Report on the CAOT Professional Issue Forum
"Palliative & End-of-Life Care: Holding Space for Dying in the Face of Living"
CAOT 2021 Virtual Conference

Professional Issue Forums (PIFs) are held annually at the Canadian Association of Occupational Therapists' (CAOT) Conferences. PIFs address priority health and social issues, and emerging practice areas in occupational therapy. PIFs involve presentations from a panel of experts and participants are invited to contribute their perspectives. Discussions lead to strategies and recommendations for action by: CAOT, occupational therapists and stakeholders to advance occupational therapy practice, research and education.

The PIF on palliative and end-of-life care took place virtually on May 19, 2021, and was attended by 57 delegates. Key messages included the importance of the engagement of all occupational therapists in bringing the palliative approach to care (Quality End of Life Care Coalition of Canada, 2013) into their practice by including the elements of dying, suffering, loss, and bereavement.

INTRODUCTION

The occupational therapy role in palliative care enables individuals to connect to the meaning in valued occupations, a role that is central to the occupation-based palliative care model (Essential Yeh & McColl, 2019). Much of the discussion held at the PIF involved elements of that model. It frames valued and meaningful occupations within the concepts of doing, being, becoming, and belonging, which occupational therapists may integrate into their roles when using a palliative approach to care. It also allows for occupations to occur in context of affirming life, as one prepares for death in a safe and supportive environment.

This forum modeled interprofessional collaboration for learning together and discovering the essence of the palliative approach to care, which includes special attention to grief and bereavement.

The presenters brought to the PIF a conversation to enable Canadian Association of Occupational Therapists (CAOT) members and conference delegates to experience first-hand the flow of Wilcock's (1999) work on "Doing, Being and Becoming," found in the occupation-based palliative care model, with the additional concept of "Belonging." By balancing theory with experience, presentation, and breakout group discussions, the PIF created an encounter that enabled the participants to integrate the meaning of spirituality and its influence on the opportunities for occupational therapists to play a significant role in the practice of palliative and bereavement care.

OBJECTIVES

This PIF aimed to build on the theoretical foundations of occupational therapy to equip OTs to confidently use a palliative approach to care continuum in all settings.

Specifically, this PIF strived to:

- Raise the awareness of palliative and end of life issues, including bereavement, and expand the possibilities for OTs in their own practice;
- Discuss how a palliative approach to care is both feasible and valuable;
- Explore how OTs can assist clients to find meaning through occupational engagement that can transform end-of-life experiences; and
- Explore further advocacy to establish occupational therapy within palliative care services across Canada.

PRESENTERS

Julie Wilding, OT Reg. (Ont.), is a PhD student researching palliative care and currently practicing with a palliative approach in outpatient rehabilitation. Julie is also chair of the CAOT Palliative Care and End-of-Life Practice Network, CAOT representative on the Quality End-of-Life Care Coalition of Canada, and a soul midwife.

Catherine Dirks, OT Reg. (Ont.), has practiced as an occupational therapist for over 30 years in acute care, and the last 11 years in cancer and palliative care. Catherine is a founding member the Palliative Care and End-of-Life Practice Network.

Peter Barnes, BSc, M.Div, DMin, CCC, SEP, is a psychospiritual therapist, supervisor educator in clinical pastoral education, and spiritual care practitioner. Peter has worked in mental health and palliative care, specializing in grief and bereavement. He is a member of the Education Committee of the Quality End-of-Life Care Coalition of Canada and has a part-time private practice in spiritual guidance and psychospiritual therapy.

A copy of the panelists' presentation can be found here.

ROUNDTABLE DISCUSSION

The three breakout discussions, held in the same small groups, posed the following questions, of which the main discussion points were summarized:

Think about a time when you encountered a difficult change, grief, suffering, or bereavement. What questions do you have about how this experience impacts a person's daily life or the practice of occupational therapy?

The attendees, in sharing their experiences, began to recognize that they are positioned to provide a palliative approach to care, as there is meaningful occupation in assisting the dying and their families. However, being with suffering is challenging. Occupational therapists, although positioned to address a person's suffering, continue to be limited by organizational barriers, existing cultural norms in health care systems, and their own vulnerability. The focus is often on a person's health condition, therefore, their individuality, personality, and humanity go unrecognized. It is common for health care practitioners who are not prepared for these situations, including occupational therapists, to have their own task-focused agenda. Unfortunately, this does not go unrecognized by clients and families, and adds to their suffering. The fluid nature of practice in palliative situations (i.e., the quickly changing needs of these individuals) compounds the challenges. Issues involving accessibility to palliative care services and the need for upstream intervention were identified. Concern was expressed that the

systemic neglect of facing the realities of decline and death often prevents clients and families from preparing for death and focusing on what is important to them to allow for a healthy grieving process.

