American Journal of Hospice & Palliative Medicine®
1-8

DOI: 10.1177/10499091211011712
journals.sagepub.com/home/ajh
SAGE

Quality of Life for Older Cancer Patients: Relation of Psychospiritual Distress to Meaning-Making During Dignity Therapy

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Abstract

Background: Nearly 500,000 older Americans die a cancer-related death annually. Best practices for seriously ill patients include palliative care that aids in promoting personal dignity. Dignity Therapy is an internationally recognized therapeutic intervention designed to enhance dignity for the seriously ill. Theoretically, Dignity Therapy provides opportunity for patients to make meaning by contextualizing their illness within their larger life story. The extent to which Dignity Therapy actually elicits meaning-making from patients, however, has not been tested. **Aim:** The current study examines (i) extent of patient meaning-making during Dignity Therapy, and (ii) whether baseline psychospiritual distress relates to subsequent meaning-making during Dignity Therapy. **Design:** Participants completed baseline self-report measures of psychospiritual distress (i.e., dignity-related distress, spiritual distress, quality of life), before participating in Dignity Therapy. Narrative analysis identified the extent of meaning-making during Dignity Therapy sessions. **Participants:** Twenty-five outpatients (*M* age = 63, *SD* = 5.72) with late-stage cancer and moderate cancer-related symptoms were recruited. **Results:** Narrative analysis revealed all patients made meaning during Dignity Therapy but there was wide variation (i.e., 1—12 occurrences). Patients who made greater meaning were those who, at baseline, reported significantly higher psychospiritual distress, including greater dignity-related distress ($r = .46$), greater spiritual distress ($r = .44$), and lower quality of life ($r = -.56$). **Conclusion:** Meaning-making was found to be a central component of Dignity Therapy. Particularly, patients experiencing greater distress in facing their illness use the Dignity Therapy session to express how they have made meaning in their lives.

Keywords

palliative care, dignity, spiritual distress, life story, narrative analysis

Introduction

Cancer patients' sense of dignity is a marker of their personal well-being. Feeling a lack of dignity and an absence of spiritual support is common for patients facing serious illnesses such as late-stage cancer.[1,2] Dignity Therapy (DT) is a therapeutic intervention[2] that provides a structure for guiding seriously ill patients, primarily those approaching end-of-life, to narrate their life story. DT frames the telling of one's life story as a way of leaving a legacy for loved ones.[2] Theoretically grounded in life review,[3] DT involves a trained provider using a standard set of interview questions to prompt the patient to reflect on their life values, relationships, and accomplishments (see Table 1). This type of life review, or reminiscence, activity is considered particularly productive for those in later adulthood[4] and reflects a long tradition of incorporating life review techniques into healthcare (e.g., mental health counseling, nursing, palliative care).[5-8] While DT is useful

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Table 1. Dignity Therapy Question Protocol (Chochinov et al, 2005).

Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
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?
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?
What are your most important accomplishments, and what do you feel most proud of?
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?
What are your hopes and dreams for your loved ones?
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, others)?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future? In creating this permanent record, are there other things you would like included?

Table 2. Patients' Cancer Diagnosis and Stage.

Diagnosis-stage	# Patients
Pancreas-2	4
Ovarian-3	1
Lung-3	1
Lung-4	4
Ovarian-4	1
Ovarian-1	2
Pancreas-4	1
Rectal-4	2
Breast-4	2
Bone Marrow-2	1
Liver-4	1
Stomach-4	1
Esophageal-4	1
Thymoma-4	1
Prostate-4	1

Note. One patient had a non-staged cancer.

for patients of any age, DT's focus on guiding patients to look back over their life experiences may be particularly poignant for patients in the second half of life.

A systematic review of 25 studies[9] concluded DT has high acceptability: patients reported strong an increased sense of dignity following DT. DT is considered an effective intervention that leads to high patient satisfaction.[10,11] Recently, however, there has been a call to examine the processes occurring during DT sessions. Several studies have examined patients' narration of life experiences during DT using qualitative methods that focus on identifying the *content* of patients' stories (e.g., themes such as family, friendship, accomplishment).[12,13] Little research has focused, however, on *processes* involved in telling one's life story, that is, how patients narrate their life experiences. Literature suggests one important aspect of the narrative process is the extent to which patients engage in *meaning-making* about life's events.[12,14,15]

