PALLIATIVE CARE NURSES AUSTRALIA INC

Palliative Care Nurses Australia Inc Submission

Senate Standing Committees on Community Affairs'

Inquiry into the Provision of Palliative Care in Australia

March, 2012

SUMMARY

Palliative Care Nurses Australia Inc (PCNA) has provided recommendations to the Senate Standing Committees on Community Affairs inquiry into palliative care in Australia.

This submission includes the following:

PALLIATIVE CARE NURSES AUSTRALIA INC

Palliative Care Nurses Australia (PCNA) is a national membership organisation for all nurses working with people who are dying and their families. The PCNA membership base includes those who are specialist palliative care nurses and nurses of all levels who work in non-specialist roles in the care of people at the end of life. Nurses work in a variety of settings - including (but not limited to) palliative care units, hospices, community, acute hospitals, residential aged care facilities, universities and research centres. The vision of PCNA is to promote excellence in palliative care nursing for our community, through *leadership*, *representation* and *professional support*.

THE ROLE AND CONTRIBUTION OF NURSES WITHIN PALLIATIVE CARE

Palliative care nurses bring a unique set of skills and qualities that enhance the care and support provided to people facing the end of life and to the families and communities that support them. These skills and qualities are developed through many years of interdisciplinary clinical practice and continuing education and they are informed by the founding philosophies of palliative care.

Palliative care nurses demonstrate leadership in autonomous and collaborative practice, in modelling end of life care, and in providing mentorship and education to other nurses and health care professionals. They have extensive knowledge and experience in the management of pain and complex symptoms associated with terminal illness.

Palliative care nurses work collectively and with other professional groups to advance the body of knowledge about end of life care, initiating and conducting research and incorporating research findings into their practice where appropriate. They work collaboratively with others to advocate for change and provide policy advice to Government and professional organisations regarding a wide range of clinical, professional and service related issues.

Palliative care nurses' knowledge of end of life issues, combined with a strong commitment to the palliative care philosophy, often extends the work of the specialist nurses beyond the bedside to advocating the need for palliative care on the sociopolitical level, and to promoting optimal well-being at the end of life regardless of a patient's location or financial position.

Palliative care nurses are also advocates for the families and friends of palliative care patients, and by promoting and teaching positive approaches to grieving they extend the benefit of palliative care to promote health in the wider community.

PALLIATIVE CARE IN AUSTRALIA—TERMS OF REFERENCE

Palliative Care Nurses Australia welcomes the opportunity to offer input to this inquiry, in the recognition that quality improvement in palliative care provision for the community is a pressing matter of national significance. PCNA's submission specifically addresses the terms of reference as follows.

Note: Specific recommendations are bulleted.

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

(i) people living in rural and regional areas,
(ii) Indigenous people,
(iii) people from culturally and linguistically diverse backgrounds,
(iv) people with disabilities, and
(v) children and adolescents;

To ensure that there is equity of access to specialist palliative care, regardless of where people live, their background, or their age, PCNA recommends:

- Adequately funded systematic palliative care education programs, available nationally, for nurses and other health professionals. Such education should be available online, and use other innovative educational techniques such as Smartphone apps and e-books to allow and encourage access by health professionals in rural, regional and metropolitan areas
- A structured palliative care education program for Aboriginal and Torres Strait Islander Health Workers
- Development of end of life pathways for people with disabilities, children and adolescents

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

Current sub-acute funding arrangements focus on bed numbers, whether in hospital or community, and also have a major focus on capital funding, whereas much palliative care takes place in the home, where no capital funding is required.

- A unit of funding for palliative care in the community should be developed that takes into account the nature of domiciliary nursing and provision of other health services in the home setting.

Provision of palliative care in the community setting is often hampered by limited access to General Practitioners (GPs) with an interest in providing palliative care.

- GPs must be adequately remunerated for the time involved in provision of complex care in a palliative care situation.

(c) the efficient use of palliative, health and aged care resources

The '*Guidelines for a Palliative Approach in Residential Aged Care'* of 2006, are dated and no longer reflect the current clinical realities of contemporary practice in the field of residential aged care. The aforementioned guidelines and the aged care funding instrument (ACFI) are both in need of review and update. The embedding of advance practice nursing roles (Nurse Practitioners - NPs) within residential aged care facilities requires widespread promotion and prescribing support through improvement to the Medicare Benefits Scheme (MBS).

