

Long –Term Care Residents and Their Families’ Experiences and Perceptions of Palliative Care

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Perspectives of Residents and Families

Strong Desire to Stay in LTC Home

“If anything is going to happen to [my family member] it’s going to happen [at the LTC home].” (Family Member)

“... it is like I live here now, it’s my house, you know.” (Resident)

Strong Relationships with LTC Home Staff

“They [the staff] just make me feel better, they make me feel good, you know just the caring and I know they care, and the expressions and the, their words that they say to me.” (Family Member)

Lack of Awareness

“I would consider that there has been a change of [health] status in my dad, no one has really discussed that with me or the inevitable, which at this point, I am thinking is sooner rather than later. So I might say maybe there’s a gap there in terms of what I can expect.” (Family member)

“I’ve never heard of it [palliative care], so I don’t know what’s involved. I just accept what they do for me. You have to accept, what else is there really?” (Resident)

Desire Opportunities to Discuss Palliative Care

“It’s just a relief to me to know things are going to be taken care of. If I didn’t do anything like this and I got the one call, I think I would... go out of my mind. This way, if anything happens, I don’t have to worry about it. They know what to do.” (Family Member)



Background

- Long-term care (LTC) homes are a major location of death for people in Canada. However, **formal palliative care programs** in LTC homes that aim to relieve suffering and improve the quality of living and dying **are rare**.
- Involving residents and families** in palliative care program development, reflects a resident-centred philosophy, embraced by LTC legislation.
- Setting: Four Ontario LTC homes

Goal

- A goal of a five year Community University Research Alliance funded by the Social Sciences and Humanities Research Council (SSHRC) entitled *Improving the Quality of Life of People Dying in Long Term Care Homes* is to bring forth an increased **awareness of palliative care philosophy** to LTC residents and their families.
- These perspectives will be integrated by the LTC homes to create a more holistic palliative care approach.

Methods

- Sample**
 - (n=12) residents and (n= 75) family members
 - Due to the vulnerable and fragile nature of the sample population, **resident recruitment was low**.
- Study Design**
 - Comparative case study** design guided by **Participatory Action Research** methodology
 - Data collected as part of an initial **environmental scan assessment**
 - Data were collected from residents and their family members using **surveys, focus group discussions, and individual interviews**

Implications

- Resident and family members’ perceptions and experiences can assist organizations in developing a **sustainable holistic palliative care program**.
- Participants have identified key areas for **training in palliative care** for staff and family members, and described their vision for palliative care.
- Over 30 national and international researchers and 40 community organizations, partnered with this project, will **work collaboratively** to co-create interventions to address issues from the data.