Identifying therapeutic approaches for cancer patients to make meaning is an important part of palliative care delivery. Theoretically, DT provides an opportunity for patients to make meaning by, for example, contextualizing their current illness experience within their larger life story.[12] Making meaning can involve a variety of psychological processes, including more basic (e.g., lessons and insights[16]; event integration[17]) and complex (e.g., existential meaning reconstruction through sense making and benefit finding while grieving[18]; ruminative searching for clarification of event meaning[19]; searching for life's meaning[20]) positive and negative forms of meaning-making. For the purposes of this study, we consider positive meaning-making by way of productive evaluation of life events . This form of meaning-making occurs when patients appraise their life experiences, affirm core values and reconcile life challenges. This form of positive meaning-making is thus an important psychological outcome in itself, as has been demonstrated by its relation to subsequent well-being.[21-23] For example, cancer patients who self-report greater meaning feel higher self-esteem, optimism, and self-efficacy.[24]

Patients respond uniquely to their illnesses. Those who are struggling to maintain psychospiritual wellbeing may particularly need opportunities, like DT, to make meaning of their life's experiences.[25-28] That is, patients currently grappling with dignity distress, spiritual distress, or distress about their overall quality of life may be even more likely to use the guided DT session as an opportunity to make meaning, re-interpreting their diagnosis by contextualizing their illness within their larger life story.[22] The specific aims of the current research were, therefore, to: (1) determine the frequency of older cancer patients' meaning-making during DT, and (2) investigate whether higher psychospiritual distress at baseline (i.e., dignity distress, spiritual distress, lower quality of life) relates to greater meaning-making during the DT session.

Method

Participants

This study was approved by the institution's ethical review board (IRB: 201601190). All participants provided written consent and data were collected between February and November, 2019. Participants were 25 cancer outpatients, aged 55-75 years ($M_{age} = 63$; $SD = 5.72$; 52% women) recruited from 2 U.S. Academic Medical Centers as part of a larger study.[29] Fifteen patients had Stage 4 cancers (see Table 2 for patient diagnoses and cancer stage). Patients reported mild to moderate illness-related symptoms on the ESAS ($M = 3.48/10$; $SD = 2.95$) and most (88%) had Palliative Performance at 60-80%, indicating that they had some illness-related problems, somewhat reduced ability for self-care, but were fully alert. The sample was majority (72%) White but also included

16% African American, 4% American Indian/Alaskans and 8% who reported race as Other. Participants received $50 for participation.

Design and Measures

Data include responses to standard measures administered to assess patients' psychospiritual distress at baseline (i.e., feelings of dignity-related distress, spiritual distress, and quality of life). The extent to which patients engaged in meaning-making during DT was derived through reliable narrative analysis of the transcript of their DT session. Narrative analysis has a long history and is well-established for content-analyzing autobiographical reflections[14,30] such as occur during DT. We purposely chose narrative analysis as an appropriate, rigorous method that leads to ecologically-grounded understanding of patients' unique lived experience.[31]

Demographics and health status. Information collected at baseline included demographic characteristics and cancer diagnosis. To characterize the sample, symptoms and severity of illness were measured with valid measures, the Edmonton Symptom Assessment Scale[32] and Palliative Performance Scale.[33]

Patients' dignity-related distress. The 21-item Patient Dignity Inventory (PDI)[34] measures sources of dignity-related distress commonly affecting seriously ill patients, across several theoretically central domains of personal dignity. The PDI was administered at baseline, before DT. Patients responded to Likert scales (1 = not a problem; 5 = an overwhelming problem; Cronbach's $\alpha = .93$). Subscales include: Symptom Distress (6 items; $\alpha = .79$; e.g. *uncertain about my illness and treatment*), Existential Distress (6 items; $\alpha = .85$; e.g. *life no longer has meaning or purpose*), and Dependency (3 items; $\alpha = .85$; e.g. *not being able to carry out tasks associated with daily living*). Two subscales were administered but not used in analyses due to low Cronbach's alphas: Peace of Mind (3 items), and Social Support (3 items).

Patients' spiritual distress. To describe the extent to which patients faced religious or spiritual conflict (e.g., involving negative thoughts or emotions surrounding a relationship with a deity, religious institution, or personal spirituality) prior to participating in DT, a 14-item version of the Religious/Spiritual Struggles Scale (RSSS)[35] was administered (e.g., *felt confused about my spiritual beliefs*) at baseline. Patients indicated distress about spiritual matters over the past month on a Likert Scale (1 = not at all/ does not apply; 5 = a great deal; $\alpha = .89$).

Patients' quality of life at end of life. The Quality of Life at the End of Life Measure (QUAL-E)[36] assesses multiple psychosocial dimensions of seriously ill patient's quality of life. For this study, 2 subscales of this measure were assessed at baseline: patients' feelings of being prepared (e.g., *I have regrets about the way I have lived my life; reversed*) and having a sense of completion (e.g., *I feel at peace*). Ratings were made on Likert scales (1 = not at all; 5 = completely; $\alpha = .73$).

