

Participant Feedback



- **Benefits**
 - Step-back - Place caregiving in context of whole relationship
 - Processed emotions - Forgiveness, Guilt, Regret – no other counseling or book had done that.
 - Provoked thoughts and emotions in between sessions
 - Stimulated communication
 - Speaking with a stranger on phone – provided anonymity
- **Others concerns not addressed**
 - Frustration with care providers and lack of communication in healthcare team

Participant Feedback



- **Timing**
 - Various points in caregiving spectrum –needs change
 - ✦ Immediate post diagnosis would not be helpful
 - ✦ Post hospice admission - dying role crucial
- **Implications**
 - Content – would there be more tailored content
 - Timing – pre or post hospice, etc.

Step back from day-to-day



“Her questions make you reflect. As a caregiver you get very busy doing just that - the day to day business of feeding and bathing and the whole nine yards. So, I think its always good to sit down and think about not the mundane day-to-day routine activities, but to think about the spiritual, mental, and the inward processes that are going on with you.”

Express emotions



“[The intervention] was an excellent experience for me to go through. There were times that it was very provocative in that it caused me to focus on words like guilt, which I had not focused on before in any of our conversations.... Dealing with that word *guilt* made me realize, yes, I was still angry at him.”

Spawned communication



“There are times when it was nice to bring up something and tell him about it and how it was kind of helpful. He thought it was very interesting...It helped me open up the communication with him a little bit more than waiting for a symptom to come up for us to discuss.”

A Chaplain as Interventionist



- Overwhelmingly positive
 - Non-religious

“I think that she is a person first and I’m not religious. I had to tell her that and I did. I thought she was very good really.”

- Religious

“Since I’m a fellow Christian it made me feel more relaxed and feel like we were on the same page. Now if I was someone that didn’t believe in God, it might have been a different story. But for me it was a very good fit. “



Chaplain Feasibility & Acceptability



- This intervention is feasible & acceptable to chaplaincy care
 - “*Caregiver Outlook* “ has particular benefits for the chaplain’s toolkit
 - Generally, manualization may be possible for many chaplains to engage
- The intervention’s style/foci are familiar to healthcare chaplaincy
 - clinical pastoral care (therapeutic frame, clinical sensitivity required)
 - narrative-based approaches (spiritual assessment/pastoral conversation)
 - open-ended questions ,focused probing, elbow room for adjustments, p.r.n.
- Offered a supplement to spiritual assessment & care planning
- The intervention elicited information re: specialized pastoral care

Opportunities for the Chaplain Toolkit



- An evidence-based and manualized intervention
 - ✦ Human development theory, palliative care research, targeted questions
- Formal process for establishing care-relationships
 - ✦ 3-part conversation crucible (beginning, middle, end; rapport/trust/topic)
 - ✦ Tool for care with palliative , worsening chronic conditions, end of life
 - ✦ Possible training tool for clinical pastoral education (4th Unit Residency)
- Elicits information for partial assessment/planning
 - ✦ One can gather information in at least 10-areas helpful for chaplaincy care
- Non-sectarian language allows room for diversity

Challenges for the Chaplain Toolkit



- Primarily, it limited usual chaplain role/scope of service
 - ✦ No initial belief-set screening/spiritual history/assessment
 - Unable to assess risk for offense or spiritual injury/re-injury in regard to “forgiveness” topics being explored by a “chaplain”
- Unable to probe and explore spiritual needs/resources
 - ✦ Though sometimes could assess from information volunteered
- Unable to provide pastoral care when asked/assessed
- Caregiver-only communications
 - ✦ Due to study limitations, no contact with pt/team/community
 - ✦ Due to study, could not engage additional “interventions”

Potential Adaptations for the Chaplain's Scope of Service and Schedule



- **Spiritual Assessment & Pastoral Care Planning**
 - Integrate into the entire process
 - Front-load or back-load around the intervention
 - Offer to implement intervention as part of care-plan
- **Caregiver Support Group**
 - Adapt sessions to weekly group format (*60-min+*)
 - Increased chaplain availability (*serve 6-8/60-min*)
 - Pre-screen & build rapport (*assess distress, et al*)
 - Co-facilitate (*chaplain /other psycho-social clinician*)
 - Outpatient/inpatient (*clinic, specialized unit, phone*)

Skills and Abilities for Using Intervention



- Chaplain follows semi-structured script
- Proven pastoral care and counseling skills
 - effective probing and active listening without judgment/interpretation
 - fluid, adjustable, and able to adjust to caregiver's emotional needs
- Awareness of theories, terminology, and distinctions
 - human development field (i.e., tasks, planning/completion, legacy...)
 - pastoral care, chaplaincy care, religious care, and philosophy/ethics
- Proficient in healthcare chaplaincy
 - ideally, an experienced “Board Certified Chaplain” (BCC)
 - adept at conveying respect for person with beliefs different from self (spiritual, philosophical, socio-cultural, political, geographical, generational...)

Conclusions



- Feasible and acceptable to caregivers
 - Religious and non-religious participants
- Feasible and acceptable to chaplains
 - Integration and modification
- ALS caregivers - an unmet needs
- Outcomes to be tested in full sample