

Introduction

The role of occupational therapy (OT) in end of life care in Australia has recently gained interest from the profession, consumers and other health disciplines. Factors contributing to this interest include concerns by service providers attempting to cope with an ageing population, changing patterns of disease, new models of service delivery and emerging research into the benefits of OT for people who are dying.

As occupational therapy researchers committed to promoting the role of OT in end of life care, we commend the authors of a recent publication '*The role of occupational therapy in end of life care*' (Burkhardt, Mack, Kannenberg, Low, Marc-Aurele and Youngstrom, 2011) published in the *American Journal of Occupational Therapy*. This thought provoking article articulates 'best practice' OT for end of life care in the United States (US). However, there are many differences between Australia, the US and other countries regarding the role of OT in this practice context. The purpose of this paper is to discuss these differences with particular reference to research completed in Western Australia but generalisable to Australia. Additionally, recommendations will be made to assist the OT discipline work towards the 'best practice' model discussed by Burkhardt et al (2011).

The first discussion point is the key difference in public versus private versus no funding for the receipt of health services; an issue which confronts US citizens. In the US, only citizens who have access to private health insurance or financial resources might benefit from 'best practice OT'. In contrast, while all Australians have access to Commonwealth funded health care, there is variable uptake of services at the end of life. Research completed by Rosenwax and McNamara (2006) demonstrated that access to palliative care continues to be inconsistent, with just 68 per cent of people with cancer and eight per cent of people with non-cancer conditions receiving specialised palliative care. People who require end of life care are not always able to access services in a timely and efficient manner. Many complex variables contribute to this issue including geographical location, marital status, diagnosis (malignant versus non-malignant conditions) and socio-economic status. Inconsistencies in access to care are evident for indigenous Australians, the elderly and people residing in residential aged care facilities (Palliative Care Australia, 2009).

Specifically in WA, but generalisable to much of Australia, referral to specialised palliative care services continues to be problematic. Uncertainties exist around if and when to refer; often creating unnecessary delays and crises. These uncertainties may be related to the

dichotomy of active treatment versus palliation with some relationship to the treating physicians' speciality (oncology versus haematology versus other specialties) (McNamara, Rosenwax, Holman, & Nightingale, 2004). Choices regarding the place of care and preferred place of death may be limited. Dedicated tertiary palliative care services, both public and private, often consist of palliative care beds spread throughout hospitals serviced by a palliative care team. The 'hospice ethos' is limited to several private inpatient facilities which offer palliative care 'wards' with access to specialised services. Community-based, public funded palliative care is delivered predominately in the metropolitan area and larger rural towns by a single organisation but their services, 'hospice at home', are not delivered to people living in residential aged care facilities.

In summary, there is evidence that many of the internationally accepted 'standards' for best practice in specialised palliative care are certainly not being implemented in WA, as with many other locations in Australia. This is a situation which requires urgent exploration and should include looking towards the current standards and practices in other Australian states and internationally as a benchmark with which to base current and future services.

The occupational therapy role in end of life care

The OT role in end of life care is well documented in the international literature. Occupational therapists assist people with life-limiting illnesses through continued participation in meaningful occupations, the employment of specific strategies to reduce pain and other symptoms (e.g. anxiety, depression, breathlessness, fatigue) and adaptation of environmental and occupational factors to improve their quality of life and that of their informal carers/families (Burkhardt et al., 2011).

Recent research conducted in the United Kingdom (UK) and the US highlights opportunities for people who are dying to engage in short term rehabilitation programs aimed at improving functional skills. Occupational Therapists offer a valuable contribution to the team of professionals enabling the dying person to return home following these brief programs. This assists them to achieve the goal of dying at home with loved ones, if preferred as opposed to extended hospital care (Lowrie, 2006; National end of life care programme, 2011). Recent developments signify further opportunities for OTs to demonstrate their unique role in the care of dying people; to date, there is no evidence of this approach being implemented in WA.

Australian researchers have published a number of descriptive studies that outline the potential role for OT in end of life care. Keesing & Rosenwax (2011) confirmed the role that OTs provide for dying people and their carers with opportunities for participation and engagement in occupation regardless of a 'terminal' diagnosis. However, there seems to be differences in the inclusion of OTs as part of the team of professionals providing care for dying people. In the US, OTs appear to have a significant and respected role within the palliative care team as 'direct care providers and consultants' (Burkhardt, et al., 2011). Likewise in Canada, eight to twelve per cent of the OT workforce was working in palliative care in 2005 (Canadian Association of Occupational Therapists, 2005).