Narrative analysis of meaning-making. Transcripts of the life stories patients shared in their DT session were content-analyzed for meaning-making using a standard codebook theoretically derived from the classic meaning-focused coping model.[37,38] This model suggests several aspects of meaning-making are critical for reappraisal of, and emotional adjustment to, stressful life events such as illness. The codebook provides clear guidance on how to recognize manifestation of meaning-making in participant narratives, including: *finding benefit* (i.e., patient uncovers positive aspects of an experience), *allocating responsibility* (i.e., patient assigns responsibility regarding a challenge to make the challenge feel more meaningful), *religious-spiritual explanation* (i.e., patient provides religious/spiritual understanding of an event), *downward social comparison* (i.e., patient reframes situation to realize there may have been worse possible outcomes) and *personal growth* (i.e., patient describes self-development from their experience).

Coding DT transcripts. Two coders were trained over several weeks using the standard coding manual and practice materials. Following best practices in narrative analysis, 20 practice narratives were coded independently by both coders to establish inter-rater reliability (kappa = .74) before coding the study data. Coders met weekly to discuss and resolve any coding discrepancies. To enhance ecological validity, coders not only read the DT session transcript but did so while simultaneously listening to an audio-recording of the patient telling their life story during the DT session. Before coding, transcripts were separated into multiple idea units, largely delineated by responses to the core DT interview questions (See Table 1). Then, for each idea unit, a zero (no occurrence) or 1 (occurrence of meaning-making) was coded if any aspect of meaning-making was present (i.e., any combination of finding benefit, allocating responsibility, religious-spiritual explanation, downward social comparison, or personal growth). To control for differing lengths of DT session transcripts, the sum of the raw frequency of meaning-making occurrences in the entire transcript was divided by the number of idea units, creating a standardized percentage score for each patient.

Procedure

Palliative care providers referred potentially eligible outpatients who, if interested, were first visited by members of the study team and the therapist. During this information session, the goals were to establish rapport between the therapist and patient and to explain the history and process of DT.[29] This session is vital, as it allows patients time to consider if they want to engage in DT[39] and to review guiding questions in advance, if desired. During this information visit, research assistants administered informed consent and baseline measures and then scheduled an appointment for the 1-on-1 DT session with the therapist. Sessions occurred at the medical center where patients were receiving treatment. DT providers

had undergone extensive training.[40] Participating patients were provided in advance with core questions used to guide the DT session (See Table 2). Sessions closely followed the Dignity Therapy Protocol[2] and lasted, on average, 42.56 minutes (range = 23-57 minutes; $SD = 10.45$). Patients' life story narratives in responses to core questions were a good length, on average, 3843.76 words (range = 1315-7184 words; $SD = 1629.39$). Sessions were audio-recorded, professionally transcribed, and verified by the patient.

Results

Strengths of the narrative analysis[30,41] method are that it can identify rich exemplars of central constructs such as patient meaning-making (Aim 1) while it also results in frequencies that can be quantitatively related to measures of psychospiritual distress (Aim 2). Example narratives included below are drawn from full transcripts of DT sessions examined in the current study.

Frequency of Meaning-Making During DT

Extent of Meaning-Making during DT sessions varied widely across individual patients (range = 1 to 12 occurrences; $M = 5.24$; $SD = 2.88$). Percentage of the DT session that included Meaning-Making also ranged, from 11-75% across patients. As patients shared their unique life experiences, Meaning-Making occurred in a variety of forms. The following exemplars from patients' DT transcripts illustrate the powerful life reflection patients engaged in during DT.

One way Meaning-Making was evident was in patients' life stories was in terms of finding benefit from previous negative life events. This included even very difficult events such as their own previous loss experiences. For example, this 56-year-old woman contextualized her own illness by remembering gratitude and relief during her husband's passing:

> *When I went back in the room and saw my husband wasn't breathing anymore, that was like, oh, thank God . . . 'cause he was in pain. He wasn't good . . . It is gonna be a big relief for [my family] when I'm gone. They don't have to worry anymore. I want my family to feel like when I'm gone, "thank God she's gone."*

This narrative example shows how the patient made meaning of the loss of her husband, using that experience to consider how her family might relate to her own eventual death, potentially seeing it as an end to her suffering.

