Legacy Building Activities: healing distress and promoting quality of life

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Disclosures

We have none
Objectives

1. Name 4 key benefits legacy making offers patients and their families.

2. Compare and contrast 4 modalities of legacy work.

3. Discuss successful ways to promote patient participation in legacy making activities.

4. Learn about local and national resources for legacy work.
What are 5 things someone would notice about you when you walk into a room?
What are 5 things that make you YOU?
LEGACY
What is legacy?

- **Legacy** = values vs valuables
  - a gift by will especially of money or other personal property
  - something transmitted by or received from an ancestor or predecessor or from the past
  - Merriam Webster dictionary

- **Legacy work** = taking time to purposefully create something for the people you love and care about
  - captures core values
  - MD Anderson Cancer Center
Opportunities within Legacy Work

- To reflect & capture The Four Things That Matter Most:
  - expression of love, gratitude & forgiveness
  - “the ways in which our lives have been shaped and moved by each other.“
  - can transform the legacy that’s left

- To celebrate relationships & shared experiences
  - can spark heartfelt talks

- May leave people better prepared to say goodbye

- Ira Byock, 2014
Benefits & applications of Legacy Work:

**Patient:**
- Autonomy
- Improvement in quality of life & emotional wellbeing
- Reduction in existential distress
- Meaning making, value of life
- Reconciliation

**Family & caregivers:**
- Strengthens relationships & connectedness
- Bereavement support
When to consider offering Legacy Work as an intervention

- During life’s transitions
- Think the 5D’s
  - every Decade
  - upon the Death of a loved one
  - at Divorce or other family change
  - upon new Diagnosis
  - Decline
- Loss of identity
- Disconnect of core values
Considerations in identifying “ideal” participants

- Psychosocial developmental stage (*Erikson*)
  - 40-65: Generativity vs Stagnation
  - 65 and older: Ego Integrity vs Despair

- Limited life expectancy

- Capacity to participate
  - moderate cognition

- *Consider degree of* insight and prognostic awareness

- Patient motivation
Legacy work modalities

- Activities can be *direct* or *indirect*
  - *May need to tailor title of activity & disclosure to meet patient’s level of prognostic awareness*

- The overall goal is to reconnect patients back to core values
  - *May need to reframe or reflect back to activities patients are already engaged in*

- Remember the *process* is just as important as the *product*
Ethical Will

- Roots in Jewish tradition - has modern relevance regardless of faith

- Articulate values for future generations - the “voice of the heart”
  - Pass on personal wisdom, values, beliefs or blessings
  - A gift of “spiritual health”
  - May inform future decision making (re: valuables)
  - Requests for forgiveness or regretted actions

- Situational approach
  - Could be open ended and evolving
  - May be discreet with use of template or prompts
  - Can serve as a therapeutic intervention
Letter writing or story telling

- **Template vs free form**
  - Stanford Friends and Family Letter Project (online or apps)

- **Broad vs intentional**

- **“Illness Letter” vs. “healthy letter”**

- **Writing prompts**
  - Acknowledge people in your life
  - Remember key moments or life highlights
  - Ask for forgiveness/forgive others
  - Say thank you, I love you, and goodbye

- **Shared while alive or plan for distribution after death**
Dignity Therapy

- Initial interview that is recorded, approx. 1 hour long
- Framework of questions asked by interviewer
  - aimed to have participant reflect on special life events/moments, & evoke wisdom for loved ones
- The interview is then transcribed & edited.
- Final copy presented back to patient & loved ones as a booklet
- It is recommended to have the process completed within 2 weeks
  - Chochinov, 2012
Healing Arts:

- Performance
- Music
- Handprints, hand casting
- Videography
- Scrapbooking
- Creative writing
Integrating art into your practice

- Collaborate with an Art Therapist (or a student!)
- Collaborate with an Artist, Writer, Musician, Volunteers
- Use common-place or repurposed materials
  - eg. file folders, waiting room magazines
- Have art materials accessible in your office
- Host an art activity for staff
- Donations from friends, families, businesses
- *Think outside the box & get creative!*
Legacy Boxes
Legacy Alters: spaces to maintain connection
Legacy Timelines: rivers of our lives
Legacy Hands
Mona Rutenberg: Hand casting
Pearls to offering legacy activities to patients

- **Sensitivity to timing**
  - Suddenness could be off-putting or healing

- **Who is it for?**
  - Be aware of intertwined staff moral distress
  - Who’s looking to find the beauty?

- **Sensitivity in disclosure/description**
  - Is it appropriate to leave loaded words out

- **Watch for anticipatory grief reactions**
Challenges to implementing Legacy activities:

- Access to resource & materials
- Limited awareness of appropriate modalities
- Limited time to explore & create
- Patient acuity:
  - imminent prognosis
  - limitations caused by physical and psychological symptoms
Case discussions

1. What legacy making modality(s) would you consider?

2. How would you introduce it?

3. How would you implement the activity?
Case 1

Vikki is 83 yo woman with end stage heart disease who is at maximal medical management.

- She has associated mild cognitive impairment, impacting her prognostic awareness.
- You learn that she has been a poet and writer for the majority of her life.
- She taught creative writing at a community center but never actually published her work.
- She has many copies of her writings in her apartment and still loves to talk about language and words.

1. What legacy making modality(s) would you consider?
2. How would you introduce it?
3. How would you implement the activity?
Case 2

Mindy is a 57 yo woman newly diagnosed with early stage breast cancer.

- She lost her husband of 40 years 6 months ago and now must face her illness alone.
- She leads a quite and private life, she has no children or close friends.
- The couple were each others’ support system.
- Mindy is overcome with grief and wonders who she is and what her life means now.

1. What legacy making modality(s) would you offer?
2. How would you introduce it?
3. How would you implement the activity?
Case 3

Jake is 39 years old and has been struggling with metastatic testicular cancer for the last 5 years.

- Over the years, he was very stoic with treatments and let few people in on how sick he was becoming.
- He is estranged from his family who live in Florida, including his 15 yo daughter.
- Things have taken a turn for the worse and he is now intubated in the ICU with multisystem organ failure, unable to talk though aware.
- He has a fiancée who is attentive and present much of the time.
- He expressed before he was intubated his fear that his daughter would not know how much he loves her.

1. What legacy making modality(s) would you offer?
   2. How would you introduce it?
   3. How would you implement the activity?
Summary

- Autonomy, emotional wellbeing, improvement in existential distress, & bereavement support are among the many benefits that patients and their loved ones can experience when creating and receiving legacy work.

- Ethical wills, letter writing, dignity therapy and healing art projects are interventions that can be especially helpful when patients are struggling with feeling disconnected from their core values, a loss of identity, or experiencing a transitional time in their life.

- In order to promote successful patient participation for legacy making activities, consider traits of an “ideal participant,” be mindful of the timing, ask yourself “who is this is being offered for?” and carefully consider which modality(s) would be the best fit.

- There are many direct and indirect activities that can capture one’s legacy or core values. Several local and national resources exist as guidance; projects can be simple or intricate.


https://www.merriam-webster.com/dictionary/legacy