Published in final edited form as:

Psychooncology. 2015 December ; 24(12): 1823–1825. doi:10.1002/pon.3790.

Piloting an abbreviated Dignity Therapy intervention using a legacy-building web portal for adults with terminal cancer: A feasibility and acceptability study

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Introduction

Adults with terminal cancer face great physical, psychosocial, and spiritual challenges as they near death. In a group of patients with advanced cancer and a median survival of 4.4 months, approximately 60% demonstrated signs of inhibited acceptance of the terminal nature of their illness [1]. Loss of dignity, hope, and meaning in life, has been shown to contribute more to a wish for hastened death than physical pain and other distressing symptoms [2]. Past research has acknowledged the need for more supportive therapy to preserve dignity and create meaning at end of life (EOL) [3].

Dignity therapy (DT) is an individualized therapeutic approach to support adults at (EOL) in the creation of a legacy project that communicates their memories, wisdom, and core life values, thus, bringing meaning and purpose as they near death. Furthermore, the legacy project succeeds the person in death and is handed down to surviving loved ones, ensuring continuity to those who are left behind. DT is grounded in the empirically-derived Dignity Model [4]. DT has been shown to benefit adults with terminal cancer [2, 5] and their legacy project recipients [6]; however, it requires a DT-trained therapist, institutional resources, and can take up to 10 hours to deliver [7, 8]. These are critical barriers to DT uptake in the community and overall progress in the field. In addition, past DT participants stated they would prefer to create a dynamic, self-edited legacy that can be modified based on their evolving EOL needs [7]. Traditional DT does not readily provide for this.

To address these barriers, we developed a legacy-building intervention based on DT that included a novel web portal to facilitate legacy building and dissemination to family members. We assessed the feasibility and acceptability of the web-enhanced and abbreviated DT intervention to determine if it could be a user-friendly alternative to traditional DT. We collected data on secondary outcomes, including measures of existential well-being and dignity.

Methods

Design overview

Our pilot legacy-building intervention used the nine DT questions developed from the Dignity Model [4] (See Table 1), but differed from traditional DT in three ways: (1) Participants had one face-to-face meeting with a DT-trained oncology social worker or clinical psychologist who asked the three DT questions (1, 2, and 5) that were associated with the most emotional tenderness based on our past research [7]. (2) Participants (with or without the help of trusted others) were asked to use a web portal to respond to the remaining six DT questions with text and/or other materials (e.g., photographs). (3) Participants received brief weekly facilitative calls from the interventionist to add flexibility to the more rigid structure of a web-based intervention. These calls included a brief patient-centered discussion of each participant's progress creating their legacy (which the interventionist reviewed prior to the scheduled call), a discussion of questions about navigating the website, and support to address emotional distress.

Participants

Potentially eligible patients (n=58) were identified by study recruiters in the outpatient oncology clinic of an academic medical center. Interested patients were screened for eligibility using the following criteria: (1) at least 21 years of age; (2) diagnosed with incurable and advanced-stage solid malignancies; (3) rated by their oncologist as having < 50% chance of one- year survival; (4) impaired in existential well-being (as determined by a score of ≤ 25 on the FACIT-Spirituality (FACIT-Sp) Meaning and Peace subscale [9]); (5) able to read, write, and understand English; and (6) regular users (at least once a week) of the Internet and email. Recruitment rates were initially low (14%) because several interested patients were deemed ineligible due to having FACIT-Sp scores of > 25 . We amended the study protocol to eliminate the impaired existential well-being criterion, making the final recruitment rate 36.4% (n=16).

Procedures

After consenting, participants received one abbreviated face-to-face DT session that included audio recording each participant's responses to three DT questions and orientation to the legacy-building web portal. The face-to-face intervention was completed in the participant's preferred location (72.7% in the participant's home, remainder in the oncology clinic). Within one week of this session, participants received an electronic copy of their transcribed responses and three subsequent weekly phone calls to aid self-led legacy building. Participants completed baseline and post-intervention surveys assessing primary (feasibility and acceptability) and secondary (existential well-being and dignity) outcomes. Participants were provided \$25 gift cards for completing each survey.

Measures

We collected demographic information to describe the sample. To measure feasibility, we determined percentages of patients who completed both study assessments compared to the total number who enrolled, the percentage of participants who completed a legacy project

that expressed 2 core values, as assessed using content thematic analyses with the DT Coding Framework [10], and the percentage of participants who used the web portal to complete their projects.

To measure acceptability, participants were asked to rate their satisfaction with the legacy-building intervention, their final legacy project, and the web portal. Satisfaction was determined using a Likert scale ranging from 0 (extremely unsatisfying) to 10 (extremely satisfying).

Existential well-being was assessed using the FACIT-Sp [9], which measured meaning in life across a range of religious and spiritual traditions. The FACIT-Sp consisted of 8 items rated on a 0-4 scale (sample item, "I feel a sense of purpose in my life") with higher scores indicating greater existential well-being. It has demonstrated good internal consistency ($\alpha = 0.87$).

Dignity was assessed using the Patient Dignity Inventory [11], which measured various sources of dignity-related distress among patients nearing EOL. The Patient Dignity Inventory consisted of 25-items rated on a 1-5 scale (sample item, "I have not made a meaningful contribution in my life") with higher scores indicating greater dignity-related distress. It has demonstrated good internal consistency ($\alpha = 0.93$).