Another way that Meaning-Making manifested in DT sessions was through patients' recognizing instances of growth and learning in their life story. For example, a 58-year-old male patient, when asked the DT core question "When did you feel most alive?" responded by saying:

> *Wow. Probably right now, after having gone through this cancer. Because when you think you're checking out, [laughs] you learn to appreciate everything, I think, a lot more than you ever did before . . . There's a lot of ways you can phrase it, but it does make you think about your life and what you've accomplished and what you've yet to accomplish.*

This patient acknowledged his brush with death as meaningful experience from which growth had occurred in his life. He framed his current cancer in terms of appreciating his life, valuing his accomplishments, and having agency about his future accomplishments.

Several patients made meaning in yet another way, striking a positive note through downward social comparison. This involved contrasting their own challenging illness circumstances with others who they perceived as having even worse situations. This 63-year-old woman compares her own mindset about her diagnosis to how others approach their illness:

> *I've met people who are so bitter [about their cancer diagnosis]. "Why me?" Some are so angry. You see it on their faces . . . I never wanted to be in that bitter place, so I have an acceptance of it.*

This patient's recognition that she has the power of acceptance, and her perception that others suffer more through their anger and denial, provided a helpful social comparison that bolstered her own feeling about dealing with her illness.

Another way that patients made meaning during DT was through religious or spiritual explanations. In talking about his life, this 59-year-old man spoke of God's will for him to live on despite illness:

> *This is my second bout with cancer, and when I got it [the first time], they were giving me DNRs, wanting me to go through Hospice and I'm like, "Okay, the Lord has something else for me to do—or I would not be here."*

This patient came to understand his journey with illness within his own religious framework. He viewed his recovery as a message from the Lord about his need to make further contributions during his life.

Baseline Psychospiritual Distress Relates to Meaning-Making During DT

To address the second aim, to identify relations between baseline measures of psychospiritual distress and patients' subsequent Meaning-Making during their DT session, bivariate correlations were computed relating each of the measures of psychospiritual distress (i.e., Dignity-related Distress, Spiritual Distress, and Quality of Life at the End of Life) to standardized scores of Meaning-Making frequency in the DT session (see Table 3). Patients who reported greater dignity-related distress ($r = .46$), spiritual distress ($r = .44$), and lower quality of life ($r = -.56$; $ps < .05$) at baseline made meaning more frequently during DT.

To further explore the relations between Dignity-related Distress at baseline and later Meaning-Making in the DT session, correlations for each subscale of the Dignity-related Distress scale were conducted. Experiencing both higher Symptom

Table 3. Means, Standard Deviations and Zero-Order Correlations of Baseline, Psychospiritual Distress Variables With Meaning-Making During DT.

Psychospiritual distress variable	*M*	*SD*	Relation to meaning-making
Quality of Life at End of Life	3.38	0.61	-.56*
Spiritual-related Distress	1.98	0.56	.44*
Dignity-related Distress Overall	1.82	0.61	.46*
Symptom Distress Subscale	2.08	0.72	.46*
Existential Distress Subscale	1.81	0.75	.46*
Dependency Subscale	1.57	0.87	.17

Note: * $p < .05$.

Distress ($r = .46$) and more Existential Distress ($r = .46$; $ps < .05$) was related, with relatively large effect sizes, to patients showing greater Meaning-Making during their DT session. Meaning-Making was not related to Dependency ($r = .17$.). See Table 3 for details about subscales of dignity distress and their relations to Meaning-Making during DT.

Discussion

Helping patients maintain psychospiritual wellbeing when faced with a serious cancer diagnosis is an important aspect of palliative care. This research highlighted meaning-making as a central process of DT, particularly for patients experiencing higher psychospiritual distress at baseline. Our findings demonstrate that meaning-making occurs frequently during DT and that higher distress relates to greater meaning-making. Meaning-making manifested in a variety of forms, such as finding benefit in difficult situations, realizing that growth can occur through hardship, comparing one's own situation to possible worse scenarios, or cherishing the spiritual-religious significance of one's unique life events.

Study findings support that seriously ill patients may be interested in sharing their life stories with providers and benefit from such activities. This may be particularly true for those suffering psychospiritual distress. Creating space within standard healthcare settings for narrative sharing[1,42] may offer benefits to psychospiritually distressed patients. Findings from the current study can be used to refine protocols for training and provision of psychospiritual care to cancer patients, specifically supporting strategies that providers can use to encourage meaning-making during DT. A few examples are provided here of how positive meaning-making might be elicited as part of care provision. First, counseling sessions between seriously ill patients and chaplains might benefit from explicitly encouraging meaning making through forging religious-spiritual explanations of past challenges. Goals of care discussions with nurses, physicians, or social workers may benefit from discussion of central life experiences which have encouraged personal growth as a way of understanding their long-standing values and beliefs.

