

Disclosures

• None



Outline

- What is a legacy?
- Dignity therapy
- Meaning-centered psychotherapy
- Other legacy-making activities

Definitions

- "The process of passing one's self through generations, creating continuity from the past through the present to the future." (Hunter)
- "The process of leaving something behind" (Hunter)
- "Legacy is an enduring representation of the self its qualities, experiences, effects, and relationships built and bestowed across generations. Whether concrete or intangible, intentional, or serendipitous, legacies are avenues of connection, education, inspiration, or transformation." (Boles, 2021)

Legacy and Bereavement

- 12 parents and 12 healthcare providers interviewed
- ∘ >6 months after child's death

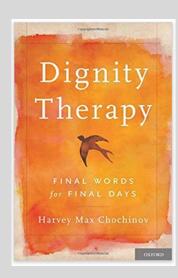


Themes:

- Creating legacy artwork facilitates <u>family bonding</u> and <u>memory making</u> and <u>opens communication</u> regarding the child's impending death
- Legacy artwork provides opportunities for parents to engage in life review and meaning-making of the child's death
- After the child's death, parents display the legacy artwork in their home <u>and take comfort in using these projects to continue</u> their bond with their deceased child
- Participating in legacy artwork <u>ameliorated parents' grief after their child's death</u>
- Legacy artwork <u>may reduce compassion fatigue</u> among healthcare providers by providing an outlet for coping with their patients' deaths (healthcare providers)



- Developed by Harvey Chochinov @ University of Manitoba
- Defined dignity as "being deserving of honor, respect or esteem"
- Patients who were greatly concerned about loss of dignity significantly more likely to have psychological/symptom distress, increased dependency needs, and loss of will to live (Chochinov 2002)
- Guided therapy to help a person express how their life has been worthwhile



Dignity therapy question protocol

- 1. Tell me a little bit about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- 2. Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- 3. What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)? Why were they so important to you and what do you think you accomplished in those roles?
- 4. What are your most important accomplishments and what do you feel most proud of?
- 5. Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- 6. What are your hopes and dreams for your loved ones?
- 7. What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your son, daughter, husband, wife, parents, other(s)?
- 8. Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- 9. In creating this permanent record, are there other things that you would like to include?



SOURCE: M. MARTÍNEZ ET AL / PALLIATIVE MEDICINE 2016

KNOWABLE MAGAZINE

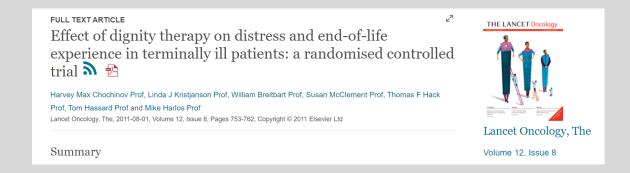
Dignity therapy uses this standard set of nine questions as a starting point for discussion. The questions invite the dying person to evaluate their life and offer their wisdom to family and friends.

 https://knowablemagazine.org/article/society/2021/dignity-therapymaking-last-words-count

Session takes about 1 hour and is recorded (often broken up into several sessions)

Patient's answers transcribed and built into a written narrative

Transcript edited by patient and given to their loved ones



- 441 patients >18yo with prognosis <6 mo receiving palliative care in Canada, US, and Australia
- Randomized to dignity therapy, client-centered care, or standard palliative care
- Primary outcomes: difference in PPS, FACIT-Sp, patient dignity inventory, hospital anxiety/depression scale

• Results:

- No significant difference in primary outcomes
- Secondary outcomes: Dignity therapy significantly more likely to:
 - Be helpful
 - Improve quality of life
 - Increase sense of dignity
 - Change how their family saw and appreciated them
 - Be helpful to their family
 - Improve spiritual well being
 - Lessen sadness and depression (compared to standard palliative care)

- 27 patients at San Diego Hospice
- Dignity therapy completed over average of 4 sessions
- Resultant narratives reviewed for common themes
- 70% (19 patients) w/ cancer diagnosis



Table 2.

