

# Experience of Care during the End of Life: A Population-Based Mortality Follow-back Study

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*Inspiring Minds. Impacting Communities.*

**NELS** | Network for End of Life Studies  
**ICE** | Interdisciplinary Capacity Enhancement



# Background

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- Past research has identified variations in health service **utilization** by population characteristics
  - Among cancer patients:
    - Elderly less likely registered with a palliative care program
    - Males more likely to die in hospital.
- Are these variations inequalities or inequities?
- Focus has been on cancer
  - Little knowledge of service use among people dying of disease other than cancer.

## Information gaps we seek to fill ...

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- An estimation (or tentative definition) of “need”
- Data on decision-making and choices (“wishes”)
- Location of EOL care; provided by whom
- Overall experience of EOL care
- Inclusion of all chronic disease deaths.

# Project goal

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- To examine the experience of end of life care (EOLC) among adults in Nova Scotia and to identify unmet needs & unfulfilled wishes regarding care preferences and satisfaction with EOLC using a population-based approach.

# Specific objectives

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From the perspective of the informant:

1. Estimate the prevalence of unmet need
2. Estimate whether decedent care preferences (wishes) were fulfilled
3. Estimate the satisfaction with EOL care received
4. Examine the associations between age, sex and location of care with decedent unmet need, unfulfilled care preferences (wishes) & satisfaction with EOL care.

# Approach – Mortality follow-back survey

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- A population-based design strategy to describe the events around death
  - Used in the UK, USA and Italy
- Retrospective data collection
  - Family or informal caregivers (informants)
- Allows representative sampling of decedents
  - Avoids challenge of identifying who is terminally ill
  - Burdening the very ill
  - Reduces the risk of missing data due to poor function, cognition etc.
- Limitation: validity of proxy responses.

# Method

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## Design

- Population-based mortality follow-back survey
  - Administered by telephone

## Subjects

- Death certificate informants of all who died within 4-9 months of sampling date (target n=1200)
- Exclusion criterion:
  - <18 years at death
  - Death due to external causes, medical or surgical complications, war, assault, accidents, self-harm
  - Incomplete informant contact information.

# Process

## Population

All eligible deaths between June 1, 2009 to May 31, 2011, (~15,000 over 2 years)



## Subjects

'Informants' listed on the death certificate  
Contacted in six 'waves', every 4 months, 4 to 9 months following the decedent's date of death



## Contact

Initially by mail (express post) via Nova Scotia Vital Statistics

- Letter of invitation, study information

Interested informants return their contact information to researchers

- Telephone interviews are then arranged



# Survey

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- ‘After-death bereaved family member interview’ (Teno J et al. 2004)
  - Good validity, reliability
  - Adapted for Canadian use
  - Added a number of questions of interest to the study
- Items target care, needs and care preferences (wishes) for both the **last month & last few days** of life.

# Primary outcomes

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- Unmet need
  - Physical comfort & emotional support
    - Pain control, breathing problems, anxiety or sadness
  - Focus on individual
    - Help with personal care, treatment with respect & dignity
- Unfulfilled care preferences (wishes)
  - Advanced care planning
    - Desire for medical treatment, medical procedures & provision of care being consistent with decedent wishes
- Location of death (desired vs realized)
- Satisfaction.

# Where are we now ...

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## Process

- Now in the 3rd year of 4
  - Wave 1: February 2010
  - Wave 5: June 2011
  - Wave 6: October 2011

## Participation

- Invitations sent: 4268
  - 311 known to be non-eligible (not delivered; contacted as a sudden death)
  - **Total potentially eligible: 3957**
- Response rate: 26%
  - ~ 800 interviews completed (Aug/11).

