Dignity Therapy: Advancing the Science of Palliative Care

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Objectives

- Describe COVID-19 impact on a Dignity Therapy clinical trial.
- Discuss outcomes of Dignity Therapy trials among (a) patients with cancer receiving outpatient palliative care and (b) frontline healthcare providers
- Consider future directions for Dignity Therapy in clinical practice and future research.

2016-2022 Wilkie, D.J. (contact MPI), Emanuel, L. (MPI), Fitchett, G. (MPI), Handzo, G. (Co-I), Chochinov, H. (Co-I). Dignity Therapy RCT led by Nurses or Chaplains for Elderly Cancer Outpatients, 1R01CA200867-01, $3,917,265. NCT03209440

Problem

Gap

- Spiritual concerns are issues for 86% of patients with advanced cancer.
- Little research available to guide interventions for spiritual care respecting one's personhood.

Palliative Care for the Elderly

Solution

- Our thesis was that Dignity Therapy would systematize spiritual care processes and improve patient outcomes (spiritual and cancer prognosis awareness).

Dignity Therapy Research

Conclusion

- Previous studies of DT demonstrated clear feasibility and inconsistent efficacy of DT with virtually no evidence of its mechanism of action.

Evidence

- 12 studies of DT (8 uncontrolled feasibility; 4 mostly small sample efficacy RCTs) showed DT to be an important intervention when delivered by nurses and mental health professionals, but effects on patients' distressing physical or emotional symptoms of life-threatening illness have been inconsistent.

Evidence

- Compared to usual care, patients who received DT reported significantly higher dignity impact ratings.
- DT facilitated awareness of cancer prognosis outcomes and will-to-live.
- Lack of DT effect on physical symptoms could be that symptoms only moderate the DT effect, so conceptualizing symptoms as the relevant outcome is mismatched to the operative DT elements.
- Spiritual distress could moderate the DT effect on patients' sense of meaning and purpose.

Study Aims

Aim 1 Compare usual palliative care and usual palliative care with DT (nurse-led, chaplain-led) groups for effects on:

a) patient outcomes (dignity impact, existential tasks, and cancer prognosis awareness). We hypothesize that, controlling for pretest scores, each of the DT groups will have higher scores on the dignity impact and existential tasks measures than the usual care group; each of the DT groups will have better peaceful awareness and treatment preference more consistent with their cancer prognosis than the usual care group; and

b) b) processes of delivering palliative spiritual care services (satisfaction, unmet spiritual needs). We hypothesize that the DT groups will show increased patient satisfaction with spiritual care services and fewer unmet spiritual needs compared to the usual care group.

Aim 2 Explore the influence of physical symptoms and spiritual distress on the dignity impact and existential tasks effects of usual palliative care and nurse-led or chaplain-led DT. We hypothesize that physical symptoms and spiritual distress will significantly affect intervention effects. This rigorous trial of DT will constitute a landmark step in palliative care and spiritual health services research.

