Legacy Work in Palliative Care: Experiences on the TPCU
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OBJECTIVES

- To define and clarify Legacy work.
- To understand the role of Legacy work in Palliative Care.
- To define considerations when identifying patients who are appropriate for this intervention.
- To describe patient, family and staff experiences with Legacy work at the End of Life on the TPCU.
DEFINITIONS OF LEGACY

“Legacy-making can be defined as doing, or saying something that is remembered including both intentional and serendipitous legacies.”
- (Foster, T., et al. (2012). National survey of children’s hospitals on legacy making activities. Journal of Palliative Medicine, 15, 5, 573-578)

“Legacy activities [are] projects that may: (1) assist individuals and families in initiating the process of life review and (2) result in a product that can be enjoyed by family and friends prior to and after the individual’s death.”
DEFINITIONS OF LEGACY…cont’d

Wendy Griffith, L.C.S.W of MD Anderson (Houston, Texas) describes Legacy work as this:

- “Legacy work isn’t about death and dying, it’s about life and living. It’s about making connections and sharing precious moments with the special people in your life.”

- “Leaving a legacy gives your loved ones something tangible to hold on to, something that can provide health and comfort year after year…”

- “…legacy work provides a unique opportunity to reflect on your life and process through events and people who shaped it, while still planning for the future. It can be a powerful coping tool not only for you, but the people around you.”
LEGACY WORK IN PALLIATIVE CARE

- The most recent and well known form of Legacy work in palliative care is Dignity Therapy developed by Harvey Chochinov
  - “This relatively simple and straightforward psychotherapy can help patients obtain the sense of peace they need to die with dignity.” (2005)

- Meaninglessness about life can result in despair or hopelessness, while the knowledge that aspects of one’s life can transcend death can provide comfort to the dying.
  - (Chochinov, 2002; Rayburn, 2008; Sulmasy, 2006)
LEGACY WORK IN PALLIATIVE CARE


  - Randomized contact control group look at the efficacy of a family based intervention designed to decrease caregiver stress and increase family communication.

  - Depression may be reduced by participation in pleasant activities

  - 42 families entered project, 31 completed follow-up
LEGACY WORK IN PALLIATIVE CARE

- Family based intervention (17)
  - Personal Legacy project
    - Scrapbook, audio taped stories, cook book
    - Facilitated by a home based interventionist (training)
      - 3 home visits

- Control Group (14)
  - 3 supportive telephone calls

- Duration 9-10 weeks

LEGACY WORK IN PALLIATIVE CARE

- **Measures:**
  - MMSE
  - Physical Self-Maintenance Scale and IADL Measures
  - Subjective Well-Being
  - Edmonton Symptom Assessment Scale—modified
  - Additional symptom assessments
  - Brief Multidimensional Measure of Religion and Spirituality
  - Depression
  - Caregiver Stressors Scale—Revised
  - Project Evaluation Survey
LEGACY WORK IN PALLIATIVE CARE

• Results:
  ○ Intervention
    ○ Caregivers showed reduced stress
    ○ Patients reported decreased breathing difficulty and increased religious meaning
    ○ Greater social interaction and improved family communication
  ○ Control group
    ○ Caregivers showed increased stress
CONSIDERATIONS

- Timing is important in the introduction of Legacy work. If introduced too early; it may cause the patient distress. If introduced too late; the window of opportunity may be missed.

- Chochinov et al. (2005) notes that psychosocial distress and physical suffering are of equal concern. This emphasizes the importance of leaving a Legacy and allows the patient to work through some of their psychosocial distress.
CONSIDERATIONS...

Some of the main things to consider in determining appropriateness:

- Cognition
- Energy Level
- Expressed interest
- Loved ones in mind
- Physical, mental and Psychological abilities
  - Fine motor
  - Anxiety
  - Depression
  - Ability to attend
Our Experiences on the TPCU
TPCU EXAMPLES

- “The Bead Goes On”
- Tile Tales
- Letter Writing
- Song Writing/CD’s
- Audio/Video Recording
- Fingerprint Jewelry
- Scrapbooking
- Memory Pendants
"The Bead Goes On"

- Is a creative outlet to assist with grief (both anticipatory and the loss of loved ones), distraction from the present situation, and finding a sense of meaning and purpose in one’s life and in death.

- It has enabled many of our patients to express the successes and losses they have experienced throughout their lives and during their illness.

- Completion of this legacy project results in a bracelet that becomes an important legacy item for not only the maker, but also for the loved one(s) who are left behind.
**Tile Tales**

- Participants will be given with an opportunity to tell a visual story on an eight-inch square tile and then expand on the story through words.
- Images are sketched on a sheet of paper that is the same size as the tile. This template allows them to work with their ideas before beginning to paint the tile.
- Participants are encouraged to write a story, poem or single sentence that accompanies their visual image. Together, the image and the words become each participant’s “Tile Tale.”

- These tiles line the hallways leading to the TPCU
Tile Tales
**LETTER WRITING**

- We encourage patients to complete this project in their own handwriting if possible.

- Can be a story to pass along to a loved one, a collection of values and beliefs, or a series of letters for significant events along the way.

- These can be given to loved ones before or after the person has died.
SONG WRITING/AUDIO/VIDEO RECORDING

- Allows patients the opportunity to share a story or express emotions through songwriting.

- Audio recordings can include:
  - Song dedication
  - Mixed cd’s of meaningful music
  - Voice recording
    - Recording a patient reading a book, telling a story, imparting advice
  - Video recording
    - Usually is where a patient shares advices, words of wisdom and messages for important events in the future.
**Fingerprint Jewelry**

- The patient makes a piece of jewelry (i.e. pendant) customized with their own fingerprint.
SCRAPBOOKING

- Provides the patient with an opportunity to share their life story/illness journey or hospital experience with pictures and words.
MEMORY PENDANTS

- Is a simple project that patients can create quickly with minimal effort.

- A meaningful item for a loved one to keep/wear in remembrance of the person.
LESSONS LEARNED

- Timing is EVERYTHING!!

- This intervention is so much more than keeping peoples hands busy.