Health Care Aides’ ‘Experience of the Ethical’ in Caring for Dying Seniors in a Personal Care Home

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With Gratitude.....
Conflict of Interest

I have no conflict of Interest to Declare

I have no relationship with a commercial entity such as:

- a pharmaceutical organization;
- medical device company;
- communications firm;
Out of the Shadows: Extending the Boundaries of Hospice Palliative Care 2013 Conference
WHY?
Canada’s Aging Population
Canada’s Aging Population
**Figure 1.2** Chronic illness in the elderly typically follows one of three trajectories. Copyright 2003, RAND Corp. Reprinted with permission.
Who provides the majority of end-of-life care in a personal care home?
Health Care Aide Profile
Regardless of Where It Occurs....
What’s Missing?
What’s Missing?

- Micro-dimension of ordinary, day to day events
- Contextual & interpersonal dimensions
- Voices of health care aides
Unsatisfactory resolution of ethical issues
Research Question

- What is the essence of health care aides’ lived experience of the ethical in caring for dying seniors in personal care homes?
Design

- Critical truths about reality found in people’s lived experiences
- Interpretive phenomenological design
- a qualitative research method for gaining an insight into how an individual perceives a phenomenon.
Study Procedures

- Ethical approval and PCH site access
- Purposive sample of 12 health care aides meeting inclusion criteria
- Proprietary/non-prop. facilities
Study Procedures

- Face to face interviews
- Demographic data
- Data analysis
Who Participated?

- Gender?
- Age?
- Experience?
- Training?
Findings

Relational Engagement

Respect

Trust

Mutuality
Relational Engagement

Respect

Due regard for the feelings, wishes, or rights of others
Relational Engagement

Trust

Firm reliance on the integrity, ability, or character of a person or thing
Relational Engagement

Mutuality

Views relationships as processes that are negotiated and collaborative, in which all of the parties involved participate, choose, and act.
Broken Covenant
‘Experiences of the Ethical’

- Inadequate pain control
- Perfunctory care
- Resource issues (personnel & supplies)
- Disregard of resident wishes re EOL care
Inadequate Pain Control:

“I just couldn’t stand seeing someone in so much pain. I felt helpless and really angry at the nurse and my superiors for not doing something”.

Current findings from nursing homes point to:

- high incidence of unrelieved pain (Miller, Mor, Wu, Gozalo, & Lapane, 2002)

- poor assessment and management of pain and other symptoms (Teno et al, 2004)
Responses

Inadequate pain control

- Petition nurses
- Use higher chain of command
- Family teaching
- Suffer vicariously
Response

“Even though we are health care aides, we still have to look out for the resident. And that means sometimes going against family wishes, going to the social worker or even management. You have to stick to it…..”
Perfunctory Care:

“These people are dying. It's not for us just to walk in the room, change their pad, slap lotion on them, and walk out.”
Personhood is highly soluble within patienthood
Responses

Perfunctory care

- Occasional chastisement
- Pick up the slack
“I just wish everybody would kinda be on the same page. Though I wasn’t looking after that lady I would try my hardest to get in there and do it. And your co-workers are saying,

“That’s our person! Don’t do her. And then that causes hard feelings. Stepping on toes, you know…”
Resource Issues

“Very challenging because they need a lot from us, but there’s no time. We have others to look after too…. "
Responses

Resource Issues

- Miss breaks/stay late
- Challenge status quo through non-adherence to institutional routine
- Anxiety, frustration, altered sleep patterns
Disregard of Resident Wishes Regarding Care

“They were going against what she wanted, left and right. And I knew what she wanted. No transfusions, no operations, and no CPR. And I knew what she wanted. They said she changed her mind. But there was no way. She was too confused to do that. I just don’t thing that was right. Her rights were violated…..”
Current findings from nursing homes point to:

- excessive reliance on hospitalizations
  (Castle & Mor, 1996; Jones, Mackerud & Boyle, 1997)

- inattention to advance care planning revision
  (Castle, 1997)
Responses

- Disregarding of Resident Wishes re plan of care

  - “Go to bat”
  - Feeling a failure/devalued
  - Pull back from advocating
Discussion/Implications

- Relationship itself that supports and informs ethical reflection and decision making in HCAs

- Proximity and attachment calls HCAs to action (also overwhelms!)
Discussion/Implications

- Contextual & processual factors impede relational engagement
- Communication challenges are significant
Discussion/Implications

- Attention to education & support needs
- Pain management education
- Education in end-of-life care for HCAs
Future Directions

- Creative staffing solutions to allow for extra care needs of dying residents
- Opportunities for debriefing when ‘experiences of the ethical’ occur
- Examination of staff, residents, families & care contexts in shaping relationships & fostering respect, trust & mutuality
Questions/Discussion