Further, the palliative approach in residential aged care would be better supported with the national rollout of the Comprehensive Evidence-Based Palliative Approach In Residential Aged Care (CEBPARAC) tool kit, developed through an NH&MRC funded project.

- Update the evidence base and rewrite the now out of date 'Guidelines for a Palliative Approach in Residential Aged Care'
- Review and update the aged care funding instrument (ACFI) including:
    - Better training for validators to address discrepancies in interpretation of question 12: Complex Care regarding claims for a 'palliative care program'
    - Universal, well defined triggers for identifying when a resident requires a 'palliative approach'.
- Rollout the CEBPARAC toolkit to all Australian RACFs
- Increase the number of palliative care Nurse Practitioners in residential and community aged care.
- Provide better funded and more appropriate MBS item numbers for Nurse Practitioners working in residential and community aged care to attract staff to provide such services

(d) the effectiveness of a range of palliative care arrangements
(including hospital care, residential or community care and aged care facilities)

Improving communication with, and between, all stakeholders involved in care of a resident/client is vital – yet extremely difficult to facilitate within current arrangements in residential aged care. Universally implemented (mandatory) palliative care case conferences which are appropriately funded through the ACFI would resolve this issue and ensure better care for palliative residents.

Outcomes of this would constitute evidence for an automatic ACFI claim for palliative care. Triggers would be when:

Answering 'no' to:

- *"Would you be surprised if the resident died within the next six months?"*

Or where:

- There has been a significant functional or medical decline.
- There are problems around the goals of care (perhaps after an acute event).
- The resident is transferred or admitted to the RACF specifically for comfort care or palliative care.

Careful consideration also needs to be given to the implications of high numbers of staff from non English speaking backgrounds who provide the bulk of end of life care in RACFs. Issues include communication/language barriers as well as cultural issues around death and dying.

In the acute hospital setting, services such as the Hospital in the Nursing Home team at Royal Brisbane and Women's Hospital work to prevent inappropriate admissions of aged care facility residents to the acute setting. Such programs reduce stress for patients/residents and families, prevent inappropriate use of scarce funding and resources, and help ensure a dignified death at home rather than in an Emergency Department.

- Endorse and implement palliative care case conferences as best practice within a national palliative approach to care, with appropriate funding through the ACFI
- Assess and address the need for cultural and communication training for all RACF nursing staff
- Provide all RACF nursing staff with systematic education in the principles and practice of a palliative approach
- Broaden the scope of, and adequately fund, services such as the nurse-led Hospital in the Nursing Home team at Royal Brisbane and Women's Hospital to prevent as far as possible inappropriate admissions of the aged population and those more appropriately cared for at home.

(e) the composition of the palliative care workforce, including

(i) its ability to meet the needs of the ageing population
(ii) the adequacy of workforce education and training arrangements

As numerous federal health ministers have cited, nurses form the very backbone of any health system. In palliative care, this backbone of nurses needs to be valued with a committed investment of funds for workforce staffing, support and development needs. The current number of FTE nurses will not be adequate to provide quality palliative care for the ageing population.

Within an already under resourced sector, those nurses currently practising in the highly demanding field of palliative care are facing the prospect of 'burnout', which leads to workplace injury/illness and overall attrition of the palliative care workforce. These in turn, lead to poorer care outcomes for palliative care patients. Furthermore, there is not only an ageing population, but also an ageing workforce in palliative care.

This presents pressing issues of generational change within the profession, with issues of recruitment and retention requiring specific consideration for the future palliative care workforce. Generation Y for example, present a markedly different employee profile to that of current and past generations of palliative care nurses. The unique needs of younger generation palliative care nurses can be met in part by expanding the Palliative Care Curriculum for Undergraduates program (PCC4U). Futhermore, a structured mentoring program between senior and junior palliative care nurses would be effective, not only in consolidating the PCC4U program, but in ensuring effective knowledge transfer between workforce generations and succession planning.

- A higher level of exposure for nursing students and graduates to palliative care environments is required to equip nurses to work in palliative care and promote the field as an attractive career choice.

- Palliative care education should be embedded as a core component of all undergraduate nurse education in Australia.

- A structured mentoring program by experienced palliative care nurses for their junior colleagues be developed to support the future workforce.

