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Outcomes of a Dignity Therapy/Life Plan Intervention for Patients With Advanced Cancer Undergoing Chemotherapy

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Abstract

Dignity therapy is a psychosocial intervention provided at the end of life to improve patient outcomes, but many persons cannot complete it because of health decline. Patients also reprioritize their life plans as death becomes imminent. As part of meeting standards to provide psychosocial palliative care simultaneously with cancer treatment, we provided a dignity therapy/life plan intervention to 18 patients with advanced pancreatic or lung cancer receiving cancer treatment. The study aim was to evaluate patient-reported outcomes of dignity therapy/life plan. Dignity therapy entailed interviews during 3 outpatient oncology encounters, which then became a legacy document for family. Participants documented life goals as their *life plan*. Distress, quality of life, spirituality, dignity, and purpose in life were measured at baseline, immediately post intervention, and 3 months later. No variables were significantly different from baseline to post intervention and 3 months later, except for less distress between baseline and 3 months ($P=.04$). Although this intervention did not show improvements in outcomes, patients with advanced disease receiving active treatment typically experience worsening symptoms overall. Maintaining psychosocial outcomes may be preventing further morbidity in an advanced cancer population during treatment and bears further exploration. Given our small sample size, further research is warranted.

Keywords

dignity therapy; life goals; lung neoplasms; palliative care; pancreatic neoplasms

Patients with pancreatic and advanced lung cancer experience some of the most severe psychological distress of all patients with cancer.^{1,2} Survival is limited for those with

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metastatic disease, with 5-year survival rates of 3% for pancreatic cancer and 4% for advanced non-small cell lung cancer.^{3,4} Of all cancer deaths, advanced lung cancer is the primary cause for 27% of men and 25% of women.³ The prevalence rate of distress is 36.6% among those with pancreatic cancer and 43.4% for those with lung cancer; both groups report the most depression and anxiety among all those with cancer.⁵ When distress and suffering persist, persons can lose their sense of meaning/purpose and wish for death to come sooner.⁶

Although clinicians provide treatment to prolong survival for those with advanced cancer, similar efforts must be made to relieve distress and suffering and preserve or improve quality of life (QOL). Because of their potentially shortened lifetimes, these patients should be provided interventions to alleviate distress and suffering as soon as possible after cancer diagnosis. Providing palliative care earlier in the cancer disease course is associated with improved QOL and longer overall survival.^{7,8} The current standard of care is to provide palliative care interventions along with chemotherapy or radiotherapy from diagnosis onward, especially for those with advanced disease.⁹ Therefore, patients with advanced pancreatic or lung cancer may especially benefit from psychosocial interventions from the time of diagnosis or early disease progression onward to improve QOL and other psychosocial outcomes. For patients still undergoing treatment in outpatient oncology settings, however, providing psychosocial interventions may have additional challenges.

Dignity therapy (DT) has great potential to be an important psychosocial palliative care intervention. Chochinov and colleagues^{10–12} designed DT as a brief psychotherapeutic intervention to address dignity for those at the end of life, to enhance a sense of purpose, meaning, dignity, and overall QOL. Loss of dignity, not uncommon for those undergoing cancer treatment, has been associated with increased pain, decreased QOL, loss of will to live, and higher degrees of depression, hopelessness, and anxiety.^{10,11} Those who have experienced DT report high rates of satisfaction with the intervention, improved sense of dignity, increased sense of purpose and meaning, greater will to live, and decreased sense of suffering.^{10,11,13}

Although DT has been shown to be useful in palliative care and end-of-life settings, its potential benefits for cancer patients undergoing active treatment are unclear. Given the recent recommendations to incorporate palliative care interventions earlier than at the very end of life, effective psychosocial interventions are needed for those with potentially poor prognoses, along with a compressed time frame for such interventions.⁹ DT has been shown to be feasible for patients with advanced colorectal cancer undergoing second-line chemotherapy¹⁴ and for patients with advanced pancreatic or lung cancer receiving outpatient chemotherapy.¹⁵ Although results have been mixed in previous studies of persons with life-limiting illness at the end of life, it is important to examine outcomes for those with advanced cancer experiencing DT while undergoing active treatment.

