Feasibility & Preliminary Effects of an Intervention for Caregivers of Newly Admitted Hospice Patients

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Objectives

- Background
- Purpose
- Methods
- Results
- Limitations
- Implications
Life is pleasant. Death is peaceful. It’s the transition that’s troublesome.

--Isaac Asimov
Background

- Family caregivers:
  - Experience high levels of anxiety & depressive symptoms (Salmon et al, 2005)
  - Feel uninformed about what hospice services include (Casarett et al, 2005)
  - Lack skills to assess and provide symptom management (Kutner, et al, 2007)
  - Don’t know what to expect in a disease and dying trajectory & how to help loved one (Carter, 2001)
  - Feel unprepared in their role (Hebert, 2006)
  - Don’t know how to care for themselves during this stressful time (Chentsova-Dutton et al, 2002)
Background

• Physicians do not routinely discuss end-of-life options with patients and/or families, unless patient was symptomatic or patient and/or family asked for information (Keating, et al, 2010)

• Admission to Hospice (Glare & Sinclair, 2008)
  – Sudden and Unexpected
  – Focus of Care changes

• Only 6 intervention studies for population (Lindstrom & Melnyk, 2009)
  – Multiple methodological issues
Proposed Problem

Caregivers of dying loved ones lack a cognitive schema and skills for this new experience and role as a caregiver of a dying loved one.
Theoretical Framework: Self-Regulation Theory

- Cognitive Schema:
  - A picture in a person’s brain that contains knowledge and meaning about an experience
  - Provides a way to interpret what is being experienced

(Johnson et al, 1997)
Theoretical Framework: Role Theory

• The role of caring for a dying loved one is focused on holistic symptom management for both patient and caregiver

• Successful enactment of a caregiver role is feeling prepared in the role and appropriately caring for a person
Study Significance

- Everyone dies and that number is increasing
- 2,450,000 people died in the U.S in 2010
- Most people prefer to die at home, and yet, only 40% (470,596) of hospice patients died at home
- Innovative theoretical framework to address anxiety, depressive levels and increase skill building for optimal care of dying persons.
- Multiple methodological issues with existing studies; Urgent need to help caregivers
- 21 days is median length of stay on hospice: Intervention must be implemented at admission to hospice services to help caregiver
Purpose

• Test the feasibility and preliminary effects of a theory-based intervention program (ESI-CH: Education and Skill-building Intervention for Caregivers of Hospice patients) that targets cognitive schema development and skill building for family caregivers of loved ones newly admitted to hospice
Explanatory Model: How the Intervention was expected to Impact Outcomes

**Intervention (ESI-CH)**

**Self Regulation Theory**
Objective, Concrete Components: 2 Sessions
1: Dying process 3-4 months from death
2: Dying process last week of life

**Role Theory**
Individualized component on assessment & skill building on managing common symptoms of a dying loved one and taking care of themselves

**Mediator**
Beliefs-
Caregiver of Family Member on Hospice
(A Caregiver’s belief/confidence in their ability to care for their dying loved one)

**Emotional Coping Outcomes**
- Anxiety
- Depressive Symptoms

**Functional Coping Outcomes**
- Disruption in Usual Activities

**Role Outcomes**
- Caregiver Involvement in Loved One’s Care
- Preparedness

*PracticeReady for Long-Term Care*
Methods

• One group, pre-experimental feasibility pilot study, Pre-Post
• Approved by Arizona State University IRB and Ethics board of Hospice Company in the Mid-South region of Tennessee
# Timeline of Study

<table>
<thead>
<tr>
<th>Hospice Day 1</th>
<th>Hospice Day 2</th>
<th>Hospice Day 3-4 T0—co-PI</th>
<th>Hospice Day 6-8 T1—co-PI</th>
<th>Hospice Day 8-10 T2—co-PI</th>
<th>Hospice Day 20-24 T3—RN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission to Hospice</td>
<td>Hospice RN Visit #1 Or phone call by co-PI</td>
<td>Informed Consent</td>
<td>Session Two: ESI-CH Mutual Agreement</td>
<td>Telephone: Scripted Questions on Session Two and Mutual Agreement Schedule remaining data collection visits</td>
<td>Data Collection from Participant during Routine Nursing Visit (Including Participant Self-report of Involvement with care of loved one)</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Screened for Inclusion Criteria</td>
<td>Baseline Data Collection</td>
<td>Delivery of CD Player Session One: ESI-CH Mutual Agreement</td>
<td>5-10 minutes</td>
<td>RN Observation: Participant involvement</td>
</tr>
<tr>
<td></td>
<td>Schedule appointment for Informed Consent</td>
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Measures

