

# Reflections on services for people in palliative or end-of-life care

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In line with the Quality End-of-Life Care Coalition of Canada (2012), “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” (CAOT, 2011, para.1). This excerpt from the CAOT position statement on occupational therapy and end-of-life care got us thinking. Our experience as therapists and researchers in palliative care showed us this right was often jeopardized. We decided to look at each component of this fundamental statement in order to gain a better grasp of what it means. The objective of this paper is to share reflections about the main constructs of the opening statement of CAOT’s position statement. It is written to provide readers with ‘food for thought’ about palliative care.

## People of all ages

As Coquet (2010, p. 7) aptly stated, “while we may not all be equal by birth, we are made brothers and sisters by the physical death that we will all experience sooner or later.” Age is not a protective factor when it comes to death; even newborn babies die. Our experience shows that the older a person is, the more normal his or her death seems and therefore the easier it can be accepted. As a result, there is potential that end-of-life processes might become trivialized for the elderly and consequently they may not receive the support they need (Durivage, Hébert, & Nour, 2012). It is important that occupational therapists, when assessing the occupational needs of clients of any age in the end stages of life, have the courage to directly broach the subject of death, are attentive to their clients’ verbal and non-verbal cues, and are able to cope with the silences that sometimes arise during such discussions.

## Quality end-of-life care

What do we mean by ‘quality care’? What exactly does it look like? Who decides what constitutes ‘quality’?

Whereas assessing the quality of services can be seen as the purview of managers and clinicians, who are deemed experts in the matter, it is now generally accepted that clients’ views are an important part of the evaluation process. The quality of services is then determined, on one hand, by clients’ expectations and, on the other hand, by administrative and professional standards and good practices (Institut de la statistique du Québec, 2010). We encourage occupational

therapists to find out about their clients’ expectations and end-of-life preferences, not only at the outset of the therapeutic relationship but throughout its course. It is not enough, however, merely to know what those preferences are; it is also crucial to gear services towards meeting these preferences and continually reflect on one’s professional standards and practices regarding quality end-of-life care. Checking regularly that practices are evidence-based will help ensure or improve the delivery of quality occupational therapy services. While further research on occupational therapy care at end of life is needed to strengthen the theory base, literature is available (in occupational therapy and in other disciplines) that may guide therapists on the quality of their practices.

As the Quebec Ministry of Health and Social Services (2010) underlines, quality of services – a very broad concept that covers many realities – must be present at each stage of the process (assessment, service delivery, follow-up, and so on). In this document, enhancement of quality refers primarily to the quality of services provided directly to clients and to their friends and family. It means engaging in sympathetic communication and taking the correct action to alleviate the physical and mental suffering of clients and their loved ones, as appropriate, and to promote quality of life.

‘Quality of life’ is rooted in the notion of ‘happiness,’ which has been interpreted in various ways across time and in different contexts. It has been seen as a natural right, a private good or as a matter of social efficacy. Today, happiness is seen as a form of personal goal; something that individuals must achieve for themselves. Quality of life



Illustration by Jo-Anne Dupéré.

comprises several dimensions (e.g., spiritual, physical, social and emotional well-being), and has meaning only in context (Schalock & Siperstein, 1997). With their holistic vision, occupational therapists are trained to pay attention to all of these dimensions in order to contribute, as much as possible, to maintaining or improving clients' quality of life. They do this on the basis of theoretical models such as the Model of Human Occupation (MOHO) and the Canadian Model of Occupational Performance and Engagement (CMOP-E), or by drawing on components from a variety of conceptual frameworks while also being guided by the intention and desire to instil a sense of well-being in others.

If we draw a parallel between quality of life and quality of services, does that mean that a quality service is a socially effective service – one that people are entitled to receive, that contributes to their personal development and that makes them happy? If we accept this meaning, then 'quality,' as a crucial aspect of service delivery, will make a difference in the lives of people who have only months or weeks to live. Aiming to provide quality end-of-life care, the occupational therapist can offer a quality presence as a therapeutic tool; this involves respect, empathy, cultural and self awareness, listening, reflective silence, identification of feelings (Page, 2008) and compassion. The quality of occupational therapy care is guided by the goal to improve the quality of the client's life.

