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

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- Health Care Aides
Statement of the Problem

- Canada’s aging population
- Chronic health conditions
- Limited social support
- Functional Cognitive decline
- Admission to PCH until time of death
Statement of the Problem

- Majority of end-of-life care provided by Health Care Aides (HCAs)
- Minimal training in palliative care or ethics
- Ethical problems at end-of-life prevalent & complex
Statement of the Problem

- Micro-dimension of ordinary, day to day events not considered

- Contextual & interpersonal dimensions ignored
Statement of the Problem

- Unsatisfactory resolution of ethical issues = multiple *negative* consequences

- Voice of HCA’s in clinical ethics virtually absent

- Understanding of ethical issues in practice incomplete
Research Question

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

- 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
- Field notes
- Data analysis
Findings: Demographic data

- Female
- 30-60 yrs old
- 7 mos. -30+ yrs experience
- HCA training
- 3/12 training in end of life care
Findings

Relational Engagement

Respect

Trust

Mutuality
Broken Covenant
‘Experiences of the Ethical’

- Inadequate pain control
- Perfunctory care
- Resource issues (personnel & supplies)
- Disregard of resident wishes
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.’

Violation of trust
- resident’s belief that HCA will assist him/her in achieving positive outcomes
- reliance on another’s good will
Responses

Inadequate pain control

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

- Lack of Respect
  - failure to treat others as inherently worthy
  - objectification of the resident
Responses

- Occasional chastisement
- Pick up the slack

Perfunctory care
Resource Issues

- “It's very challenging because they need a lot from us, but there's no time. We have others to look after too....

- Lack of Respect & Violation of Trust
  - worthy of care but not receiving it (rationing of care)

  - patterning of actions to make institution work ➔ marginalizes engagement
Responses

Resource Issues

- Miss breaks/stay late to ensure resident didn’t die alone
- 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…..

- Lack of respect, violation of trust, absence of mutuality (relationship as negotiated, collaborative process)

-unwillingness to/understand listen to HCA
Responses

- Disregarding of Resident Wishes re plan of care

- “Go to bat”

- Feeling a failure/devalued

- Pull back from advocating
Discussion/Implications

- It is the relationship itself that supports and informs ethical reflection and decision making in HCAs

- Contextual factors impede relational engagement
Discussion/Implications

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

- Attention to education & support needs
Discussion/Implications

- Need for pain management education
- Education in end-of-life care for HCAs
- Creative staffing solutions to allow for extra care needs of dying residents
- Opportunities for debriefing when ‘experiences of the ethical occur’
Future Directions

- Examination of staff, residents, families & care contexts in shaping relationships & fostering respect, trust & mutuality