Unmet needs & unfulfilled wishes at the end of life: A population-based mortality follow back study


**Background**

- Have identified variations in health service utilization by population characteristics
- Focus on cancer deaths
  - Elderly less likely registered with a palliative care program (PCP)
  - Males more likely to die in hospital
- No knowledge of service use among people dying of other chronic disease.

**Do these inequalities represent inequities?**

- An inequity may occur if:
  - People with the *same needs* receive different care due to *non-need factors* (e.g., age, sex, income, culture, geography)
  - People with *greater need* do not get more care than those with less need

**However …**

- Inequalities may be due to variations in patient preferences for care (wishes)
  - The elderly may decline intervention or PCP enrollment
- No population based measures of patient need or their care preferences (wishes).

**Inequities in end of life (the particularly vulnerable)***

<table>
<thead>
<tr>
<th>Group</th>
<th>Inadequate End of Life Care</th>
<th>Evidence Indicating Possible Increased Risk for Inadequate End of Life Care</th>
<th>Those who have Less Option to Manage Risk of Inadequate End of Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>The elderly</td>
<td>X</td>
<td>Refer to PCP 85–94y AOR = 0.8 75–84y AOR = 0.7 85+ AOR = 0.4</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>X</td>
<td>Refer to PCP  AOR = 0.8</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>X</td>
<td>Refer to PCP  Low-middle AOR = 0.7</td>
<td></td>
</tr>
<tr>
<td>People with low SES</td>
<td>X</td>
<td>AOR = 0.8</td>
<td></td>
</tr>
<tr>
<td>People in rural areas</td>
<td>X</td>
<td>Francophone AOR = 0.6</td>
<td></td>
</tr>
<tr>
<td>Cultural, religious and ethnic minorities</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*NELS ICE WIP June 6, 2007

**Future Directions***

- Biggest gap is estimate of “need”
- We require age and gender specific data on utilization and outcome
- Also, require age and gender specific data on decision-making/choices

- In moving toward a prospective study we might first consider a “mortality follow back survey” approach

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Project goal

- 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

From the perspective of the decedent’s family or informal caregiver (informant), we will:

- estimate the proportion of unmet needs
- estimate whether decedent care preferences (wishes) were fulfilled
- estimate the satisfaction with end-of-life care (EOLC) received
- examine the associations between age, sex and location of care with decedent unmet need, unfulfilled care preferences (wishes) and satisfaction with EOLC.

Mortality follow-back survey

- A population-based design strategy to describe the events around death
  - Used in the UK, USA and Italy
- Data are collected retrospectively
  - Family or informal caregivers (informants) about a decedent’s EOLC
- Allows representative sampling of decedents
  - Avoids challenge of identifying who is terminally ill, burdening the very ill & reduces risk of missing data due to poor function, cognition etc.
- Limitation: validity of proxy responses

Linkage to conceptual model for examining EOLC

Anderson’s behavioural model of health service utilization

Method

Design

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

Subjects

- Death certificate informants of all who died within 6 months of sampling date (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

Sampling

- Simple random sample of all eligible deaths
  - Representativeness by sex and age expected
- Poor response rate expected due to sampling process
  - Vital statistics will contact the informant by mail who must then contact us if interested …
  - Project the need to sample 3000 informants to obtain 1200 completed interviews
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**Sampling process**

- The timing of the initial contact & interview needs to be consistent
- Ideally each interview completed within 8 months of death
  - To maximize response
  - Reduce recall bias
- Random sampling process will be repeated in ‘waves’ (~6) over a 24 month period

**Survey Instrument**

  - Adapted for Canadian use
  - Good validity, reliability
  - 6 problem score domains; 2 scale scores
- Items target care, needs and care preferences (wishes) for both the last month & last week of life
  - Fulfillment of needs or wishes are only asked if the need or wish had been voiced or desired

**Other data needs**

- Administrative health data
  - To validate provincially funded service provided
  - MSI, DAD, NSCC, PCP
  - Link to survey response to assess actual use
- Canadian census information
  - To develop an urban/rural indicator

**Measures**

**Primary outcomes**

- Unmet need
  - Physical comfort & emotional support *
    - 5 items tap pain control, breathing problems, dealing with decedents feelings of anxiety or sadness
  - Focus on individual *
    - 6 items tap unmet need for help with personal care, treatment with respect & dignity
- Unfulfilled care preferences (wishes)
  - Advanced care planning *
    - 3 items voice desire for medical treatment, medical procedures & provision of care being consistent with decedent wishes

* problem scores

**Other variables**

**Predictors of interest**

- Age
- Sex
- Location of care (5) – also an outcome

**Covariates**

Using Andersen model as guide …

- Environmental factors
  - Health system factors (residence, year of death)
- Population characteristics
  - Predisposing characteristics
  - Enabling resources
  - Need (evaluated & perceived)
- Health behaviours

**More primary outcomes …**

- Desired vs actual location of death
  - Hospital
  - Long term care
  - Home
    - With PCP support
    - With home care
    - With no external support
- Satisfaction
  - 5 item scale scoring patient focused, family centered care
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Analysis

• Descriptive
  • All items, problem score domains, scales
  • Outcomes – proportion with unmet needs, unfulfilled wishes

• Chi square
  • Assess association of each predictor (age, sex, location of care) & each outcome

• Multiple regression
  • Model interaction effects
  • Linear & logistic
  • Modeling to assess confounding/modifying effects of additional covariates

Assessment for potential bias

• Selection bias
  • Compare sample distribution of age, sex, cause of death to all eligible NS deaths (chi-square)

• Informant recall bias
  • Compare provincially funded health services provided to informant survey responses

• Proxy informant bias
  • Sensitivity analysis by adjusting for proxy respondent characteristics

Where are we now?

• 4 year study
  • Ethics the first major hurdle (June) …
  • Additional modifications to the survey required
    • Convenience pilot of survey (Fall)
  • Fine tune a workable process with Vital Statistics (ongoing)
  • Hire an interviewer familiar with research methods but also sensitive to bereavement issues … hope to begin January 2010!