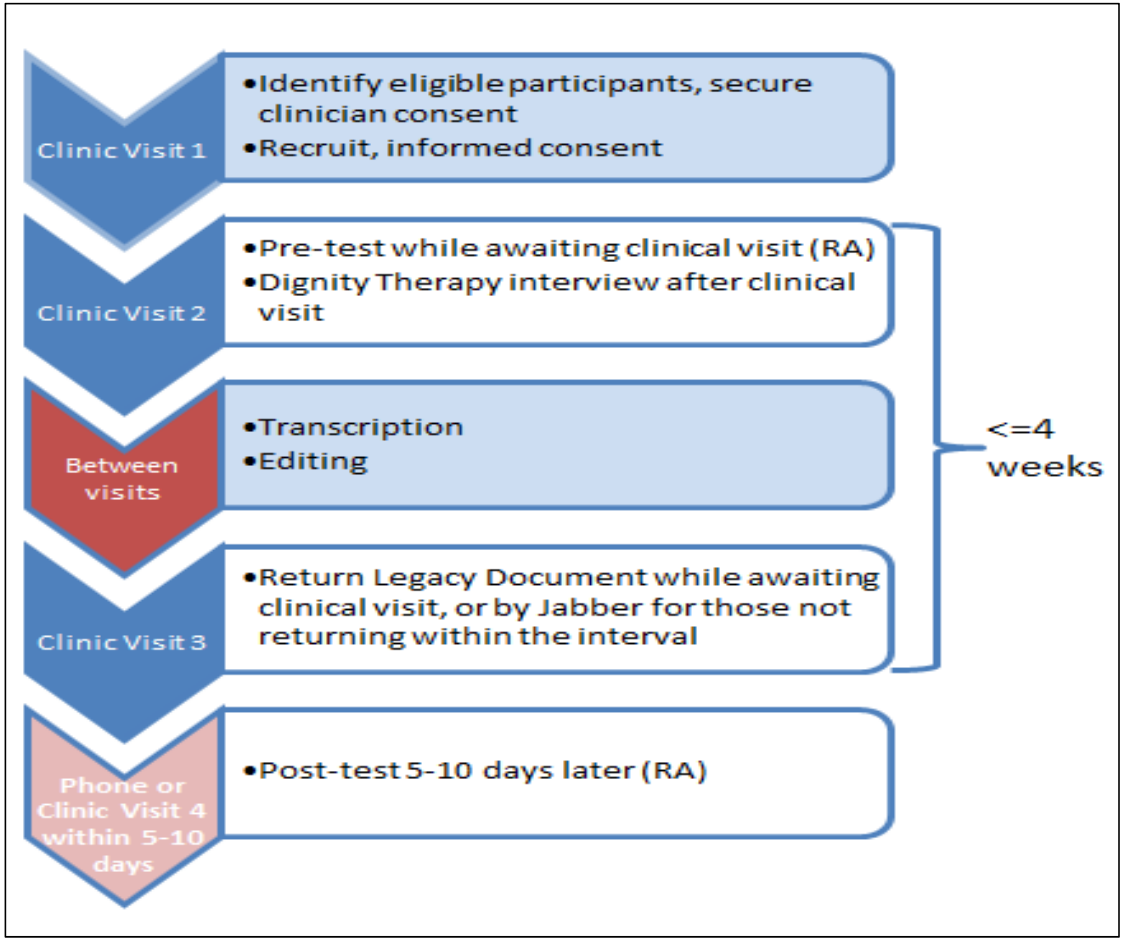
Stepped-wedge design N per step per site

Step (Year)	1	2	3	4	Total N
Site 6	23	23	23	24	93
Site 5	23	23	23	24	93
Site 4	24	23	23	24	94
Site 3	24	23	23	24	94
Site 2	24	23	23	23	93
Site 1	24	23	23	23	93
Patients / Step Period	142	138	138	142	**560**
Usual Care					280
Nurse-Led DT					140
Chaplain-Led DT					140
Step Period Duration (mo)	12	12	12	12	48

Palliative Care for the Elderly

Clinical Sites	
Nurse Intervention	**Chaplain Intervention**
Northwestern	Rush
MD Anderson	U Florida
Emory	UCSF

Study Flow Diagram



Measures, Time Points, & Person who Completes		
Measure (Concept-Aim); [Number of Items]	**Pretest**	**Posttest**
Patient Interviewed to Complete:		
Dignity Impact (Aim 1); [7]	X	X
QUALE-E (Existential Tasks-Aim 1); [11]	X	X
Cancer Prognosis Awareness (Aim 1); [3]	X	X
Treatment Preferences (Aim 1); [3]	X	X
Patient Satisfaction with Chaplain/Nurse Care (Aim 1); [7]		X
Edmonton Symptom Assessment Scale (Physical Symptoms-Aim 2); [10]	X	
Religious and Spiritual Struggles Scale (14 item; Spiritual Distress-Aim 2); [7]	X	X
Demographic and Patient Characteristics; [16]	X	
Chaplain/Nurse Completes:		
Unmet Spiritual Needs (Aim1)	X	
Chaplain/Nurse Activity Report (descriptive data)		X
RA Completes-Screening Tools:		
Palliative Performance Scale	X	
Mini Mental Status Exam; [20]	X	
Patient Dignity Inventory; [25]	X	

Dignity Therapy

- Three 15 min to 60 min sessions (~2 hours total) delivered in person, by phone and Zoom
  - 1) Framing Interview
  - 2) Dignity Therapy interview (audio recorded)
  - Transcription and editing
  - 3) Review and document with patient, edit as requested
- Provide patient with final legacy document (in person or by mail or email)

