

The intentional pursuit of everyday life while dying: A longitudinal study of working-aged adults living with advanced cancer

Julie Brose BScOT(Hons), MIPH, MA, PhD Candidate

Supervisors: Dr. Deidre Morgan and Emeritus Professor Eileen Willis

Until something happens that challenges how we live our lives, such as an advanced cancer diagnosis, everyday life is often taken for granted. Advanced cancer results in constant change and loss, and what follows is often feelings of uncertainty and a loss of control. The incidence of cancer is increasing, and people are living longer with advanced cancer, so addressing challenges to everyday life at end-of-life is crucial (Langbaum & Smith, 2019). The medical system often prioritises symptom management: however, it is important to not lose sight of why symptoms need to be managed (Canadian Hospice Palliative Care Association, 2015). Symptoms are managed *in order to* facilitate continued engagement in everyday life (Morgan et al., 2017). Occupational therapists refer to this as meaningful occupational engagement, describing occupation as everything that occupies a person's time. People living with advanced cancer want to be able to continue doing activities that are important to them (Morgan et al., 2017; Svidén et al., 2010; von Post & Wagman, 2017; Vrkljan & Miller-Polgar, 2001). Unfortunately, people living with advanced cancer are not consistently afforded the opportunity to adapt to changes arising from disease progression, negatively impacting their experience at the end of life. This is demonstrated in how people define intolerable suffering when choosing medical assistance in dying. According to the 2020 *First Annual Report on Medical Assistance in Dying in Canada*, the top two reasons people experience "intolerable suffering" are self-reported as "loss of ability to engage in meaningful life activities" (i.e. occupational engagement) and "loss of ability to perform activities of daily living" (Health Canada, 2020, p. 32). Despite the need, limited research has been conducted on the experience of occupational engagement and how this changes over time for working-aged adults living with advanced cancer.

My PhD research studied the lived experience of occupational engagement for working-aged adults living with advanced cancer. This longitudinal study followed participants as their disease progressed, exploring what everyday life looked like. It included their habits, roles, relationships, values, and interests within the context of their abilities and environment (Taylor, 2017). Participants in the study wanted to continue to engage in everyday life activities as long as possible in the midst of bodily deterioration and functional decline. They wanted to continue engaging everyday activities, as it helped maintain a sense of control, competence, and identity despite cancer progression. Activities related to meaningful relationships become increasingly significant, such as making dinner for their family or meeting a friend for coffee. Participants were able to adapt to constant change and uncertainty due to disease progression through continuing to do that which was important to them.

A multidisciplinary approach to palliative care is crucial. Occupational therapists are uniquely able to address the priorities of people at the end of life by facilitating continued engagement in

everyday activities. Assisting others to adapt to functional decline can significantly impact their sense of self, fostering meaning at the end of life (Hammill et al., 2019; Morgan et al., 2017).

Full findings will be available at a later date as formal publications. Watch out on Twitter (follow @RePaDD1 and @JulieBroseOT) and the Australian Allied Health in Palliative Care (@AAHPC_) for notification updates of publication.

References

- Canadian Hospice Palliative Care Association. (2015). *The Way Forward National Framework: A roadmap for an integrated palliative approach to care*.
<http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf>
- Hammill, K., Bye, R., & Cook, C. (2019). Occupational engagement of people living with a life-limiting illness: Occupational therapists' perceptions. *Australian Occupational Therapy Journal*, 66(2), 145-153. <https://onlinelibrary.wiley.com/doi/abs/10.1111/1440-1630.12557>
- Health Canada. (2020). *First annual report on medical assistance in dying in Canada 2019*.
<https://www.canada.ca/en/health-canada/services/medical-assistance-dying-annual-report-2019.html>
- Langbaum, T., & Smith, T. J. (2019). Time to study metastatic-cancer survivorship. *The New England journal of medicine*, 380(14), 1300-1302.
- Morgan, D. D., Currow, D. C., Denehy, L., & Aranda, S. A. (2017). Living actively in the face of impending death: Constantly adjusting to bodily decline at the end-of-life. *BMJ Supportive & Palliative Care*(7), 179-188.
- Svidén, G. A., Tham, K., & Borell, L. (2010). Involvement in everyday life for people with a life threatening illness. *Palliative & Supportive Care*, 8(3), 345.
- Taylor, R. R. (Ed.). (2017). *Kielhofner's Model of Human Occupation: Theory and application* (5th ed.). Wolters Kluwer.
- von Post, H., & Wagman, P. (2017). What is important to patients in palliative care? A scoping review of the patient's perspective. *Scandinavian Journal of Occupational Therapy*, 1-8.
- Vrkljan, B., & Miller-Polgar, J. (2001). Meaning of occupational engagement in life-threatening illness: A qualitative pilot project. *Canadian Journal of Occupational Therapy*, 68(4), 237-246.