



MULTIDISCIPLINARY USE OF DIGNITY THERAPY AND LIFE REVIEW WITH PATIENTS AND BEREAVED FAMILIES

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TEXAS IS THE BEST COUNTRY IN THE WORLD

EILEEN SPINNER, MA, LPC

"We make a living by what we get. We make a life by what we give."

URSU LIN ACADEMY

UNIVERSITY OF DALLAS

SAINT LOUIS UNIVERSITY

nurse care hospice heart

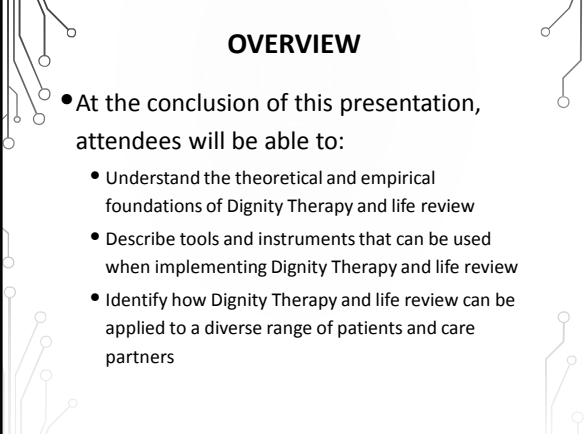
love

faith

friends

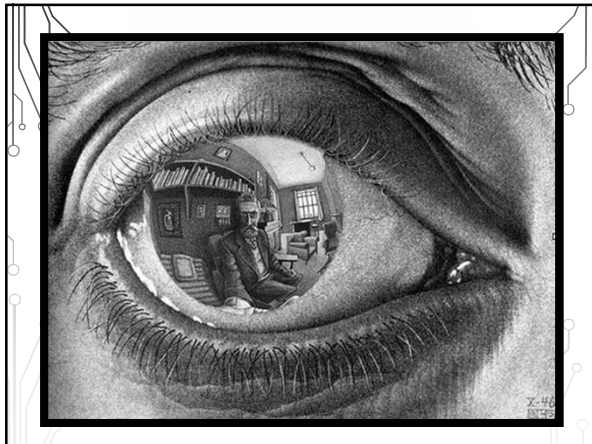
family

RUN

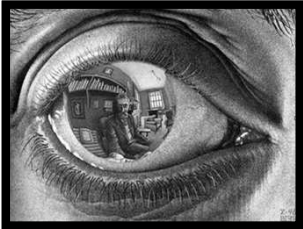


OVERVIEW

- At the conclusion of this presentation, attendees will be able to:
 - Understand the theoretical and empirical foundations of Dignity Therapy and life review
 - Describe tools and instruments that can be used when implementing Dignity Therapy and life review
 - Identify how Dignity Therapy and life review can be applied to a diverse range of patients and care partners



HOW DO YOU SEE ME?



*Adaptation of M.C. Escher painting
Used at Dignity Therapy Workshop, 2016*

- Recognize the notion of “appearance”
- Patients are looking for a reflection of themselves in our eyes
- Are we being a skilled witness? Are we offering an affirming reflection?

“CARE TENOR”

- The “fragrance of care”
- The tone of care
- Are we fully present when we are visiting a patient?
- We can be technically perfect but have a terrible “tone of care”
- A patient can be *seen* but never *heard* if we don’t treat them with “dignity conserving care”
- How can we maintain their dignity?
- Consider the more “intimate dependencies of care” (bathing/ dressing / incontinency)
- How do we personalize these issues? How do we keep their physical dignity intact?
- We want to create an ethos around their personhood – Everything about you is important. *Time* matters. *You* matter. What do *you* want to do with this *time* you have?

*Dr. Harvey Chochinov
Dignity Therapy Workshop, 2016*

DIGNITY THERAPY IS...

A brief therapeutic approach designed to decrease suffering, enhance quality of life, and bolster a sense of dignity for patients approaching death. It invites patients to discuss issues important to them and articulate things they would most want remembered as death draws near. DT has a growing evidence base, with positive outcomes for both patients and their bereaved family members. There is also research that shows that DT improves staff satisfaction when put into practice.

DIGNITY THERAPY IS...

- Dignity Therapy is about affirming personhood
- It's about asking the patient, "What should I know about you as a person to help me better care for you?"