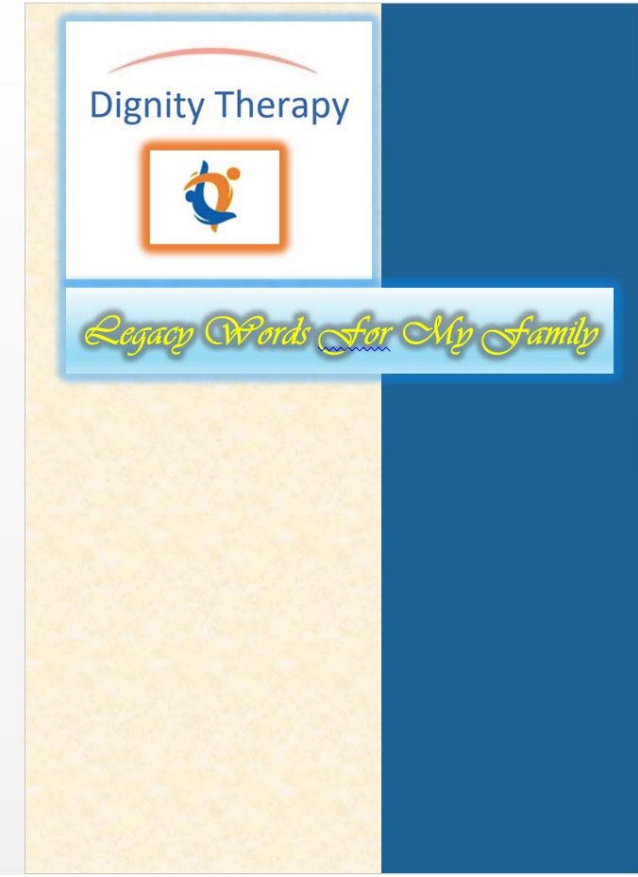
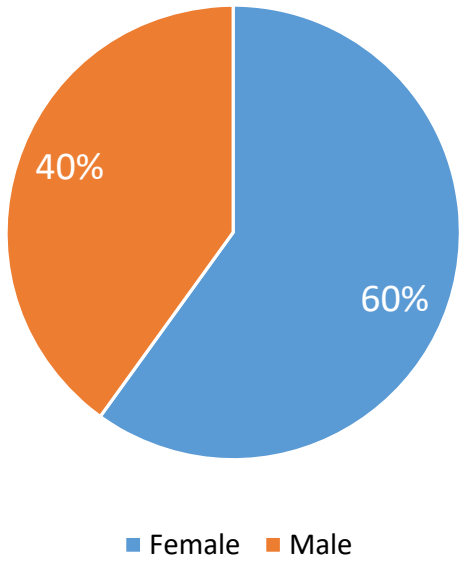


Table 1. Examples of the Dignity Therapy Question Protocol
1. Tell me about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
2. Are there specific things that you would want your family to know about you, and are there 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, & what do you feel most proud of?
5. What are your hopes and dreams for your loved ones?
6. What have you learned about life that you would want to pass along to others?
7. What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?
8. 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?
9. Are there words or perhaps even instructions you would like to offer your family, in order to provide help to prepare them for the future?
10. In creating this permanent record, are their other things that you would like included?

