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Improving End of Life Care in Long Term Care Facilities: Perspectives of Providers

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Context

Barriers to optimal end of life care for elderly residents of long term care facilities have been described, although few pertinent studies have been in the Canadian healthcare context. In addition, few studies have focused on gathering data to inform strategies for overcoming these barriers.

Aim

Deepen understanding of challenges in end of life care for elderly persons in long term care within the Capital District Heath Authority (CDHA) of Nova Scotia, Canada.

Elicit proposed solutions from healthcare providers on how to overcome these challenges.

Method

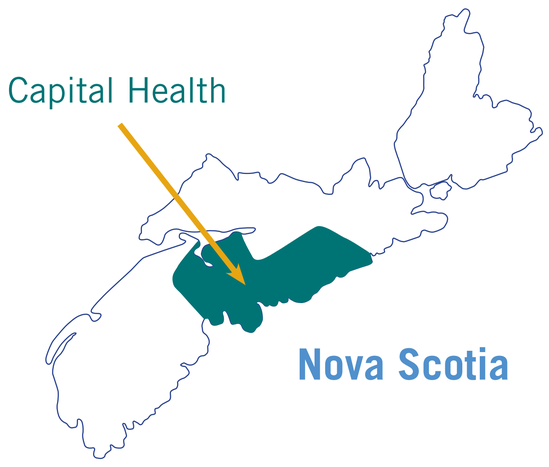
Design

Qualitative methodology.
Four homogenous focus groups:

1. Medical Directors
2. Directors of Care or Nurse Managers
3. Registered Nurses or Licensed Practical Nurses
4. Continuing Care Assistants or Personal Care Workers

Setting

Participants recruited from each of the 20 long term care facilities within CDHA, the most populous health authority in Nova Scotia (see map).



Recruitment

Administrators approached via telephone and/or e-mail and asked to assist with recruitment of healthcare providers.

charts in both time periods (EMR implemented June 2007)

Additional inclusion criteria were dependent on individual QI subgroup definitions.

Focus Group Format

Presentation

Summary of literature describing barriers to optimal end of life care in long term care.

Discussion

Why interested in participating?

Did issues raised in presentation resonate with your experiences in long term care?

What are your ideas re: strategies for improvement?

Analysis

An inductive thematic analysis of audio taped focus group transcripts was performed, involving coding, categorizing and theme identification.

Results

Themes and subthemes

Four main themes emerged from the data:

Mindset in keeping with philosophy of palliative care, where treatment emphasis shifts towards prevention and relief of suffering, pain and other physical, psychosocial and spiritual problems associated with life-threatening illness (see example 1).

Health service organization supportive of palliative care (see example 2).

Consensus regarding care plan among resident, family caregivers and healthcare providers (see example 3).

Alliances between residents, family caregivers and healthcare providers (see example 4).

Figure 1 represents our proposed thematic framework, depicting the hierarchical relationships of the four main themes, in terms of their contribution to achievement of optimal end of life care. Complex inter-relationships also exist between these themes, as indicated by the double arrows between them.

Figure 2 depicts several additional subthemes, which represent contributing factors for building consensus (see example 5).

Isolation also emerged as an important theme. Specific examples of isolation described include isolation from acute care settings, from other long term care facilities, from community family physicians, and from best practice preventative care (see example 6).

Competence of end of life care providers was an additional major theme. **Figure 3** depicts four additional subthemes, which are proposed to contribute to achievement of competence.

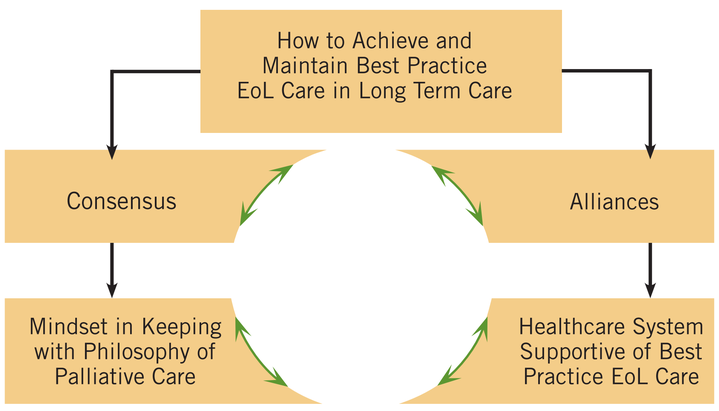


Figure 1. Thematic Framework. Four principal themes and their proposed hierarchical relationships.

Participants

Type of Health Care Provider(s) in Focus Group	Number of participants	Employed at urban or rural facilities	Median years of experience
Medical directors	9	urban	12.5
Nurse managers/directors of care	6	urban	8
Registered nurses/licensed practical nurses	8	1 rural	8
Continuing care assistants/personal care workers	11	3 rural	15

example 1: Quotations to illustrate theme of mindset.

"There are an awful lot of people out there who haven't come to terms with mortality of any kind… and they want mum or dad to live on forever, regardless of how much misery they're in. And sometimes they're quite unreasonable."

"…if in fact we get over that hurdle with families, and they're able to go there…"

"I still find that there are nurses who are afraid to give that last dose of morphine. It's still a mentality that they hold, and it's really hard to get them through to the other side."

example 2. Quotation to illustrate theme of organization of health services.

