FACING THE FUTURE:

FORWARD THINKING IN END-OF-LIFE FAMILY CAREGIVING FOR PERSONS WITH DEMENTIA

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SHPICA Conference, June 13, 2013; Regina SK
ACKNOWLEDGEMENTS

• Funding:
  • Canadian Gerontological Nursing Association
  • University of Saskatchewan: Start-up Funds

• Ethical approval:
  • Research Ethics Board, University of Saskatchewan, Saskatoon, Canada
OUTLINE

1. Background
2. Objective and methodology
3. Key findings
4. Conclusions
5. Group discussion
BACKGROUND...

Dementia and end-of-life

Terminal disease

Clinical course

Hesitation

Ambiguities

(Mitchel et al., 2009; Caron, Griffith, & Arcand, 2005; Thompson, McClement, Menec, & Chochinov, 2012; Gnaedinger, Robinson, McIvor, & Koebel, 2012)
BACKGROUND

• Family Caregivers
  • Who they are
  • What they do
  • Their journey with dementia

(Chambers, Hendriks, Hall, Raina, & McDowell, 2004; Lum et al., 2011; Peacock et al., 2010)
BACKGROUND...

End-of-life decisions

- Family anxiety
- Vague directives
- Unprepared
- Combining values
- Complicated by loss

(Caron, Griffith, & Arcand, 2005; Thuné-Boyle et al., 2010)
BACKGROUND...

• Family caregivers value:
  • Comfort care
  • Kindness and respect of staff
  • Information
  • Care conferences near end of life
  • Emotional and instrumental support

(Gnaedinger, Robinson, McIvor, & Koebel, 2012; Palmer, 2012; Shanley, Russel, Middleton, & Simpson-Young, 2011)
OBJECTIVE

To describe the end-of-life decision-making experience of bereaved caregivers who cared for a person with dementia.
METHODOLOGY

• Secondary analysis
• Open-ended interviews
• Qualitative description:
  
  Provide an uninterpreted description of participants’ experiences

(Sandelowski, 2000)
METHODOLOGY...

Setting
- Conducted in Saskatoon, SK
- Partnered with a long-term care community

Inclusion Criteria:
- 18 years of age or older
- Cared for someone who died with advanced dementia within the last year
- Able to read and write English
METHODOLOGY…

Participants
• $n = 11$ participants (27 interviews)
• Aged 49 to 89 years old
• Four males, seven females
• Four cared for a parent, seven cared for a spouse
KEY FINDINGS

• Thematic analysis of 27 transcripts

• Resulting themes:
  • Weight of making decisions
  • Preparing in advance
  • Honouring wishes
  • Key safeguards

(Lubrosky, 2009)
KEY FINDINGS...

• Weight of making decisions

“You’re taking somebody else’s life and making these decisions…” Lois, wife

“I felt a lot of guilt and I don't really know just perhaps being a caregiver by profession I guess you always figure you should be doing more for them. But then there comes a point that you can’t.” Claire, daughter
• Preparing in advance

“So to me, get your ducks in a row and do what needs to be done in a timely fashion so you can move forward, and realize that what you’re doing is for this person.” Laurie, daughter

“Helen and I used to talk about things and death was one of them… what we’d do, what we should do, and we had made all our funeral arrangements at the Funeral Home.” Rudy, husband
KEY FINDINGS...

• Honouring wishes

“I thought well, you know, he wanted to die… He was lying there peaceful and I said, ‘Hey, you did it. Good for you.’ So, I couldn’t wish anything better for him than to die peaceful in his sleep.” Betty, wife

“Ultimately the goal is to carry out your mom’s wishes.” Laurie, daughter
KEY FINDINGS...

• Key safeguards

“Get a will, have a Power of Attorney, give some direction to your family or friends as to what you want at the end because when the onus falls on family they’re dealing with enough stress as it is.” Laurie, daughter
CONCLUSIONS

• Need for:
  • Planning in advance
  • Involvement of family in decision-making
  • Flexibility and fluidity in planning
CONCLUSIONS, CONTINUED...

• Need for:
  • Communication and information-sharing
  • *Death on the table* at admission to LTC
  • Education for staff
THANK YOU!

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DISCUSSION QUESTIONS

1. In your experience, what are some barriers and facilitators to end-of-life decision-making?
2. What actions or interventions have made end-of-life decision-making easier for you/your clients?
3. How can individuals, families, staff and institutions create more positive end-of-life decision-making experiences?
4. What are some individual-level changes that could improve family and client experiences around end-of-life decision-making?
DISCUSSION QUESTIONS

5. What are some system-level changes that could improve family and client experiences around end-of-life decision-making?
RECOMMENDATIONS

- For Individuals
- For families
- For staff
- For institutions
REFERENCES