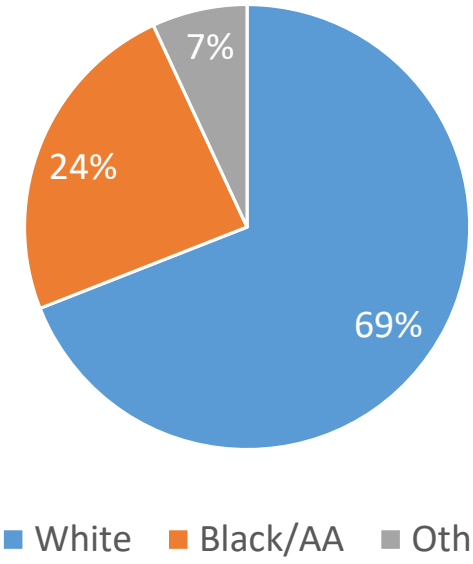
Results

Recruited 645 patients, 588 completed baseline, & 462 completed study

Gender



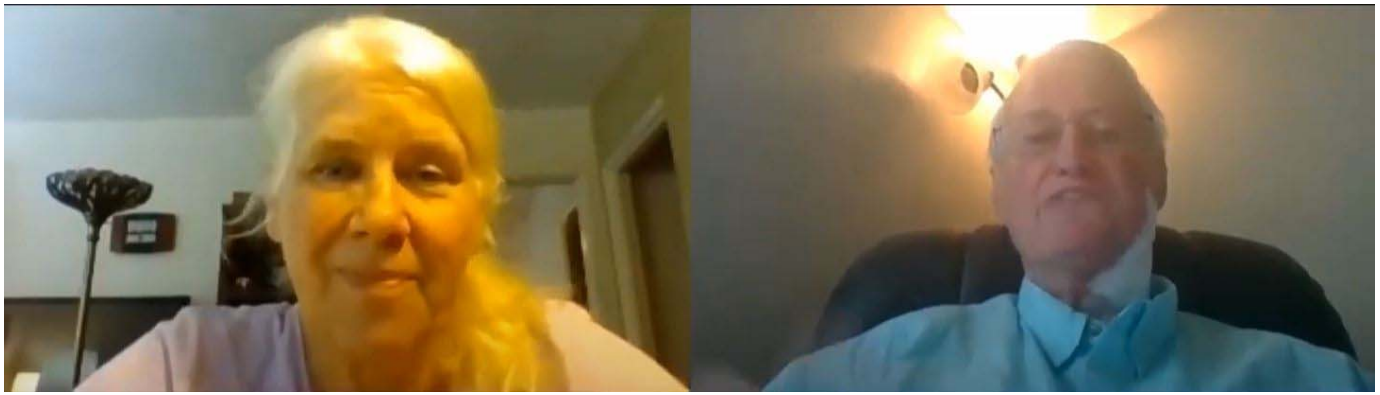
Race



Preliminary Main Outcome: Dignity Impact

From baseline to posttest, the dignity impact scores (ranges from 7-35 possible) in the DT group improved by 2.0 (SD 3.8), while those in the usual care control group changed by 0.4 (SD 3.7).

Adjusting for the baseline scores, the mean posttest dignity impact score was 1.8 point higher in DT group (p=.004) than the usual care group.



https://youtu.be/aU4JSlago3Y

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Investigators: MPIs--Linda Emanuel, MD, PhD Northwestern U, George Fitchett, PhD Rush U, Co-Is--Yingwei Yao, PhD UF, and George Handzo, MDiv HCC NY, Harvey Chochinov, MD, PhD, U Manitoba

Site Directors: Tammie Quest, MD Emory U, Josh Hauser, MD Northwestern U, Sean O'Mahony, MD Rush U, Marvin Delgado Guay, MD, MDA CC, Michael Rabow, MD UCSF

UF Data Collection Team: Amelia Greenlee, Destiny Gordon, and Tyra Reed

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Specific Aims: Feasibility Study

Carma Bylund, PhD & Susan Bluck, PhD

The overarching goal of this project was to determine feasibility for analysis of the process and products of the DT sessions by testing the application of our analysis methods to audio and narrative data collected during the visits.

Aim 1: Process: Assess empathic communication during the *process* of DT, particularly the extent of empathy in dyadic interactions between patients and those providing the therapy.

Aim 2: Product: Analyze frequency of themes (purpose in life, meaning-making, communion with others) in the Legacy Document.

Method: Design

- Analysis of initial data from multi-site NIH R01CA200867 (MPIs: Wilkie, Emanuel, Fitchett).

Process: Assessing Empathy in Communication

- The one recorded visit each between DT therapist and patient was coded using the Empathic Communication Coding System (ECCS).
  - ECCS: Interaction analysis system that identifies patient-created empathic opportunities and provider responses
  - This coding allows for both:
    - descriptive analysis of empathic communication
    - analysis of relation of empathic process to themes in the Legacy Documents

Patient-Created Empathic Opportunities (EOs)	
Progress	Any progress or positive occurrence in the pt's life
Challenge	Any challenge or negative occurrence in the pt's life
Emotion	Any explicit statement of emotion by the pt.

Bylund & Makoul, 2002; Bylund & Makoul, 2005; Bonvicini et al., 2008; Pehrson et al., 2016

Provider Responses	
Shared Feeling/Experience	Provider shares (similar) own experience or feeling
Validation	Provider conveys that the EO expressed is valid or normal.
Pursuit	Provider acknowledges central issue + pursues it
Acknowledgment	Provider acknowledges central issue in EO
Implicit Recognition	Provider responds to medical or other issue, missing the real EO
Perfunctory	Provider gives automatic, scripted-type response.
Denial	Provider ignores EO.

Product: Analyzing Themes in Documents

How individuals tell their life story affects psychological well-being

Product: Thematic Content Analysis

- Modified standard codebooks for use with Legacy Documents
- Trained teams of three coders on each scheme
  - Purpose in Life, Meaning-making, Communion
- Coder training
  - Trained using practice materials
  - Achieved inter-rater coder reliability; kappa = .80
- Code narratives
  - Met regularly to resolve disagreement, avoid ‘coder drift’

Beyond Feasibility: Long-term Goals

Long-term goals

1. Year 1: Demonstrated feasibility of coding schemes (N = 32)
2. Apply for NCI R01: analyzed all study data (N = 280). Link coded variables to DT outcomes, Dignity Impact Scale, and...
    - e.g., death preparation, patient satisfaction, peaceful awareness
4. Evidence-based refinement of DT for elderly cancer patients and others

