



Report of the Professional Issues Forum on **Occupational Therapy and End-of-Life Care** Charlottetown, PE CAOT Conference 2004

Introduction

The CAOT Professional Issue Forum on Occupation Therapy and End-of-Life Care was held in Charlottetown June 25, 2004 from 1:30 to 4:30 pm. There were approximately 65 participants in attendance. This number included the speakers and invited representatives of CAOT constituent and stakeholder groups, and other delegates to the CAOT conference.

Objectives of the forum were to:

- Examine and discuss end-of-life or hospice palliative care as an emerging practice area in occupational therapy;
- Hear from a panel of interdisciplinary experts who represent policy development, advocacy, practice, research and education on topics related to end-of-life /hospice palliative care;
- Present a draft of the Canadian Association of Occupational Therapists (CAOT) Position Statement on Hospice Palliative Care for forum participants to comment on;
- Provide an opportunity for forum participants to comment on four initiatives proposed by CAOT to promote quality of life and occupational engagement of clients and caregivers receiving hospice palliative care.

Format

The forum consisted of panel presentations and roundtable discussion. Although a large group discussion was planned, there was only time for participants to walk around and read other groups' flipcharts. The facilitator who highlighted key points for the larger group.

Facilitator

Lili Liu, PhD, OT (C), OTR, Associate Professor, University of Alberta, Faculty of Rehabilitation Medicine, Department of Occupational Therapy

Panelists:

Honorable Senator Sharon Carstairs, Chair of the Subcommittee to Update Of Life and Death of the Standing Senate Committee on Social Affairs, Science and Technology, Minister with Special Responsibility for Palliative Care, Senator for Manitoba and former Leader of the Government in the Senate.

David Morrison, PhD, FRSA, spiritual care provider, PEI Cancer Treatment Centre

Ms. Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association (CHPCA)

Presentations

The following are summaries of presentations by each panelist.

Honorable Senator Sharon Carstairs – “The big picture of End of Life Care in Canada – Canada’s commitments present and future”

- Palliative and end-of-life care defined as services that “provide comfort and dignity for anyone who is in the latter stages of terminal illness”. She emphasized that the care is “not synonymous with death” rather it is about living as best as one could with the time that is left.
- The experience of death is universal and involves the Canadian health care system, therefore “government must be involved”.
- She initiated a Senate subcommittee which generated a report called “Quality End of Life Care: The Right of Every Canadian”. The final report listed 14 recommendations, in 5 areas, for federal government:
 - National strategy on end of life care;
 - Income and job protection for caregivers;
 - Education and training for health care providers; homecare and pharmacare programs;
 - Research and dissemination of findings.
- Health Canada now has a special Secretariat for palliative and end-of-life care which coordinates a national strategy on palliative care
- Federal government created a \$500 M. fund to help provinces develop Telehealth and other technologies to deliver health services at a distance.
- Senator Carstairs helped launch the Canadian Virtual Hospice (www.virtualhospice.ca)
- Since January 2004, Canadians can access Employment Insurance benefits for six weeks in order to care for a dying family member
- Soon, palliative care training will be mandatory in undergraduate medical programs.
- Fewer than 20% of dying Canadians have access to quality end-of-life care.
- We must look at best practices, new ways to support all caregivers, develop a national outline to ensure the same standard of care across the country.

Dr. Lili Liu – “What are the human resources, practice, education, research needs? Where occupational therapy fits into the Big Picture”

- In Enabling Occupation: An Occupational Therapy Perspective (CAOT, 1997) spirituality is illustrated as the core of the occupational performance model. Occupational therapists practice their profession using a client-centred approach and believe in the worth of all persons (CAOT 1997). OT’s view their clients holistically.
- Practice needs: The roles of OT in palliative care include: pain management, comfort and positioning, mobility, energy conservation, relaxation and anxiety management, self-expression, complementary and alternative medicine.
- According to the 2003-04 CAOT Membership Statistics 59.4% of OTs work with older adults. There is a wide range of client population: HIV/AIDS (0.3% of OTs), ALS (1.4), dementia (20.5), multiple sclerosis (6.9), oncology (4.0).
- Practice settings include LTC facilities, homecare, community clinics or agencies, general hospitals, group homes and homes for the aged. OT services in primary settings include advocacy, assistive technology, caregiver support or education, client education, feeding and swallowing, palliative care, stress management and home support.
- Human resource needs: End-of-life care can occur in any of the above roles and practice settings. Yet, with the exception of New Brunswick (12.6%), the proportion of OTs working in palliative care is less than 8% in all other provinces and territories (0% in NWT & NU). Therefore, considering that each year 160,000 Canadians need hospice palliative care (Canadian Hospice Palliative Care Association, 2004), and it is estimated that 5 to 15% of Canadians have access to this care, more health service providers, including occupational therapists are needed to practice in this area. This

is particularly urgent if we consider that each death affects the immediate well being of an average of five other people (or over 1 M Canadians) (CHPCA, 2004) and that due to health restructuring, it is projected by 2046, there will be twice as many people who require homecare compared to 1996 (CHPCA, 2004).

