

CAOT Position Statement: Occupational therapy and end-of-life care

The Canadian Association of Occupational Therapists (CAOT) believes all people of all ages in Canada have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. To achieve quality end-of-life care for all, Canadians require a collaborative, well-funded and sustainable national strategy for hospice, palliative, and end-of-life care and services from a team of health professionals that includes occupational therapists.

CAOT Initiatives

1. Advocate for involvement of occupational therapists in end-of-life services and planning initiatives to promote quality of life and meaningful participation.
2. As a member of the Quality End-of-Life Care Coalition of Canada (QELCCC), work with and participate in appropriate advocacy initiatives related to end-of-life care strategies or programs.
3. Promote occupational therapy specific and interdisciplinary research studies that expand the knowledge base for end-of-life care in Canada.
4. Facilitate the development of continuing professional education content and material that meet practice needs.

Recommendations for occupational therapists

1. Continue to develop partnerships with relevant organizations and stakeholders to promote access to end-of-life care for the people of Canada that promote quality of life and meaningful occupation.
2. Promote the development of research among stakeholders that will advance best practices in end-of-life care.
3. Engage in continuing professional education to use best practices based on research evidence for quality outcomes in end-of-life care.
4. Promote quality occupational therapy service standards.

Background

End-of-life care aims to relieve suffering and improve the quality of life for persons who are living with or dying from advanced illness or who are bereaved. End-

of-life care is appropriate for any individual of any age and/or family living with or at risk of developing a life-threatening illness due to any diagnosis and with any prognosis (Adapted from Ferris et al., 2002).

Occupational therapists are university educated, regulated health professionals in all ten provinces of Canada. They use evidence-based approaches to enhance the quality of life of individuals and their caregivers by encouraging participation in meaningful occupation and valuable experiences. The values and core attention to spirituality and holistic client-centred practice make occupational therapy a natural fit with the philosophy and approach of end-of-life care. Therefore occupational therapy should be an integral part of an end-of-life care team.

Occupational therapy practice in end-of-life care needs to be consistent with the national guidelines of practice, be evidence-based and contribute to the knowledge base through research and education.

Research findings indicate that occupational therapy in end-of-life home care assists individuals to live safely and comfortably at home, despite decreasing capacity to participate in their occupations of life. Occupational therapy services are effective in preventing injury, controlling pain and carrying out valued activities. Occupational therapists provide education, support and modifications to the environment for individuals and caregivers (Bye, 1998; Dawson & Barker, 1995; MacLeod, 1997; Rahman, 2000; Sykes, Johnson, & Hanks, 1997). Occupational therapists assess client and caregiver needs for assistive technology which can play a major role in enabling people to engage in their occupations of choice and participate fully in their communities. Appropriate use of assistive technology promotes independence and prevents illness and injury (CAOT, 2004).

In June 2004, CAOT held a professional issue forum on occupation and end-of-life care. The purpose of the forum was to shape the future of occupational therapy practice in end-of-life care in Canada. There were approximately 65 participants, comprising of CAOT members and stakeholders, who identified the following issues and action items in the area of end-of-life care:

1. Access to occupational therapy services

According to Pan-Canadian Partnership for Palliative and End-of-Life Care (QELCCC, 2007) 259,000 Canadians

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were expected to die in 2007. By the year 2020, the number of deaths will increase to more than 330,000 per year. Since chronic diseases account for 70% of all deaths, it was predicted that 181,300 Canadians in 2007 and 231,000 by 2020 will need access to hospice palliative care services and programs. They identified that 75% of deaths take place in acute care hospitals and long-term care facilities.

The final report on the Commission of the Future of Health Care in Canada, *Building on Values*, recommends a commitment of \$89.3 million annually to the Canadian health system to address end-of-life care needs (Romanow, 2002).

According to 2007-2008 CAOT membership statistics, occupational therapists work in a wide variety of practice settings including, but not limited to hospitals, home care and independent living facilities.

Occupational therapy services include provision of assistive technology, caregiver support, client education, case management and chronic pain management. End-of-life care can occur in any of the above roles and practice settings.

Considering that each year 180,000 Canadians need end-of-life care (QELCCC, 2007) and it is estimated that 5-15% of Canadians have access to this care, more health service providers, including occupational therapists, are needed to practice in end-of-life care. This is particularly urgent if we consider that each death affects the immediate well-being of an average of five other people, or over one million Canadians (Carstairs, 2000).

2. Professional Education

More research and education is needed to raise the profile for end-of-life care (Dawson & Barker, 1995). Education of students of occupational therapy in the areas of spirituality and issues related to end-of-life care should be addressed in entry-level professional programs (Rose, 1999). Courses or workshops offered by interdisciplinary groups can be beneficial for entry-level occupational therapists (Hillier, Coles, Mountford, Sheldon & Turner, 2001). Consideration should be given to increasing access to professional development in end-of-life care.

3. Research

The personal-professional connection and experiences of working in end-of-life care occupational therapy has

been examined by Prochnau, Liu and Boman (2003). Further research is needed to examine the relationship between these themes and strategies for recruiting and retaining occupational therapists in end-of-life care.

It has been shown that self-rating, as is required for the Canadian Occupational Performance Measure (Law et al, 2005), is difficult to use in end-of-life care (Norris, 1999). Future research is required to identify and describe meaningful methods of assessing occupation, spirituality and other related outcomes in end-of-life care.

Further research in occupational therapy practice and end-of-life care includes effective pain and symptom management, psychosocial aspects of care, and effective methods of delivering services, including home care (Harding & Higginson, 2003; Smeenk, van Haastregt, de Witte, & Crebolder, 1998).

4. Advocacy

CAOT is a member of the QELCCC that is a 30 member organization that advocates for quality end-of-life care for all Canadians. QELCCC calls on the federal government to take a strong leadership role in improving access to palliative and end-of-life care. A significant accomplishment of the QELCCC through its advocacy was changes to the Compassionate Care Benefits resulting in expanded eligibility for the benefit in 2006.

QELCCC advocates for an on-going, well-funded, sustainable national approach to end-of-life care in the 2007 document, *A Pan-Canadian Partnership for Palliative and End-of-Life Care*. The document offers three major recommendations: develop a multi-level, multi-department consultation to steer the construction of a clear action plan; create a broad-based advisory committee to guide the development of new policies; and support continued research to help deepen understanding of end-of-life care issues.

Glossary of Terms

Enabling (verb) – Enablement (noun): Focused on occupation, is the core competency of occupational therapy – what occupational therapists actually do – and draws on an interwoven spectrum of key and related enablement skills, which are value-based, collaborative, attentive to power inequities and diversity, and charged with visions of possibility for individual and/or social change (Townsend & Polatajko, 2007).

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Enabling occupation: Refers to enabling people to choose, organize, and perform those occupations they find useful and meaningful in their environment” (CAOT 1997, 2002, p. 180).

Occupations: Groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture; everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity); the domain of concern and the therapeutic medium of occupational therapy (CAOT, 1997, 2002); a set of activities that is performed with some consistency and regularity; bring structure and are given meaning by individuals and a culture (adapted from Polatajko et al., 2004 and Zimmerman et al., 2006).

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