

# Caregiver Outlook: An Evidence-based Intervention for the Chaplain Toolkit



**DUKE UNIVERSITY**

**HEALTH CARE CHAPLAINCY  
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# Project Team



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*“There was a full code in progress. I walked in the room and could see this person had no hair and one breast was missing. And I said, “Wait a minute, why are we flogging this person?” They said the husband wasn’t ready for her to go.”*

*- Emergency Department Nurse<sup>1</sup>*

# Background



- Most caregiver interventions
  - Symptom management
  - Coping skills
- Less is known about
  - Caregiver relationship
    - ✦ preparation and completion
  - *Meaning* of caregiving role



# Caregiver Preparation and Completion



- Reviewing one's life, relationship with patient
- Offering receiving forgiveness
- Legacy - identifying wisdom gained and future goals
- Unmet needs may influence caregiver well-being and decision making
- Higher sense of meaning is associated with lower burden
- Tasks are central to palliative care and chaplaincy

# Purpose – Caregiver Outlook



Developed a chaplain-led intervention to assist caregivers, of those with life-limiting illness, with tasks of preparation and completion and meaning-making.

# Specific Aims:



1. Is a manualized chaplain-led intervention to improve well-being of caregivers of patients with life-limiting illness feasible and acceptable?
1. Examine trends in outcomes associated with Caregiver Outlook including: caregiver anxiety, depression, anticipatory grief, quality of life, and burden.



# Specific Aims: Qualitative



3. Examine intervention qualitative theme content and variation associated with gender, ethnicity, SES, type and stage of illness, and levels of spirituality.
3. Examine intervention responses for themes that lead to integration with spiritual assessment and other approaches to chaplaincy and pastoral care planning.

# Conceptual Model



## Caregiver Conditions

Caregivers of those with advanced illness

## Developmental Tasks

Sense of completion in relationship with family and friends

Expressions of regret and forgiveness

Gratitude and acceptance

Sense of meaning  
Transmission of wisdom

## Intervention Content

Relationship review

Forgiveness

Legacy

## Caregiver Outcomes

Anxiety

Depression

Completion/P reparation

Anticipatory Grief

Burden



# Methods: Design and Aims



- 1 arm – feasibility and acceptability
  - Will caregivers enroll?
  - Will caregivers complete?
  - How is intervention received by caregivers?
  - How is intervention received from Chaplain?
  - How does Chaplain experience intervention as potential tool?
- 3 intervention sessions, plus pastoral check-in

# Session #1- Relationship life story



- Would you tell me a about your life and background.
- When and how did you come to know [patient]? What is your first memory of [patient] Story of life together?
- What have been most important places, events, times?
- What are most cherished moments together?
- What are things in your relationship that make you proud?
- If someone were to make a movie of your life together, what would be important to include?
- What was happening in your life when you began caregiving?  
How did you come to be caregiver?

# Session #2 - Forgiveness



- Things if you could do over, would do differently.
  - Challenging times you have encountered before illness?
- Things you might even say you regret.
- Things in relationship for which you want to ask forgiveness?
- Things for which you want to offer forgiveness
- Things unsaid or undone?
- Since caregiving, what have been challenges?
  - Things if you could do over, would do differently.
- To what extent do you feel at peace in relationship?

# Session #3 - Legacy



- How has experience of knowing patient shaped your life?
- How has caring for [patient] shaped your life?
- What have you learned from this relationship?
- What have you learned from caregiving?
- What things do you think [patient] may have learned from you?
- Caregiving described about challenging and meaningful? What are your thoughts about that mix?
- What wisdom may you want to share with others?
- Are there things that you wish to express on own or share with [patient]?

# Intervention Timeline



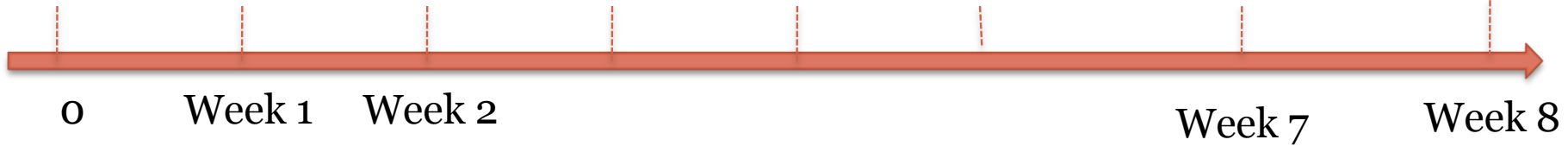
Consent/  
Enroll

Baseline

Intervention window

Post-test 1

Post-test 2



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Week 1

Week 2

Week 7

Week 8

# Methods: Participants



- Informal caregivers -
  - spouses/partners, adult children, parent
- Duke Hospital and outpatient clinics
  - clinical staff
  - brochures in waiting room
- Palliative care, could be hospice eligible
  - Not surprised, if died within 6 month
- Advanced illness (e.g. CA, CHF, ALS)