Underway 2021-2024

Bylund, C. (contact MPI), Bluck, S (MPI), Wilkie D.J. (Co-I), Kittelson, S. (Co-I), Yao, Y., (Co-I), Handzo, G. (Consultant), Chochinov, H. (Consultant), Emanuel, L. (Consultant), Fitchett, G. (Consultant), Hauser, J (Consultant).
Dignity therapy for elderly cancer patients: Identifying mechanisms to promote desired outcomes. R01CA253330-01A1, $1,032,069

Dignity Therapy to Reduce Death Anxiety, Professional Burnout and Increase Quality of Life and Sense of Peace for COVID-19 Frontline Healthcare Providers

Problem

- Frontline HCPs have been challenged to maintain pride, enhance continuity of self, and ultimately make meaning of their life during the COVID-19 pandemic that threatened their lives and wellbeing.
- These HCPs faced not only the usual challenges of their jobs, but also the vast numbers of deaths from COVID-19 and the daily reality that they could be infected by this life-threatening virus and spread it to their families.
- Unfortunately, little research was available to guide interventions for HCPs facing pandemic threats to their own lives.

Purpose

The purpose of this pilot study was to determine the feasibility of a legacy-oriented intervention, Dignity Therapy (DT), to help HCPs toward existential maturity with less death anxiety and professional burnout and greater quality of life and sense of peace during this time of crisis.

Methods

Design:

Single group, pre/posttest pilot study with a 3 to 4-week protocol

Setting:

Virtual

Sample:

Recruited by convenience

September 2020 and February 2021

13 Frontline HCPs (emergency department or critical care)

- 5 chaplains
- 3 nurses,
- 5 physicians

Methods

Instruments:

Completed via Qualtrics

- death anxiety
- professional burnout
- quality of life
- sense of peace
- study acceptability questionnaire

Analysis:

Descriptive statistics, pairwise t tests

Dignity Therapy Protocol

Frontline Healthcare Providers During COVID-19 Pandemic

Visit 1
- Identify eligible participants (email or phone)
- Recruit, informed consent (by phone & email)
- Pre-test (30 min by Zoom)

Visit 2
- Introduction & Orientation Framing phone call (15 min)
- Dignity Therapy (1-hour interview by Zoom)

Between visits
- Transcription
- Editing

Visit 3
- Read the Legacy Document and verify edits (~45 min by Zoom)
- Deliver Legacy Document (email, mail)

<=2-3 weeks

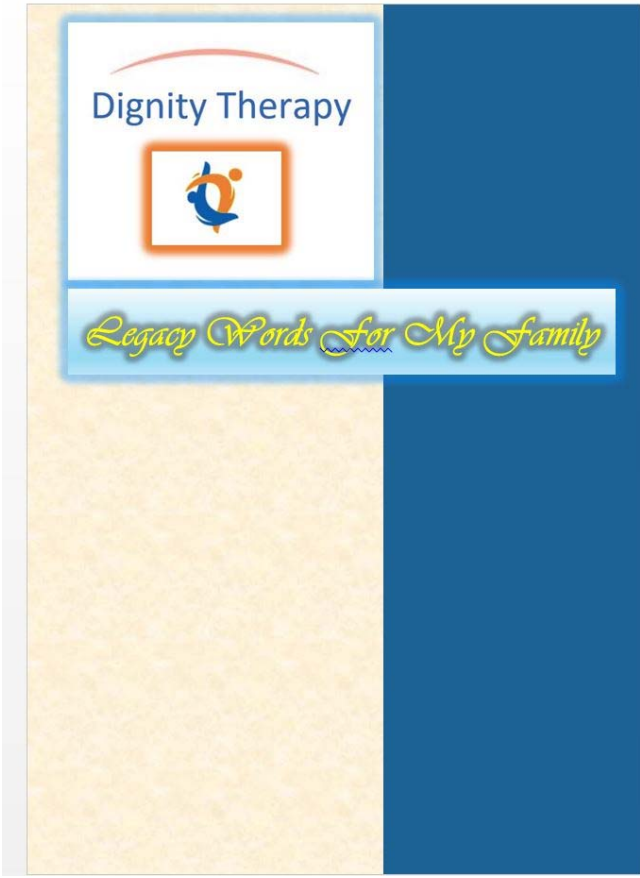
Visit 4 within 5-10 days
- Post-test 5-10 days later (30 min by phone or Zoom)

Methods

Intervention:

