Experience of care during the end of life: Early results from the Nova Scotia mortality follow-back study

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Outline

• Background
• Objectives
• Approach
• Primary outcomes
• Survey examples
• Initial findings
• Next steps
Background

• Past research has identified variations in health service utilization by population characteristics
  o 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
  o Little knowledge of service use among people dying of disease other than cancer
Information gaps we sought to fill

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

Design

• Mortality follow-back survey
  o A population-based strategy to describe the events around death
  o Data are collected retrospectively from the perspective of the ‘informant’.

• Allows representative sampling of decedents
  o 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.
Participants

• ‘Informants’ (family or informal caregiver)
  o Recorded on the death certificate of all Nova Scotians who died between June 2009 – May 2011.

• Exclusions:
  o <18 years at death
  o Death due to external causes, medical, surgical, pregnancy complications, self-harm
  o Incomplete informant contact information
  o Sudden unexpected death (information obtained upon contact)
**Process**

**Population**
All eligible deaths between June 1, 2009 to May 31, 2011, (~6,000 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 through Nova Scotia Vital Statistics
- Letter of invitation, study information
Interested informants return their contact information to researchers
- Telephone interviews arranged
Survey

• ‘After-death bereaved family member interview’ (Teno J et al. 2004)
  • Personal & emotional support
  • Personal care
  • Shared decision making
  • Wishes/planning
  • Communication near death
  • Co-ordination of care
  • Satisfaction
    o Adapted for Canadian use
    o Added additional questions of interest
• Targeted the last month & last few days of life.
Primary outcomes

• **Care preferences** *(wishes)*
  - Location of death/preferred location of death
  - Advanced care planning

• **Need**
  - Physical comfort & emotional support
  - Focus on individual
    - Help with personal care, treatment with respect & dignity

• **Satisfaction.**
Data collection is complete

- Data collection phase
  - Wave 1: February 2010
  - Wave 6: October 2011
  - Completed: May 15, 2012

- Analyses
  - Summer 2012, ongoing

- Service validation
  - Fall 2012

Response rate: 26.4%

- Invitations sent
  - N=5848

- Returned/Not eligible (known)
  - n=477

- Eligible (potentially)
  - N=5371

- Total consenting to take part
  - N=1410

- Completed
  - n=1358
Findings

Participants

Informants (care-givers) n=1316

• Female (70%)
• Average age: 63.9 yrs. (std 11.4); Range: 27-96
• Relationship to decedent:
  o Child (48%)
  o Spouse (36%)
• Highly educated
  o 50% postsecondary graduate or higher!
Decedents

- Female (51%)
- Average age 79.1 yrs.
  - Range 19-107
- Marital status:
  - Married (48%)
  - Widowed (39%)
- Education
  - Postsecondary (26%)
  - Less than high school (43%)
- Lived alone (17%)
- Visible minority (7%)
- Cause of death
  - Cancer (38%)
  - Non-cancer (62%)
- Location of death
  - Home (18%)
  - Hospital (57%)
  - Long-term care (25%).
Cause of death*: Nova Scotia 2011

- Cancer: 36%
- Circulatory system: 34%
- Respiratory system: 9%
- Nervous system: 5%
- Other: 16%

*Ineligible accidental deaths are not included in denominator, however sudden deaths are...
Location of care during the last 30 days

Initial questions sought to identify where care was provided and for how long …

a. About a month or 30 days before ‘John’ died, where was he staying?
   i. For how many days was that?

b. Did he go anywhere after that?
   i. Where was that?
   ii. How long was he there?

Questioning continued until the place of death.
30 days before death

Home

n=274

*  

Home

Hospital

% of decedent:

1.1 1.4 0.4 32.1 2.9 3.3 56.2 2.5

Place of death

Hospital

Home

Hospital

Home

Hospital

*
30 days before death

Place of death

% of decedents

LTC n=147

Home

Hospital

LTC

Hospital

LTC

Hospital

0.7

0.7

0.7

73.5

19.0

4.1

0.7

0.7

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30 days before death

Place of death

% of decedents

Hospital n=98

- Home: 8.2%
- Hospital: 73.5%
- LTC: 1.0%

* Home: 5.1%
* Hospital: 9.2%
* LTC: 1.0%

* Home: 1.0%
* Hospital: 1.0%
Location of majority of care

- **Home**: 20.2% (Last few days) vs. 40.3% (Last 30 days)
- **Hospital (all other units)**: 21.4% (Last few days) vs. 33.9% (Last 30 days)
- **Hospital-Palliative inpatient unit**: 9% (Last few days) vs. 20.4% (Last 30 days)
- **Long-term care**: 25.5% (Last few days) vs. 29.3% (Last 30 days)
Services provided

Palliative care (PC)

