

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

NELS Network for End of Life Studies
ICE Interdisciplinary Capacity Enhancement

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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)
- or
- 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)*

	Those who have increased risk for inadequate end of life care beyond individual control	Evidence indicating possible increased risk for inadequate end of life care	Those who have less option to manage the risk of inadequate end of life care
The elderly	X	Referral to PCP 65-74yr AOR = 0.8 75-84yr AOR = 0.7 85+ AOR = 0.4	
Women	X	no	
Men		Referral to PCP AOR = 0.8	
People with low SES	X	Referral to PCP Low-middle AOR = 0.7	X
People in rural areas	X	AOR= 0.8	X
Cultural, religious, and ethnic minorities	X	Francophone AOR=0.6	X

*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

*NELS ICE WIP June 6, 2007

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:

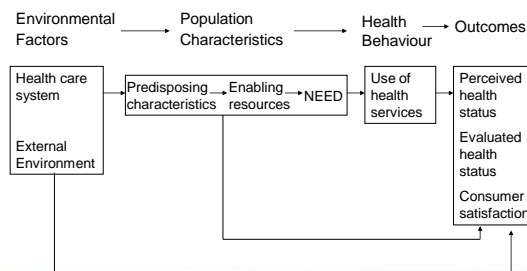
- estimate the proportion of unmet needs
- estimate whether decedent care preferences (wishes) were fulfilled
- estimate the satisfaction with end-of-life care (EOLC) received
- examine the associations between age, sex and location of care with decedent unmet need, unfulfilled care preferences (wishes)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

Andersen'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

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

- 'After-death bereaved family member interview' (Teno J et al. 2004)
 - 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

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

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

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!