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SENATE COMMITTEE ENQUIRY INTO PALLIATIVE CARE SERVICES IN AUSTRALIA 2012

This is the submission of the ***Occupational Therapy Australia Victoria Division Oncology & Palliative Care Interest Group*** to the Senate Committee Enquiry into Palliative Care Services in Australia.

If required, the co-convenors of the Interest Group can appear before the Committee to respond to any additional questions.

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The role of occupational therapy in palliative care

The focus of occupational therapy is to assist people manage the limitations caused by illness or injury so that they can best perform the activities that are important and meaningful to them. These include self-care (e.g. showering and dressing), home and domestic duties, community activities, work and leisure/recreational activities. Occupational therapists consider all aspects of a person (including physical, cognitive, psychological, social and environmental aspects) when assessing a persons ability to perform activities of everyday life.

Occupational therapists working in palliative care have specialised skills and knowledge regarding the impact that cancer and its treatment can have on patients and their families. They work with patients to enhance their quality of life by optimising and maintaining full or part independence wherever possible, safety and/or comfort (ensure adequate pressure care). A rehabilitative approach is adopted to achieve these ends, however, as our comments will attest, accessing rehabilitation for this population is somewhat problematic.

The Oncology & Palliative Care Interest Group

Occupational Therapy Australia Limited is the peak body representing occupational therapists in Australia. The Victorian Division Oncology & Palliative Care Interest Group meets on a regular basis to:

- address issues affecting occupational therapists working in palliative care
- collaborate on research for occupational therapists working in palliative care
- network with clinicians, peak palliative care bodies (PCV), research organisations (Centre for Palliative Care), local universities, Caresearch (www.**caresearch**.com.au) to produce and share resources
- coordinate and conduct professional development activities, for example, workshops and guest speakers
- provide a community of practice for occupational therapists working in the palliative care sector

Members of the Interest Group work across a wide variety of settings including public hospitals, community palliative care services, inpatient palliative care units, hospices and community health. They work with patients receiving palliative care in specialist tertiary palliative care units as well as in oncology units and the community.

Terms of reference and practice issues for occupational therapists working in palliative care

The terms of reference issues that are particularly salient to occupational therapists working in palliative care include;

a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

- There is a lack of positions for occupational therapists within community-based palliative care teams. This is inconsistent with NSW, who have more community palliative care occupational therapists. Occupational therapists working in community-based palliative care can maximise patient quality of life, maximise patient and carer safety (reducing secondary costs associated with pressure areas and falls), reduce necessity for inpatient admissions into hospitals/palliative care units and address continuity of care (as patients can require repeated assessment and intervention as condition deteriorates)

- Access to equipment funding poses significant difficulties for these patients and their families which can add to their overall burden, placing carers at risk and sometimes leaving them in financial difficulty

- Access to regular rehabilitation services for palliative clients is problematic for the following reasons:

    - There are no appropriate palliative rehabilitation services across Victoria

    - Rehabilitation clinicians do not have the exposure and specialist skills required to work with palliative patients. Rehabilitation clinicians can have difficulty identifying appropriate and realistic goals for palliative patients

    - A traditional rehabilitation model of care is not congruent with the needs of most palliative patients (Morgan, 2012). However, emerging evidence suggests that people at the end of life can and do benefit from gentle rehabilitation to optimise function (Belchamber & Gousy, 2004; Guo & Shin, 2005; Javier & Montagnini, 2011; Kasven-Gonzalez, Souverain, & Miale, 2010; Oldervoll, 2005; Oldervoll et al., 2006)

- Waiting lists for community based occupational therapists can be excessive (e.g. 24 months) and are not responsive enough to meet the urgent and ever-changing needs of palliative patients

- All the above issues are often exacerbated for rural patients

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

- Younger patients are financially disadvantaged, as they are ineligible for HACC funded services

- Major metropolitan tertiary hospitals are not funded to provided outpatient services unless within 30 days of admission

- Community-based palliative care teams regularly contact acute hospital occupational therapy departments due to lack of appropriate community based occupational therapy services

- Not all inpatient palliative care units have an occupational therapist on staff. Many palliative care units are under-resourced for occupational therapy services, putting pressure on length of stay

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

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

- The overarching principles of providing palliative care services are not consistently applied across a variety of settings, i.e. an inpatient hospice setting will manage many aspects of care quite differently to an acute hospital setting

- Assessing the most appropriate setting for end of life care can be difficult e.g. high level care *vs.* inpatient palliative care resulting in extended stay in an acute hospital environment and increased costs associated with this

- Not all services work with the National Standards and evidenced-based guidelines for psychosocial and bereavement support

- Comprehensive care planning by multidisciplinary team needs to involve the patient and family in an ongoing manner which is often not available within or across services