Most Common Emergent Themes and Subcategories Rank Ordered by Percentage of Patient Endorsement

Emergent themes	Theme frequency	% of patients endorsing theme
Autobiographical Information	852	100% (n = 27)
(Subcategories) Geographical Context	189	
Family	150	
Love	642	100% (n = 27)
Nostalgia	197	
Endearment	131	
Lessons learned	294	100% (n = 27)
Accept/acknowledge one's imperfections	106	
Celebrating/appreciating what you have	31	
Defining roles	288	96.3% (n = 26)
Career/Vocation	129	
Hobbies	110	
Accomplishments	178	92.6% (n = 25)
Pride for Children	74	
Character traits	133	92.6% (<i>n</i> = 25)
Giving/service to others	25	
Extrovert	12	
Adventurous	12	
Problem solver/logical	12	
Religious/spiritual	12	
Hard-working	11	

Unfinished business	173	88.9% (n = 24)
Regret	91	
Unresolved family conflict	28	
Hopes and dreams for others	86	77.8% $(n=21)$
Hope they know how much I love them	16	
Hope for happiness	14	
Hope for education/career	10	
Catalysts	87	74.0% (n = 20)
Career/vocation/education change	18	
Desire to be with others	17	
Wanting adventure/change	15	
Need to meet others' expectations	13	
Overcoming challenges	93	74.0% (n=20)
Hard work	28	
Pride	15	
Resilience	15	
Stretched my boundaries	15	
Guidance for Others	78	66.7% (<i>n</i> = 18)
Accept/acknowledge one's imperfections	16	
Just do it (even if it's hard)	10	
Find your passion	10	

- Allows for creation of legacy document
- Likely decreases patient suffering and depression while increasing dignity and purpose
- May benefit family members (McClement, 2007)



Meaning Centered Psychotherapy

- Based on writings of Viktor Frankl (Man's Search for Meaning)
 - Meaning is created in various ways*
- Performed as group or individual therapy
 - 8 sessions if in group, 7 sessions if in individual
- Encourages consideration and review of legacy project (session 5 & 8)

Table 1

Topics, sample content, and sample experiential exercises within the 8 sessions of meaning-centered group psychotherapy^a

	General topic	Sample content and experiential exercises
Session 1	Concepts and sources of meaning	Introductions of group members; "List 1 or 2 experiences or moments when life has felt particularly
•		meaningful to you"
Session 2	Cancer and meaning	Identity before and after cancer diagnosis; "Write down 4 answers to the question, 'Who am I?' and How has cancer affected your answers?"
Session 3	Historical sources of meaning (past legacy)	Life as a legacy that has been given (past); "When you look back on your life and upbringing, what are the most significant memories, relationships, traditions and so on that have made the greatest impact on who you are today?"
Session 4	Historical sources of meaning (present and future legacy)	Life as a legacy one lives (present) and gives (future); "As you reflect upon who you are today, what are the meaningful activities, roles, or accomplishments that you are most proud of?"
Session 5	Attitudinal sources of meaning: encountering life's limitations	Confronting limitations imposed by cancer, prognosis and death, introduction of legacy project; "What would you consider a 'good' or 'meaningful' death?"
Session 6	Creative sources of meaning: engaging in life fully	Creativity, courage, and responsibility; "What are your responsibilities? What are you responsible to and for?"
Session 7	Experiential sources of meaning: connecting with life	Love, nature, art and humor; "List three ways in which you 'connect with life' and feel most alive through the experiential sources of love, beauty, and humor"
Session 8	Transitions: reflections and hopes for the future	Review of sources of meaning, reflections on lessons learned in the group; "Do you feel like you have a better understanding of the sources of meaning in life and are you able to use them in your daily life? If so, how?

Meaning Centered Group Psychotherapy

- 90 patients with stage 3/4 cancers
- Randomized to meaning centered group psychotherapy
 vs. supportive group psychotherapy
- MCGP with greater improvements in spiritual well being, sense of meaning at completion of 8-week intervention and 2 months after completion
- Significant attrition (MCGP < supportive group psychotherapy)

 $\underline{\text{Psychooncology.}} \ \text{Author manuscript; available in PMC 2013 May 9}.$

NIHMSID: NIHMS463041

PMCID: PMC3648880

Published in final edited form as:

Psychooncology. 2010 Jan; 19(1): 21–28.

