



It Takes a Village: Enhancing Community Support to Rural Informal Providers of Care at the End of Life

Community Engaged Research
Research Exchange Group on Aging

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Research Question

- What is the current state of P/EOL services in rural NL, and how does this impact (either positively or negatively) the capacity of informal caregivers to provide effective P/EOL care in rural communities?
- *Conceptual Framework:*

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My Conceptualization of Intermediate Resources (IR):

- Using a concept analysis model to move from conceptualization to measurement (Sartori, 1984)
- Intermediate resources are non-intimate (informal), non-professional (formal) helping encounters
 - **Boundaries, Membership, Measurability**

A Continuum of “support” and “care”:



- When informal care is not available
- When formal care is downsized or eliminated
- When informal providers live at a distance
- When informal care is not the preferred option

My Conceptualization of Intermediate

Resources cont'd:

- **Boundaries:**
 - Referents of the concept that contribute to boundedness
 - IR require some level of organization
- **Membership:**
 - Referents that further the concept's discriminatory power
 - IR emphasize choice and control by user
- **Measurability:**
 - Referents that provide the operational definition
 - IR relates to activities of Instrumental and Advanced Activities of Daily Living (ADL) scale

Levels of Functional Assessment:

- Basic Activities of Daily Living (ADLs)
 - Feeding, Toileting, Dressing, Bathing,
- Instrumental Activities of Daily Living (IADLs)
 - Cooking, Cleaning, Laundry, Shopping, Transportation, Managing money, Managing medication
- Advanced Activities of Daily Living (AADLs)
 - Socialization, Recreation

Examples of Intermediate Resources:

- meals on wheels or wheels to meals program
- transportation
- visiting or respite
- home maintenance assistive devices (training and support)
- spiritual support

What We Know:

- The majority of individuals prefer to die at home
- Identified as a basic human right (aspirational)
- Costs of care at home are significantly lower
- Focus is on quality of life for patients and their families
- Includes management of pain, symptoms, stress, and bereavement
- Delivered by collaborative and seamless models of care



Palliative Care in Canada

- 1990s Special Senate Committee on Euthanasia and Assisted Suicide
 - Identified absence of P/EOL care and led to a subsequent report 2010
- 70% of Canadians do not have access to P/EOL care
- As a result “many [see] euthanasia and assisted suicide as their only hope of dying with dignity” (Carstairs, 2010)

Rural Palliative Care

- Heavier reliance on informal care
- Gaps in education and ongoing training and support
- Geographic isolation – fragmented services, entangled personal and professional roles, inadequate coordination and standardization of care
- Also – social solidarity, close relationships and community commitments

Facilitators and Barriers to Receiving P/EOL care in rural settings

- Cultural sensitivity
- Practical tangible support
- Emotional support
- Spiritual support
- Solidarity of “place”
- Communication
 - HCP ↔ caregiver
 - family ↔ community

Facilitators and Barriers cont'd

- Pain and symptom control is managed
- “Patients valued being treated with respect, maintaining dignity; integration of symptom control with practical, emotional, financial, and spiritual care ...” (Grant et al., 2011)

P/EOL Care in NL

“an urgent need for the provincial government to allocate an equitable percent of the total health care budget to adequately meet the needs of the population and their families who are terminally ill and, or living with life limiting diseases throughout Newfoundland and Labrador” (O’Shea, 2008, p.12)

Learning Essentials in Palliative and End-of-life Care Training (LEAP)

- ...the implementation of a regional ‘team’ based model of palliative care organized by geography and orientation of care (long term and acute).
- Aimed primarily at formal care providers (physicians, nurses, pharmacists, social workers, etc.)

It Takes a Village!

- There is a notable lack of attention specifically to the role of the family/friend provider of P/EOL in the rural community.
- It is this gap that this project seeks to address.
 - Intermediate resources

A Strengths Based Approach

- Building on what exists (Kelley et al., 2011)
- Deep knowledge of a community's liabilities and assets as they impact the continuum of care
- Environmental scan – high and low tech
- To advance communities' capacity to undertake full spectrum of planning and delivery of P/EOL care

Objectives of the Research

- The goal of this project is to utilize a combination of high and low technology to undertake a comprehensive environmental scan and gap analysis of the state of P/EOL care in rural NL, and to assess community capacity to support effective P/EOL care especially as it pertains to informal (family/friend) caregivers.

Phase One

- What is known about P/EOL programs and services in NL?
- Phase 1: High and Low Environmental Scan
- Advisory group members will identify health care professionals (n=12, 3 from each health authority) who will be contacted to participate in a telephone interview

Phase Two

- What are the impressions of local/regional service providers and residents about the reach of P/EOL programs in rural NL?
- In Phase 2, participation in town hall style meetings will be secured through public announcements and posters (n = 80-120, one meeting in each of 8 communities - 2 from each health authority, 10-12 participants in each).

Phase Three

- What do end users – family friend providers and care receivers - of P/EOL support describe as the assets and challenges of dying in place?
- In Phase 3, in-depth interviews will be conducted with informal providers and receivers of palliative/end-of-life care (n = 12).

Recruitment (Steinhauser et al. 2006)

- Challenges:
 - Poor prognostic accuracy
 - Gatekeeping
 - Variation in interpreting eligibility
 - Lack of time and incentive
- Facilitators:
 - Establishing long term reciprocal commitment
 - Paired consent
 - Setting boundaries

The Deliverable:

- An enhanced ability of each community to understand its capacity and needs
- A better understanding and appreciation of the variables that may differentially affect the relative strengths and needs of rural communities more generally, and
- The inclusion of the views of carers and receivers of EOL care at home in rural communities

Waldrop and Kirkendall (2010)

- the importance of context: “meeting people where they are – both geographically and on their disease course” (p. 283).



Thank You!
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