Who provides information and care at home in the last 30 days of life: Opportunities for primary care

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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.

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
• 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.

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.

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.