Dignity Therapy -- three 15 min to 60 min sessions
(~2 hours total)
delivered by Zoom

legacy document
delivery by email

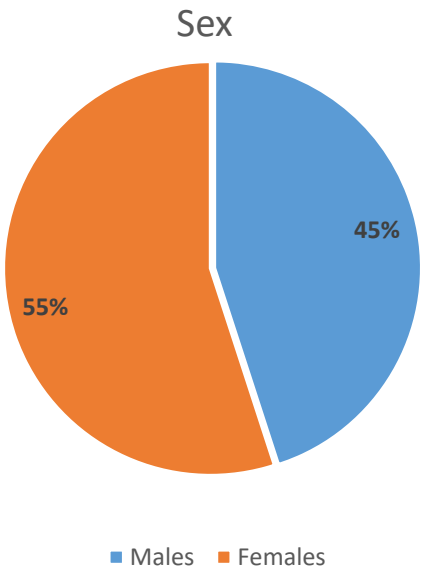


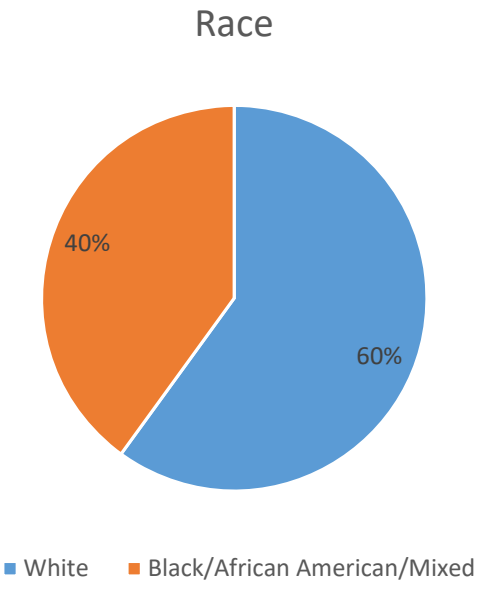
Results

Of the 13 HCPs, 11 completed the study

Mean age 42.5 ± 9.4 (28 to 58 years)

