Dying patients on acute care wards

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Objectives

- To describe the landscape of dying in acute care settings
- To explore the challenges and triumphs inherent in caring for patients at the end of life in acute care settings
- To explore ways in which acute care nurses can be supported to improve the quality of care that they provide
The landscape of dying in acute care

- The vast majority of Canadians die in the context of an acute care setting
- Research indicates that these patients die experiencing uncontrolled symptoms and poor emotional support
- There is a philosophical divide which exists which makes it difficult to reconcile curative and end of life care

(Chan et al, 2014)
The Privilege of Working with Dying Patients

- Opportunity to provide holistic care (Fortin & Bouchard, 2009)

- Feeling rewarded and feeling a strong commitment to help terminally ill patients experience a good death.

  (Richard B. Arbour, Debra L. Wiegand 2014, Judith Gagnon, Wendy Duggleby, 2013)
« I discovered that the experiences I had with patients at the end of life gave me the opportunity to develop strengths and to have meaningful interactions. It is also a great opportunity to explore psychosocial and spiritual aspects of care. »

(Fortin & Bouchard, 2009)

« I don’t think I’ve ever enjoyed work as much as with my palliative patients. The atmosphere that’s created in this work is so generous. It allows for so much. »

(Wallerstedt & Andershed, 2007)
Torn Between Two Philosophies of Care

- Difficulty to prioritize a patient requiring acute care over a dying patient.
- Conflicting demands related to providing curative and palliative care simultaneously

Balancing two priorities of care

End of life care

Acute curative care
« I feel guilty afterwards... This [dying] patient is one of my priorities, he needs me, but on the other hand, I have patients who are medically unstable, I have to treat them.”

(Fortin & Bouchard, 2009)

« When you have somebody that’s palliative you feel like it’s a tug of war. You want to be there for the family, you want to be there for the patient, but you also have your other patients you have to take care of.»

(Thompson, McClement & Daeninck, 2006)
Feeling Like the Lone Advocate

The **most demanding** issue reported by nurses was not having to deal with death, dying and suffering, but, rather, **having to fight** to ensure decent care for the patient.

(Gélinas, Filion, Robitaille, Truchon, 2012, Fortin & Bouchard, 2009)
« I suggested **scopolamine** for a this patient who was drowning in his secretions, but they are so reluctant to prescribe it! »

(Fortin, bouchard, 2009)

« I find a difficulty with acute care physician is, in general, they don’t always want to give larger dose of narcotic because of fear of having them die sooner. It can be, basically, fighting for what we feel is best for the patient »

(Thompson, McClement & Daeninck, 2006)
Need for Support

- Nurses perceive physicians as being insecure when close to the dying patient, and sometimes even afraid. Nurses felt that physicians would often rather do things instead of talking with the patient and relatives.

  (Wallerstedt & Andershed, 2007)

- EOL PC not part of the culture of care and not seen as a priority

  (Bloomer, et al., 2013, Gagnon & Duggleby, 2013, Fortin & Bouchard, 2009)
« I do not feel supported at all. The doctors did not want to speak to the family at all. They did not even want to come in the room. It took 30 minutes after his death for them to come and pronounce death. »

(Fortin, Bouchard, 2009)

«You have to keep on nagging the doctors that they should talk with the patients, talk with the relatives and maybe discontinue treatment. Its also hard to keep on, to keep on giving antibiotics right up until the last breath. There’s a lot of that, treat, treat, treat. »

(Wallerstedt & Andershed, 2007)
Lack of knowledge

- Nurses have clearly identified a need for more education to prepare them to care for patients at the end-of-life.

« At school, we never learned that. I never had a stage in palliative care settings. I never had to do that and I never even thought about that. When I had my first experience, it was overwhelming. My patient had a lot of dyspnea and I didn’t know what to do. »

(Fortin, Bouchard, 2009)

« If their main symptom is shortness of breath, that is tricky. Physicians don’t know how to deal with it, nurses don’t know how to deal with it, and it is not properly acknowledged. »

(Wotton, Borbasi & Redden, 2005)
Nursing Education for End of Life Care

- 2% of content in nursing texts devoted to end of life care
  (Ferrell, Virani & Grant, 1999)

- EOL education has a positive effect on nurses’ attitudes toward care of the dying patient
• Nurses report:
  • Difficulty recognizing the end of life
    • Feeling unable to provide optimal care due to lack of time and resources
  • Difficulty reconciling palliative and curative approaches

(Davidson et al, 2002; Hopkinson et al, 2003; Thompson et al, 2006; Wotton et al, 2005)
Nursing Education for End of Life Care

