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[1]
- Ongoing care requirements due to length of illness, often resulting in burnout[2]
- A caregiver's loss of freedom which can lead to depression and burnout[3]

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
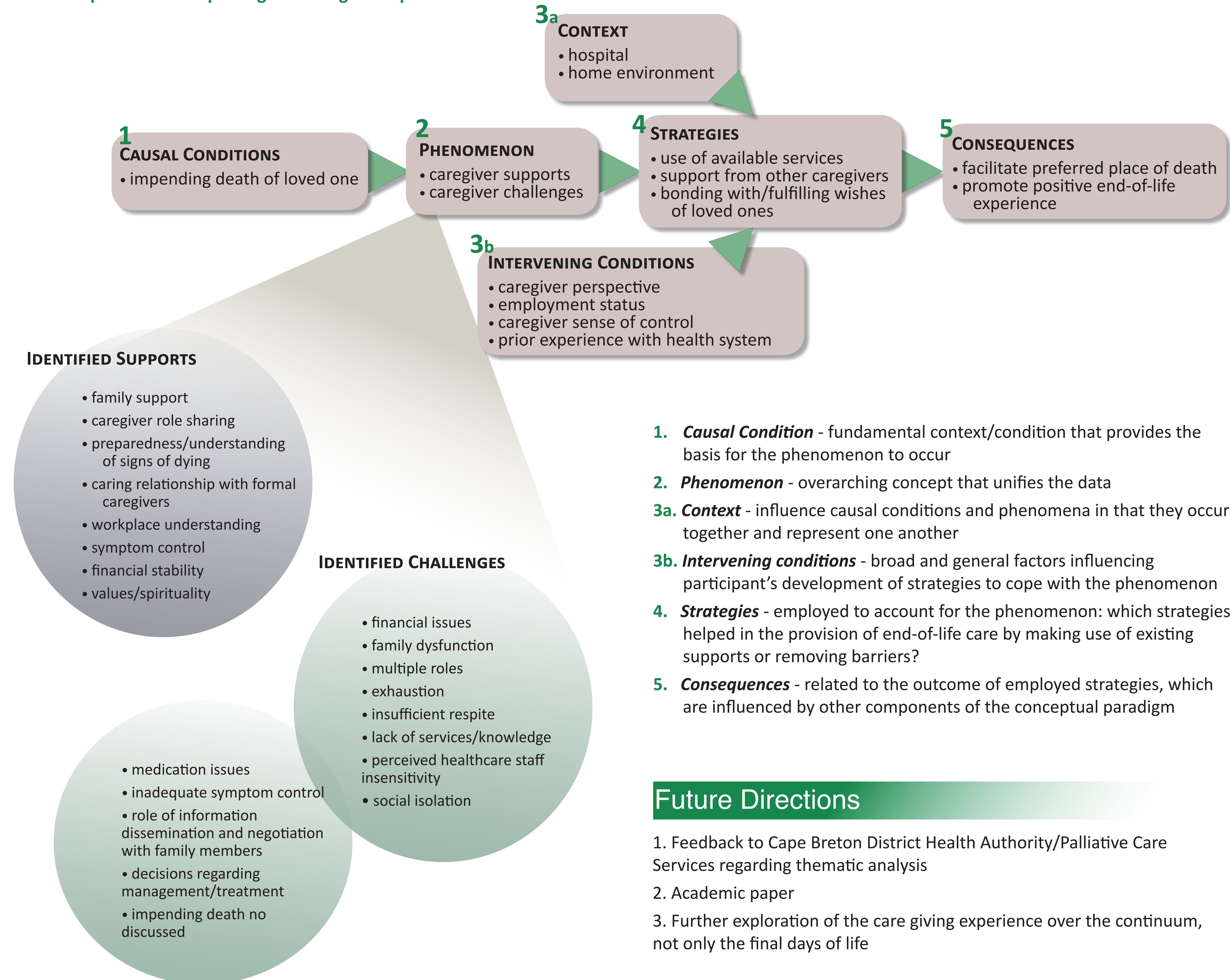
Qualitative, Grounded Theory (GT)

- 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.

Stages in Grounded Theory Analysis[4]

Open Coding	Data is collected, compared, often line by line, and categories naturally emerge
Axial Coding	Recognizing categories, and specifying relationships between these categories
Categorization	A concept or group of concepts that has been revealed by constant comparison
Classification	Sorting of the revealed concepts into explanatory theories

Results

Conceptualization of paradigm of caregiver experience[5]

3a CONTEXT
- hospital
- home environment

1 CAUSAL CONDITIONS
- impending death of loved one

2 PHENOMENON
- caregiver supports
- caregiver challenges

4 STRATEGIES
- use of available services
- support from other caregivers
- bonding with/fulfilling wishes of loved ones

5 CONSEQUENCES
- facilitate preferred place of death
- promote positive end-of-life experience

3b INTERVENING CONDITIONS
- caregiver perspective
- employment status
- caregiver sense of control
- prior experience with health system

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

- medication issues
- inadequate symptom control
- role of information dissemination and negotiation with family members
- decisions regarding management/treatment
- impending death no discussed

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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