PMID: <u>19274623</u>

doi: 10.1002/pon.1556

Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial

William Breitbart, 1,* Barry Rosenfeld, 2 Christopher Gibson, 1 Hayley Pessin, 1 Shannon Poppito, 1 Christian Nelson, 1 Alexis Tomarken, 1 Anne Kosinski Timm, 1 Amy Berg, 1 Colleen Jacobson, 2 Brooke Sorger, 2 Jennifer Abbey, 2 and Megan Olden 2

Meaning Centered Individual Psychotherapy

- 321 patients w/ stage 4 cancer
- IMCP vs supportive psychotherapy vs usual care
- IMCP vs usual care w/ improvements in:
 - quality of life, sense of meaning, spiritual well being, anxiety, desire for hastened death
- IMCP vs supportive psychotherapy:
 - Trend towards improvement but not statistically significant

Cancer. Author manuscript; available in PMC 2019 Aug 1.

Published in final edited form as:

Cancer. 2018 Aug 1; 124(15): 3231–3239.

Published online 2018 May 14. doi: 10.1002/cncr.31539

PMCID: PMC6097940

NIHMSID: NIHMS961726

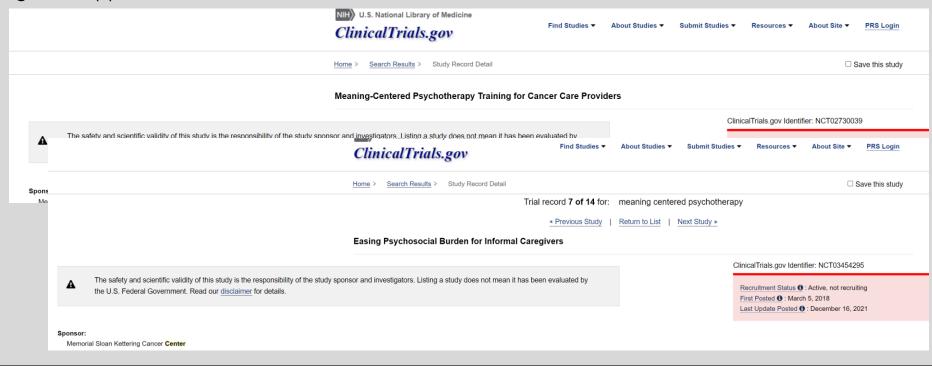
PMID: 29757459

Individual Meaning Centered Psychotherapy for the treatment of psychological and existential distress: A randomized controlled trial in patients with advanced cancer

William Breitbart, Hayley Pessin, Barry Rosenfeld, Allison Applebaum, Wendy G. Lichtenthal, Yuelin Li, Rebecca Saracino, 1,2 Allison Marziliano, 1,3 Melissa Masterson, 2 Kristen Tobias, 2 and Natalie Fenn 1

Meaning Centered Psychotherapy Variations

- For palliative care setting (Rosenfeld, 2017)
 - Modified IMCP over 3 sessions
- For caregivers (Applebaum, 2015)





Social Media/ Blogging

Journal of Adolescent and Young Adult Oncology, Vol. 9, No. 4 | Original Articles



Reaching Adolescent and Young Adult Cancer Patients Through Social Media: Impact of the Photographs of Meaning Program

Megan E. Pailler 🖂, Lynda K. Beaupin, Erin Brewer-Spritzer, Pei C. Grant, Rachel M. Depner, Kathryn Levy, and Kelly E. Tenzek

Published Online: 4 Aug 2020 | https://doi.org/10.1089/jayao.2019.0140

Table 1. Weekly Themes					
Week	Theme				
1	Who am I?				
2	Living with cancer: How has cancer changed who I am?				
3	What matters most?				
4	Understanding my roots or history				
5	What makes me proud?				
6	Coping with bad days				
7	Living life to the fullest				
8	Experiencing the moment (Love, Beauty, Humor)				
9	My story of uncertainty and hope				
10	Review week: What picture stands out the most?				
Sample prompt questions:					
(1) Tell us why you chose the picture.					
(2) Tell us how it tells the story of (theme).					

