

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

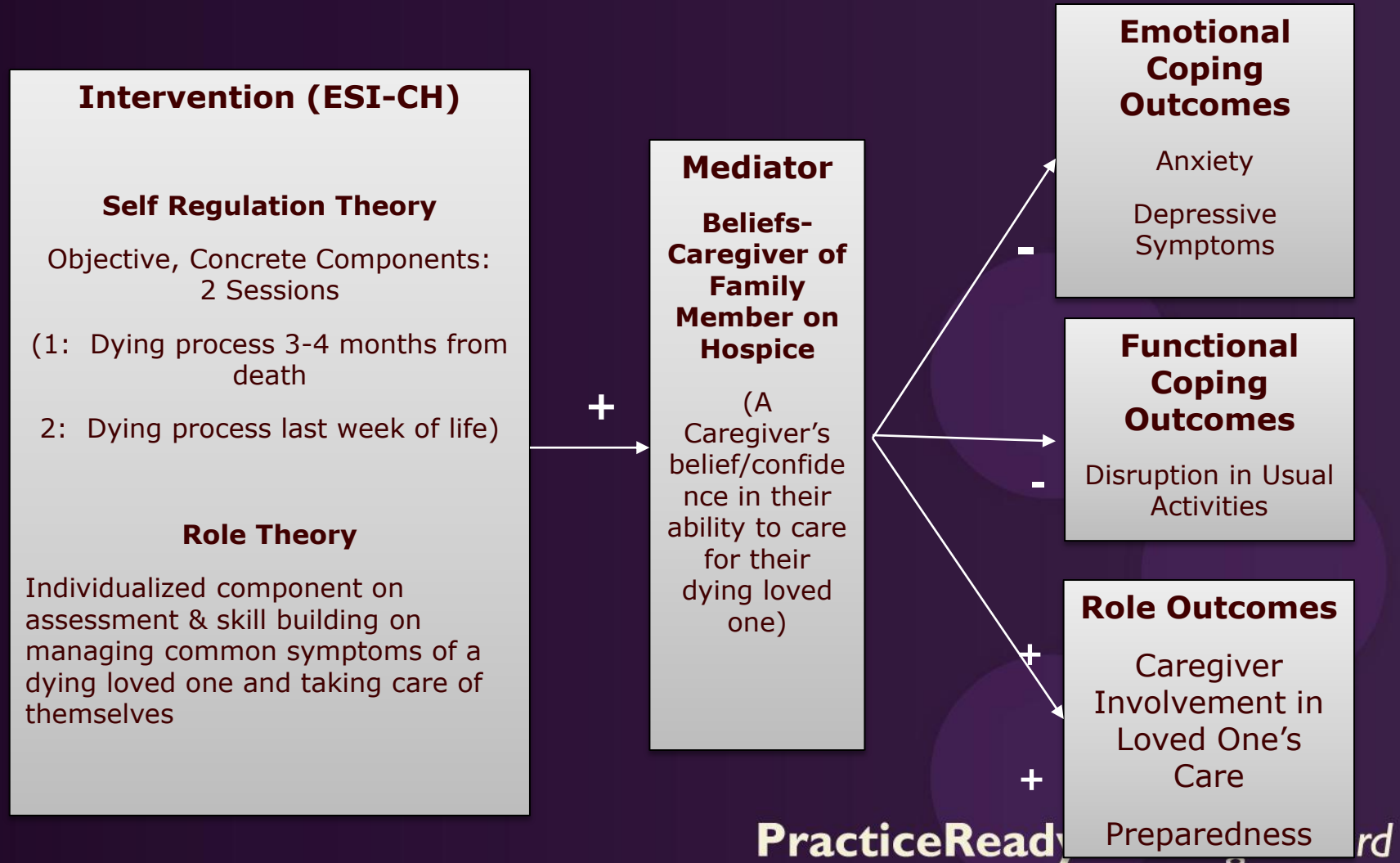
Study Significance

- 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



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

Hospice Day 1	Hospice Day 2	Hospice Day 3-4 T0 –co-PI	Hospice Day 6-8 T1—co-PI	Hospice Day 8-10 T2-co--PI	Hospice Day 20-24 T3--RN
Admission to Hospice	<p>Hospice RN Visit #1 Or phone call by co-PI</p> <p>Screened for Inclusion Criteria</p> <p>Schedule appointment for Informed Consent</p> <p>15 minutes</p>	<p>Informed Consent</p> <p>Baseline Data Collection</p> <p>Delivery of CD Player Session One: ESI-CH</p> <p>Mutual Agreement</p> <p>90 minutes</p>	<p>Session Two: ESI-CH</p> <p>Mutual Agreement</p> <p>45 minutes</p>	<p>Telephone: Scripted Questions on Session Two and Mutual Agreement Schedule remaining data collection visits</p> <p>5-10 minutes</p>	<p>Data Collection from Participant during Routine Nursing Visit (Including Participant Self-report of Involvement with care of loved one)</p> <p>RN Observation: Participant involvement</p> <p>45 minutes (RN—15 minutes)</p>

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

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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))

Overall Evaluation	Poor (1) Good (2) Very Good (4) Excellent (5)	91.7%
Length of Program	Just right	100%
Timing of Program	Just right	100%
Content of Program	Very Helpful	91.7%
Recommend to Friends	Yes	91.7%
Liked Written Notebook & CD Player	Yes	100%

Preliminary Effects of Intervention

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

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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Thank you for your time!

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