- Specialised Graduate Nurse Programs in palliative care should be developed, as has been done in Mental Health Nursing.

Advanced practice nursing roles in palliative care need to be effectively embedded within service models; this includes the training and employment of Nurse Practitioners with prescribing authority (confined to their scope of practice).

- Nurse Practitioners need to be better utilised, and palliative care services better resourced to achieve this.

Regarding education and training, there should be dedicated scholarship funding for postgraduate studies in palliative care on a national level, rather than palliative care clinicians having to rely on being awarded funds under the generic and highly competitive *Postgraduate Nursing and Allied Health Scholarship and Support Scheme* (NAHSSS).

Many clinicians wanting to further their clinical knowledge and develop advanced practice skills in palliative care are consistently missing out on funds through the generic NAHSSS. This results in frustration and disillusionment regarding any higher education aspirations such clinicians may have held.

Such barriers to further education ultimately impede quality improvement of clinical staff practising in a dynamic environment of evidence-based practice (with an everchanging evidence base) and adversely affect bedside care of palliative patients.

- Ongoing dedicated scholarship funding should be provided for postgraduate studies in palliative care on a national level.

Palliative care nursing, whilst recognised as a specialty field of practice in its own right, can be bolstered by national utilisation of the *competency standards for specialist palliative care nursing practice*. At present, these standards—whilst developed as a theoretical framework—lack the practical utility to achieve the assurance of quality and excellence in palliative care nursing where it will benefit patients.

A discipline-specific credentialling program for palliative care nurses would provide a more robust foundation of specialist nurses to lead the field of palliative care into the future. A credentialling program similar to that implemented by the mental health nursing workforce would provide an educational benchmark (requiring a minimum of a *Graduate Diploma in Palliative Care*) for recognition as a specialist palliative care nurse.

- Consideration should be given to supporting the creation of a credentialling program for recognition of specialist palliative care nurses.

- Competency standards for specialist palliative care nursing practice (already developed) should be rolled out nationally, with appropriate funding to support their dissemination and uptake.

(f) the adequacy of standards that apply to the provision of palliative care
(and application of the 'Standards for Providing Quality Care to All Australians')

Spirituality is reflected implicitly in the *Standards for Providing Quality Care to All Australians* (Palliative Care Australia, 2005) through the palliative care philosophy which is intrinsically holistic. However spirituality and spiritual care warrant the *explicit* detail and attention afforded by inclusion in the Standards as a separate standard.

Spirituality is best understood in terms of the web of relationships that gives coherence to our lives, uniquely identifying each person; thus spiritual care is integral to palliative care for those living with dying. Responsibility for spiritual care is shared by palliative care nurses and across the multidisciplinary team, although led by pastoral carers as specialists in spiritual care.

- The current palliative care standards should be reviewed for the inclusion of a new, and separate standard for spiritual care
- Greater consideration should be given to the many people of Cultural and Linguistically Diverse (CALD) backgrounds receiving palliative care in Australia, by reflecting their unique needs explicitly within the standards.

(g) advance care planning

Advance care planning needs to be the remit of *all the population*;
not just at the end of life.

A clear separation in health care policy and organisational processes of advance care planning from end of life (palliative) care is required.
This is consistent with the position of the peak body for palliative care in Australia, Palliative Care Australia.

Furthermore, there is a tremendous need for nurses to be formally trained in advance care planning; to better understand appropriate language to use and legislative implications across the multiple jurisdictions of Australia.

- Make distinct and separate organisational processes from the broader health care policy around advance care planning
- Assess and address the educational needs of the palliative care workforce in advance care planning – through funded training programs

(h) the availability and funding of research, information and data about palliative care needs in Australia

Contemporary evidence-based practice in palliative care nursing is only as effective as the quality and currency of the research evidence upon which that clinical practice is based. Therefore, there is a requirement for ongoing research funding dedicated to palliative care nursing research studies. Currently the National Health and Medical Research Council (NHMRC) funding rounds are not adequately supporting the growing demand for research into palliative care nursing practice. Ultimately, investment in research funding transfers to quality health outcomes for palliative patients and their families.

The future improvement of palliative care practice will largely be contingent on the funding of future research studies to inform and enhance palliative care nursing practice.

- Significant funding increases should be provided for:
    - o palliative care research centres and
    - o higher research degree scholarships at Masters and PhD level

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