



PALLIATIVE CARE CASE OF THE MONTH

"Legacy Projects and Life Review in Palliative Care" by Tara Cook, MD

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Case: Mrs. LR was a 42-year-old woman with widely metastatic melanoma. Her cancer progressed despite multiple lines of immunotherapy. Her goal throughout was life prolongation. In the year prior to her death she was admitted to the hospital multiple times, each time for about a month.

Given that she was alert and interacting with her family, she wished to continue aggressive treatment with the hope that this would allow her to continue to be interactive and have additional time with her family. The medical team struggled with what to offer her and her family that would be valuable.

Discussion: Our challenge in this case was how to make the short time the patient had remaining more valuable to her and her family. We realized that talking about forgoing treatments was not consistent with her wishes, and we did not know what would help her, given she was unable to leave the hospital. Legacy projects that incorporate life review are one way to meet the psychosocial and spiritual needs of patients nearing the end of life. These discussions allow patients to bond with their families and engage in meaningful activities.

Life review and legacy projects allow patients to reflect on their core values and the experiences that have given their lives meaning, communicating these to their family and friends through a variety of mediums.¹ Kehl, through a concept review of the literature, determined that affirmation/value, optimization of relationships, and leaving a legacy were key tenets in defining the concept of a “good death.”² In 2000 Steinhauser, et al surveyed patients with a variety of life-limiting illness and their families as well as physicians and other caregivers. Two of these items were rated by participants as important to a good death that are promoted by these projects: remembering personal accomplishments; resolving unfinished business.³ Life review involves the patient interacting with him or herself and their loved ones--analyzing, evaluating and synthesizing life events.³ This important work- of- life review can be done through legacy projects even if a patient does not know or does not want to know they are dying.

Chochinov’s Dignity Therapy is a validated method for performing life review with the creation of a legacy document that can be shared with loved ones. In Dignity Therapy, patients perform life review through a series of psychotherapy protocol questions. These answers to these questions are transcribed and then edited with the patient into a document that they can leave to someone important to them. Chochinov and colleagues studied their intervention with hospice patients. They showed a high-level of satisfaction (93%), helpfulness (91%), sense of dignity (76%), sense of purpose (68%), and sense of meaning (67%) as well as decreased psychosocial and existential distress, both in those with elevated levels and those with non-elevated levels of distress prior to completing the intervention.⁴

Other studies have shown similar results.⁵ In addition to the time it takes to conduct Dignity Therapy (roughly six hours in one study), it is limited by the need to be administered by a psychotherapist trained in dignity therapy.

Some recent studies have shown that modified interventions performed by non-therapists using fewer questions are also effective in facilitating life review with production of a legacy product. Bernat, et al found that adults with terminal cancer were highly satisfied after creating a legacy document through the use of a web portal or a word-processor following a single meeting with a dignity trained therapist.⁶ Allen, et al created a three-part intervention based on The Hospice Foundation of America’s book *A Guide for Recalling and Telling Your Life Story* in which community-based, pre-hospice patients with life-limiting illness and their family members worked together to create a legacy project through life review.⁷ Using psychology and social work graduate students to administer the intervention, Allen found increased talkativeness without increased discomfort in patients, decreased caregiver distress, and improved family communications.⁷ A follow-up study using retired senior volunteers was just as effective.⁸

One of the most common legacy projects that people can do on their own is letter writing. The Legacy Center offers examples of letters for authors in various age groups (<http://thelegacycenter.net>).⁹ The AMA, through their Steps Forward program, offers letter templates as well as strategies for patients to share this letter with their families and strategies for updating their letters over the course of their disease progression (<http://stepsforward.org>).¹⁰ Stanford University champions the Letter Project, archiving letters in their What-Matters Most letter bank to aid in guiding and inspiring others (<http://med.stanford.edu>).¹¹ Story Corps works through partners such as cancer centers and hospice organizations to provide means for patients to preserve and pass on their spoken stories (<https://storycorps.org>).¹²

A new area that requires more research is that of online illness blogs which allow patients and families to publically connect with others as well as share legacies.¹³ Other legacy projects include patients making memories and mementos with those close to them such as videos, scrapbooks, and cookbooks. Allen’s Legacy Participant Notebook is available online as a pdf to guide patients in families in choosing and creating a legacy.¹⁴

Hospital clinicians might wonder what they can do to promote life review particularly for patients who want to continue life prolonging therapy. First, one should ask permission; “Some patients find it helpful to talk about their life and what they have learned.” These are messages they can share with their family.



(Discussion Continued)

"Is this something you would find useful?" Examples of questions regarding life story may include "Tell me about your life" and "Of what are you most proud?"¹⁵ Questions to engage on legacy may include "If you could choose one thing to share, what would that be?" and "What are your most valuable lessons learned?"⁷ Questions probing forgiveness may be, "If you were to do things again, what might you do differently?" and "Is there anyone you would like to offer or ask forgiveness?"¹⁵ The answers to these questions may open the door to discussing the creation of a tangible legacy project.

Resolution of Case: Over the course of her hospitalization, Mrs. LR's husband, parents, and two sons, ages 13 and 10, kept close vigil at the bedside. During the time that she was interactive with her family, the palliative care social workers worked with her on legacy projects. She eagerly completed the Open Letters: Shooting Stars legacy project that focused on meaning-making activities for patients and families facing a terminal illness using the patient's own personal audio and written narratives. She also made thumbprint necklaces for her children and a special gift for her spouse. She died 22 days after being admitted to the hospital.

References:

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Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the Supportive and Palliative Care programs at PUH/MUH, 647-7243, pager # 8511, Shadyside, 647-7243, pager # 8513, Perioperative/Trauma Pain, 647-7243, pager # 7246, UPCI Cancer Pain Service, pager 644-1724, Interventional Pain 784-4000, Magee Women's Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's pager 958-3844.

With comments about "Case of the Month" call Dr. Robert Arnold at (412) 692-4834.