SUBMISSION TO:

AUSTRALIAN SENATE
COMMUNITY AFFAIRS
REFERENCES COMMITTEE

RE:

INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER

FROM:

Australian Council of Community Nursing Services (ACCNS)

Lyndie Spurr
President
ACCNS
lspurr@rdns.com.au
(03) 9536 5267

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Thank you for providing ACCNS with an opportunity to review and submit comments to the Committee on the 'Inquiry into services and treatment options for persons with cancer.'

Overview of Australian Council of Community Nursing Services (ACCNS)

ACCNS is the national peak body for community nurses and provides nursing leadership and promotion of community nursing throughout Australia.
Providing a united voice for both individual and corporate members, ACCNS represents its membership on advisory committees and works to inform the strategic direction of community nursing.
ACCNS is responsive in the development of community nurses and health care through research, education and quality improvement.

ACCNS response to the Terms of Reference of the Senate Inquiry into Services and Treatment Options for Persons with Cancer

(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**

A multi-disciplinary approach to cancer treatment is viewed as crucial to the provision of high quality palliative care and yet this area is often poorly resourced.

Significant gaps are apparent, particularly in the area of Allied Health where there is inconsistency across Australian in funding models and resource availability. This can force palliative care services to choose where to expend limited resources (eg. on either a social worker, physiotherapist or chaplaincy) to the detriment of a holistic approach to client/family care.

Rural and remote areas frequently do not even have the opportunity to engage a truly multi-disciplinary team due to the unavailability of allied health professionals in the region or the funding to engage them.

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

Given the breadth of multidisciplinary services, and complexity of services required by people with cancer, case management/case coordination is an important element, and one that is often picked up by nurses without being formally recognized or compensated.

Care needs to be taken in the interchangeable use of the terms 'case management' and 'care coordination' as from community nursing perspective they represent different levels of responsibility and accountability. Case management is viewed as a formal appointment with authority to 'prescribe' a care plan comprising of a number of community service provider organisations and often includes a brokerage function. Whereas case coordination is a less rigid appointment, and therefore less powerful, is often taken on by almost by default by the service most centrally involved in the client's care, and does not have a brokerage function, rather a role in trying to ensure communication lines between involved service providers are effective.

Without case management, service to the client frequently becomes fragmented, duplicative, causes confusion for clients and their families and is inefficient and less effective.

Case management can foster strong communication between a multi-disciplinary team. However, there must be very clear role definitions for each provider involved in a client's care plan in order to fully succeed.

The case manager role is often intense and time consuming. Where this has not been taken into consideration by the service provider assuming case management responsibility, it can lead to a token and unsatisfactory response which not only impacts directly on the quality of care received by the client but the ability of other involved service providers to satisfactorily fulfill their role.

Another aspect to be avoided is the nomination of multiple case-managers which is a contradiction in terms but at times occurs. There needs to be some mechanism for co-coordinating cancer services. For example, the Victorian State Government has recently implemented a Cancer Services Policy which offers a comprehensive approach to the model and allocation of services.

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

There tends to be a void in the area of meeting psychosocial needs with the physical/tasks often being 'easier' to address by healthcare providers.

Psychosocial aspects of client care, including the support of carers, needs greater recognition and funding. One working model that is doing this well is that which is in place at the Women's and Children's Hospital in Adelaide. In this model, a social worker is allocated to each client at the point of diagnosis and remains working with the client throughout the course of the disease process until death.

A lack of bereavement services is widespread across the sector and increased funding to support the development of these programs would be welcomed by client's families and service providers.

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

The lack of available skilled personnel and mainstream oncology services in regional Australia means that cancer sufferers frequently must relocate to metropolitan areas for, at times, extensive periods of treatment. The separation from home, family and informal support networks is particularly difficult for clients from indigenous or CALD communities and undoubtedly causes additional stressors in an already difficult situation.

Where clients of indigenous or CALD backgrounds are able to receive care close to their home, this could be enhanced by the provision of culturally specific training to service providers in both hospitals and community service settings.

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

The following factors are viewed as areas that would need to be addressed in order to achieve best practice:

- Adoption of a consistent definition of ‘palliation’ and the point at which a client enters a ‘palliative care’ phase.
- Greater consistency in models of service delivery
- Role boundaries - for example the hesitancy of some medical staff to allow certain tasks to be undertaken by other disciplines or in a community setting. In some States, oncologists are reluctant to allow the delivery of chemotherapy or blood transfusion in the home.
- Lack of available staff with specialist oncology/palliative care skills – Palliative care consultants (both medical and nursing), allied health, bereavement counsellors, psychologists, volunteers
- Better multi-disciplinary coordination processes including those across the acute oncology – community care interface.
- Need for greater availability of, or access to, respite care services. (Particularly in-home respite)
- Improved access to oncology and palliative care services in rural and remote areas.
- Improved transportation and accommodation assistance for clients forced to travel from rural and remote areas for treatment.
- Development of best practice guidelines for the delivery of palliative care.

(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

A place for complementary treatments in the care of those with cancer must be considered and further researched. Increasingly, these modes of care, particularly reflexology, aromatherapy and acupuncture, are being embraced overseas and the general community is becoming increasingly aware and informed of this. In some instances there is already a reasonable body of evidence to support some treatments. However, overall there is a need to ensure that treatments included in a treatment plan have a reasonable evidence base to support them. There will always be situations where, as a last resort, patients/their carers will resort to other treatments without supportive evidence.

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

Attitudes, often formed by a lack of knowledge or belief, held by many health professionals are a barrier and would need to be addressed through education.

The development of positions such as Professor Marc Cohen at RMIT in Victoria (Head of Department of Complementary Medicine) is a positive move in ensuring that best practice and evidence are used to differentiate those alternative/complementary treatments that can indeed show real benefit.

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

It could be argued that there is a role for government in regulating complementary therapies (as it does more ‘traditional’ treatment modalities). This would be a positive step but the capacity to actually deliver on this at present must be questioned due to the lack of evidence for some treatments (and therefore an inability to set appropriate criteria/standards to allow regulation of practice). In addition, the administrative burden of setting up individual regulatory boards for numerous types of practice can be a barrier to progressing this. It may be possible to come up with some sort of generic regulatory board but this would need considerable investigation as to the feasibility of such a body. It is a concern, however, that there are ‘therapists’ in the community who can/do take advantage of people who are extremely vulnerable, and promise outcomes that they know will not be achieved.

Governments also need to have a role in funding and supporting research into complementary therapies. This would include the establishment of ethics committee frameworks, licence approvals, advertising principles, use of medications, for example the review of limitations on client eligibility for certain drugs.

CONCLUSION

ACCNS appreciates the opportunity to inform the Senate Inquiry into services and treatment options for persons with cancer of our observations and perceptions of the significant challenges that now and will in the future impact on the delivery of effective and efficient oncology and palliative care services throughout Australia.