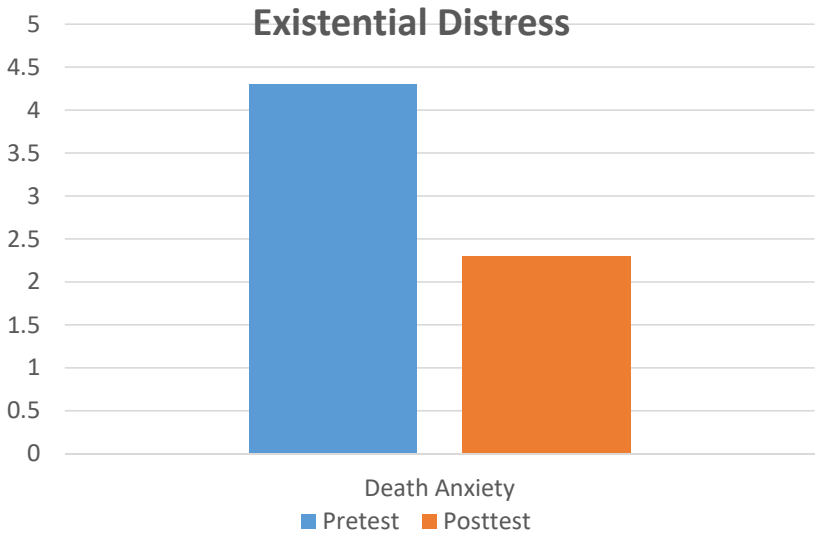
91% married/partnered

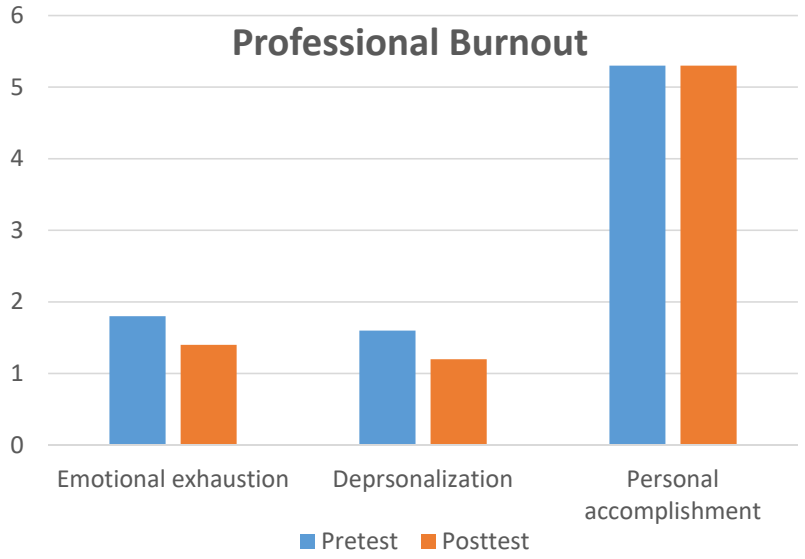




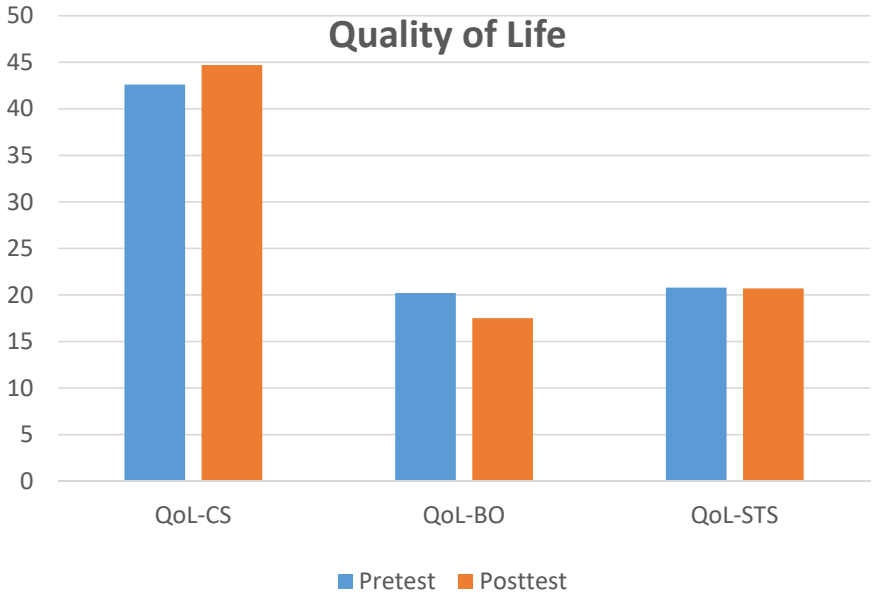
9% Hispanic Ethnicity

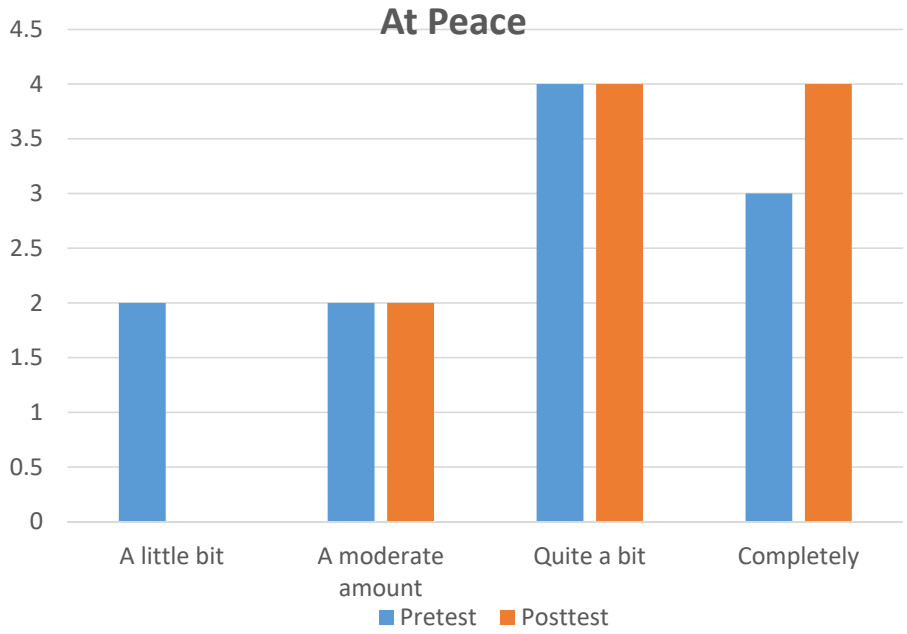
Results


Existential Distress
5
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Death Anxiety
Pretest
Posttest


Professional Burnout
6
5
4
3
2
1
0
Emotional exhaustion
Deprsonalization
Personal accomplishment
Pretest
Posttest

Results


Quality of Life
50
45
40
35
30
25
20
15
10
5
0
QoL-CS
QoL-BO
QoL-STS
Pretest
Posttest


At Peace
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
A little bit
A moderate amount
Quite a bit
Completely
Pretest
Posttest

Results: Feasibility

Recruitment:

87% of the goal — 4 months longer than projected

Retention Rate:

Goal 80% — Actual 85%

Acceptability:

89% not too hard — 89% enjoyed or somewhat enjoyed

89% right length

Not difficult to: complete study (100%)
schedule DT (89%)
complete questionnaires (100%)

Found DT helpful (56%) or somewhat helpful (44%)

Others would accept (56%) or somewhat accept (44%)

Conclusions

- DT holds promise for reducing death anxiety among HCP's facing mortal threat of a pandemic, such as COVID-19.
- Feasibility indicators were mixed, but indicate potential for successfully conducting a larger study with more effective recruitment strategies.

