Using Memories to Facilitate End-of-Life Discussions

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Overview of the Problem

- It is estimated that 571,000 people will die in the United States of cancer in 2012 and patient education has not changed the completion rate of 20-30% for advance directives over the past 20 years.\(^1,\!^2,\!^3\)

\(^1\)ACS (2012);
\(^2\)Welch, Teno, & Mors (2005);
\(^3\)Durbin, Fish, Bachman, & Smith (2010)
End-of-Life Background

- 77% of all cancers are diagnosed in people 55 years and older
- Advance Care Planning includes the completion of Advance Directives
  - 85% of 108 people with terminal cancer did not make a decision about an advance directive\(^1\)
  - Disagreement between patient and families about preferences at the end-of-life\(^2\)

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\(^1\) Kierner, Hladschik-Kermer, Gartner, & Watzke (2009)
Autobiographical Memory
Background

- Autobiographical memory serve 3 functions – self, social, directive
- Directive - remembering situation that occurred in the past in order to apply what was learned to direct their present (or future)
- 53% of directive ABMs were r/t a stressful event, death/funeral, injury/illness (n=120; 18-33 yrs)
- Hospice volunteers (n=52) had reduced death anxiety using ABMs
- Hierarchical memories (specific and general – categorical)
  - People with brain injury, clinical depression, cognitive issues have more general memories
- Simple instruction and highly visual cue words (p < .001)
- No difference in gender, age with ABM

1Pillemer (2001)
2Rasmussen and Berntsen (2009)
3Bluck, Dirk, MacKay, & Hux (2008)
4Williams, Chan, Crane, et al. (2006)
5Conway and Bekerian (1987)
6Kaviani, Rahimi, Rahimi-Darabad, & Naghavi (2011)
7Williams and others (2006)
8Williams, Goddard, and Bluck
9Goddard, Howlin, Dritschel, & Patel (2007)
Research Methods

- **Design**: A two-phase, two-group, quasi-experimental pilot
- **Site**: A single, large hospice in Southwest United States
- **Sample**: Convenience, 50 people with terminal cancer
- **Approval**: Huntsman Cancer Institute, IRB at the University of Utah, Ethics Committee at the Houston Hospice
- **Research Team**: PI, QA Asst, Research RN
- **Data Collection**: CY2011
- **Inclusion Criteria**
  - Diagnosed with terminal cancer
  - Actively receiving home hospice care
  - Read/speak English
  - Age $\geq$ 55 years
  - Cognitively intact per hospice nurse’s clinical judgment
  - Palliative Performance Scale score $\geq$ 30%
- **Exclusion Criteria**
  - Diagnosed with HIV, dementia, or Alzheimer’s disease
  - Resided in acute care or IP hospice facilities
  - Executed a living will or a MPOA
Procedures

- Recruitment
  - All new patients electing hospice were eligible for study
- Screening
  - PI screened candidates (PPS) -> emailed QA Assistant
- Approach (QA Assistant)
  - Provided an introduction to the study, sent outcome to PI
- Informed Consent Visit (PI)
  - Checked EMR and called home before the visit
  - Reviewed consent form
  - Confirmed **Demographic and Clinical Characteristics**
- Consent Visit -> Intervention
  - Control group: details about diagnosis, treatment...
  - Experimental group: ABM intervention
- Evaluation
  - Phase 1- **ACP Survey**
  - Phase 2- **ACP Survey, Participant Evaluation, Researcher Observation**
- Post-Evaluation
  - Thank you letter with $10 gift

Data Collection Instruments
Instruments

- Advance Care Planning Survey – Likert, likelihood scale, 22 items, Decision making and Communication
  - Measured Living will, Ventilator, Oxygen, Feeding tube, IV fluids, Blood transfusions, Antibiotics, Surrogate, OOHDNR form, Resuscitation, and Calling 911

- Participant Evaluation – open ended questionnaire
  - Measured Effectiveness, Process, Outcome, Design, and Utilization

- Researcher Observation – open ended questionnaire
  - Measured Adherence, Prompting, Encouragement, Flow of memories, and Duration
Data Management and Analysis

- REDCap Software -> SPSS v20.0
- Descriptive statistics
- Chi-square for categorical data
- Inferential statistics for ACP Survey
  - Independent samples T-test
  - Mann-Whitney U
Study Aim

To examine the efficacy of the ABM intervention on ACP on specific aspects of advance care planning for people with cancer.

- RQ1A: To what extent does the ABM intervention increase the likelihood of decision making and communication with respect to specific aspects of advance care planning (i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics, etc.) compared to the control group?

