Submission to the Senate Inquiry into Palliative Care

The Australian Senate's Community Affairs References Committee

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Thank you for the opportunity to make a submission to the Senate enquiry. As will be seen by our response we strongly believe that Occupational Therapy (OT) and Physiotherapy (PT) are essential to the delivery of effective palliative care and both professions have much to offer in the provision of this service.

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Background

It is important to set our comments in context and we hold the view that a definition of "palliative" does not rely on prognosis, only that prognosis is limited. It is also important to note that the gap between time of diagnosis and death is ever widening as effective treatments prolong survival rates. We propose that PT and OT play a vital role in optimising function for people diagnosed with a life limiting illness. Optimising function has potential to reduce carer burden, enable people to remain at home for longer, improve quality of life and decrease burden on an already incredibly stretched inpatient health service.

However, currently there is insufficient access to both specialist palliative care OTs and PTs, or other OTs and PTs who are able to employ a palliative approach. While palliative care is featuring more in allied health undergraduate university curriculums, a more concerted effort is required to educate undergraduate and existing clinicians of all disciplines on the important contributions that can be made by PT and OT to palliative care. As we prepare to meet the needs of population that is both ageing and living longer with more disability attributable to chronic diseases, it is vital we plan for ways to manage ongoing care in health service and community sectors.

Factors influencing access to and choice of appropriate palliative care that meets the needs of the population

- The number of PTs and OTs working in palliative care is insufficient for the current clinical need, let alone to cope with a predicted increase of 4.6% per annum. Palliative care related diagnoses are growing at a faster rate than the total population (The Victorian Health Priorities Framework 2012-2022: Metropolitan Health Plan).

- The National Service Improvement Frameworks (NSIF) (2006) was developed to inform and guide policy makers and health professionals. Several of these, cancer and heart, stroke and vascular disease, hold particular relevance to palliative care. Critical intervention points along the continuum of care are identified in the frameworks and the NSIF proposes that appropriate models of care need to be developed at the end-of-life. We propose that rehabilitation to optimise function at the end-of-life is an essential component of palliative care and has potential to support patients goals of not feeling like a burden, helping them adjust to functional decline and meeting practical needs associated with this (NHAPC, 2006). Further it is consistent with (WHO, 2002) policy of helping people live actively until they die.

  A growing body of evidence outlines the vital contributions that OT and PT play in palliative care rehabilitation (non curative) and earlier in the curative phases of disease trajectory. (Cole, Scialla, & Bednarz, 2000; Kasven-Gonzalez, Souverain, & Miale, 2010; la Cour, Johannessen, & Josephsson, 2009a; la Cour, Josephsson, Tishelman, & Nygard, 2007; Oldervoll, 2005; Oldervoll

et al., 2006; Paltiel, Solvoll, Loge, Kaasa, & Oldervoll, 2009; Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008; Yoshioka, 1994).

Put simply we view palliation as not simply an endpoint but rather a means to an end which is ongoing participation in valued and essential everyday activities.

Palliative rehabilitation has been found to not only improve quality of life but also the confidence to participate in everyday activities (Javier & Montagnini, 2011; Schleinich, et al., 2008). A recent Randomised Controlled Trial (RCT) comparing standard oncological treatment plus palliative care to only standard oncological treatment, found that patients receiving palliative care not only had higher Quality of life (QOL) but also lived on average 3 months longer (Temel et al., 2010). This Temel paper raises significant issues from a PT and OT perspective. If effective palliative care does indeed prolong life and improve QOL then we need to ask ourselves for what purpose? Surely it is not to remain in bed or sitting in a chair, but to engage in everyday life with family, to the best of one's ability.

- While we note this Senate inquiry is examining palliative care, if more people with cancer were able to access rehabilitation early in the disease trajectory, they would be more responsive to OT and PT interventions during the palliative phase of care. Furthermore, this would aid maintenance of function and reduce hospital admissions.

- Currently OT and PT (in both inpatient and ambulatory care settings) are not available to the majority of palliative patients; therefore patients who have adequate symptom control and wish to be more active are not receiving the right care appropriate to their needs, particularly in respect to optimising their functional capacity (Keesing & Rosenwax, 2011; Morgan, 2012).

