

Living well, and dying well, with schizophrenia

February 22 2023, by Gillian Rutherford



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A University of Alberta nursing researcher is working to change the way people with schizophrenia and other chronic mental health conditions in Canada are cared for at the end of their lives.

One in five Canadians experiences a [mental health issue](#) in their lifetime and yet there is little focus on these conditions in palliative care, according to new research from Tanya Park, associate professor in the Faculty of Nursing.

"If you have schizophrenia (or any other chronic [mental health](#) condition), it carries with you your whole life, and it really just struck me that at the end of your life, this thing that has dominated your life is now just dismissed," Park says. "Once you go to palliative care, the focus switches to whatever you are there for."

For the study, Park interviewed [mental health professionals](#) about how palliative care might help their patients, building on a previous study on palliative care professionals' knowledge of mental health. She discovered that the two groups know little about each other's area of expertise. The paper is published in the *Journal of Palliative Care*.

Park is now testing an online cross-disciplinary educational tool to teach palliative care professionals more about mental health. Her ultimate research goal is to develop and test a new model of palliative care for patients with chronic mental health conditions.

Learning from lived experience

Park co-developed the teaching tool with Lauren Kennedy West, who runs the Living Well With Schizophrenia YouTube channel, which has 191,000 followers from around the world. Both health care workers will learn more about the condition from people with the diagnosis.

Park notes that people living with chronic mental health conditions have a higher risk for conditions such as cancer, [cardiovascular disease](#), [metabolic syndrome](#), diabetes, obesity and smoking-related lung

diseases.

"People with a [mental illness](#) continue to be marginalized, and not cared for, a failing of the health system and the health care workers who 'care' for others," she says.

For the most recent study, Park carried out in-depth interviews with 16 mental health professionals, including 12 registered nurses, two registered psychiatric nurses, a [social worker](#) and a psychologist, from a variety of care settings including inpatient, emergency, [intensive care](#) and geriatrics. She found the quality of end-of-life care they could provide was limited by the complexity of the patients' needs, patients' social isolation, limited collaboration with health care professionals from other disciplines, and misconceptions about palliative care.

In the earlier paper, 20 end-of-life care professionals were interviewed. Again, Park found that disciplinary silos and a lack of training about mental health care prevented them from providing adequate palliative care to patients with chronic mental health conditions.

Redefining care

The next phase of Park's research seeks to reimagine what caring could mean for people with chronic mental health conditions at the end of their lives. Thanks to a Social Sciences and Humanities Research Council Insight Development Grant, Park is teaming up with co-investigator Tim Barlott, occupational therapist and assistant professor in the Faculty of Rehabilitation Medicine. Park is also a member of the Women and Children's Health Research Institute.

Using a technique called "collective narrative," they will bring together small groups made up of someone living with a chronic mental illness, a nurse working in [palliative care](#) and a research assistant with lived

experience of mental illness. This storytelling approach acknowledges that care is relational and goes both ways in the nurse-patient relationship.

"Through collective narrative, we aim to help palliative health-care practitioners think differently about care and to change the experience of care for people with schizophrenia in their dying," Park says.

More information: Tanya Park et al, Mental Healthcare Providers Understanding and Experiences of Palliative Care: A Qualitative Analysis, *Journal of Palliative Care* (2022). [DOI: 10.1177/08258597221134865](https://doi.org/10.1177/08258597221134865)

Provided by University of Alberta

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