Story Corps

Story

- Started as recording booth in Grand Central Terminal (NY) in 2003
- Recorded interviews which are then archived and available to the public
- Sessions take 40 minutes and can be done in person, online, or via their app

Story Corps

GREAT QUESTIONS FOR ANYONE:....

- Can you tell me about the person who has been kindest to you in your life?
- 2. Can you tell me about one of your happiest memories?
- 3. Can you tell me about one of your most difficult memories?
- 4. Can you tell me about someone who has had a big influence on your life? What lessons did that person teach you?
- 5. What do you feel most grateful for in your life?
- 6. What are some of the most important lessons you've learned in life?
- 7. What is your favorite memory of me?
- 8. What are you proudest of in your life?
- 9. Can you remember a time in your life when you felt most alone?
- 10. How has your life been different than what you'd imagined?

COVID-19 PANDEMIC QUESTIONS:

- How has living through this experience made you feel?
- 2. Are you afraid? What frightens you?
- 3. What has given you comfort and hope during this time?
- 4. What has been the most challenging part of this experience?
- 5. What is the toughest part of your days right now?
 The best?
- 6. What's the biggest way your life has changed because of the pandemic?
- 7. Is there someone you can't see right now who you really wish you could?
- 8. How is this experience different from other historical events you've lived through?

- 9. If you could ask anyone from your life, living or dead, for advice on getting through this, who would it be and what would you ask them?
- 10. Do you or have you had COVID-19? What is/was that experience like for you?
- 11. What memory of this time do you think will stay with you?
- 12. Has this experience changed you? If so, how?
- 13. What have you learned from this experience?
- 14. Who do you most worry about in your family or circle of friends right now?
- 15. If the quarantine ended tomorrow, what's the first thing you'd do?
- 16. Is there anything you want to say to me given what we're living through at this moment?

StoryWorth

- \$100 subscription
- Weekly question/prompt for one year via email
- Patient replies to email with story/response
- Responses bound as a book

How it works

Think of Storyworth like a conversation



Stop O1

Once a week, choose a question to inspire someone to write.



Step 0

They'll simply reply with an email, which is shared with you.



Step (

At the end of a year, their stories are bound into a beautiful keepsake book.





Music Therapy Heart Sounds



- Study performed @ Nemours Children's Hospital (Delaware)
 - Surveyed families of 12 deceased children who had participated in music therapy heart sounds program prior to their death
 - All families found MTHS program meaningful and would recommend it to other families
 - ½ of families listened to recording at least monthly

Proposed cause of death				
Hypoxic ischemic encephalopathy	9% (N = 1)			
Sepsis	18% (N = 2)			
Status asthmaticus	9% (N = 1)			
Status epilepticus	9% (N = 1)			
Leptomeningeal glioneuronal tumor	9% (N = 1)			
Acute lymphoblastic leukemia	9% (N = 1)			
Graft versus host disease (IPEX syndrome underlying disease)	9% (N = 1)			
Hypoplastic left heart syndrome	18% (N = 2)			
Epidermolysis bullosa	9% (N = 1)			

Music Therapy Heart Sounds

"

[My daughter] was my center and we would lay and hold her close to me. The heartbeat recording allows me to live in that memory whenever I want to. Thank you for that endless gift.

I love having my son's heartbeat in a song we always sang together.

Do anything we can to preserve the short time we had with him. Thank you all.

I will still be able to hear my son's heartbeat even though he has passed.

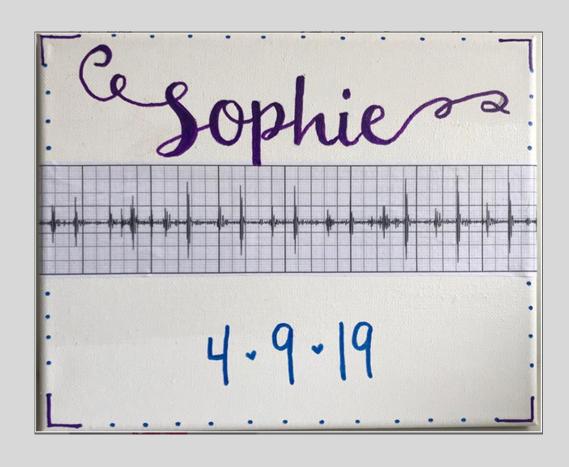
It keeps her here with me.