- Access to OT and PT is influenced by a number of factors
  - limited awareness by other clinicians of the contribution OT and PT
  - limited funding to employ appropriately skilled OTs and PTs
  - culture of current rehabilitation and palliative care services (Morgan, 2012)
  - funding structure of inpatient rehabilitation services (geared to improvement only)

- limited focus in undergraduate education on the role of OT and PT in palliative care. While this is being addressed somewhat by PPCU4U (Palliative Care Undergraduate Curriculum for Undergraduates) which is funded by the Australian Government through the National Palliative Care program more can be done to challenge the current clinical and academic focus that emphasises supportive care, to one that acknowledges the importance of optimising function (Jordhoy et al., 2007).

Efficient use of palliative and aged care resources

- Education and provision of practical, functional assistance is an integral part of palliative OT and PT assessment and treatment (Kealey & McIntyre, 2005). Increasing the numbers of OTs and PTs in community palliative care services and community rehabilitation programs has the potential to maintain functional capacity and time spent at home, thereby reducing admission to acute hospitals.

- Palliative OTs and PTs are also skilled at setting up home environments for ongoing and also for terminal care, through the prescribing of assistive equipment to ease transfers, mobility, management of pressure care needs and provision of practical support and training for families and carers.

- Evidence to support the inclusion of PTs and OTs in palliative care teams includes
  - the earlier that allied health intervention (such as OT and PT) occurs, the better the functional outcomes (Yoshioka, 1994).
  - emerging research demonstrates that even during later stages of disease PT and OT interventions can improve and optimise function (Dahlin & Heiwe, 2009; Javier & Montagnini, 2011; Oldervoll, 2005; Oldervoll, et al., 2006; Paltiel, et al., 2009).
  - effective screening is required in order to identify and address unmet functional needs (Jeyasingam, Agar, Soares, Plummer, & Currow, 2008; Taylor & Currow, 2003) and identify palliative rehabilitation goals to address these needs (Schleinich, et al., 2008).

Composition of palliative care workforce

- Current academic and clinical palliative care practice focuses extensively on ameliorating suffering, particularly physical symptom control or psycho-spiritual distress (Jordhoy, et al.,

2007; Morgan, 2012). Palliative care teams routinely consist of medical, nursing, social work, music therapy, art therapy, and counselors. However teams comprised in this way are limited in their ability to address issues pertaining to functional decline. The contribution that PT and OT can make has been under-recognised and underutlised in palliative care inpatient and community teams.

- Given that a person can receive palliative care for weeks to years in some circumstances, and experience progressive functional decline, the traditional focus of symptom management and psycho-spiritual care needs to be reviewed. Functional decline is experienced as a side of effect of radiotherapy, chemotherapy and prolonged bed rest. This decline is most pronounced in the three months preceding death (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003) and has a significant impact on the every day lives of both patients and carers. The impact of this decline is broader than just physical disability and results in significant carer burden (Dumont et al., 2006). OTs and PTs are skilled at optimising functional ability and supporting families and patients to cope with everyday activities both in inpatient and community settings.

- PTs and OTs have a potentially significant role to play in consultancy and community palliative care and this is supported anecdotally by staff currently working in the palliative care sector. We strongly suggest that OTs and PTs be viewed and employed as integral members of palliative care teams (i.e. inpatient, ambulatory care services & community palliative services).

Availability and funding of research about palliative care needs in Australia

- Availability of competitive NHMRC PhD training scholarships and other grants has enabled clinicians to undertake research that would otherwise not have occurred. There are at least 3 OTs who have either completed or are completing their PhDs into clinical and professional issues related to palliative care. Findings of this research have been disseminated widely at national and international palliative care and occupational therapy conferences and have a huge potential to educate and inform clinician best practice.

- While this research is informing clinical care, it also points to the need for further research particularly in the areas of functional decline and palliative rehabilitation which requires a different focus to that of traditional rehabilitation.

- OT and PT clinicians and researchers have collaborative relationships with state and national peak bodies, universities, state and national health services and organisations such as CareSearch in order to develop a strategic approach to future research and current care. We welcome the opportunity to engage in further research that will guide care and determine the most appropriate modes of assessment, treatment and rehabilitation as well as addressing issues of workforce development and sustainability.

Conclusion

As Australia prepares to meet the needs of an ageing population who will require palliative care for ever increasing periods of time, we believe that OT and PT can play a vital role in the care of patients and carers in home, acute and subacute settings. In particular we can play an integral role in optimising function for as long as possible, supporting people to make the most of the time they have left**...**enabling people to live until they die. This is consistent with Palliative Care Australia's and World Health Organisation's definition of effective palliative care World Health Organization,(WHO, 2002).

Thank you for considering our submission. We would welcome the opportunity to discuss this further,

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