DIGNITY THERAPY PROTOCOL

- 1) Tell me a little bit about your **life history**; particularly the parts that you either remember most or are more important? When did you feel most alive? (Imagine a photo album of your life – what is the first picture you see? When you turn the page, what is the next picture you see?)
- 2) Are there things that you would want your family to know or **remember about you**?
- 3) What are the most **important roles** you have played in your life (family, work, community service, etc.)? Why were they important to you, and what did you accomplish?
- 4) What are your most **important accomplishments**, and what makes you feel most proud?
- 5) Are there things that you feel **need to be said** to your loved ones or things that you would want to say 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 guidance** would you wish to pass along to your child(ren), husband, wife, parents, other(s)?
- 8) Are there **important words or instructions** you would like to offer your family?
- 9) In creating this permanent record, are there **other things that you would like to include**?

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Original Article

Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial

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Abstract

Context. Dignity therapy (DT) is a psychotherapeutic intervention with increasing evidence of acceptability and utility in palliative care settings.

Objectives. The aim of this study was to evaluate the legacy creation component of DT by comparing this intervention with life review (LR) and waitlist control (WC) groups.

Methods. Seventy adults with advanced terminal disease were randomly allocated to DT, LR, or WC followed by DT, of which 56 completed the study protocol. LR followed an identical protocol to DT except that no legacy document was created in LR. Primary outcome measures were the Brief Generativity and Ego-Integrity Questionnaire, Patient Dignity Inventory, Functional Assessment of Cancer Therapy-General, version 4, and treatment evaluation questionnaires.

Results. Unlike LR and WC groups, DT recipients demonstrated significantly increased generativity and ego-integrity scores at study completion. There were no significant changes for dignity-related distress or physical, social, emotional, and functional well-being among the three groups. There were also no significant changes in primary outcomes after the provision of DT after the waiting period in the WC group. High acceptability and satisfaction with interventions were noted for recipients of both DT and LR and family/careers of DT participants.

Conclusions. This study provides initial evidence that the specific process of legacy creation is able to positively affect sense of generativity, meaning, and acceptance near end of life. High acceptability and satisfaction rates for both DT and LR and positive impacts on families/careers of DT participants provide additional support for clinical utility of these interventions. Further evaluation of specific mechanisms of change post-intervention is required given DT's uncertain efficacy on other primary outcomes. *J Pain Symptom Manage* 2017;55:162–170 © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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Hospice Staff Perspectives on Dignity Therapy

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Methods Go to:
 Eighteen hospice staff members who referred patients for Dignity Therapy were asked to rate the value of the treatment. The staff also completed qualitative interviews to gather more detailed information about their most common reasons for referral; their perspectives regarding the therapy's impact on patients; and their beliefs about the costs, benefits, and barriers to treatment. The staff interview responses were qualitatively analyzed to measure the most common emergent themes.

Results Go to:
 Hospice staff members rated Dignity Therapy as worthwhile, and somewhat able to reduce patients' pain and suffering. The vast majority (92%) of hospice staff members believed the treatment would help patients' families in the future, and 100% reported a desire to recommend the treatment to others. Qualitative analyses revealed that staff commonly viewed Dignity Therapy as a positive, affirming experience for patients and felt the emotional or time requirements of the treatment were justified. As a result of offering the service, the staff noted an increased connection with patients and related increases in job satisfaction.

YOU CAN CREATE A LIFE REVIEW PROGRAM THAT IS INFORMED BY DIGNITY THERAPY TOO!

REMEMBER... RESEARCH SHOWS US DIGNITY THERAPY MAKES A DIFFERENCE!

Subjects and methods: Sixty family members of deceased terminally ill patients who previously took part in Dignity Therapy completed a questionnaire to elicit feedback about the impact of Dignity Therapy on both the dying patient and themselves.

Results: Ninety-five percent of participants reported that Dignity Therapy helped the patient; 78% reported that it heightened the patient's sense of dignity; 72% reported that it heightened the patient's sense of purpose; 65% reported that it helped the patient prepare for death; 65% reported that it was as important as any other aspect of the patient's care; and 43% reported that Dignity Therapy reduced the patient's suffering. Regarding family members, 78% reported that the generativity document helped them during their time of grief; 77% reported that the document would continue to be a source of comfort for their families and themselves; and 95% reported they would recommend Dignity Therapy to other patients of family members confronting a terminal illness.

Conclusion: Family members endorse Dignity Therapy as a therapeutic intervention that moderates their bereavement experiences and lessens suffering and distress in terminally ill relatives.

McClement S., Chochinov H.M., Hack T., Hassard T., Kristjanson L.J., Harlos M. (2007). Dignity Therapy: Family Member Perspectives. *Journal of Palliative Medicine*, 10(5), 1076-82.

Dignity Therapy is...

A brief therapeutic approach designed to decrease suffering, enhance quality of life, and bolster a sense of dignity for patients approaching death. It invites patients to discuss issues important to them and articulate things they would most want remembered as death draws near. DT has a growing evidence base, with positive outcomes for both patients and their bereaved family members. There is also research that shows that DT improves staff satisfaction when put into practice.