- Education needs: spirituality and issues related to end-of-life care should be addressed in the entry-level programs but is not in most British programs (Rose, 1999). Courses or workshops offered by interdisciplinary groups can be beneficial for entry-level OTs in training (Hillier et al. 2001). Practising OTs can access post-diploma certificate programs (ex. Grant MacEwan College in Edmonton). More such programs offered at a distance via the internet are needed. The literature suggests that professionals spend time examining their personal characteristics prior to and during their work in hospice palliative care. Volunteering with persons receiving hospice palliative care is also suggested as a way to transition into the practice.
- Research needs: More research and education would raise the profile for this area of practice (Dawson & Barker, 1995).
- The personal-professional connection and experiences of working in palliative care occupational therapy has been examined by Prochnau et al. (2003). Further research is needed to examine the relationship between these themes and strategies for recruiting and retaining OTs in hospice palliative care. For example, are continuing education needs and personal support services available to help OTs grow and continue to serve their clients effectively and meaningfully?
- In the area of assessment it has been shown that the concept of self-rating, as is required for the COPM is difficult to use in palliative care practice (Norris, 1999). Future research is required to identify and describe meaningful methods of assessing occupation, spirituality and other related outcomes in hospice palliative care.
- Other research topics that relate to occupational therapy practice include: what are effective pain and symptoms management using complementary medicine strategies (Pan et al., 2000), understanding the psychosocial aspects of palliative care, effective methods of delivering services and palliative care programs (Harding & Higginson, 2003), including home care (Smeenk et al., 1998).
- The Big Picture: The values and core attention to spirituality and holistic, client-centre practice make Occupational therapy a natural fit with the philosophy and approach of hospice palliative care. Therefore, occupational therapy should be an integral part of a Hospice Care Team. OT practice needs to be consistent with the national norms of practice, be evidence-based, contribute to the knowledge base through research and education. Finally, OTs have an important role in advocacy for programs that are accessible (ex. adult hospice day care as an adjunct to home care an inpatient care).

Dr. I. David Morrison – “Spirituality as an essential component of well-being”

- Dr. Morrison cited the definition of Palliative Care according to the World Health Organization’s (2002).
- Spirituality in the context of occupational therapy was described with reference to the Enabling Occupation: An Occupational Therapy Perspective (1997) and Spirituality and Occupational Therapy (McColl, 2003).
- Spiritual care development among health professionals is becoming more important. Palliative issues are most often associated with cancer but can many other illnesses.
- Spiritual care professionals are an integral part of the health care team. They are well-trained and respect religious differences. There is evidence to show that spiritual care reduces need for pain medication, shortens hospital stays, ease conflict situations, bridges gap between hospital and rest of one’s life, and makes people healthier.

- Symptoms of spiritual distress include fear, depression, anger, loneliness, guilt, among many others.
- Quality of life – “the recognition that healing never ends can make a person’s life whole”. It is personal and relative. Dr. Morrison gave the example of a dying friend who was excited to learn “his life expectancy might be a bit longer”.
- Spiritual assessments exist, but applying them in palliative care needs careful thought. Health professionals need to be aware of their comfort in addressing end-of-life issues with their clients.
- There is a gap in the research literature on spiritual issues and the effect of spirituality-based interventions.

Ms. Sharon Baxter – “Where does advocacy fit in the Big Picture: Call to action. How do we work together?”

- Participants were provided with copies of “A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice” (Canadian Hospice Palliative Care Association, March 2002). Additional copies can be obtained at <http://www.cPCA.net>.
- Ms. Baxter presented the facts related to the growing demand for hospice palliative care in Canada, access to this care, training, research, roles of informal caregivers and home care as well details on funding for hospice palliative care programs and research. The content of this presentation that relate to the facts of the CHPCA can be found on the three page Fact Sheet Hospice Palliative Care in Canada http://www.manitobahospice.mb.ca/Factsheet_HospicePalliativeCareinCanada_Feb2004_EN.pdf
- She emphasized the need for collaboration between the disciplines in promoting public awareness and in following the national principles and norms of practice.
- The Quality End-of-Life Care Coalition is an advocacy model represented by “diverse groups coming together on a common issue”.

