Is Medical Care that Respects Patient Wishes Associated with Having an Advanced Directive or Living Will in Place

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Background

• Advance directives or living wills (AD/LW) are encouraged to document one’s expressed wishes and conversations about healthcare choices at the end of life

• Having such a document can potentially increase the family’s satisfaction with the decedent’s care.
• As part of a population-based survey to examine the experience of end-of-life care from the family’s perspective, we asked questions about the presence of an AD/LW and satisfaction with care.
Objective

• To examine the association between the key informant rating of medical care provided that respected the decedent’s wishes and whether there was an AD/LW.
Method

Setting

• Nova Scotia, Canada
• population ~950,000.
Overall project approach

Design

• Mortality follow-back survey
  o A population-based strategy to describe the events around death
  o Data were 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)
  - Recorded on the death certificate of all Nova Scotians who died between June 2009 – May 2011

• Exclusions:
  - <18 years at death
  - Death due to external causes, medical, surgical, pregnancy complications, self-harm
  - Incomplete informant contact information
  - Sudden unexpected death (information obtained upon contact).
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
Interested informants return their contact information to researchers
• Telephone interviews arranged
Survey

• ‘After-death bereaved family member interview’ (Teno J et al. 2004)
  - Adapted for Canadian use
  - Additional questions of interest were added

• Items target care, needs and care preferences (wishes) for both the last month & last few days of life.
Measures

Outcome
  Rating of how well the medical care provided to the decedent during the last 30 days of life respected their wishes (scale 0-10)

Primary variable of interest
  Decedent having a signed AD/LW providing medical treatment directions

Potential Covariates
  • Decedent and informant demographics, additional private health insurance, location of majority of care.
Analysis

• Descriptive
• Cross tabulations
• Logistic regression
  - Univariate followed by multivariate.
Results

• Data collection spanned two years
  o February 2010-March 2012.
• Total of 1358 completed surveys
  o Response rate: 26.4%
• 1316 available for analysis
Participants

Informants (caregivers)

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

- Female (51%)
- Average age 79.1 yrs
  - Range 19-107
- Cause of death
  - Cancer (38%)
  - Non-cancer (62%)
- Lived alone (17%)
- Married (48%)
- Home care (Yes: 23%)
- Specialized palliative care (Yes: 46.2%).

Location of majority of care during last 30 days of life:

- Home: 40%
- Hospital-Palliative Unit: 29%
- Hospital-All other: 21%
- Long term care: 9%
## Rating of medical care by having a AD/LW

<table>
<thead>
<tr>
<th>Having a signed AD/LW</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Rating of the medical care provided that respected the decedent’s wishes‡</td>
<td></td>
</tr>
<tr>
<td>Best possible care (ratings of 9-10)</td>
<td>551 (61.1)</td>
</tr>
<tr>
<td>Possible gaps in care (rating &lt;9)</td>
<td>144 (48.3)</td>
</tr>
</tbody>
</table>

Chi square tests of association ‡$p<0.0001$
### Odds of receiving the ‘best possible care’ that respected the decedents wishes

<table>
<thead>
<tr>
<th>Variable</th>
<th>Adjusted Odds ratio ( 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signed AD/LW (vs No)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.6 (1.2, 2.1)</td>
</tr>
<tr>
<td>Location of majority of care in last 30 days (vs Hospital – all other units)</td>
<td></td>
</tr>
<tr>
<td>Hospital palliative unit</td>
<td>3.1 (1.6, 5.9)</td>
</tr>
<tr>
<td>Home</td>
<td>1.5 (1.0, 2.1)</td>
</tr>
<tr>
<td>Long term care</td>
<td>1.1 (0.7, 1.5)</td>
</tr>
<tr>
<td>Lived alone (vs No)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.5 (1.1, 2.1)</td>
</tr>
<tr>
<td>Informant sex (vs Female)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.6 (1.2, 2.2)</td>
</tr>
</tbody>
</table>
So….

- Having a signed AD/LW at the end of life is positively associated with the family’s rating of medical care being in keeping with the decedent’s wishes.

- Important to note this is the informant’s perception which may differ from others or the decedent.

- Primary healthcare providers can play a role in advocating AD/LW with their patients.