

Local News

Strengthening communities of care for people living with dementia

Making the decision that a person needs to enter a long-term care home is emotionally difficult for individuals and families.

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University of Saskatchewan PhD student Mariana dos Santos Ribeiro hopes to find the best way to strengthen community support systems for a better quality of life for persons living with dementia and their families. Supplied photo

Living with dementia or being a caregiver for someone with dementia can be a daunting experience for all involved. University of Saskatchewan PhD student Mariana dos Santos Ribeiro hopes to find the best way to strengthen community support systems for a better quality of life.

Making the decision that a person needs to enter a long-term care home is emotionally difficult for individuals and families. Often, the choice is made when care and support needs can't be met in the home and community.

Ribeiro, a graduate student in the U of S College of Nursing and a researcher within the BetterLTC research team, has first-hand experience with the challenges of living with dementia and being a caregiver.

When Ribeiro was 11, her grandparents came to live in the house next door to her family's in Brazil. Her mother became the primary caregiver for her grandfather, who lived with blindness, and her grandmother, who lived with dementia for more than a decade.

"I have learned from a young age what it means to care for older adults with special care needs and persons living with dementia," Ribeiro said. "I have recognized both the joys and challenges of caregiving."

After becoming a community nurse and moving to Saskatchewan in 2021, Ribeiro began volunteering at the Crossmount Memory Café, a social and recreational support group designed for people living with dementia and their families. The stories and experiences she learned about on the job became crucial to her research interest.

"We are unprepared, individually and as a society, to care for persons living with dementia," Ribeiro said. "It is critical that we, as members of the community of Saskatchewan, know how to be a kind and supportive presence to persons living with dementia and their families."

Ribeiro is developing a research project examining how caregiver supports can be enhanced within one's own community, reducing the resource burden and extending the time a person living with dementia may be able to stay in their home community.

She said hearing from and working directly with people in communities — including health-care experts, people living with dementia, and caregivers — is integral to developing community care approaches that work and are sustainable for people who need them.

"Understanding that community care is also part of the health-care system, that investments in this area diminish expenditures, is necessary for

strengthening care that is responsive to the wishes of people living with dementia and their families,” she said.

How does one begin to examine the types of community supports that are needed? Ribeiro said telling stories and listening to them is the most important part of her work. She will begin listening to the stories of families affected by dementia as the first part of her research data collection. The project will be supervised by Dr. Roslyn M. Compton (PhD), an associate professor in the College of Nursing.

Ribeiro will explore how people living with dementia feel in their communities, what kind of support they feel they receive, and what improvements may be necessary to address gaps. The conversations will include sharing memories through photographs, other objects, and activities that have meaning to the study participants.

The goal is to change the way communities engage with people living with dementia, and to use their stories to inspire social change and create new policies that support this outcome.

The BetterLTC research team says it plans to attend to the stories and experiences shared by people living with dementia and their families to co-identify gaps and strengths to bring a change in culture and policy that builds “strong age and ability-friendly communities in Saskatchewan.”

“As a child, I wanted to change the world with big hopes,” Ribeiro said. “Later, I got into a more introspective phase, reflecting on how I could change myself to be a better person and nurse. Now, I understand I can be a catalyst for change within communities and health-care systems.”

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