In contrast, just 1.6 percent of the OT workforce in Australia was employed in palliative care in 2006 (Australian Institute of Health and Welfare, 2006). Clearly, there are significant differences between these countries with regards to the size and capacity of the OT workforce to provide services in end of life care. The authors propose that in Western Australia, and possibly other Australian settings, there are two potential reasons for this. First, the limited range of care palliative care settings which are primarily hospital based, and second, at the organisational level OTs are not routinely included as essential members of the care team. Keesing, Rosenwax and McNamara (2011) determined that in 2010, just 6.15 full time equivalent (FTE) OTs were employed to work in palliative care settings and these therapists were limited to acute public and private hospitals. When compared with the potential number of people in WA who died from conditions amenable to palliative care over a one year period, this represents a ratio of one OT per 875 people (Keesing & Rosenwax, 2011). Currently, no OTs are employed in the private community hospice or community 'hospice in the home' service. Similarly, limited opportunities for OTs were available to provide palliative care for people living in residential aged care facilities.

Research undertaken by Halkett, Ciccarelli, Keesing and Auon (2010) may offer further explanation as to the barriers preventing OTs from providing services to people who are dying, their families and (unpaid) primary carers. These barriers include an inconsistent understanding by other professionals of the contribution that OTs can make for people with palliative care needs, insufficient promotion of the OT role and inadequate funding to support an OT workforce .

There is also limited evidence of the important role that OT can play in palliative care. Studies conducted by Western Australian researchers determined that referral to OT and other allied health professionals did not occur consistently as part of the usual practices of care for people who were dying (Keesing & Rosenwax, 2011; McNamara & Rosenwax, 2010). Often the referral was to provide assistive equipment or home modifications and for just one occasion of service (Keesing & Rosenwax, 2011). This study also indicated an obvious gap in services. Occupational therapists were not employed as part of the team of health professionals providing services to people who chose to die at home, leaving OTs working in the hospital-based services overwhelmed by the job limitations and dissatisfied with their role.

It is recognised that OTs have a responsibility to add to the evidence base in this practice context, however, very few Australian studies would be considered as ‘high level’ evidence. Further research using well designed and resourced studies will add to the existing evidence about OT practice. Several authors have demonstrated that OT assists in increasing a person’s quality of life during the palliative period (Marcil, 2006; Unruh, Smith, & Scammell, 2000) yet very few large scale studies demonstrate the value of occupational engagement for people who are dying. The Canadian Association of OTs (2011) revised their ‘Position Statement’ to include the promotion of OT at the end of life with a focus on pain and symptom management, the psychosocial aspects of care and the delivery of services in the dying person’s home.

In Australia, the profession is beginning to work towards a more consistent approach in this practice context. This is demonstrated by the recent formation of a group of allied health practitioners, Allied Health in Palliative Care Australia (AHPCA), which seeks to represent OTs as part of a comprehensive effort to raise the profile and contributions of allied health practitioners in end of life care. It is anticipated that a ‘Position Statement’ will be developed by OT clinicians and researchers that will be embraced by the national association- Occupational Therapy Australia Limited (OTAL). Other activities include the establishment of special interest groups for OT in oncology and palliative care operating in Victoria, New South Wales and WA (to date).

Occupational therapists practicing in the variety of care environments will need to demonstrate the value of their services from a cost/benefit viewpoint; can OTs assist to prevent hospital admissions and therefore save valuable financial and personal resources?

Our own recent study supports other existing evidence that OTs also have a potential role with (unpaid) carers of people who are dying, providing them with vital strategies and supports during and after the palliative period (Keesing & Rosenwax, 2011). This emerging role may serve as a further opportunity for OTs to establish and validate their unique contributions as health professionals working in end of life care.

It is estimated that by 2016 the demand for palliative care services will outweigh available services in WA (Department of Health Western Australia, 2008). Consequently, policies, models of service delivery and organisational strategies must be developed so that dying people and their carers are able to receive quality, timely and easily accessible care, including OT, during the palliative period. As Australian OTs and researchers in end of life care, we are determined to bring about change for dying people and their carers. Action is needed to ensure that this change occurs in a strategic and timely manner. We offer the following approaches for consideration. First, ‘champions of change’ within the profession are needed to promote the role of OT in this care setting. Occupational therapists who are passionate about this area of practice must promote and advocate for their role. Education of consumers, families, other health professionals, and the wider community as well as policy developers is needed to improve others’ understanding of the essential contributions made by OTs within the end of life care team. Second, the education of OT students must include knowledge and skills for work in this field such as palliative care content in the curriculum, case based/simulation tasks and fieldwork placements (Meredith, 2010). Educators must ensure the provision of evidence-based material. Third, OTAL can assist with the promotion of the role, via the interest groups, education and resources, and the development of a Position Statement advocating for the value of the profession in end of life care. Finally, it is essential that rigorous research is conducted at the local level to evaluate services. Together, this will enable OTs working in end of life care to review and contribute to the published evidence, while providing quality, cost effective and relevant services to people who are dying, their carers and families.

