Submission to the Parliamentary Inquiry into Palliative Care

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The University of Queensland/Blue Care Research and Practice Development Centre (RPDC) was established in 2006. It is a joint initiative by the University of Queensland School of Nursing and Midwifery and Blue Care, Queensland largest not for profit provider of aged care. The objectives of the RPDC are to:

1. Identify new models of service in response to changing community and client requirements with respect to aged care.
2. Develop evidence that will inform policy in relation to aged care, including aged care provision, cost effectiveness and outcome evaluation.
3. Develop and support implementation of innovative staff development and consumer education programs.
4. Investigate specific aged care practices.
5. Disseminate outcomes and results within Blue Care, other service providers, product manufacturers, policy makers, funding bodies and other consumers both nationally and internationally.

A key research focus of the RPDC is palliative care and specifically palliative care for older people.

In making this submission I limit my response to terms of reference (d), (e) and (h).

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

Internationally, the World Health Organization has recognised the importance of palliative care for older people with the publication of a document – Better Palliative Care for Older People (1). In Australia palliative care for older people has received increasing attention. This has included the development of national guidelines for a palliative approach in residential aged care (2) and most recently a palliative approach for aged care in the community setting (3). The palliative care needs of older people are often more complex than those of younger people. Older people are more likely to have multiple medical problems which lead to greater impairment, increased care needs, a greater risk of adverse drug reactions and iatrogenic illness.

While only approximately 7% of Australians aged persons aged over 65 years live in a residential aged care facility, for these individuals death is the most likely exit point from care. The percentage of separations by death in residential aged care facilities in Australia has increased steadily from 70% in 1993 to 87.8% in 2008 Of these residents, 16.5% had stayed for less than 3 months, 18.6% for between 3 months and 1 year. (4)

Residential aged care is funded by the Commonwealth government using the Aged Care Funding Instrument (ACFI) and this funding is to provide all the care that is required by residents. However, this funding does not extend to the funding of specialist palliative care services to provide education or clinical consultation. As specialist palliative care services funds are administered by State governments it is not generally accepted by specialist palliative care services that they have a responsibility to support residential aged care facilities to provide palliative care. As palliative care is core business for all residential aged care facilities the education and clinical support of staff is essential. This is not to say that every dying resident or their family requires the expertise of a specialist palliative care service. In some instances where complex pain and symptoms exist this may be required. The current dilemma for this sector is that the level of support provided by specialist palliative care services is ad hoc and dependent on local relationships and priorities. Some specialist services such as the Brisbane South Metropolitan Services have clinical staff exclusively to educate and provide clinical support for the residential aged care facilities located in their district. Other residential aged care providers report no support is available. In Victorian, this is currently being addressed by employment of specialist palliative care nurses in each region to support residential aged care facilities. I applaud this initiative although current funding does not provide the level of support that is required to truly make an impact for all older Australians dying in this setting.

While the training and employment of specialist palliative care nurses will improving the quality of palliative care for older people in residential aged care the sheer volume of work will require that all staff regardless of level (RN, EN, AIN) will require basic skills.

Under the Department of Health and Ageing EBPRAC program the UQ/Blue Care Research and Practice Development Centre developed and implemented an evidence based model of palliative care in residential aged care facilities using the NHRMC endorsed guidelines for a palliative approach in residential aged care (5).

This model involved three key processes of care (advance care planning, palliative care case conferences and an end of life care pathway) and assessment and management strategies for five main symptoms experienced by older people at the end of life. Key to the model was the training of link nurses or champions who were supported by specialist palliative care nurses. The model was evaluated in nine RACFs over 4 states. There were significant improvements in documentation of end of life (EOL) wishes, evidence that next of kin were involved in EOL discussions, the use of palliative care case conferences and an EOL care pathway. There was a significant improvements in pain assessment, effectiveness of non-pharmacological treatments for pain, effective use of regular analgesia and prn analgesia. Significant increases were also found for assessment of dysponea and the use of non-pharmacological strategies for dysponea The model was positively evaluated by staff at all levels. Of the 42 residents who died in the study, 41 (95%) died in the RACFs.

To ensure the model could be adapted to other RACFs an education toolkit for staff which provides a step by step approach to implementing a palliative approach has been developed. **This Palliative Approach Toolkit** so far has not received funding for wider distribution beyond the original facilities involved in the project. See the following website for details of the Toolkit http://www.uq.edu.au/bluecare/the-palliative-approach-toolkit.

Recommendation: That specialist palliative care services are funded to provide clinical and educational support to the residential aged care facilities in their region.

Recommendation: That a national rollout of the Palliative Approach Toolkit is funded by the Commonwealth. .

(e) The composition of the palliative care workforce, including its ability to meet the needs of the ageing population

As indicated above the current palliative care workforce is not adequately funded to support residential aged care facilities to provide palliative care. Nurse practitioners who have skills in both palliative care and aged care could address this gap. General Practitioners currently provide medical care for people dying in residential aged care facilities. While the majority of General Practitioners provide this care competently funding does not support the level of care that may be required and in many instances the demands of the General Practitioner running an office based practice does not match the flexibility required by residential aged care facilities to plan and document comprehensive care required for claiming ACFI, schedule and conduct palliative care case conferences and commence end of life care pathways.

Recommendation: That nurse practitioners in palliative aged care be funded to provide clinical and educational support to the residential aged care facilities in their region.

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

The current research funding for palliative care is inadequate and is not keeping pace with initiatives in other developed countries. There appears to be no coordinated strategy of priority funding areas that are agreed by both researchers and clinicians. The emphasis in the future should be on translational research such as funded under the Enhancing Best Practice in Aged Care initiative. No infrastructure in the form of collaborative research centres or capacity building for a future research workforce is in place. For Australia to maintain its current high ranking in the provision of palliative care the ad hoc approach to research priorities and funding needs to be addressed.

Recommendation: A national research framework for palliative care is required following extensive consultation with researchers and clinicians.

References

1. Davies E, Higginson I. Better Palliative Care for Older People. Copenhagen2004.
2. Commonwealth of Australia. Guidelines for a palliative approach in residential aged care facilities - NHMRC endorsed edition. Canberra http://www.nhmrc.gov.au/publications/synopses/ac12to14syn.htm2006.
3. Australian Government Department of Health and Ageing. Guidelines for a Palliative Approach for Aged Care in the Community Setting -best practice guidelines for the Australian context. 2010.
4. Australian Institute of Health and Welfare. Residential aged care in Australia 2007-2008: A statistical overview. Canberra2009.
5. Parker D, Hughes K, Tuckett A. Implementing and evaluating a comprehensive model of palliative care in residential aged care facilities. Report to Department of Health and Ageing. 2011.