"Basically, what facility X has done is limited their physicians to three who come every week. Before they had physicians who wouldn't come for months, a year at a time. Everything was done through the fax machine or with the phone. And then basically, when person B and I were care coordinators, we just, we went to management and said "Look, this is not safe, this is not doing anything for the people that we're caring for."

example 3. Quotations to illustrate theme of consensus.

"It's breaking the gaps between physician, families, nurse, caregiver, and you can really see, as a navigator, as a palliative care nurse, how everybody can be on the same page and ultimately provide that ultimate end-of-life care."

"But it was getting everyone onboard so that it wasn't just A doing it or B doing it or C doing it or D; everyone felt that same comfort that yes, they made the observations and they talked with family, talked it over with the staff that were there and it was decided that this is time."

example 4. Quotation to illustrate theme of alliances.

"…what's important, as you said (Person X), it's an alliance between the physician in long-term care. And that should be expanded to a therapeutic alliance in your own facility so that a relationship of the physician with the PCW, LPN, the staff nurse, the social worker, the family and the patient becomes like spokes of a wheel, where we can bring this particular brainstorming here and, you know, responsible caregivers bring to and extend it."

example 5. Quotations to illustrate several subthemes of consensus.

Acceptance of mortality "…it comes down to the family's denial of the family member passing away. They don't want to have that conversation because that means I'm admitting that the end is coming."

Fear of responsibility "…nobody wants to make that decision if Mom and Dad is incapable because they don't want to be held accountable if Mom and Dad die, Mom or Dad die because they didn't get resuscitated."

Communication "…and sometimes the family members aren't getting that support or explained to them what's going on in the process. They just come in and it's like all of a sudden they're not breathing. Well, why? Why aren't these people breathing? Well they're not explained what apnea is. They're not explained the process of dying, what the breathing sounds like. So when they're walking in, they're getting that, and the next you know they're standing there going "They just died. What happened?""

example 6. Quotation to illustrate theme of isolation.

"we know there's all kinds of research happening in relation to end of life, but we don't have the links, I think. We become very insular in our facilities with what's happening, almost cut off from the rest of the health care system in some regards"

example 7. Quotations to illustrate several subthemes of competence.

Comfort level/experience "… my observation has been the more experienced staff members who've been there the longest usually are dead-on or quite comfortable starting the standing orders for palliative care, they're quite comfortable giving the prns."

Mentorship "But it's the ongoing education, especially for new people coming onboard. For the people who have never witnessed a death, have never witnessed a dying, either personal or professional, there's a lot of growth and a lot of education has to occur."

Compassion "You know our last lady there was there for 13 hours, because she died at night time and he didn't get in till after lunch the next day, because he said "Do not call". You know, where's your compassion?"

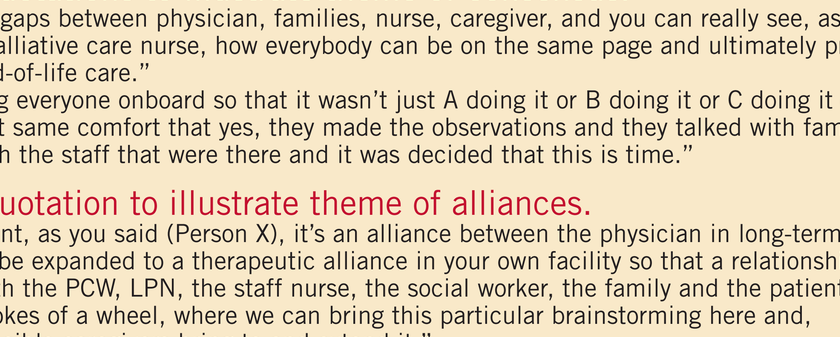


Figure 2. Subthemes of Consensus

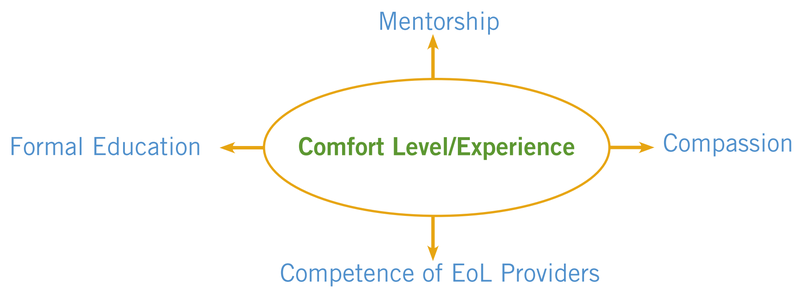


Figure 3. Subthemes of Competence

Conclusions

Canadian long term care facilities face barriers to optimal end of life care similar to those described in other nations.

There were many themes representing necessary, but not sufficient factors associated with optimal end of life care in long term care facilities.
These themes had complex inter-relationships. Health service interventions for improvement of end of life care in long term care facilities should target the major themes

1. Promulgating a mindset in keeping with palliative care.
2. Appropriate organization of health services.
3. Consensus and alliances between residents, family caregivers and healthcare providers.
4. Fostering end of life care provider competence.