

Quality palliative care for people living with dementia

When a person has a terminal illness, they and their family may not receive optimal palliative care. Quality palliative care focuses on alleviating suffering and promoting quality of life, rather than treating the illness itself. Some conditions, such as dementia, raise challenges for this approach as patients may be perceived to be unable to know and communicate their needs. At **Lakehead University** in Canada, **Dr Nisha Sutherland's** research with people living with dementia suggests that, with the right approach, it is possible for people living with dementia to live and die the way they wish.



Dr Nisha Sutherland

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Fields of research

Nursing, healthcare, ageing, gender and health

Research project

Using qualitative research methods to explore how end-of-life decision-making for long-term care home residents with dementia can be just and inclusive

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PROFILE

Talk like a ...

nursing researcher

Dementia — a general term for memory loss which leads to loss of thinking abilities, such as communicating and problem-solving, due to changes in the brain. The most common cause of dementia is Alzheimer's disease

Palliative care — an approach to care that promotes quality of life and focuses on providing relief from pain and other symptoms of a serious illness, rather than curing the condition

Qualitative research — research that focuses on understanding context, experiences and characteristics, rather than measured (quantitative) data

Relational citizenship model of care (Kontos et al.) — This theory views that people are embodied and they can express themselves through habitual and culturally learned movements and gestures, even when they lose the ability to remember and think. In this way, we are obliged to create an environment in which people living with dementia have opportunities to express their wants and needs

Terminal illness — a disease that cannot be cured and will eventually lead to the person's death

Palliative care is a model of care that is focused on comfort and quality of life for people living with a terminal illness. However, in contrast to cancer diagnoses, for people living with chronic illnesses, such as Alzheimer's disease and other related dementias, the time of dying is often unpredictable. In this context, people living with dementia are often denied palliative care and may experience unnecessary pain and

symptoms or transfer to unfamiliar hospitals. Moreover, because healthcare providers often associate dementia with a 'loss of self', people living with dementia are often excluded from decisions related to how they live the rest of their lives.

At Lakehead University, Dr Nisha Sutherland and her research team suggest that through a relational citizenship approach, the

people within the care circle, including the healthcare providers, are responsible for creating an environment in which people living with dementia are included in end-of-life decision-making and ensuring that they live the remainder of their lives the way that they want.

Caring for those with dementia

Dementia affects a person's ability to think,



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reason and remember, which often makes communication difficult. When a person has challenges in communicating their needs and wants, high-quality palliative care becomes harder to achieve. “There’s an assumption that people living with dementia lose their ‘selfhood’ and their ability to know and express their needs,” explains Nisha. “This has led healthcare providers to often dismiss the preferences of people living with dementia.”

These issues are compounded by a focus on biomedical aspects of care in many care facilities, with less attention given to the personal knowledge of family members and healthcare professionals who look after and understand the people living with dementia. “Long-term care home cultures that focus on medical needs lack an understanding of the importance of a relational citizenship model of care, which focuses on the relationship-building that’s fundamental to humane decision-making processes,” says Nisha. “Barriers to relational models include heavy staff workloads, high staff turnover, lack of private spaces, insufficient resources, and a lack of palliative care policies.”

A palliative approach aligns with a relational model of care. “A palliative approach is focused on relationships rather than the disease,” explains Nisha. “It involves early and ongoing discussions with everyone in the care circle, including residents, providers and family.”

Studying decision-making towards a palliative approach

Nisha and her team conducted research that involved working closely with long-term care

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homes that had received training in palliative approaches, engaging closely with care home staff, residents living with dementia, and residents’ family members. “We conducted formal interviews with family care partners and with staff,” says Nisha. “For residents with dementia, we conducted a total of 477 hours of observation.” This included spending time with these residents to get to know them, taking part in leisure activities and mealtimes, and helping out during these times. “We observed how residents spent their time and how they interacted with staff, family members and other residents,” explains Nisha. “We observed their everyday activities and the staff routines.”

Engaging with people living with dementia requires an adaptive approach. “We worked with eight residents living with dementia and approached each person as a unique individual with their own desires and needs,” says Nisha. “For each, we first acquired background information from family and staff.” The team was attentive to verbal, non-verbal and implied expressions of well-being, reluctance and objection, and assessed how each person preferred to interact and

communicate. “We participated in activities with them and often sat with them while they were resting or sleeping, observing the room and the noises and activities going on around them,” says Nisha.