- RQ1B: What are the remarks reported by participants on the post-intervention evaluation interview and the observations of the research team associated with the utility and implementation of the ABM intervention?
Results

- Ineligible: 91%
- Consenters: 3%
- Non-Consenters: 6%
Results: Demographic Data

- Chi-square analysis showed no difference in gender, marital status, ethnicity or race, or insurance between the consenter and non-consenter groups, as well as, control or experimental groups.
Demographic and Clinical Characteristics

- 56% Males (n=28); 44% Females (n=22)
- 70 years (median age); range 55-88 years
- 70% Caucasian; 30% Minority
- 26% lung, 16% pancreatic, 12% breast
- 34% diagnosed < 1y to hospice enrollment
- 88% completed HS/GED or more education
- 76% had Medicare for insurance
Results: Patient Evaluation

Twelve participants responded:
- 100% recalled memories of family and close friends
- 100% said it was not difficult to talk about decisions using memories
- 100% said it was not uncomfortable recalling memories
- 100% answered it was easier to talk about decisions using memories
- 100% would not change the process
- 100% did not make suggestions
- 100% did not want to share anything else
## Results: Researcher Observation

<table>
<thead>
<tr>
<th>Prompting for the intervention</th>
<th>17 (68%)</th>
<th>8 (32%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Average (range) minutes to complete:</th>
<th>46 (20 - 90)</th>
<th>43 (25 – 120)</th>
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<tbody>
<tr>
<td>Control group interview</td>
<td></td>
<td></td>
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<tr>
<td>Experimental group intervention</td>
<td></td>
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</tbody>
</table>

Name one thing you learned after this experience.
“remembering how others died helped me make my own decisions”
“how memories impact your life”
"It gave us a way to talk about a difficult topic without upsetting my daughters."

<table>
<thead>
<tr>
<th>Did you share these memories with others?</th>
<th>11 (92%)</th>
<th>1 (8%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
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</tbody>
</table>
## Results: Researcher Observation

<table>
<thead>
<tr>
<th>PI Observations of Recalled Memories</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific Memories</td>
<td>39</td>
</tr>
<tr>
<td>1\textsuperscript{st} degree relatives</td>
<td>23</td>
</tr>
<tr>
<td>2\textsuperscript{nd} degree relatives</td>
<td>6</td>
</tr>
<tr>
<td>Unrelated person</td>
<td>9</td>
</tr>
</tbody>
</table>

| Avg number of visits to complete intervention | 1.00 |
| Avg number of memories/participant           | 1.95 |
| Range for these memories                     | 1 - 4 |

- Recalled End-of-life memories: 25 (100%)
- Specific memories: 13 (52%)
- General memories: 5 (20%)
- Both (specific and general memories): 7 (28%)

Total number of memories: 55
Results: ACP Survey

- Central tendency (mean) = 4.04 – 5.96
- Negatively skewed data
- Non-parametric: Mann-Whitney U statistical tests
Results: ACP Survey

Statistically significant set with an alpha of (.01)

Experimental group had a trend toward significance:

- higher likelihood of making a decision:
  - IV therapy ($p = 0.023$)
  - feeding tube ($p = 0.063$)

- higher likelihood of communicating the decision to the surrogate:
  - antibiotics ($p = 0.005$)
  - feeding tube ($p = 0.018$)
  - OOHDNR form ($p = 0.039$)
  - blood ($p = 0.094$)
Limitations

- New instruments
- Generalization
  - Small, convenience sample
  - One hospice site
  - Terminally ill with cancer
Discussion

- Reduce patient-related barriers
  - Appropriate eligibility criteria
  - Requires an excellent prognostic screening tool
  - Simplify the enrollment process and reduce papers (consent)
- Organizational structure
  - Access to the electronic medical record
  - Education and training for PPS
  - Sufficient study pool
  - Insider help 5 day comprehensive assessment period
- Study specific barriers
  - Rapid decline; short LOS; near death referrals
Nursing Implications

- Practice: ABM intervention is a sensitive and compassionate approach to ACP
- Policy: Need consistent use of prognostic tools
  - In the last 2 weeks of life, 6-10% received chemotherapy, 4-18% received CPR
- Research: Pilot (insider) H&PC research studies

Conclusions

- Future Work includes RCT, ACP Survey reliability and validity, and Model testing with the ACP Model
- Preliminary result found an effective ABM intervention to improve ACP
  - Statistical significance
  - Non-burdensome
  - Non-threatening
  - Brief in duration
- One chance to “get it right”
Time present and Time past are both present in Time Future

Doctoral Degree Scholarship in Cancer Nursing DSCN-070221-01 from the American Cancer Society from 2007-2009