BJC Hospice's Lumina program is...

Informed by DT. It offers patients and their families the opportunity to review their lives as well as preserve stories, values, experiences, and life lessons in the form of journals, scrapbooks, memory boxes, letters to loved ones, and video or audiotaped statements. Interviews are conducted in the home by the program coordinator and/or intensively trained Hospice volunteers.

LUMINA SURVEY RESULTS ARE POSITIVE TOO!

Survey Question	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
The Lumina program positively impacted my family member on hospice.	71.79%	12.82%	2.56%	0.00%	0.00%	12.82%
The Lumina program gave my family member a sense of meaning, purpose, and dignity.	66.67%	15.83%	5.13%	0.00%	0.00%	12.82%
The Lumina program was as important as any other aspect of hospice care.	75.00%	15.00%	0.00%	0.00%	2.50%	7.50%
The Lumina program helped my family member leave a meaningful legacy for his/her loved ones.	77.50%	10.00%	0.00%	2.50%	0.00%	10.00%
The Lumina program comforted surviving caregivers/family members during our time of grief.	77.50%	7.50%	2.50%	0.00%	0.00%	12.50%
I would recommend the Lumina program to other families.	82.50%	5.00%	2.50%	0.00%	0.00%	10.00%

A LIFE REVIEW PROGRAM INFORMED BY DT CAN PROVIDE MANY THINGS


- Letters to loved ones
- Memory books/journals
- Scrapbooks
- Memory videos (using pictures/videos/music)
- Audio recordings
- Memory boxes
- Genograms (family trees)
- Lifelines (detailing life events)
- Memory pillows, bears, and quilts made from the patients' clothing

All of these items can be created through life review with the adult or pediatric patient, as well as through collaboration with the family and loved ones before and after the patient's death.

LUMINA WITH MARTIN

Martin took time to reflect on his past and document his life through a book and video. He was happy to revive his own memories and give his children and grandchildren a better understanding of his history.

<https://www.youtube.com/watch?v=P1JRmh1F164>



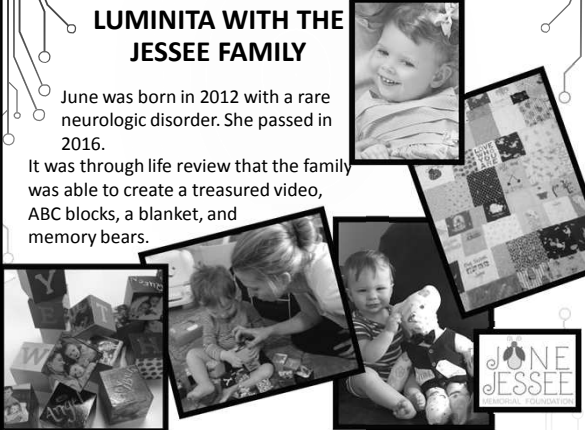
Martin Schweig, Jr.

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LUMINITA WITH THE JESSEE FAMILY


June was born in 2012 with a rare neurologic disorder. She passed in 2016.

It was through life review that the family was able to create a treasured video, ABC blocks, a blanket, and memory bears.



JUNE JESSEE

BEREAVEMENT SUPPORT TURNS INTO LASTING GIFTS

- Alma's Voice 
- Mary's Memory Box for her husband 
- Grandpa Song with music therapist 
- Memory Pillows and Bears 

- Nicole's ABC Books for her children



YOUR TURN!

Dear _____

Letters I have thought so much about all I love and appreciate about you

When I think about loving and leaving you, I know I'll miss


I hope you'll remember my

and smile when you're sick


What I want most for you in your future is


I will ALWAYS love you.

PRINTED ON RECYCLED PAPER



EXAMPLES OF PROJECTS





MUST-HAVE COMPONENTS WHEN STARTING A DIGNITY THERAPY PROGRAM

- Volunteers (and at least one staff member) are essential
 - Not a lot... just a few
 - Assess skills
 - Develop program around the strengths of your volunteers/staff
- Staff “buy-in”
 - Resources: recorders, iPhones, voice memos, take notes, release form
- Time and Patience
- Supervision

SUMMARY

- There is a lot of DT research out there! Continue to read about the theoretical and empirical foundations of DT – it has been shown to improve patient and family quality of life, reduce sadness, depression, and give the patient a greater sense of well-being at the end of life (and it improves staff satisfaction!)
- Use the dignity therapy model as a foundation to create a system that will work for your organization – create tools and instruments that work for you, your patients/families, and your environment!
- Volunteers and staff buy-in are critical, and they will need ongoing supervision
- **START SMALL!** You CAN do this!

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