• 62% reported PC was presented as ‘an option’
• Of those who said yes:
  o 74% indicated a specialized PC program was involved at some point during the last 30 days
    • Involvement ranged from 1 to 30 days
    • 65% had involvement in the hospital (all units)
    • 50% in the home
    • 18% in long-term care
Services provided
If the majority of care was provided in the home (n=623)

Palliative care (PC)
- 67% reported PC offered as an option
  - 84% had some PC program involvement

Home care
- 49% received some homecare services
  - 75% of these were offered by the province

Nursing Care
- 63% received services from a visiting nurse

Family physician visits
- 27% received at least one home visit
- 40% made at least one office visit
  - 62% had at least one home or office visit
Openness about dying during the last 30 days of life

Informants

“During ‘John’s’ last 30 days, did YOU know that he didn’t have long to live?”

- Yes: 64%
- No: 30%

The Decedent

“Did John know that he didn’t have long to live?”

- Yes: 49%
- No: 35%
- Not sure: 15%

“Did he speak openly about the fact he was dying?”

- Yes: 40%
Care preferences (wishes)
Survey question examples

Location of death (preferred vs actual)
- Did ‘John’ ever say where he would prefer to die?
- Where was that?
- Was this always their wish?
- Where did his death take place?
Location of death

• **48%** voiced a preferred location of death
  - 73% home
  - 16% hospital (more than half specified a palliative care unit)
  - 10% long-term care

• **For 86%** this was always their wish & remained so.
Comparison of last preferred and actual location of death

- **Long-term care**
  - Preferred: 10.2%
  - Actual: 25.2%

- **Hospital**
  - Preferred: 15.7%
  - Actual: 56.8%

- **Home**
  - Preferred: 73.4%
  - Actual: 17.9%

Proportion of decedents
Of those who voiced a preference …

- If the decedent wished to die:
  - At HOME: 39% were able to (175/446)
  - In HOSPITAL: 91% did (87/96)
  - In LONG-TERM CARE: 84% did (52/62).
Why people changed locations …

• Primarily due to ‘medical emergencies’
  o Bleeding, bowel obstruction, inability to eat, vomiting, breathing problems
  o ~ 24% expressed caregiver burden, family and/or decedent preference

• Large discrepancy between preferred and actual location of death
  o Most would prefer to die at home, but few do
  o Need to support Nova Scotians who wish to die at home & their families.
Care preferences: more question examples

Advanced care planning
(Desire for medical treatment/procedures & provision of care being consistent with the decedent’s wishes)

- Did ‘John’ have specific wishes or plans about the types of medical treatment he did or did not want while dying?
- Did his doctor or other medical staff speak to him or you about making sure the care received was in keeping with his wishes?
- Did ‘John’ have a signed Living Will or Advanced Directive of some sort giving directions for the kind of medical treatment he would want if he could not speak for himself?
Care preferences (wishes)
Advanced care planning

- Had a signed Living Will or Advance Directive: 54.6%
- Had a signed Enduring Power of Attorney for Health Care: 64.1%
- Care was in keep with decedents wishes: 84.3%
- Had specific wishes about medical treatments: 60.3%

Proportion of decedents
Advance directives
Associations from regression analysis with having a signed living will or advance directive (LW/AD) – all decedents

Positive associations:
• Majority of care in last 30 days in long term care (vs home)
• Informant was decedent’s child (vs spouse/partner)
• Informant age – younger age groups (vs 85+)

Negative associations:
• Death due to non-cancer
• Majority of care in last 30 days in hospital acute units (vs home)
• Marital status: divorced/separated (vs married)
Survey question examples

‘Need’

Physical comfort & emotional support
(Pain control, breathing, anxiety or sadness)

- During ‘John’s’ last 30 days while ‘at home’ did he experience feeling of anxiety or sadness?
- How much help in dealing with these feelings did he receive – less than was needed or the right amount?
- Who provided this help?

- During this time did someone talk with you (the caregiver) about your religious or spiritual beliefs?
During the last 30 days of life …

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% who experienced this symptom</th>
<th>% who received the right amount of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>59</td>
<td>78</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>45</td>
<td>84</td>
</tr>
<tr>
<td>Anxiety and sadness</td>
<td>52</td>
<td>64</td>
</tr>
</tbody>
</table>
Physical comfort
Help with anxiety or sadness

• **52%** experienced feeling of anxiety or sadness
  - Cancer patients reported more (56% vs 49% for death due to non-cancer)

• Of those with these feelings:
  - **64%** felt the ‘right amount’ of help was received
    - Particularly those dying of cancer (71% vs 59%, non-cancer)
  - Help was provided by the caregiver (53%), nurses (33%), physicians (25%), others (17%).
Odds of receiving the ‘right amount’ of help for anxiety or sadness

