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## Background

Improving care at the end of life (EOL) is important for Canadians.

Although most Canadians tend to die in hospital, a large proportion receive their EOL care in the home during the last month of life.

Given the increasing trend to keep people in the community as long as possible, we wondered who was providing care and information to the dying and their families.

## Approach

Prospective approaches to dying persons present many challenges such as:

- The identification of who is terminally ill
- Burdening the very ill
- Missing data due to poor function, cognition etc.

## Mortality Follow-back Surveys

- Retrospective examination of the experience of EOL care from the family's perspective
- Used internationally (UK, USA, Italy)
- Allows for representative sampling
- Limitation: validity of proxy responses.

## Objective

To describe, from the family's perspective, who provides EOL information and care to adults spending the majority of their last 30 days of life in the home.



## Acknowledgement

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## Method

Population based mortality follow-back survey, administered by telephone.

## Setting

Nova Scotia, Canada (population ~950,000).



## Subjects

Death certificate informants of all Nova Scotians (18+ years) who died of chronic disease during a two year study period (June 2009-May 2011).

## Process

- Informants are invited to participate across six waves by a couriered letter from Nova Scotia Vital Statistics.
- Due to privacy concerns, they cannot be contacted directly by the researchers.
- Informants must then contact the researchers directly to take part.

## Survey Instrument

- The 'After-death bereaved family member interview' (Teno J et al. 2004)
- Adapted for Canadian use.

## Measures

- Location of care
- Care preferences
- Care and information provided :
  - by whom
  - what to expect
  - what to do at death
  - about medications
  - symptom management.

## Analysis

Primarily descriptive, proportions, percentages, means for this reporting.

## Conclusions

Data collection is ongoing. Preliminary analysis suggests much of the EOL information, help and care provided to those at home are provided by nurses and informal caregivers. There are many opportunities for Primary Care to fill some gaps.

## Results

As of October 2010, two of six waves were completed

- 24% response rate
- 244 completed surveys.

The inability to directly contact potential participants is a major challenge that has affected response rates.

## Decedent characteristics

- 50% female, mean age 74 (SD 14.5)
- 61% married
- 60% had private health insurance above provincial coverage

Figure 1: Major cause of death

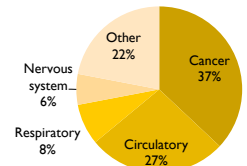
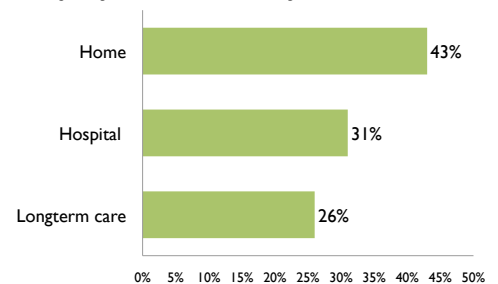


Figure 2. Location where decedents spent the majority of their last 30 days



## Information needs

Of decedents who spent the majority of their last 30 days in the home:

- 39% were **NOT** told what to expect near death
- 54% did **NOT** know what to do at time of death
- 27% did **NOT** have information about the medications used for symptom management
- When this information was received, specialist physicians and palliative nurses provided it.

## Care in the home

Of decedents who spent the majority of their last 30 days in the home:

- Informal caregivers provided the majority of care for the decedent's pain (62%), breathing (43%) and anxiety/sadness (62%) needs
- Family provided 81% of the help for the decedent's personal care needs.