In summary

This paper raises points of difference between the experiences of OTs working in end of life care in WA and the US, possible reasons for these differences and suggestions to reduce the gaps between the two service delivery contexts. It is anticipated that the publication which prompted this viewpoint will serve as a useful future resource for Australian OTs. A

dedicated, strategic and evidence based approach is required to enable OTs to be recognised as highly skilled professionals who make a real difference to dying people and their carers.

References

- Australian Institute of Health and Welfare. (2006). Occupational therapy labour force 2002-2003, from <http://www.aihw.gov.au/publications/hwl/otlf02-03/otlf02-03.pdf>
- Burkhardt, A., Ivy, M., Kannenberg, K., Low, J., Marc-Aurele, J., & Youngstrom, M. (2011). The role of occupational therapy in end-of-life care. *American Journal of Occupational Therapy*, 65(6), S66- S75.
- Canadian Association of Occupational Therapists. (2005). Occupational therapy and end-of-life care. *Canadian Journal of Occupational Therapy*, 72(2), 121.
- Canadian Association of Occupational Therapists. (2011). CAOT Position Statement: Occupational Therapy and end of life care Retrieved 21 March, 2013, from <http://www.caot.ca/default.asp?pageid=1284>
- Department of Health Western Australia. (2008). *Palliative model of care*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia. Retrieved from http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Palliative_Care_Model_of_Care.pdf.
- Halkett, G., Ciccarelli, M., Keesing, S., & Auon, S. (2010). Occupational therapy in palliative care: Is it underutilised in Western Australia? *Australian Occupational Therapy Journal*, 57(5), 301-309. doi: 10.1111/j.1440-1630.2009.00843x
- Keesing, S., & Rosenwax, L. (2011). Is occupation missing from occupational therapy in palliative care? *Australian Occupational Therapy Journal*, 58(5), 329-336. doi: 10.1111/j.1440-1630.2011.00958.x
- Keesing, S., Rosenwax, L., & McNamara, B. (2011). 'Doubly deprived': A post-death qualitative study of primary carers of people who died in Western Australia. *Health and Social Care in the Community*, 19(6), 636-644. doi: 10.1111/j.1365-2524.2011.01005.x
- Lowrie, D. (2006). Occupational therapy and cancer-related fatigue. In J. Cooper (Ed.), *Occupational therapy in oncology and palliative care* (2nd ed., pp. 61-82). West Sussex: Whurr Publishers.
- Marcil, W. (2006). The hospice nurse and occupational therapist: A marriage of expedience. *Home Health Care Management and Practice*, 19(1), 26-30. doi: 10.1177/1084822306292514

- McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science and Medicine*, 70(7), 1035-1041. doi: 10.1016/j.socscimed.2009.11.029
- McNamara, B., Rosenwax, L., Holman, C., & Nightingale, E. (2004). Who receives specialist palliative care in Western Australia- and who misses out. Perth: The University of Western Australia.
- Meredith, P. (2010). Has undergraduate education prepared occupational therapy students for possible practice in palliative care? *Australian Occupational Therapy Journal*, 57(4), 224-232. doi: 10.1111/j.1440-1630.2009.00836.x
- National end of life care programme. (2011). *The route to success- achieving quality for occupational therapy*. Retrieved from <http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/the-route-to-success-in-end-of-life-care-achieving-quality-for-occupational-therapy.aspx>
- Palliative Care Australia. (2009). EOL- towards quality care at the end of life (Vol. 1). Canberra: Palliative Care Australia.
- Rosenwax, L., & McNamara, B. (2006). Who receives specialist palliative care in Western Australia - and who misses out. *Palliative Medicine*, 20(4), 439-445. doi: 10.1191/0269216306pm1146oa
- Unruh, A., Smith, N., & Scammell, C. (2000). The occupation of gardening in life-threatening illness. *Canadian Journal of Occupational Therapy*, 67(1), 61-69.

(17 references)