<table>
<thead>
<tr>
<th>Variable</th>
<th>Adjusted Odds ratio ( 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cause of death (vs cancer)</td>
<td></td>
</tr>
<tr>
<td>Non-cancer</td>
<td>0.6 (0.4-0.8)</td>
</tr>
<tr>
<td>Location of majority of care (last 30 days) (vs home)</td>
<td></td>
</tr>
<tr>
<td>Hospital – Palliative unit</td>
<td>1.9 (1.0–4.0)</td>
</tr>
<tr>
<td>Hospital – All other units</td>
<td>0.7 (0.5–1.1)</td>
</tr>
<tr>
<td>Long-term care</td>
<td>1.0 (0.6–1.6)</td>
</tr>
<tr>
<td>Sex (vs male)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.3 (0.9, 1.8)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>1.0 (1.0, 1.0)</td>
</tr>
</tbody>
</table>
Survey question examples
Focus on individual

(Help with personal care, treatment with respect & dignity)

- How often were ‘John’s’ personal care needs, such as bathing, dressing, and changing bedding, taken care of as well as they should have been?
- Was there enough help available to meet his personal care needs?
- Who provided this help?
- During those last 30 days, how often was he treated with respect by those who were taking care of him?
Help with personal care

Frequency of personal care needs looked after (bathing, dressing, changing bedding)
Help with personal care

• Enough help available (78%)
• Care was primarily provided by family, nurses and personal care workers

• Significant differences associated with location of majority of care (30 days)
  o Needs were ‘always’ addressed:
    • Home (85%) vs Hospital-all other units* (66%).
Treated with respect and kindness

Proportion of decedents

Always
- Kindness: 83.9
- Respect: 84.3

Usually
- Kindness: 12.1
- Respect: 11.5

Sometimes
- Kindness: 3
- Respect: 3.3

Never
- Kindness: 0.5
- Respect: 0.5
Treated with respect and kindness

• Significant differences associated with location of majority of care (30 days)
• For both, respectful and kind treatment was perceived as more often “always provided” in the home, and least in hospital(all units except palliative care).
Communication near death …

• 61% report having received information about what to expect while their loving one was dying
  o 28% wanted some or more
• 52% were very confident in what to expect
• For those who were provided information it was provided by:
  o Nurses (74%), doctors (62%), family/friends (5%), spiritual care people (3%), others (14%)
Spiritual and emotional needs

- 35% of informants talked with someone about their spiritual or religious beliefs
  - 90% felt this was as much contact as they wanted
- 81% felt healthcare staff provided the ‘right amount’ of support to deal with their feelings about their loved one’s death
- 26% were asked by healthcare staff about their feelings
  - For those not asked, 24% would have wanted them to
Survey question examples
Satisfaction

• Overall satisfaction (last 30 days; last few days)
• Ratings:
  o 0 (worst possible care) to 10 (best possible care)
  o How well did the doctors, nurses and other professional staff who cared for ‘John’ communicate with him and the family about the illness and the likely outcomes of care?
  o How well did those taking care of ‘John’ make sure he died with dignity – that is, died on his own terms?
  o How would you rate the overall care that ‘John’ received during those last 30 days while cared for at …?
Overall satisfaction with care

• Ratings tended to be high (max 10)
  o Last 30 days of life: averaged 8.7 (SD 1.8)
  o Last few days of life: averaged 8.8 (SD 2.1)

• Rankings following adjustments for sex and age were similar for both time periods:
  1. Hospital Palliative Care Unit
  2. Home
  3. Long-term care
  4. Hospital – all other units
Overall impressions

• Overall satisfaction with care high
• There are differences with satisfaction by location
• A lot of care in community
• More AD than we anticipated
• Palliative “approach” high especially in the home
• Low rate of home visiting by family docs
• High rate of getting care needs met by homecare nurses
Challenges

• Low response rates
  o Reflect inability to contact potential participants directly
  o Cannot identify sudden deaths (ineligible)
  o Incorrect informant names/addresses listed on death certificates

• Survey design / telephone administration
  o Wonderful interview team, but there is an emotional toll
  o Participants at times frustrated by the survey structure ...

• Survey tool
  o Best fits a death trajectory with a steady decline such as cancer
  o Loss of narrative.
Rewards

• Wealth of EOLC information
  o First Canadian population-based estimates of patient need & care preferences at the EOL
  o Comprehensive information on all adult deaths due to chronic disease, going beyond cancer

• Respondents are openly thankful
  o To Dalhousie Family Medicine for conducting this survey
  o 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

• Linking the survey data to administrative health data

• Planned analyses of questions, domain and scale scores by different variables:
  o Pain by cancer vs non-cancer
  o Satisfaction by different groups

• Qualitative study

• Community based primary health care
  o Role of the family physician
  o Nurse practitioners
  o Community health teams
Thank you....