Results

Sixteen participants enrolled in the study (12 females, 4 males). The mean age of participants was 52.3 ($SD=12.0$) years. The sample was mostly white (81%), married (81%), and college educated (75%). The majority of participants had breast cancer (67%); the remainder had gastrointestinal cancers (27%) or lung cancer (7%). The majority of enrolled participants (69%) completed both study assessments (two participants died and three dropped out due to time constraints), and 69% completed legacy projects that expressed 2 core values from the DT Coding Framework [10]. Participant satisfaction was high with the intervention ($M=8.82$, $SD=1.08$) and the final legacy project they created ($M=8.55$, $SD=1.13$). Although the interventionist trained all participants in use of the web portal, fewer than half (45%) of the participants reported using it to complete their legacy project; the majority used a word processing program. Of those who used the portal, 80% reported dissatisfaction, primarily due to usability issues and a lack of clear instructions. The final legacy project's appearance varied across participants' creative expression. Some participants included only text, while others included photos. For both existential well-being and dignity measures, post-intervention outcomes did not significantly differ from baseline (see Table 2).

Conclusion

Results suggest that our legacy-building intervention was both feasible and mostly acceptable. Participants were highly satisfied with the abbreviated intervention and the final legacy projects they created, but were generally dissatisfied with the web portal. To our knowledge, this was the first intervention that attempted to make DT more widely accessible and available to the population by implementing abbreviated DT coupled with an online

platform. We still utilized a DT-trained interventionist to ensure psychosocial support; however, the time and transcription costs were minimal compared to traditional DT, which has excellent outcomes, but may not be feasible in places with limited resources [12]. Participants reported that the portal was difficult to use and the instructions were unclear, which likely led to lack of use. Future research, including in-depth interviews, will aim to understand specific issues with the web portal to improve its usability. Since our sample size was small and participants reported high levels of existential well-being and low levels of dignity-related distress at baseline, like past DT studies [2, 5], we were not able to show significant improvement in secondary outcomes. Future research should examine these outcomes in a larger and more distressed sample.

Acknowledgments

Funding: This project was funded by the Indiana University-Purdue University Indianapolis Research in Palliative and End-of-Life Communication and Training (RESPECT) Signature Center, the National Cancer Institute's Training in Research for Behavioral Oncology & Cancer Control (R25 – CA117865) award to J.K.B. and the Indiana Clinical and Translational Sciences Institute career development award to S.A.J. (funded in part by the National Institutes of Health, National Center for Advancing Translational Sciences, Clinical and Translational Sciences Award #TR000163)

References

1. Wright AA, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama*. 2008; 300(14):1665–73. [PubMed: 18840840]
2. Chochinov HM, et al. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol*. 2005; 23(24):5520–5. [PubMed: 16110012]
3. Lee V. The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer*. 2008; 16(7):779–85. [PubMed: 18197427]
4. Chochinov HM, et al. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002; 54(3):433–43. [PubMed: 11824919]
5. Chochinov HM, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*. 2011; 12(8):753–62. [PubMed: 21741309]
6. McClement S, et al. Dignity therapy: family member perspectives. *J Palliat Med*. 2007; 10(5):1076–82. [PubMed: 17985964]
7. Johns SA. Translating dignity therapy into practice: effects and lessons learned. *Omega (Westport)*. 2013; 67(1-2):135–45. [PubMed: 23977789]
8. Montross L, Winters KD, Irwin SA. Dignity therapy implementation in a community-based hospice setting. *J Palliat Med*. 2011; 14(6):729–34. [PubMed: 21548823]
9. Peterman AH, et al. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-being Scale (FACIT-Sp). *Ann Behav Med*. 2002; 24(1): 49–58. [PubMed: 12008794]
10. Hack TF, et al. Learning from dying patients during their final days: life reflections gleaned from dignity therapy. *Palliat Med*. 2010; 24(7):715–23. [PubMed: 20605851]
11. Chochinov HM, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *J Pain Symptom Manage*. 2008; 36(6):559–71. [PubMed: 18579340]
12. Lindqvist O, et al. Reflections on using biographical approaches in end-of-life care: dignity therapy as example. *Qual Health Res*. 2015; 25(1):40–50. [PubMed: 25189536]

Key Points

- Many adults with terminal cancer experience loss of dignity and meaning at end of life (EOL).
- Dignity Therapy promotes meaning making through legacy building to ease EOL suffering, but it requires resources to deliver and is not widely accessible.
- We tested an abbreviated version of Dignity Therapy that utilized a legacy-building web portal.
- Our intervention was feasible and acceptable; however, participants reported dissatisfaction with the web portal.
- Our intervention warrants further investigation of the efficacy of legacy-building web portals in a randomized controlled trial.

Table 1
Dignity therapy questions from the Dignity Model

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- *1. What parts of your life do you remember most or think are most important?
 - *2. What do you want people to know and remember about you?*
 3. What are your most important roles in life?
 4. What are your most important accomplishments?
 - *5. Are there particular things you believe 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 advice or instructions do you wish to pass along?
 8. Are there words you would like to offer your family to help prepare them for the future?
 9. In creating this permanent record, are there other things you would like included?
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* Question asked in the face-to-face DT session

Table 2
Baseline to post-intervention changes in secondary outcome measures

	n	Baseline, T0 Mean (SD)	Post, T1 Mean (SD)	p-value T0 - T1	Effect Size (d)
Existential Well-being ^a	11	3.30 (.41)	3.15 (.43)	0.42	-0.35
Dignity-related Distress ^b	11	0.53 (.20)	0.54 (.26)	0.96	0.02

^aFACIT-Sp (0-4 scale, higher scores = greater existential well-being);
^bPatient Dignity Inventory (1-5 scale, higher scores = greater dignity-related distress)