Meaning-making was present in all of these cancer patients' life stories. As seen in the narrative examples, patients made meaning of previous life experience and of their current cancer diagnosis, sometimes linking the two. Our findings amplify recent work that suggests cancer patients are motivated to seek meaning to reframe suffering.[15] There was, however, wide variability in the extent to which meaning-making occurred: patients who had lower psychospiritual distress about their illness expressed greater meaning-making during DT. We suggest that for those with greater psychospiritual distress, DT may offer a needed opportunities to reappraise their past. That is, patients expressing urgent distress may be more inclined to engage in productive therapeutic processes, such as positive meaning-making.[43] Having an inability or lack of opportunity to make meaning has been related to existential despair and fractured dignity[44-46] in patients with serious illness.

Note that it was certain aspects of dignity distress that were related to greater meaning-making. Particularly, those patients who at baseline were experiencing higher physical distress and uncertainty about healthcare (i.e., symptom distress subscale) and existential distress more often expressed meaning-making during DT. These findings fit with recent research demonstrating that cancer patients may engage in meaning-making to cope with pain and the existential uncertainty it produces.[15]

In terms of next steps, narrative analysis of DT sessions for other intrapersonal processes conceptually central to DT provides a fruitful future direction. This could include patients' expression of communion with others,[47] of their focus on having a sense of purpose in life,[48] or of their sense of generativity[49] when telling their life story in DT. In addition, we focused on DT for older adults with cancer. DT is also, however, being provided to other illness populations[50,51] and age groups.[52,53] Investigation of the relation between psychospiritual distress and meaning-making in DT sessions in other patient populations is warranted. Finally, Engaging in DT requires cognitive effort, and forging meaning in particular may be a higher order process that requires a certain level of cognitive capacity. As such, the findings regarding meaning-making in the current study may not be applicable to those with cognitive impairment due to MCI, dementia, pain or illness severity. Within the adult population more generally, variations in cognitive functioning across individuals[54] may foster or hinder meaning-making.

Strengths and Limitations

This research benefits from use of a rich dataset of older cancer patients speaking in their own voices, telling their unique life stories during DT. This type of narrative data is critical for revealing patients' humanity by uncovering how they frame and evaluate their lives. Narrative analysis[14] provides an excellent tool for elucidating salient meaning-making themes in patients' DT sessions. Though the study provides important first evidence of meaning-making during DT, it is limited in sample size, prohibiting more sophisticated statistical analyses. For example, it is impossible in the current study's sample to test difference in DT delivery among DT providers, as potentially relating to meaning-making during DT. The study team is planning to replicate these findings in a larger sample, as well as to investigate how the meaning-making process relates to

independently-assessed improvement in patient outcomes following DT. In addition, while there was variability in the self-reported distress of patients in the study, the majority of patients reported somewhat low levels of dignity distress or spiritual-related distress, and relatively high quality of life. Future research should extend the examination of meaning-making during DT to patients experiencing chronic and debilitating levels of psychospiritual distress.

Conclusion

DT, a life review intervention, was originally designed to address dignity and spiritual distress in the seriously ill. In the current study, cancer patients were found to consistently engage in meaning-making, in a variety of forms, while telling their life story during DT. In particular, patients suffering from physical, spiritual, and existential distress were most likely to engage in meaning-making. DT appears to offer an opportunity for these patients to reframe and reappraise their illness. Study findings can be used to further refine protocols for DT training and provision, as well as larger efforts to promote meaning-making for those patients suffering distress.

Authors' Note

S.B. and C.B. contributed to the study design and conception. S.B. and E.M. contributed to manuscript development and oversaw narrative analysis. C.B., D.W., L.E., G.H., G.F., and H.C. secured project funding and contributed to participant recruitment and study development. All authors critically reviewed and revised the manuscript for intellectual content and approved the final version of the submitted manuscript. The corresponding author attests that all listed authors meet authorship criteria. No one meeting the criteria has been omitted. This study was approved by the Institutional Review Board of the University of Florida (IRB No. 201601190). The methods section of this paper includes additional information about data collection, IRB approval, and participant informed consent. Linda Emanuel is now affiliated to Mongan Institute at Massachusetts General Hospital.

Acknowledgments

The authors would like to recognize the helpful contributions of Rachel Wisolmerski and the Life Story Lab team. We would also like to express our gratitude to the participants who told their life stories.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Cancer Institute [No. 5R01CA200867] and by the University of Florida Health Cancer Center Pilot Project Awards Program.

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Supplemental Material

Supplemental material for this article is available online.

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