

Community Needs Driven Research Network

ISSUE

11

June
2014

CNDRN

Palliative, End-of-Life and Hospice

Palliative and end-of-life issues in continuing care (CC) were especially relevant for professionals in the Edmonton area. Participants in this area talked about how these developing issues will also affect other areas of the province in a larger scale, as CC clients with chronic conditions start requiring these types of services.



Main concern about continuing care:

One of the main concerns comes from the current understanding of end-of-life care held by health care professionals, which often is related to cancer patients. Health care professionals often overlook the end-of-life care when working with populations with non-cancer-related chronic conditions, such as dementia. Two main research needs were identified by participants in this area: i) staff education; and ii) end-of-life care in CC facilities across the continuum.

Staff education in palliative care:

Educating staff was one of the more important issues identified by participants. In their opinion, front-line workers are ill-prepared to face and deal with end-of-life issues and are often not able to cope with these situations. This lack of preparation impacts care as staff cannot accurately notify and support families, or the client, in their final days. Research is needed in a few areas to: i) explore the current perspectives of staff and families regarding end-of-life issues in CC; and ii) develop strategies to handle end-of-life issues in the most humane and healthy way possible. Also, if staff were trained, they could more successfully identify clients in need of these specific services and get palliative care teams involved sooner, so quality of life is increased and the cost for the systems are reduced in the long term.

What did staff say?

- “It’s really hard for staff who haven’t been in this situations, so they’re so sad. So they need to be more educated about palliative, about how to look after these palliative needs.”
- “... and I think some people maybe had the feeling that ‘Why isn’t he in the hospital?’ So we did have meeting and talked about why it is that he’s allowed to be here and pass away here, and I think that really helped the staff to understand that.”
- “We just want to have more education for the staff in the continuing care, trying to help them to identify the patients sooner than later, ‘cause that is going to affect the patient’s care, their quality of life, and also a huge cost for the system. We are assuming that there would be cost effectiveness to our involvement as well.”



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This project was funded by:
Alberta Innovates Health Solutions

· “I think people are familiar with the concept of palliative care in urban areas, but majority of the time, they have that concept associated with cancer. So our aim is to get people to think outside that box and look at non-cancer population. Because majority of the times, the term ‘palliative care’ goes hand-in-hand with prognostication and how long is the patient’s survival. And because for the majority of non-cancer patients, you cannot prognosticate as clearly as for cancer, or not as well as you do for cancer, people have difficulty identify patients who need palliative care services.”

End of life care in continuing care facilities:

The second element identified by participants related to the special situations of CC clients who identify the CC facility as home, when they need end-of-life care. Increasingly, clients are asking to die in facilities which are not always prepared to deal with this. When clients near this time, they are often referred to the emergency room, causing them to spend their final days in ICU rather than in hospice.

Participants said this issue results from the lack of shared work between palliative care teams and CC and the lack of resources to assess clients in an end-of-life situation. Research would explore the costs of ICU at the end-of-life, as well as the impact of caring for a client in the CC facility at the end-of-life.



What did front-line staff say?

- “and we just had—like, our resident that was palliative that passed away. It was really nice. His sister, she did the funeral service, arranged for the funeral home to come here and do the funeral service here, because here was where his friends were, ‘cause our residents wouldn’t go to his funeral if it was at another place. So it was really nice that we had these classrooms to use so we had space to do that in. I don’t know that—we don’t have that space at other places.”
- “So it’s people with chronic disease, but it’s also the frail elderly and dementia populations, where if they had earlier management of some of their symptoms, that advanced care planning, so they’re not ending up in acute care to spend some or most of their days. So we have some numbers in our program about the numbers of people that do have Emergency visits and acute care admissions, but is so unknown!”
- “So stuff like, we have the primary prevention, but we don’t have a lot of the secondary prevention. My background and my practice background from many years was critical care, and we knew for 34 years that people coming from long-term care to spend their last 10 days in an ICU is not an appropriate place for them to spend their last moments with their family. But it’s still occurring!”

What’s being done to address this issue?

A team of researchers from University of Alberta, Alberta Health Services, Covenant Health, Alberta Health, and Alberta Caregivers Association has been funded to look further into the experiences of families providing end-of-life care. These caregivers experience many transitions during this time, affecting their physical and mental health. This metasynthesis study will explore what influences these experiences and fill a knowledge gap in end-of-life care, providing a foundation for future research, policy, and health practices to improve health outcomes.