

Resident and Family Member Perspectives of Advance Care Planning and Directives in the Long-Term Care Setting

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Background

- In Canada, long-term care (LTC) homes are a major location of death, where approximately 39% of residents die each year.
- **Formal palliative care programs** in Canadian LTC homes that aim to improve the quality of living and dying **are rare**.
- **Involving residents and family members** in palliative care program development, reflects a resident-centred philosophy, embraced by LTC legislation.
- Advanced care planning discussions and directive documents are important components in palliative care program development.

Goals

- A goal of a five year study entitled *Improving the Quality of Life of People Dying in Long Term Care Homes*, funded by the Social Sciences and Humanities Research Council (SSHRC), is to bring forth an increased **awareness of palliative care philosophy** to LTC residents and their families.
- Gaining an understanding of residents and family members' awareness and understanding of advance care directives will assist in establishing the need for future educational opportunities or interventions.

Methods

SETTING

- Four LTC homes

SAMPLE

- (n=12) residents and (n= 75) family members

STUDY DESIGN

- **Qualitative** exploratory
- Data collected during environmental scan assessment
- Semi-structured **focus group discussions**, and **individual interviews** conducted

Implications

- Residents and family members' perspectives can assist in developing a **sustainable holistic palliative care program** that **incorporates advance care planning** and the creation of **directives**.
- Family members have expressed that **advance care planning is valuable in LTC homes**, however the appropriate timing of discussions and documentation remain unclear. LTC home staff are encouraged to consider **individual resident and family member readiness** for advanced care planning discussions.
- **Additional education** around understanding both the content and potential benefits of advance directive documents and planning discussions are supported.

Perspectives of Residents and Families

ADVANCE DIRECTIVES ARE IMPORTANT IN LTC HOMES

Honouring Resident Wishes

"... that is what she wants and it's nice to know that I can do that for her at the end of the day." (Family Member)

Establishing A Mutual Plan of Care with LTC Home Staff

"I think the [facility] should know the [family's] wishes so that at the time ... there is no surprise for the facility. They know the care the family wants, more importantly the patient has expressed their needs, [and] they can concur with those." (Family Member)

Avoiding Decision Making During Crisis

"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)

ADVANCE DIRECTIVES ARE NOT IMPORTANT IN LTC HOMES

"No, if I need something I usually just say I want it or I need it..." (Resident)

"No, I don't think it's important to over plan your life. I think that God takes care of your life..." (Resident)

TIMING OF ADVANCE CARE PLANNING DISCUSSION

After Intake

"Too much going on (at intake), suddenly your life is turned upside down, it is a new lifestyle." (Resident)

"It's so overwhelming just bringing her here... and admitting her here, you're taking them out of their home." (Family Member)

During Intake

"When we brought mom and dad here we asked them for the documents and signed them." (Family Member)

EXPLORING OPPORTUNITIES FOR EDUCATION

"Well, [resident] has definitely signed a DNR, which I get but my question is... when is enough, enough? Yeah, because to me I don't know what possible medical scenario could come up that would present itself. You know, what do you want to do here? Because I just don't have that medical knowledge or I don't have the experience in dealing with elderly to know what could go wrong other than the very black and white stuff." (Family Member)

"The [advance directive] form is not very clear ... you know, it's sort of black and white. So I don't know if they can make that, the decision a little bit easier. It's sort of you know, 'yes you want it or no you don't', so it just seems that there is no grey area in-between." (Family Member)