- Patient Demographics
- Caregiver Demographics
- State-Trait Anxiety Inventory (Spielberger, et al, 1977)
- Center for Epidemiological Studies-Depression (Radloff, 1977)
- Caregiver Activity Restriction Scale-Adapted (Williamson, Schaffer & Schulz, 1998)
- Caregiver Involvement in Care of Loved One: Measured by Self-evaluation and by the Hospice nurse
- Preparedness (Archbold, 1990)
- Family Belief Scale for Hospice Caregivers (Li, Melnyk, 2003)
Treatment Fidelity

- Delivery of the Intervention
  - Manual (reviewed by 3 expert nurses)
  - Training of 11 nurses
  - Taping of intervention sessions
- Dose of the Intervention
  - Completers did both sessions
- Receipt of the Intervention
  - 5 Multiple choice questions after each session
  - Nurse observation of caregiver behaviors
  - Caregiver self-evaluation of care to loved one
Results
Caregiver Sample

- 12 caregivers completed study (18 recruited)
- Mean age: 59 years old (range 47-80)
- Gender
  - Male: 27.8%, Female: 72.2%
- Relationship to Patient
  - Spouse: 55.6%, Adult Child: 22.2 %, Other (friend, sibling): 22.2%
- Length of Caregiving
  - 1 mo-6 mo: 27.8%; 6 mo-12 mo: 5.6%; 1-3 yrs: 43.5%; 3-5 yrs: 11.2%; 5-8 yrs: 11.2%
- Income
  - $20,000 to $40,000: 27.8%; $40,000 to $60,000: 22.2; $60,000 or above: 33.3%
Caregiver Sample

- **Education**
  - < HS: 5.6%, HS 16.7%, some college: 27.8%, college grad: 27.8%, grad degree: 22.2%
- **Children in Home**
  - Yes: 27.8%, No: 66.7%
- **Self-reported Health (scale 1-5)**
  - Physical: 3.67 of 5
  - Psychological: 3.72 of 5
  - Spiritual: 4.06 of 5
  - Social: 3.61 of 5
## Results: Feasibility (Abernathy, et al, 2009)
*(Likert Scale: 1 (poor) to 5 (excellent)*)

<table>
<thead>
<tr>
<th>Overall Evaluation</th>
<th>Poor (1)</th>
<th>Good (2)</th>
<th>Very Good (4)</th>
<th>Excellent (5)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of Program</td>
<td>Just right</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timing of Program</td>
<td>Just right</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Content of Program</td>
<td>Very Helpful</td>
<td>91.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommend to Friends</td>
<td>Yes</td>
<td>91.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liked Written Notebook &amp; CD Player</td>
<td>Yes</td>
<td>100%</td>
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## Preliminary Effects of Intervention

<table>
<thead>
<tr>
<th>Variable</th>
<th>T0 Mean (SD)</th>
<th>T3 Mean (SD)</th>
<th>Mean Diff</th>
<th>t</th>
<th>df</th>
<th>p</th>
<th>Cohen’s d</th>
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<tbody>
<tr>
<td>CES-D</td>
<td>15.39 (9.94)</td>
<td>16.42 (9.83)</td>
<td>-.17</td>
<td>-.06</td>
<td>11</td>
<td>.96</td>
<td>.02</td>
</tr>
<tr>
<td>A-State</td>
<td>43.50 (12.84)</td>
<td>40.67 (8.85)</td>
<td>3.00</td>
<td>1.22</td>
<td>11</td>
<td>.25</td>
<td>.26+</td>
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<tr>
<td>CARS</td>
<td>49.28 (10.21)</td>
<td>54.33 (9.93)</td>
<td>-4.17</td>
<td>-1.84</td>
<td>11</td>
<td>.09*</td>
<td>.40+</td>
</tr>
<tr>
<td>PREP</td>
<td>23.11 (6.53)</td>
<td>27.58 (6.36)</td>
<td>-3.42</td>
<td>-1.85</td>
<td>11</td>
<td>.09*</td>
<td>.69++</td>
</tr>
<tr>
<td>FBS-CH</td>
<td>69.28 (14.57)</td>
<td>77.50 (12.97)</td>
<td>-7.67</td>
<td>-2.35</td>
<td>11</td>
<td>.04**</td>
<td>.60++</td>
</tr>
</tbody>
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Limitations

- Lack of attention control group
- Small sample with little cultural diversity
- Hospice RNs not blinded to participants
- Use of predominantly self-report measures
- Very low educational level of 1 participant/difficulty in completing measures
Implications for Future Research

- Refinement of this innovative theory-based intervention and study protocol
- A RCT pilot study with two groups (ESI-CH & Attention Control group)
- Inclusion of ethnic and cultural diversity
- A full scale RCT to determine efficacy of the intervention
- Effectiveness study to implement it into clinical practice
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