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

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Perspectives of Residents and Families

PRCH GROVE)

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)



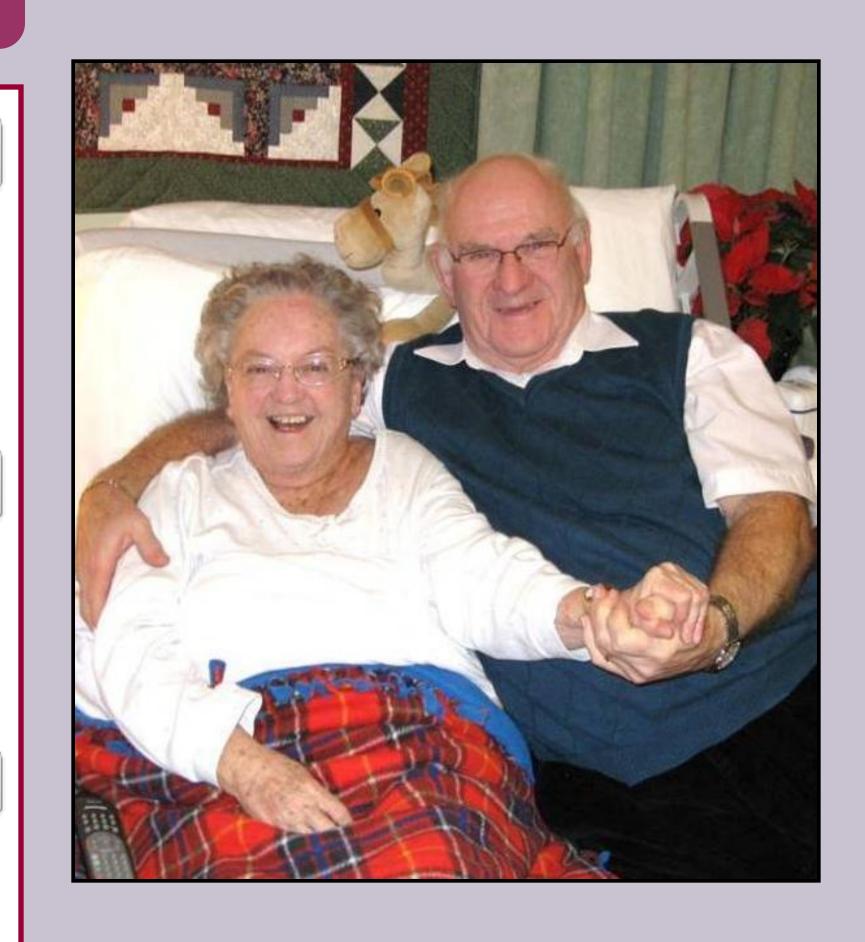
"I would consider that there has been a change of [health] status in my dad, no one has really discussed that with me or the inevitable, which at this point, I am thinking is sooner rather than later. So I might say maybe there's a gap there in terms of what I can expect." (Family member)

"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 are 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.

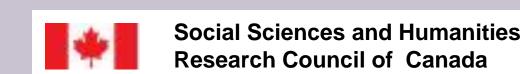












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