


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



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**hospice &
palliative care
manitoba**

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;

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At the Bedside

Sliding "Off" the Sliding Scale: Allowing Hope, Determining Capacity, and Providing Meaning When an Illness Is Becoming Worse But a Treatment May Help

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Special Section on Deep Brain Stimulation

Edited by Emily Bell and Eric Racine

Deep Brain Stimulation, Ethics, and Society

Emily Bell and Eric Racine

Consent to Deep Brain Stimulation for Neurological and Psychiatric Disorders

Walter Glannon

Hope and Patients' Expectations in Deep Brain Stimulation: Healthcare Providers' Perspectives and Approaches

*Emily Bell, Bruce Maxwell,
Mary Pat McAndrew, Abbas Sadikot,
and Eric Racine*

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Philosophical Reflections on Narrative and Deep Brain Stimulation

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Consenting to the Ineffable: The Problem of Neurostimulation and Altered Consciousness

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Infants and Children with Hearing Loss Need Early Language Access

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In Addition to Benefits and Harms: The Relevance of the Political

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Language, Identity, and Belonging: Dual Cultural and Narrative Perspectives

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Law

Legal Briefing: Consciousness, Glannon and Consciousness Reform

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WHY?

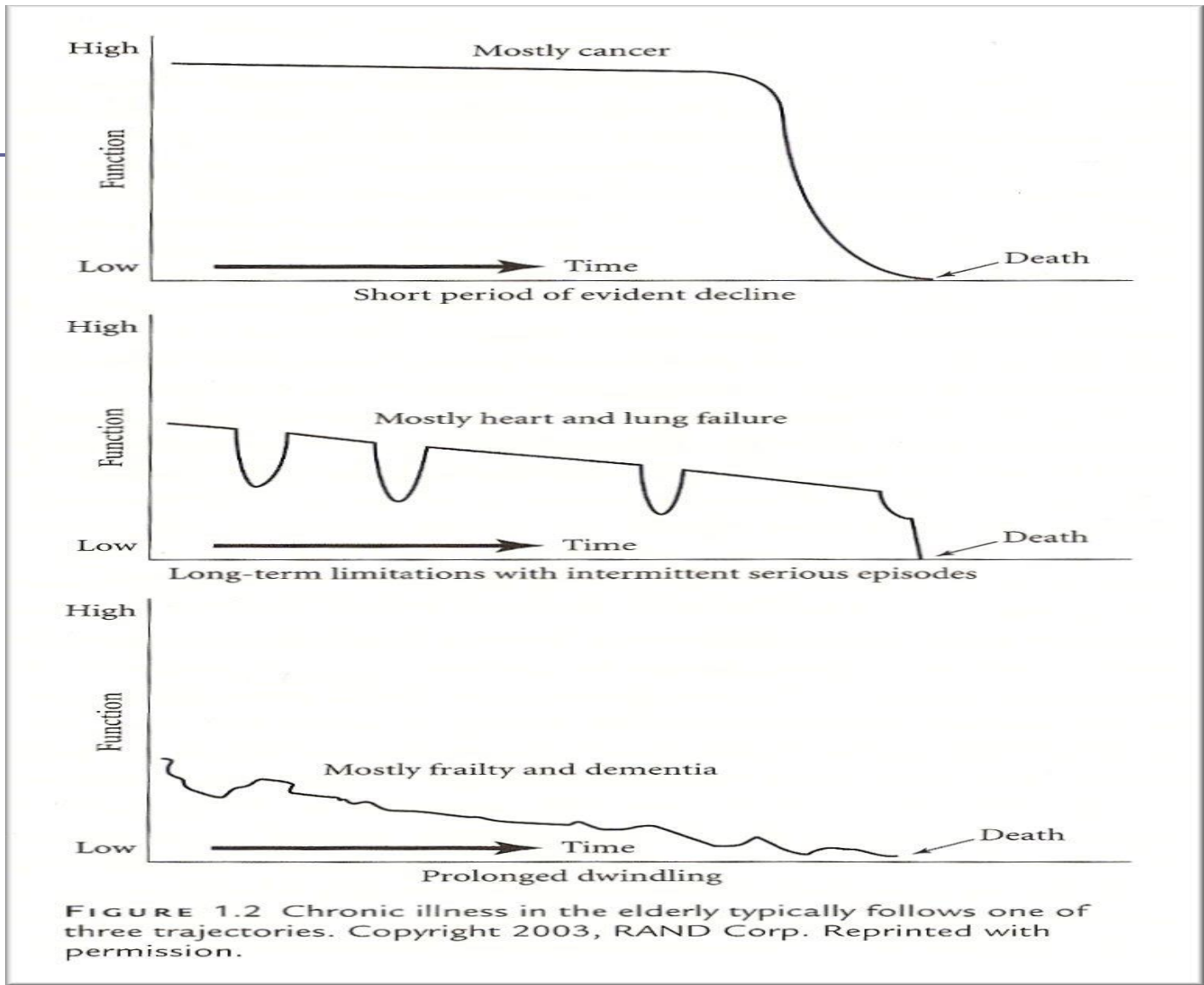
Canada's Aging Population



Canada's Aging Population



Out of the Shadows: Extending the
Boundaries of Hospice Palliative Care
2013 Conference





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**



**NEGATIVE
CONSEQUENCES**

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

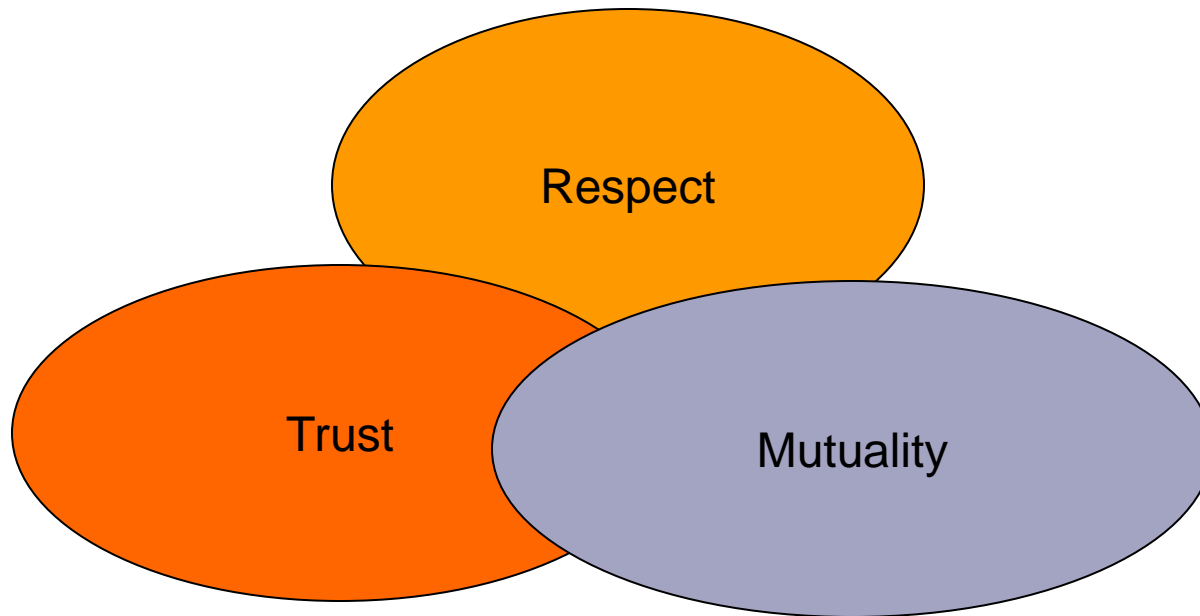
Who Participated?