I love having his heartbeat recording to remind me of the tiny heart that changed my life forever. Even though I don't have my sweet [son], I will forever be able to listen to his heart beat.

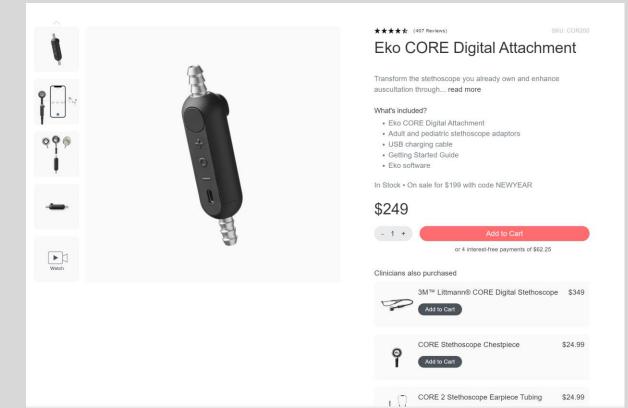
Hearing my son's heartbeat helps in my healing.

"

Music Therapy Heart Sounds







https://youtu.be/m9AkuPNSCT8

https://youtu.be/iXLW9bjklpw

https://shop.ekohealth.com/products/core-digital-attachment?variant=32764121251936

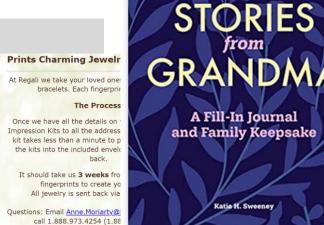
Artistic ideas

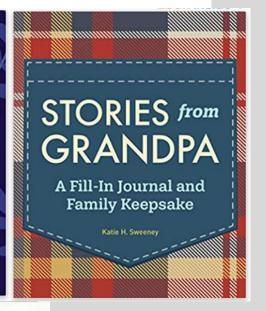
- Thumb print/handprint
- Videography
- Scrapbooking
 - Cookbook
- Legacy boxes
- Quilt of favorite shirts/ fabric items
 - Memory/bereavement bears
- Cards/gifts for future holidays
- Build-a-bear with voice recording
- Thumbprint charm/jewelry
- Storytelling/journaling
- "Heartbeat in a bottle"
- Journal











Hand Casts



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https://www.amazon.com/dp/B018DHY2FU/ref=emc_b_5_i



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https://www.amazon.com/Luna-Bean-KEEPSAKE-Plaster-Materials/dp/B01E4LWBLQ/



Hand Casts



Considerations

- Cognitive function of patients
- Limitations imposed by physical/psychological symptoms
- Prognosis/timing
- Funding

A prognosis-based timeline for legacymaking interventions

- Months to years
 - StoryWorth
 - Meaning centered psychotherapy
- Weeks to months
 - Story Corps
- Days to weeks
 - Dignity therapy
- Hours to days
 - Artistic projects
 - Music therapy heart sounds



Legacy Making Links

- Storyworth new.storyworth.com
- StoryCorps <u>www.storycorps.org</u>
- Stories from Grandpa Journal: https://www.amazon.com/gp/product/1647396123/ref=dbs a def rwt bibl vppi io
- Stories from Grandma Journal: https://www.amazon.com/qp/product/1638073600/ref=dbs a def rwt bibl vppi i1
- Thumbprint jewelry: http://regalijewelry.com/index.php
- Legacy project activities and guides: https://www.legacyproject.org/resources/activities.html
 - https://rainbowhospice.org/legacy-idea-book/
- Bereavement bears: https://thepatchworkbear.com/ (lots available on Etsy too)
- Eko Core Stethoscope: https://shop.ekohealth.com/products/core-digital-attachment?variant=32764121251936
- Hand casts (Amazon): https://www.amazon.com/dp/B018DHY2FU/ref=emc b 5 i
 - https://www.amazon.com/Luna-Bean-KEEPSAKE-Plaster-Materials/dp/801E4LWBLQ/

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