care by working autonomously but in collaboration with other health professionals as part of a multidisciplinary team.* Nurses with these qualifications will be able to be significantly involved in the quality care of people with cancer in regional areas and will provide a

model of best practice in regard to positive interaction with other health professionals and support for patients.

RCNA recommends that differing models for delivering services and treatment to Indigenous Australians specifically address the important aspect that as it is generally a disease of ageing, many Indigenous Australians do not develop cancer because the projected life span of this demographic group is less than sixty years of age.

RCNA also recommends that the models established in England in regard to rehabilitation of cancer patients be adopted.

RCNA believes that a major barrier to the implementation of best practice in regard to service delivery to people with cancer in regional Australia and in particular to Indigenous Australians is the apparent lack of consultation with the relevant stakeholders.

The National Strategic Framework for Aboriginal and Torres Strait Islander Health (2002) states that included in its principles are: *Community control of primary health care services: supporting community decision-making, participation and control as a fundamental component of the health system that ensures health services for Aboriginal and Torres Strait Islander peoples are provided in a holistic and culturally sensitive way.* Therefore, until the Aboriginal and Torres Strait Islander people have direct input into the development and implementation of best practice, the scope and effectiveness will be very limited in terms of its appropriateness for the Aboriginal and Torres Strait Islander people. This is obviously extremely significant in regard to the care and treatment of Aboriginal and Torres Strait Islander people with cancer as building community expertise in cancer treatment is required to facilitate the effective use of medical services for Aboriginal and Torres Strait Islander people.

A similar situation also exists in regard to regional areas of Australia in general, as community education regarding treatment options, side effects, outcomes and prognosis is not commonly available to isolated communities. Therefore, the perception of best practice in regional areas can be difficult to define due to the lack of comprehensive information that is made available to people with cancer, in regional areas. Nurses can to some degree fulfill this role but professional health educators with specialisation in cancer education would assist in the reduction of these barriers to best practice.

Therefore RCNA recommends that a health educator position be established to provide comprehensive information regarding cancer to people with cancer in regional areas of Australia and Aboriginal and Torres Strait Islander people.

RCNA makes the following recommendations:

That differing models be developed for delivering services and treatment to Indigenous Australians than those used for non-Indigenous Australians.

That the models established in England in regard to rehabilitation of cancer patients be adopted in Australia.

That a health educator position be established to provide comprehensive information regarding cancer, to people with cancer in regional areas of Australia and Aboriginal and Torres Strait Islander people.

(b) *How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:*

(i) *the extent to which less conventional and complementary treatments are researched, or are supported by research*

RCNA believes that the extent to which less conventional and complementary cancer treatments can be researched by the criteria of 'success' of treatment is limited. This is as a result of the difficulties in scientifically evaluating their effect over a spectrum of both physical and psychological outcomes.

Downer et al (1994) reported the results of interviews of forty-eight patients who were using complementary therapy:

overall 39 (82%) were either satisfied or very satisfied with the therapies they had chosen. Those satisfied with the therapies described the benefits as being both physical and psychological. ... Other psychological benefits reported by patients included feeling emotionally stronger, being more able to cope with the demands of the illness, and feeling more optimistic and hopeful about the future.

It is clear therefore that there would be difficulties in analyzing these benefits described through quantitative research. However, a person with cancer 'feeling better' is a treatment outcome that cannot be dismissed as unimportant.

There is also the issue in regard to people with cancer opting to use less conventional and complementary cancer treatments in that conventional medicine is inclined to dismiss the benefits of less conventional and complementary treatments and therefore do not provide any level of support for patients using these options. When people choose less conventional or complementary therapies rather than medically prescribed treatment, they are excluded from other potentially beneficial health services such as nursing, social work and psychology.

RCNA supports the concept that patients should have access to oncology physicians and surgeons (as well as general practitioners) who would be prepared to discuss all options in regard to less conventional and complementary cancer treatments without judging or intimidating them. Also that further research, using qualitative as well as quantitative

methodology, in regard to the possible benefits of less conventional and complementary cancer treatments is necessary in order to give theoretical evidence to these treatments.

- (ii) *the efficacy of common but less conventional approaches either a primary treatments or as adjuvant/complementary therapies*

RCNA considers that the concept of 'less conventional' cancer treatment is problematic, in that assessing these treatments assumes that chemotherapy, radiotherapy and medication are considered as the lone course of treatment for people with cancer. The Cancer Council of New South Wales states that: *There is evidence to show that: relaxation therapy can ease cancer pain, muscle relaxation and imagery can reduce distress in women with mild anxiety, acupuncture can ease pain.*

Hence, research regarding levels of risk of less conventional cancer treatment is important but distinction should not be made about the acceptability by oncology physicians of different treatments for people with cancer. It may be more acceptable to change the terminology from 'less conventional cancer treatment' to 'supportive care' where interventions that provide relief for physical, psychological, social, informational and spiritual distress can be further explored and included in current models of care delivery during diagnosis, treatment and follow-up stages. The change in terminology would extend current services to those individuals who choose not to have a medical intervention (chemotherapy, radiation therapy, or surgery) for their cancer disease, and who are currently excluded from access to non-medical health services.

RCNA makes the following recommendation:

That comprehensive research be undertaken to assess the benefits of using interactively conventional and complementary treatments for people with cancer.

- (iii) *the legitimate role of government in the field of less conventional cancer treatment*

RCNA considers that the role of government in the field of less conventional cancer treatment is to provide adequate funding for thorough research to occur regarding the efficacy of less conventional treatment for cancer in order that a full spectrum of options can be legitimately offered to people with cancer. Comprehensive research in this regard would expand the opportunities for all oncology professionals to offer a range of treatments to people with cancer.

The provision of community education regarding cancer and all treatment options, particularly in regional areas of Australia and to Indigenous Australians, is another important area for development. It is obviously very difficult for people in isolated areas

to access inclusive information regarding treatment options and therefore do not have the informed choices that are available to other people with cancer.

4. Conclusion

The delivery of services and treatment for persons with cancer is a significant issue for RCNA as nurses are often the 'first line of defence' when people are diagnosed with cancer and advice as to treatment options is often the first question raised by the patient. Therefore the option of having a multi-disciplinary approach to which to refer people diagnosed with cancer for support and ongoing treatment would facilitate the nurse being confident of reassigning the patient to further care and support.

The other component of this approach is that best practice can be applied in regard to psycho/social factors. It is already recognised that counselling and support with people with cancer often extends their original prognosis. In regard to this, the person with cancer needs to have the opportunity of looking at all options of treatment, including less conventional and complementary treatments. This gives the patient a feeling of greater control over their cancer which is an important factor in care of persons with cancer.

As discussed previously, the need for a multi-disciplinary team to support people with cancer in regional Australia and for Indigenous Australians is even greater than in metropolitan areas as the array of choice of medical staff is much more limited in regional areas and for Indigenous Australians. Therefore a multi-disciplinary team would be able to provide extensive support for people with cancer in regional areas and for Indigenous Australians in regard to counselling and oncology information.

5. References

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