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



Findings

Relational Engagement



Relational Engagement

Respect

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

Relational Engagement

Trust

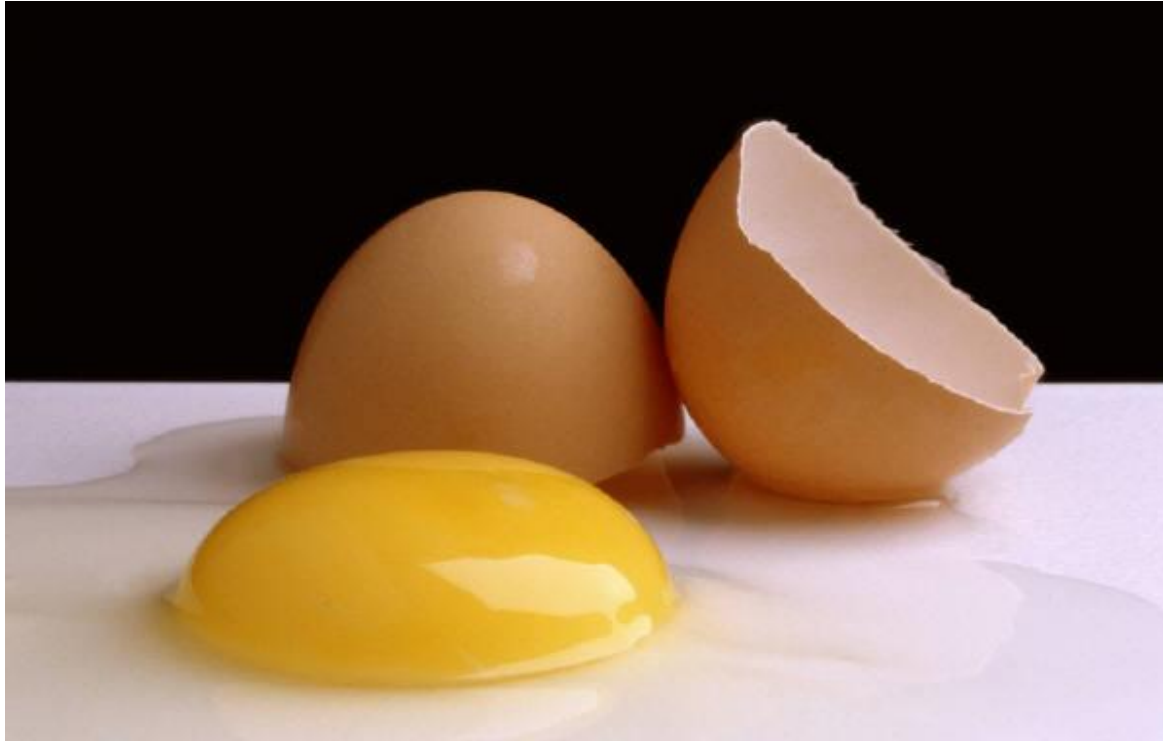
Firm reliance on the integrity,
ability, or character of a
person or thing

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**

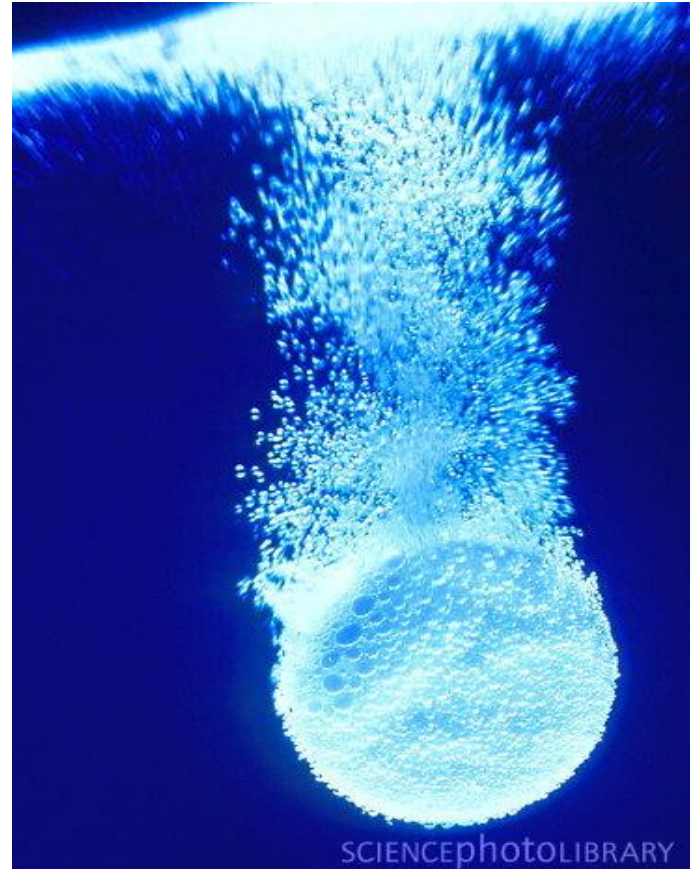
Response

- *"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. Its 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**

Responses

- *"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

“Its 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 think 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



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Questions/Discussion