Key findings

The biggest conclusion that Nisha and her team came to is that people living with dementia are able to express their wants and needs, regardless of cognitive ability. “We saw many incidents where residents were assumed to be incapable, perhaps because staff were busy and unable to take the time to read residents’ body language and attend to their issues,” explains Nisha. “Such assumptions make residents vulnerable to being dismissed and reduce the quality of care they receive.” The team also uncovered the critical role of family members in knowing and protecting their relative’s embodied selves. “This type of knowledge is often overlooked in care facilities focused on biomedical indicators and standardised technologies that shape everyday practices,” says Nisha.

With these findings in hand, Nisha hopes to raise awareness about people living with dementia. “Even in advanced stages of dementia, people can express their preferences and needs,” she says. “We must recognise the importance of family members’ knowledge in preserving their relative’s selfhood and the obligation of healthcare providers to give people with dementia the opportunities to express themselves. Promoting a focus on relational citizenship in care homes, where many residents with dementia live, can help give people living with dementia the rights and dignity they deserve in their final years.

About *nursing research*

Nursing research involves exploring the theories and applications behind nursing practice and how to enhance people's lives, particularly the vulnerable, to ensure that patients have humane care. In long-term care homes, nurses are typically responsible for the supervision of day-to-day care of residents, assessing, managing and responding to their needs, alongside other roles such as administering medications. Especially for residents with chronic conditions, nurses represent the critical interface between residents and the healthcare service and have an important responsibility in supporting their quality of life.

Nisha specialises in qualitative research, engaging with residents and those around them to understand their experiences. "The most rewarding part of this research has been developing relationships with people living with dementia, their family members, graduate students and other researchers," she says. "It's critical to make known people's experiences of healthcare, particularly those who may be vulnerable and marginalised."

As many parts of the world face an ageing population, care for the elderly is becoming increasingly critical. Research addressing this may often focus on

developing new technologies, such as for early diagnosis, treatment, and symptom management, but Nisha remains an advocate of the critical need for human-facing care driven by relationship-building and empathy. "As nurses are often at the frontlines of healthcare, there are numerous opportunities for nursing researchers to explore quality of life of older adults," says Nisha. "Nurses can study people's experiences through their illness trajectories and help to ensure that equitable access to humanising care remains amid the technologies of medicine."

Pathway from school to *nursing research*

Nisha is a firm believer in the importance of encouraging a wide range of disciplines into nursing and nursing research, to enrich the profession. Physical and life sciences, social sciences and arts subjects can all be relevant.

Higher education nursing programmes tend to require a background in chemistry and biology (in particular physiology).

To learn more about nursing qualifications watch this video from Lakehead University about the courses it offers: www.youtube.com/watch?v=nvel1qSibk0

Explore careers in *nursing research*

Nisha recommends volunteering in your local community, especially with disadvantaged people. She suggests developing relationships with people to learn about their experiences, and how they want to live and be treated by others. For instance, Lakehead University, where Nisha works, supports the North West Dementia Working Group, a grassroots advocacy group that supports efforts such as the Dementia Café, where people living with dementia can be themselves: www.nwdwg.ca/dementia-cafe

There are a wide variety of nursing careers, from nurse practitioners (those who practice nursing in patient-facing roles), through to nursing educators and nursing researchers like Nisha.

In Canada, the average salary for a research nurse is starts around CAN \$78,000 per year, according to **Talent.com**.



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Meet Nisha

When I was young, a neighbour told me that I'd be a good nurse! Their words stayed with me. I love to meet and interact with people, and I find it a special privilege to help people during challenging and significant life events.

When I was a student, I met a woman who had been left paralysed by a stroke. Her life had significantly changed in a moment. She was emotional and seemed alone. I couldn't get her off my mind. My father's death was another pivotal moment for me; the experience of having a relative die at home was very difficult. Both these moments have profoundly shaped my career.

The most rewarding moments are the little ones – the sporadic instances when I share a smile and laugh with someone, helping to make their life a little better, even if just for a short while. Additionally, I am grateful for the opportunity to work with innovative leaders such as members of the research team.

My next goal is to learn more deeply about how gender shapes the experiences of people living with dementia. For instance, I am co-investigator of the 'Dementia Gardens' project, where we will explore how gender shapes the experiences of people living with dementia through activities such as gardening. I want to continue to work in the community and advocate for people living with dementia to have opportunities to live well. I want to ensure that people who are disadvantaged receive the respect, dignity and quality of life that they deserve.

Nisha's top tip

Put away the tech and spend time getting to know the people around you. Instead of following social media trends, follow your own path.