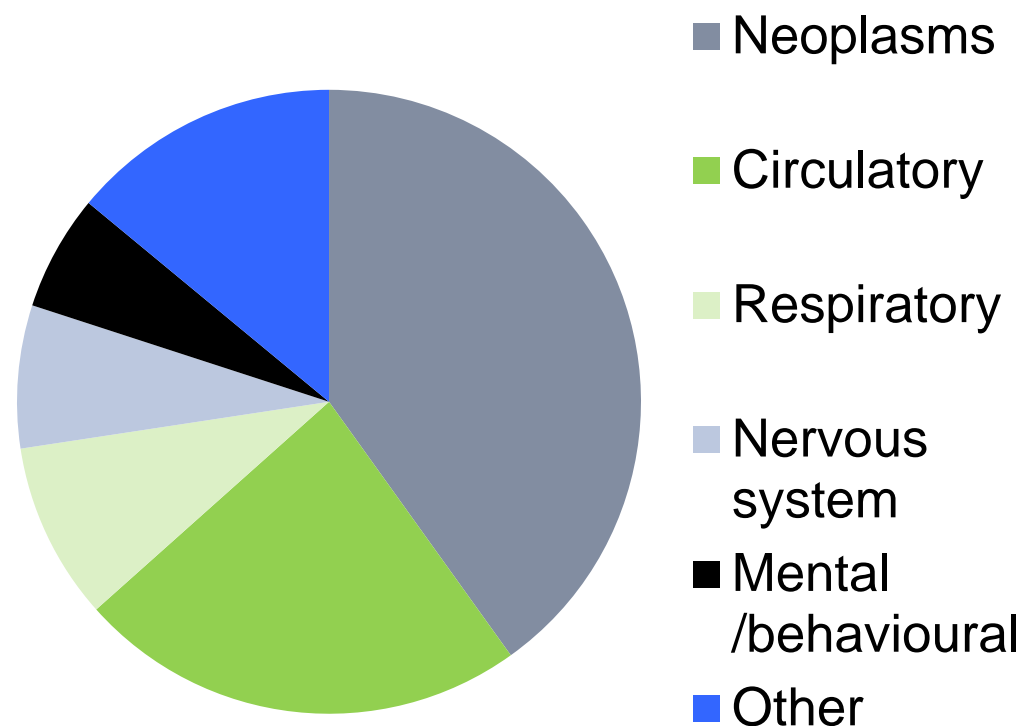
## Preliminary findings

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### Decedent characteristics (n=621)

- 54% female
- 48% married
- Mean age 79.3 (SD 12.3)
- 22% lived alone
- 57% palliative care involvement

### Cause of death



## Preliminary findings

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- Location of majority of care during last 30 days
  - Home (42%), hospital (30%), long-term care (28%)
  - 69% of **patient days** were spent in the community (home or long term care)
- Most voice the desire to die at home (70%); few do (23%)
  - Highlights the need to support those who wish to die at home
- EOL information, help & care is provided at home primarily by nurses & informal caregivers
  - Opportunities for Primary Care to fill some gaps
- Satisfaction with care
  - Trend toward lower ratings of care provided in hospital.

# Challenges

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- Low response rates
  - Reflect inability to contact potential participants directly
  - Cannot identify sudden deaths (ineligible)
  - Incorrect informant names/addresses listed on death certificates
- Survey design / telephone administration
  - Wonderful interview team, but there is an emotional toll
  - Participants often frustrated by the structured interview ...
- Survey tool
  - Best fits a death trajectory with a steady decline, such as cancer
  - Loss of narrative.

# The Rewards

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- **Wealth of EOLC information**
  - First Canadian **population-based** estimates of patient need & care preferences at the EOL
  - Comprehensive information on all adult deaths due to chronic disease, going beyond cancer
- **Respondents are openly thankful**
  - To Dalhousie Family Medicine for conducting this survey
  - For a listening ear
    - To hear their stories
    - Share their grief
    - Share criticisms with the hope of making changes in the system
    - For providing them the opportunity to potentially make a difference.

# Next steps

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- Qualitative study
  - Follow-up on:
    - The unmet needs and wishes identified from the survey
    - What works.