What are some possible ways for you to bring spirituality into your client-centred practice?
In occupational therapy, spirituality is centred on what is meaningful to the client. Barriers to weaving spirituality into occupational therapy practice were identified despite our current occupational therapy model, the Canadian Model of Occupational Performance and Engagement, having spirituality at its core (Townsend & Polatajko, 2007). Occupational therapists continue to struggle to conceptualize and operationalize spirituality in practice. It is perceived that there is no time or space for spirituality, and some health authorities have cut funding for spiritual care services. This leaves our clients alone to create a spiritual space for themselves. Attendees identified enablers to support dying as a meaningful occupation, including education, therapeutic use of self, and the integration of spiritual leaders into health care settings. Opening space for conversations is needed to understand how clients think and feel about spirituality. The importance of connection and entering the relationship to learn from a client was recognized. Attendees also noted that, when practitioners empower clients by allowing them the space to guide the way, they create opportunities to discover what they find most important.

To what degree do others experience you, an occupational therapist, as a healing presence for those declining, dying, grieving, or bereaved? How have you assisted clients to find meaning, and what else can you do to integrate a palliative approach into your practice?
Occupational therapists are positioned to create a culture shift in palliative care, to support people to understand death culture and find the positives in the experience of death. Client centeredness, although hard in the current model of medicine, continues to be possible when we shift from being just an occupational therapist to a person with whom clients can talk and connect. Needs were identified in advocacy, funding, and increasing awareness of the role of occupational therapy in palliative care—awareness both among ourselves and interprofessional colleagues. Occupational therapy practices bring possibilities for engagement in meaningful occupation, connecting those who are experiencing dying to their values, interests, culture, meaning, and joy. Occupational therapists can use a palliative approach for any loss of the client, whether it is a spinal cord injury, stroke, or end of life. Establishing relationships through connection and meaning fosters an acceptance of losses along the illness trajectory. As occupational therapists, we also need to care for ourselves in this process, to enable the healthy creation of a spiritual space with clients that also benefits us.

In summary, it was evident from the national conversation that very few occupational therapists self-identify as working in palliative care. However, as the conversations flowed, most attendees began to relate to the reality of being positioned in their varied occupational therapy roles to provide a palliative approach to care. This demonstrates not only a dedication to have a discourse on palliative care, but also a willingness to broaden our thinking and to step into these palliative care roles. Having a clear definition of the palliative approach helped foster the discussion, in identifying clients who would benefit and by bringing awareness of the current state of palliative care nationally to see where occupational therapists fit in. Important themes underpinning the conversations included grief, suffering, bereavement, and spirituality—all bringing potential for transformation, and all vital components of a palliative approach to care.

NEXT STEPS

Moving forward, here are some ways we can consider how aspects of Wilcock's framework within the occupational-based palliative care model (Essential Yeh & McColl, 2019) can begin to develop our

thinking and establish our unique professional profile amongst other disciplines who provide a palliative approach to care:

"Doing" refers to occupation and occupational performance, and how we interact with others to develop our own identity and to shape society.

- Use reflections of our own life experiences and clinical practice

"Being" refers to being true to ourselves and to our nature, and requires us to think about and reflect on our roles.

- Learn more about therapeutic use of self, including healing presence, authenticity and giving space for transformation
- Engage in the full scope of our occupational therapy roles
- Prioritize our own self-care to enable care for another

"Becoming" refers to a sense of future and potential for developing the person we are going to be.

- Advocate for funding to engage in the full scope of our role

"Belonging" refers to sharing values with others to establish in our communities.

- Join CAOT Palliative and End-of-Life Care Practice Network
- Continue and develop the conversation and actions within the CAOT Palliative and End-of-Life Care Practice Network
- Continue the discussion of our shared professional values with other professions to create collaborative interprofessional education and advocacy opportunities
- Embody the CAOT Position Statement: Occupational therapy and end-of-life care

Each of these elements challenges us to continue the conversation and reflect on how occupational therapists can transform palliative care. Death and dying occupations require us to be fully human: having this relational journey with our clients and their families holds the potential to transform their occupational experience of dying to create not just meaning for them, but also for us.

CONCLUSION

This PIF was a step towards an openness to embracing the universality of spiritual care related to the palliative approach to care, including grief and bereavement within occupational therapy practice. The attendees seemed to have grasped the intended message, as is evident in the summaries of the breakout group discussions. This understanding provides the desired reassurance that occupational therapists need to trust in themselves and believe that they have a vital role to play in the delivery of palliative and bereavement care. While occupational therapy in palliative care requires a willingness to learn from others on the interprofessional team and from clients and families, it also requires all stakeholders to recognize the valuable contribution that is made by occupational therapists in the delivery of a palliative approach to care.

ACKNOWLEDGEMENTS

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