Next Steps

Wilkie, D.J., Emanuel, L., Chochinov, Solomon, S., Robinaugh, D., Cohen, J., Yao, Y., Kittelson, Schoppee, T.,S.., Lichtenthal , W., Jackson, V., Ritchie, C., Schneider, K., Rodin, G., Lebovitz, P., Fitchett, G.

Mechanisms of Psychosocial Intervention Effects on Existential Distress after COVID-19 Mortal Threat.

Submitted to NIH 2/4/2022, $3,843,506, requested.

Welcome Your
Questions, Comments, & Insights

Publications

Peer-reviewed Articles from the Studies Reported in this Presentation

1. Scarton, L., Boyken, L., Lucero, R., Fitchett, G., Handzo, G., Emanuel, L., & Wilkie, D.J. (2018). Effects of dignity therapy on family members: A systematic review. *Journal of Hospice and Palliative Nursing, 20*(6), 542-547. PMID: 30379798 PMCID: PMC6214195

2. Kittelson, S., Scarton, L., Barker, P., Hauser, J., O'Mahony, S., Rabow, M.W., Delgado Guay, M., Quest, T., Emanuel, L., Fitchett, G., Handzo, G., Yao, Y., Chochinov, H.M., & Wilkie, D.J. (2019). Dignity therapy led by nurses or chaplains for elderly cancer palliative care outpatients: Protocol for a randomized controlled trial. *Journal Medical Internet Research, Research Protocols, 8*(4), e12213, DOI: 10.2196/12213. PMID: 30994466.

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7. Schoppee, T. M., Scarton, L., Bluck, S., Yao, Y, Keenan, G., Handzo, G., Chochinov, H. M., Fitchett, G., Emanuel, L. L., & Wilkie, D. J., (Online, 2021). Description of a Training Protocol to Improve Research Reproducibility for Dignity Therapy, an Interview-Based Intervention. *Palliative and Supportive Care*. doi: 10.1017/S1478951521000614. PMID: 34036932.

8. Damen, A., Exline, J., Pargament, K., Yao, Y., Chochinov, H., Emanuel, L., Handzo, G., Wilkie, D.J., & Fitchett, G. (2021). Prevalence, predictors and correlates of religious and spiritual struggles in palliative cancer patients. *Journal of Pain and Symptom Management, 62*(3), E139-E147. doi: 10.1016/j.jpainsymman.2021.04.024 PMID: 33984462.

9.Bylund, C.L., Taylor, G., Mroz, E., Wilkie, D.J., Yao, Y., Emanuel, L., Fitchett, G., Handzo, G, Chochinov, H.M., & Bluck, S. (In press, 2021). Empathic communication in Dignity Therapy: Feasibility of measurement and descriptive findings. *Palliative and Supportive Care*.

10.Rantanen, P., Chochinov, H. M., Emanuel, L.L., Handzo, G., Wilkie, D. J., Yao, Y., & Fitchett, G. (2022). Existential quality of life and associated factors in cancer patients receiving palliative care. *Journal of Pain and Symptom Management*, *63*(1), 61-70, doi: 10.1016/j.jpainsymman.2021.07.016 PMID: 34332045.

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Chochinov, H. M., Kristjanson, L. J., Breitbart, W., McClement, S., Hack, T. F., Hassard, T., & Harlos, M. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology*, 12(8), 753-762. Retrieved from http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=21741309

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Juliao, M., Oliveira, F., Nunes, B., Vaz Carneiro, A., & Barbosa, A. (2014). Efficacy of dignity therapy on depression and anxiety in Portuguese terminally ill patients: a phase II randomized controlled trial. *Journal of Palliative Medicine*, 17(6), 688-695. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/24735024. doi:10.1089/jpm.2013.0567

Tait, G. R., Schryer, C., McDougall, A., & Lingard, L. (2011). Exploring the therapeutic power of narrative at the end of life: a qualitative analysis of narratives emerging in dignity therapy. *BMJ Support Palliative Care*, 1(3), 296-300. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/24653473. doi:10.1136/bmjspcare-2011-000051

Vergo, M. T., Nimeiri, H., Mulcahy, M., Benson, A., & Emmanuel, L. (2014). A feasibility study of dignity therapy in patients with stage IV colorectal cancer actively receiving second-line chemotherapy. *Journal of Community and Supportive Oncology*, 12(12), 446-453. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/25866895. doi:10.12788/jcso.0096