- Some facilities do not have the resources or expertise to provide particular aspects of care. For example, bereavement support and follow-up for family and care givers after the death, discussing a patient care plan and family support plan, preparing for imminent death

- Inpatient palliative care units can/do experience difficulty meeting the highly complex needs of patients with Motor-Neurone Disease. MND patients tend to stay in their home environment longer if their carers can access high quality respite care regularly

e) The composition of the palliative care workforce

- Lack of community occupational therapists (and allied health professionals in general) in the majority of community palliative care services. Of the seven (7) metropolitan palliative care services, only two

(2) have occupational therapists on their teams. More Specialist Palliative Care Occupational Therapists are needed in the community

- Occupational therapists are skilled in maintaining functional independence which enables people to remain in their own homes – patients receiving palliative care and their carers often require such interventions. These interventions often need to be re-assessed and goals re-evaluated as normal deterioration occurs

- Current workforce structure has a medical, nursing and supportive care focus which is influenced by a focus on symptom control and psycho-spiritual support. Given recent advances in medical care, people are living for substantially longer periods of time with increasing levels of debility. Occupational therapists focus on enabling people to participate in essential and valued everyday activities to the best of their ability by optimising function, by supporting carers through training in how best to assist a person to manage self care, bed mobility and transfers, thereby minimising unnecessary admissions to hospitals

- There is a distinct lack of broader allied health input embedded in both inpatient and community-based services to provide holistic care – including physiotherapy, speech therapy, social work and psychology

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

Patients clearly articulate that they want to participate in everyday activities in an ongoing manner for as long as possible and that it is through active participation that people adjust and adapt to the changes that occur at the end-of-life (Andersson Svidén, Tham, & Borell, 2010; K la Cour & Hansen, 2012; K. la Cour, Johannessen, & Josephsson, 2009a; K. la Cour, Josephsson, & Luborsky, 2005; K. la Cour, Josephsson, Tishelman, & Nygard, 2007; K. la Cour, Nordell, & Josephsson, 2009b; Morgan, 2012). Furthermore they have active rehabilitation goals at this time in their life (Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008) which is contrary to public, clinical and often academic opinion.

In order to support and adequately meet the Palliative Care National Standards, we believe the following needs to be considered;

- Regular comprehensive assessment of changing needs is essential to address patient need (Jeyasingam, Agar, Soares, Plummer, & Currow, 2008; Taylor & Currow, 2003)

- Coordinated care to minimise the burden that occurs in both acute and subacute settings; this will require increased education and promotion about what occupational therapy can offer

- Inpatient and community capacity to respond to constantly changing needs

- Equity of care irrespective of clinical need, diagnosis, age, cultural background or geography

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

- There is an emerging group of occupational therapists, both in Victoria and nationally, who are engaging in both small and large research projects. Three occupational therapists nationally have received competitive grants (including NHMRC) and are currently completing their PhDs examining both patient functional needs as well as clinician needs. Utilisation of best available evidence will inform our clinical practice and support sustainability of practice for the profession in this growing area of care

  E.g. Deidre Morgan, *The ordinary becomes extraordinary: The occupation of living whilst dying. PhD,* Completed through University of Melbourne, supported through an NHMRC training scholarship. http://repository.unimelb.edu.au/10187/13902

- Smaller grants have also been received through the Victorian Integrated Cancer Services (ICS) which have facilitated small research grants as well as ongoing education, attendance at relevant professional conferences etc.

- 2011 saw the formation of a national Interest Group which aims to achieve similar goals to that of the state-based groups, but is coordinated on a national level. In addition, an allied health palliative care interest group (primarily occupational therapists and physiotherapists at this stage) was formed at the national Palliative Care conference in Cairns in 2011. There is a growing group of keen clinicians and researchers who are keen to collaborate with peak bodies, state and national health services in order to promote best palliative care for people at the end-of-life

EXECUTIVE SUMMARY

1. A need for mandatory community OT positions aligned with community palliative care services in Victoria

2. A need for mandatory Senior Clinician OT's on all Palliative Care Units/Hospice's in Victoria

3. Increased OT staffing in inpatient palliative care facilities (Most OT’s currently working in inpatient palliative care facilities are part time)

4. Develop specific palliative rehabilitation services both hospital and community based

5. Easier access to funding and equipment required for palliative patients (i.e. something similar to the MND equipment library where OT’s can access costly/complex equipment quickly, on an ongoing basis and without cost to family)

Occupational Therapists are health professionals who work with individuals to overcome problems in both innovative and practical ways. The OT Palliative Care Special Interest Group has much to offer and is keen to engage with federal and state government to assist with improving the outcomes of Victorians and Australians in accessing quality palliative care services.

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