- Practical experiences with dying patients
- Basic information on palliative care
- Increased skills training in communication
- Knowledge on how to appropriately care for patients’ caregivers

(Jors et al., 2015)
Nursing Education for End of Life Care

- Novice nurses have difficulty understanding the dilemma that patients and families face with transitioning to end of life care
  
  \[(\text{Moir et al., 2015})\]

- Nurses uncomfortable talking about end of life care with their terminally ill patients
  
  \[(\text{Tait et al, 2014})\]
“Patients look at health care providers as they would a mirror, seeking a positive image of themselves and their continued self worth. In turn, healthcare providers need to be aware that their attitudes and assumptions will shape those all important reflections”

(Chochinov, 2007 p. 185)
“Patients and families who are dying on the acute care ward want to feel as though they matter. When things are done quickly, when they are made to feel like they do not belong, their sense of self worth diminishes.”

(Chan et al., 2014)
• Recognition of dying
• Mattering
• Belonging
• The experience of transitioning
• Control

(Bitzas, et al, 2014; Chan et al, 2014)
Recognition of Dying

- Awareness of death
  - Cancer patients more likely to die in full open awareness compared to other illnesses
  - "Surprise question"
- Being aware of a terminal illness and accepting death are two different phenomenon
- An awareness of one’s own finitude was an experience which was extremely isolating

(Bitzas et al., 2014)
(Seale et al., 1997)
(Lynn et al, 2000)
(Thompson et al, 2009)
“I knew even before the doctors told me. I have known that I was dying for a while now...maybe a month or so”

(Bitzas et al., 2014)
Mattering

- The importance of their individual illness stories

- Receiving care versus being cared for
  
  (Chan et al, 2014)

- Threats to dignity
  
  - Symptom control
  - Existential distress
  - Approaches and models in care settings
  - Health care setting and design

  (Pringle, Johnston & Buchanan, 2015)

- Dignity as embodied

  (Bitzas, et al, 2014)
Belonging

- Feeling of not belonging
- Categorizing patients
  - “Backstage” versus “frontstage” talk
- Bed allocation

(Chan, et al, 2014)
Difficulty in categorizing patients

Acutely ill yet curable

In-between

Palliative

(Chan et al, 2014)
“Patients who are dying don’t belong on this ward. We don’t have time to hold hands, ask how they are doing. We are on the go always, just have time to stop and give meds. That’s the way it is.”

(Chan, et al, 2014)
The Experience of Transitioning

- Experience of relocation can be one of fear, loneliness and worries
  
  (Carpenito, 1993, McGrath, 2006)

- Importance of place of care, goals of care and qualifications and experiences of care providers

  (Burge, et al, 2005; Rayson & McIntyre, 2007; Reinke et al., 2008)
“I almost felt like a prisoner condemned to death, walking down the corridor to the execution chamber. Although, of course, I didn’t walk, and I wasn’t getting a last meal. I have never really been a proponent of the death penalty, and now even less. That feeling of walking towards your death, you can’t breathe. I started to feel a panic attack coming on I think when I was being brought here. So, I tried really hard to think about something else. I was watching the walls go by as I was being wheeled here. The cracks, the paint chipping, anything. Just to try to forget what was happening.”

Bitzas, et al, 2014
Control

- Relinquishing, losing and maintaining control all impact the dying experience
  (Bitzas et al, 2014)

- Loss of control can result in a reluctance to accept palliative care services and may trigger feelings of uncertainty and abandonment
  (Back, 2005; McKechnie et al, 2007; Rondaldson & Devery, 2001)
“I thought I was always in control. But now...what control? I don’t even know what is really happening. I mean, I know. I get it. I am dying of advanced, metastatic ovarian cancer. I get it. I know that. But I don’t know what is happening. I don’t understand the medicine, or the anatomy, whatever it is, of it all. This bowel obstruction – why is it there? Why won’t it just go away with treatment? (looks over to the window). And this blind. If I was in my home I would have ripped that blind right off the wall so that I could see out the window. But I can’t do that here. It’s not my blind (long pause), and I don’t even have the strength to get up and try to pull it down. I’m sorry, I am in a bit of a foul mood today”

(Bitzas, et al, 2014)
Implications for practice

- No one dies void of a past or backdrop of experience
- Timing of death awareness / recognition
- Acknowledgement that aloneness in dying does not absolve us of a responsibility to offer presence
Implications for practice

- Support during the physical transfer
  - Relocation interventions
  - Explore hopes
  - Mindfulness of lived spaces
- Role in fostering embodied dignity
“Be careful then,
and be gentle about death,
for it is hard to die,
it is difficult to go through the door,
even when it opens”

D. H. Lawrence
*All Soul’s Day*
1994