### To die with dignity

Dignity, from the Latin word, *dignitas*, means pride and self-respect (Rey, Rey-Debove, & Robert, 2010). The Quebec Commission on Ethics of Science and Technology (2010) draws a distinction between subjective dignity and objective dignity. Objective dignity invokes the sacred nature of human beings. The mere fact that we are human beings gives all people dignity. The concept of subjective dignity, on the other hand, is related to the notion of autonomy, where helping clients 'die with dignity' means showing respect for the individual's chosen treatment and manner of death. This meaning raises questions about euthanasia and aggressive treatment. These two distinct circumstances arouse ethical concerns that have to be approached according to jurisdictional laws and the people involved. We believe, after the fashion of De Hennezel (2010), that euthanasia and aggressive treatment are undesirable. Dying with dignity can mean that the individual dies in the best possible conditions – conditions that are based on what the client values, together with the necessary support he or she deserves by nature of

being human. The person-centred approach that occupational therapists value and aim to implement in practice can be understood as centering on the *value* of the individual. For example, if the client refuses hygiene care because he is in pain and wants to run the risk of contracting an infection that could speed his death, the occupational therapist, for whom the dignity of the person is paramount, will try, in collaboration with the team, to find therapeutic measures to ease his discomfort, which may in turn relieve the client's wish for death. Occupational therapists offer palliative clientele a unique therapeutic standpoint that aims to enhance the client's sense of dignity through occupational participation and adaptation of the environment.

### Without pain

Viewed from a broad perspective, the terms pain and suffering might appear to be interchangeable. According to Loeser (2000), pain is something physical, whereas suffering is emotional or mental. Furthermore, Block (2001) views suffering as the opposite of quality of life. Caregivers and health-care professionals, including occupational therapists, should seek ways to assist the client to live through his or her end-of-life experience without pain, whether it be physical or emotional. To achieve these goals, in a context of interdisciplinary cooperation, occupational therapists may use a range of therapeutic methods that are meaningful to the person at the end of life. In some cases, this may mean simply promoting the fulfillment of the client's wishes. For example, an occupational therapist asked Mr. Abbott, "What would you like to experience now?" He replied, "I would like to be able to speak to my children. I feel bad about what I did when they were young. I think that's why they didn't come and see me more than twice a year and never stayed long. There are things I want to say to them but I don't feel able to do it." After a consultation with the client and the team, it was agreed that the occupational therapist would help Mr. Abbott write to his children and the social worker would arrange a family meeting. The 86-year-old man died in peace.

### Surrounded by their loved ones, in a setting of their choice

For some clients, their 'near and dear' are far away. Family members or friends may be unable to be present for a broad range of reasons (geography, personal illness, relational tensions, etc.). A person who is unable to receive support from his loved ones may see his wish to die at home compromised.

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The human and financial resources of the Canadian health-care system are far from sufficient to ensure ongoing home care for socially isolated individuals (Falardeau, Arpin, & Lambert, 2012). Many Canadians do not have the resources to hire private care workers to meet their end-of-life needs. Often, such a person will die outside the home, in a hospital, either in a regular ward or in palliative care, in a nursing home or in a hospice. The most recent statistics show that 67% of Canadians died in hospital (Statistics Canada, 2007).

The potential to die at home, in familiar spaces surrounded by one's own things, is greater when loved ones are present on a daily basis and agree to act as caregivers. According to the Institut national de santé publique du Québec (2006), only 8% of adults aged 20 and over who were able to receive palliative end-of-life care died at home. It is important to support caregivers who provide most of the home care (Health Canada, 2005). We propose that occupational therapists consider family caregivers not only as caregivers but also as part of their clientele, as recipients of care. Doing so would help support the caregiving experience, and potentially help address issues such as caregiver burnout. In acknowledging the physical and emotional demands made on caregivers, practitioners could then tailor their interventions to also meet the occupational needs of the family members and other caregivers. It would be important, in that case, to inform decision-makers (other stakeholders, managers and politicians) of the role played by occupational therapists in this respect. By providing more support for end-of-life caregivers, there is potential that more clients would be able to live their final days and months in their home environment, if desired, and in the company of loved ones.

## Conclusion

The purpose of end-of-life care is to alleviate pain and suffering, maintain or improve safety, provide comfort, prevent injuries, and enhance quality of life by encouraging people to participate in meaningful occupations and rewarding experiences (CAOT, 2011). We propose that occupational therapy services for clients in palliative or terminal care be centred on the client's needs and values and on an understanding of all the factors, both internal (such as emotions and beliefs) and external (such as family members and the caregiving team), that may have an impact on the client's quality of life.

We encourage occupational therapists to actively listen to the needs of palliative clients of all ages and to their loved ones. In order to recognise and respect the dignity of the client, and optimize his or her quality of life in the final stages, it is important that therapists help enable the client to engage in occupations that enhance feelings of autonomy and personhood. We hope that clients are able to die in the environment of their choice, without pain or suffering, surrounded by their loved ones. With this end in view, we invite occupational therapists to also reflect on the constructs in the CAOT's end-of-life mandate, with the hope of improving the quality of practice and the quality of the end-of-life experience.

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