

## Collaborative Research about Caregivers and End of Life Care in a Small Community

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## Introduction

- How to support research in a small community?
- Interface between Cape Breton University and District Health Authority
- Research issues
- As a result: interest in palliative care

### Research team:

- Sheila Profit, BScN, RN, MAEd. Over 35 years in nursing in the areas of Public Health, Mental Health, Community Health Planning and Administration. Currently Associate Professor of Nursing, CBU
- Sue Korol, Ph.D. Psychology. Background in the psychosocial determinants of health and counseling psychology. Associate Professor of Psychology, CBU
- Anne Frances D'Intino - MD, Post Graduate Diploma in Palliative Medicine. Palliative Care Physician at the Cape Breton Regional Hospital and recently Adjunct Professor at Dalhousie and Cape Breton Universities.

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## Palliative Care Research

- Purpose is often to understand and improve the quality of life of patients near the end of life
- Paucity of research into "best practices" at end of life
- No research on palliative care in our district
- Expressed an interest in how informal caregivers are managing

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### Strengths and Challenges of Collaboration

- Many perspectives from different disciplines
- Many perspectives from different institutions
- Role of PI
- Organization of work
- Ethical approvals
- Decisions regarding authors

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### Case Study

- Initially did a case study focusing on one caregiver's perspective on her ability to provide end of life care for her loved one who died at home
- From this we developed many questions such as:
  - Is this perspective different than caregivers of a loved one who dies in hospital?
  - Is place of death determined by the caregiver or the person who is dying?

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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 (Coe & Houten, 2009).
- Ongoing care requirements due to length of illness, often resulting in burnout (Gaynor, 1990).
- A caregiver's loss of freedom which can lead to depression and burnout (Spring, Rowe & Kelly, 2009) .

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### Main Research

- **Purpose:** To 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 in Cape Breton Regional Municipality (CBRM).
  - 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.

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### CBRM

- Approx. 104,000 people
- Comprised of original areas of Sydney, Glace Bay, New Waterford, North Sydney, Louisbourg, rural area in between
- Mix of densely populated areas and rural areas
- Just recently have a palliative care unit for short term stays to help with symptom management
- No hospice in our area
- Place of death for people is at home, in our smaller hospitals and infrequently in palliative care unit
- Family members for people are often away working and not home

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### Method

- Open-ended, semi structured interviews were conducted at a mutually convenient location.
- Questions covered a range of topics related to caregivers' experiences.

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### Procedure (cont'd)

Content of questions included:

- 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.

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### Procedure (cont'd)

- Interviews were recorded on a digital audio voice recorder. In addition, handwritten notes were taken by the interviewer.
- All interviews were conducted between September 2010 and April 2011.
- All interview done by research investigators Profit and Korol as stipulated by ethical review

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### Participants

- **Participants**
- (n=30), females (n=26), and males (n=4), Age range: 28-73 years
- Relationship to loved one:
- Daughter (n=14)
- Wife (n=8)
- Son (n=3)
- Daughter-in-law (n=2)
- Husband (n=1)
- Grand daughter (n=1)
- Sister-in-law (n=1)

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**Methodology - Qualitative, Grounded Theory (GT)**

- Grounded Theory is used to uncover and explain the social processes involved in end of life care, specifically the barriers faced and supports used by caregivers.
- GT is used to help our 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.

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**Stages in Grounded Theory Analysis**

- 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.

(Hallberg, 2006)

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**Results - Conceptual paradigm** (Strauss & Corbin, 1990)

- Based on Strauss and Corbin's paradigm of caregiver experiences

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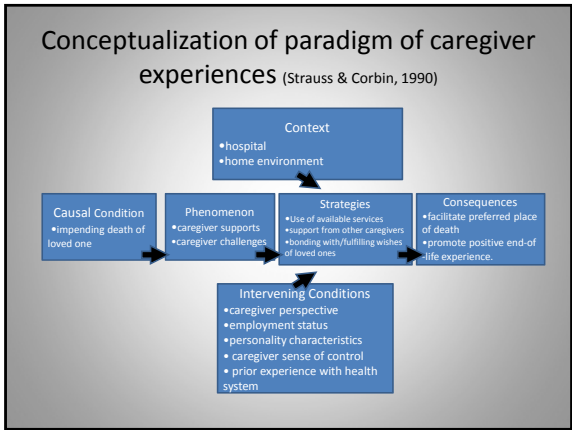
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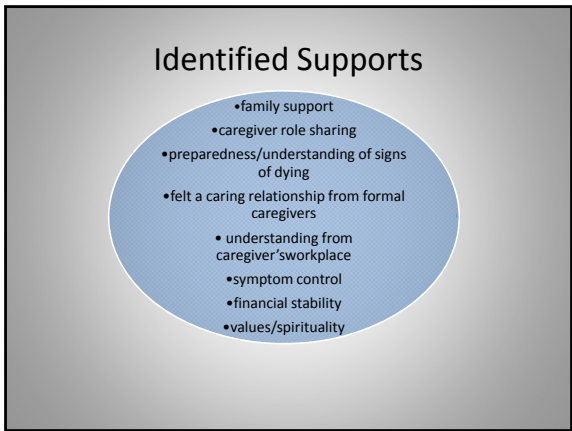
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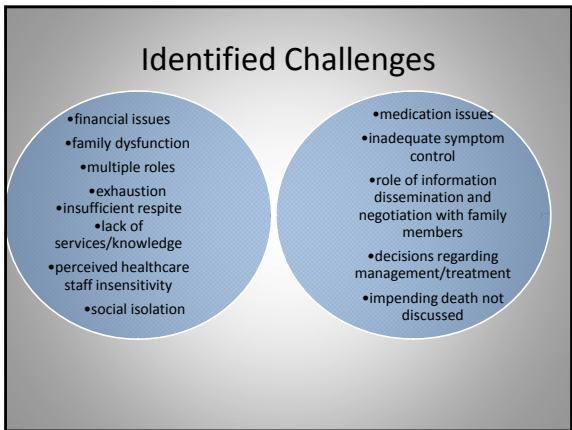
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### Other Results

- Often people who died in hospital had been there for only a few days and significant caregiving was done prior to final admission to hospital
- Caregivers also felt very responsible for their loved ones even in hospital
- Caring activities done by caregivers similar whether the person died at home or in the hospital
- Person's experience very different if died in a palliative care unit (do not have hospice unit) or if died in another part of the hospital
- Whether the person dies at home or in hospital, the interface between services provided in the home and hospital often became a source of concern for the caregiver

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### Future Directions

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

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### Spin Offs From the Research

- A request to collaborate with research teams in Cuba and Spain in the areas of palliative care and healthy aging
- On going discussion about collaboration with Dalhousie University in further qualitative research in the area of palliative care to complement the quantitative research they have been doing
- Dr. D'Intino has started a Masters in Health Research in Wales

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- Canada Research Chair (Tier 2) focusing on Determinants of Healthy Communities – Reference #CRC1103 is being advertised for Cape Breton University

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