Staff Involvement in End-of-life Decision Making for People with Dementia in Long-term Care: Barriers and Facilitators

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Funding: Lakehead University Senate Research Committee
Research Development Fund
Faculty/Presenter Disclosure

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Relationships with commercial interests: none
Background and Significance

- Decision making is complex and impacts on quality of life

- Decisions made about administering, withdrawing and withholding treatment (antibiotics, hydration, nutrition and treatment of symptoms) during last 6 months of life (Toscani et al., 2016)

- End-of-life decisions critical to survival, place of death or comfort level
Background and Significance

• Although 90% of family decision makers indicate a desire towards palliative care goals of comfort, over 50% of people with dementia are transferred to hospital (Mitchell et al. 2009, Given et al., 2012)

• In Ontario, nearly 50% of the discharges in long term care (LTC) facilities have been to acute hospitals (Hirdes et al., 2011)
Decision making in Long-term Care

- Advance Care Planning
  - Excludes the contemporaneous context
  - Inconsistent with people with dementia and death and dying

- Culture of LTC
  - Hierarchal
  - Focus on biomedical model and efficiency
Background and Significance

- Personhood is status bestowed on people is shaped by the environment (Kitwood, 1992)

- Relationships are key the experiences of people with dementia

- Despite the proximity, few have considered the role of direct care workers (Personal Support Workers [PSWs], Registered Nurses [RNs], Registered Practical Nurses [RPNs]) in decision making
Decision Making in a Palliative Approach

A Palliative Approach

• For chronic illnesses with a disease trajectory unlike cancer
• Care focused on quality of life on non-specialized units with existing staff

Quality Palliative Care in Long-Term Care (2009-2014) (Kelley & McKee, 2012)
Literature Review

- Both formal and informal discussions critical to positive decision making experiences (Black; Caron)

- Nurses’ perceived lack of power and role ambiguity (Lopez, 2009; Reimer-Kirkham et al., 2016; Sawatzky et al., 2016)

- Family members dissatisfied and want staff to discuss changes in the resident’s condition and expected outcomes (Caron et al., 2005; Davies et al., 2014; Stephens et al., 2015)
Study Purpose

- To examine nurses’ and PSWs’ perceptions of their role in end-of-life decision making for residents with dementia in long-term care

- Focus today: Examine the barriers and facilitators to involvement
Methodology

Qualitative descriptive method (Thorne, 2009)

- To locate subject experiences within common understandings and broader contexts

- To seek a theoretical understanding of practices
Methods

Data Collection

• Semi-structured, face-to-face interviews
• Focus Group

Data Analysis

• Thematic analysis (Lofland et al., 2006)
• Line by line coding
• Constant comparison
Findings

Participants

- Two not-for profit LTC facilities, 21 participants
- PSWs (n=9), RPNs (n=8), RNs (n=4)
- Full time (n=14); part time (n=7)
- Most had additional palliative care and dementia education
- Most with experience greater than 3 years
Findings

**Barriers to Involvement**
- The predominance of a biomedical model to care
- A varied understanding of a palliative approach
- Relationships with family
- Discomfort with discussing death
Predominance of a Biomedical Model

...[before discussing with family] I would have my facts...I would have to look on the documentation, I would have to look at the vitals, I would to look at their in and output...any wounds, shortness of breath, stuff that are really big triggers that somebody is dying or declining (RPN 7).
It used to take 5 minutes [to document] and now we can be on the computer for 45 minutes… and that’s not even getting on the computer to chart about the little lady who is saying, ‘Please don’t let me die.’ … but that’s not being captured If it’s not written, it’s not said or done…(PSW7).
A Varied Understanding of a Palliative Care Approach

People are always under the impression, [that residents] are palliative. Well, technically you need an order [from a physician] for somebody to be palliative (PSW2).
A Varied Understanding of a Palliative Care Approach

It’s not so much discussions, it’s just what we do- if somebody is palliative, if we know they are at the end stage and the family is here- we send a memo to dietary, dietary makes us up a cart…and we take it down to the room [for the family] (RPN2).
I’ve seen families who are in denial: ‘[Dad] eats when I’m here.’ But if we go and try, [the resident is] not going to eat for us… Sometimes the family is in denial, they don’t want to see it. They say, ‘[Dad] does that for me, so I don’t know what you’re talking about’ (PSW3).
… [families] will ask, “Is my Mom ever going to get better?” I’ve heard staff say… “Well… that’s possible, that could happen”- just because they don’t know how to let them down… [Some say] “I don’t want to burst anyone’s bubble.” But…people need to know where they stand …(PSW8)
Discomfort with Discussing Death

We just tell [family], “Oh my God, today your Mom… she was so happy, she was painting and drew a nice picture… she was enjoying, smiling, laughing…and less…if she’s not feeling good. And [if] they ask, “Why is she in bed?” ….I report it…I won’t say any negative to them …(PSW6).
Discussion & Recommendations

- **Less value placed on personal knowledge**
  - Focus on biomedical leaves absent complexities of care
  - Recognize that personal knowledge is essential alongside biomedical knowledge

- **Palliative care understood as tasks to be completed**
  - Adopt a palliative approach as a philosophy of care
Discussion & Recommendations

- **Staff-family relationships are key**
  - Recognize importance of relationship building
  - Further research needed to examine social relations

- **Competing discourses of restorative and palliative care**
  - System constructs divide between acute/palliative
  - Creates a liminal space between living and dying
  - Palliative approach must be embedded
A Positive Note
Relationships

Between family, resident and staff members:
We are the eyes, ears and heart of resident (PSW).

Between staff and co-workers:
...sometimes you have staff with different opinions...and that’s good for a team, you need to have different opinions to get the best care at times (RN).
Passion for Care Work

Enjoys care work:
…I just love working with the residents, I love working with the family members, I love my teams (PSW).

Seeks learning opportunities:
…anything I learned was through little extra courses or conferences...(PSW).
Study Limitations

- Small sample, few RNs, one focus group

- Need a better understanding of the dynamics that occur in decision making
  - Resident-family-staff interactions and involvement in decision making
  - Team relationships and work in LTC
Conclusion

• LTC policies and practices are inconsistent with a relational approach to palliative dementia care

• The predominant biomedical model, while important, must be imbued with a philosophy that emphasizes relationships

• An approach underpinned by lens of personhood should underlie LTC philosophies
Questions?