Roundtable Discussions

CAOT proposed four initiatives, followed by questions for participants to address in roundtables:

1. Monitor government initiatives that impact upon the right of all people to access quality inter-professional hospice palliative care services.

- What can occupational therapy do to monitor government initiatives? What do we do with the information? Who else needs to be involved?

2. Facilitate research and identify best practices to inform policy.

- What resources are needed to achieve this initiative?

3. Support members in their practice through continuing professional education.

- What content areas are needed? Who else needs to be involved?

4. Facilitate the development and implement a strategy to advocate for legislative, policy and programmatic changes that support quality inter-professional hospice palliative care services.

- Who needs to be involved in developing an advocacy strategy?

Summary of Discussion

The participants believed that CAOT should be involved in advocacy for clients and families receiving hospice palliative care. There were no specific comments about the wording of the draft position statement, however, there was an agreement that the development and circulation of a CAOT position statement on hospice palliative care is necessary and supported. Participants highlighted the importance of being aware of contributions of other disciplines in this area of practice. There is a need for education and awareness by occupational therapists for occupational therapists. The definitions and terms of palliative care, end-of-life care and hospice palliative care need to be examined as participants believed that the terms may have an impact on services and research. Funding was identified as an issue for services and research. Finally, there should be ongoing education about how to deal with sensitive issues.

The following notes were submitted by the six roundtable discussion groups. They correspond to the four sets of questions that participants addressed in their during roundtable discussion. For accuracy, an attempt was made to preserve the original wording.

1. Participants encouraged the professional association (CAOT) to be involved in advocacy groups, to promote continuing education and awareness by occupational therapists, to develop and share the position statement on hospice palliative care and to sponsor attendance by occupational therapists at international conferences on death and dying in Montreal September 2004. The information should be used by lobbying, to form links with other disciplines and organizations, to educate others about the role of occupational therapy and to increase awareness on all levels. Other groups that need to be involved are consumers, researchers (especially occupational therapists) and health consumers.

2. Resources needed to facilitate research are researchers who are willing and able to perform research, time and funding. In terms of strategies, it was suggested that a link be made to academic research that is being undertaken. Other approaches were:

- Form strategic partnerships (ex. With Multi-cultural, academic, industry, and religious organizations)
- Links with government, universities, NGO's, charities
- Identify possible funding partners and sources
- In terms of best practice, it was noted that an extended health benefits are needed for care providers
- Form mechanisms to share current research, for example, virtual linking, looking internationally

Suggested research topics

- What are the roles of occupational therapy in hospice palliative care?
- What are clinicians actually doing?
- What is the roles of occupation in end-of-life care?
- What is the advocating role of occupational therapy in providing end-of-life care?
- What are the end-of-life care issues in pediatrics versus other age groups?

3. Participants identified access to continuing education as important. The sources for this education included colleges, distance learning/internet, support network and interest groups. It is necessary to involve individuals who can articulate the occupational therapy perspective and model in relation to end-of-life issues. Content should include dealing with sensitive issues such as inter-personal dynamics and rapid changes that occur at the end of life. Education could also focus on interview skills, the process of life and dying, cultural beliefs and practices, medication and side-effects, assessment tools specific to end-of-life. Participants also considered it important for occupational therapists to understand what policy makers think are important (perhaps so that they could be better equipped to advocate on behalf of their clients and families).

4. Provincial occupational therapy associations and societies need to be involved in developing an advocacy strategy. Smaller provinces require support from the national association to help them advocate for the need for occupational therapy services within palliative care. Participants suggested that the definition of palliative versus end-of-life be examined in terms of constraints on services and support clients can receive. The Quality End-Of-Life Coalition (CHPCA) should have the involvement of occupational therapists. An advocacy strategy should involve taking information to the clients and occupational therapy practice community and should consider services provided in all areas of the provinces, i.e. rural and urban sites. Such a strategy should address speed and timing of services (wait lists) that clients and their families face.

Important Issues and Considerations for CAOT

1. A CAOT position statement on hospice palliative care should be used as a communication tool with other disciplines, policy makers, funders and advocates of programs.
2. CAOT could liaise or partner with the Quality End-of-Life Care Coalition and participate in appropriate advocacy roles related to end-of-life care strategy or programs.
3. There is a gap between educational needs and practice needs. CAOT could facilitate the development of education content and material that meet practice needs. This would help service providers delineate the scope of practice in hospice palliative care.
4. Research is needed among all disciplines in the area of hospice palliative care. CAOT could facilitate OT-specific and interdisciplinary research studies that expand the knowledge base for hospice palliative care in Canada.

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