A Model of Informal Caregivers’ Experiences in End-of-Life Care

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Informal caregivers’ ability to provide care for their loved ones has been linked to a number of factors including:

- The caregiver’s health status
- Ongoing care requirements due to length of illness, often resulting in burnout
- A caregiver’s loss of freedom which can lead to depression and burnout

Purpose
Identify challenges and supports used by informal caregivers that both prevented or facilitated the provision of end-of-life care at home or in a hospital setting

- Results may provide insights on sources of caregiver burnout and/or caregiver resilience
- Findings may provide some direction to the allocation of resources to assist caregivers in the provision end-of-life care

Methods
Participants
(n=30), females (n=26), and males (n=4), Age range: 28-73 years

Relationship to loved one:
- Daughter (n=14)
- Husband (n=1)
- Wife (n=8)
- Grand daughter (n=1)
- Son (n=3)
- Sister-in-law (n=1)
- Daughter-in-law (n=2)

Procedure
Open-ended, semi structured interviews conducted Sep 2010 - Apr 2011, recorded with digital audio recorder

Questions covered a range of topics related to caregivers’ experiences including:

- General perceptions of caregivers’ experiences
- Identified challenges to their provision of care
- Identified supports to their provision of care
- Caregiver’s preferred place of death
- Loved one’s preferred place of death
- The extent to which the caregiver would change parts of the experience given the opportunity to repeat it

Qualitative, Grounded Theory (GT)
- uncovers and explains the social processes involved in end-of-life care, specifically the barriers faced and supports used by caregivers
- helps understanding of the phenomena (barriers and supports) to develop an explanatory model of the challenges and facilitative factors identified by caregivers in end-of-life care.

Results

Conceptualization of paradigm of caregiver experience

- Identified supports
  - family support
  - caregiver role sharing
  - preparedness/understanding of signs of dying
  - caring relationship with formal caregivers
  - workplace understanding
  - symptom control
  - financial stability
  - values/spirituality

- Identified challenges
  - financial issues
  - family dysfunction
  - multiple roles
  - exhaustion
  - insufficient respite
  - lack of services/knowledge
  - perceived healthcare staff insensitivity
  - social isolation

Stages in Grounded Theory Analysis

1. Causal Condition - fundamental context/condition that provides the basis for the phenomenon to occur
2. Phenomenon - overarching concept that unifies the data
3a. Context - influence causal conditions and phenomena in that they occur together and represent one another
3b. Intervening conditions - broad and general factors influencing participant’s development of strategies to cope with the phenomenon
4. Strategies - employed to account for the phenomenon: which strategies helped in the provision of end-of-life care by making use of existing supports or removing barriers?
5. Consequences - related to the outcome of employed strategies, which are influenced by other components of the conceptual paradigm

Future Directions
1. Feedback to Cape Breton District Health Authority/Palliative Care Services regarding thematic analysis
2. Academic paper
3. Further exploration of the care giving experience over the continuum, not only the final days of life

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References