In addition, at the time of an initial cancer diagnosis, patients may more easily determine what is most important to them and modify previous life goals or plans. When this is done proactively, psychosocial well-being, spirituality, and QOL can be improved.^{16,17} Previous research on DT has not included this component of making a *life plan* (LP), as a modified

type of “bucket list.” Therefore, the purpose of this study was to examine the influence of the combination of interventions (DT plus LP) on various psychosocial outcomes for those with advanced cancer undergoing chemotherapy.

Methods

We performed this phase I/II pilot study to determine the feasibility and acceptability of the DT/LP intervention and to evaluate initial patient-reported outcomes (distress, spirituality, QOL, dignity, and purpose in life) among patients with advanced pancreatic or lung cancer undergoing treatment. Feasibility and acceptability have already been reported¹⁵; the current paper focuses on the patient-reported outcomes. This study was approved by our institutional review board and adhered to all guidelines for the ethical conduct of research, consistent with our institution’s human research protection program.

The study was conducted at a large Midwestern tertiary care center in the outpatient chemotherapy suite, while patients were receiving their chemotherapy treatments. If radiation therapy was the primary cancer treatment, we provided DT in the radiation oncology setting.

Participants were adults (age >18 y) at 12 months or less after their cancer diagnosis who were undergoing chemotherapy for advanced pancreatic adenocarcinoma or stage IIIb/IV non-small cell lung cancer. All patients had a prognosis of 6 months or more, spoke English, were free of cognitive deficits, and had no concurrent diagnosis of serious mental illness, as documented in the electronic health record (EHR). They were not receiving hospice or formal palliative care services and were not participating in other psychosocial intervention research studies.

We examined the electronic oncology scheduling system database for outpatient chemotherapy appointments for those with pancreatic or lung cancer to identify potential participants and reviewed their EHRs to determine eligibility. We recruited patients during treatment appointments, obtaining oral consent and signed Health Insurance Portability and Accountability Act authorization if they agreed to participate.

DT/LP was provided by an advanced practice nurse who was trained in DT techniques, using a standardized procedure guide.¹⁸ Full study procedures have been described previously.¹⁵ Briefly, DT consisted of 3 interviews, each 2 to 3 weeks apart, scheduled to coincide with patients’ cancer treatment appointments. In the first session, participants related a brief life history and identified events and people important to them in a semistructured audiotaped interview. This interview was then transcribed and edited between and during sessions 2 and 3 to reflect subject matter that participants wished to be included in a *generativity document*, which was intended to be given later to family members. At session 3, participants wrote their LP. Intervention activities are summarized in the Figure.

All psychosocial outcomes measures were completed in person at baseline (T1) and in person or by mail/telephone immediately post intervention after the third DT session (T2). Final evaluations at 3 months post intervention (T3) were done by mail, telephone, or in person during a clinic visit, depending on participants’ schedules.

Distress was measured using the *Distress Thermometer*,¹⁹ a 0 to 10 rating scale, presented as a thermometer-type visual analog scale, with anchors of 0, “No distress,” and 10, “Extreme distress,” to assess level of distress in the past 7 days. Dignity was measured with the *Patient Dignity Inventory*,¹⁸ a Likert-type measure used to identify dignity-related issues contributing to distress at end of life, with domains of symptom distress, existential distress, dependency, peace of mind, and social support (Cronbach α , 0.93; test-retest reliability, $r=0.85$).

We measured QOL with the *FACT-Hep* (Functional Assessment of Cancer Therapy-Hepatobiliary) for patients with pancreatic cancer and with the *FACT-L* (Functional Assessment of Cancer Therapy-Lung) for those with lung cancer. Each measure evaluates 4 QOL domains (physical, social/family, emotional, and functional well-being) plus disease-specific concerns for each cancer type, using a 5-point Likert scale (0, not at all to 4, very much). We chose to use only the 4 QOL domains in our analysis based on our research questions and small sample size. The FACT-Hep has good internal consistency (Cronbach α , 0.72–0.94) and test-retest correlation (0.81–0.94).^{20,21} The FACT-L also possesses good reliability (Cronbach α , 0.680)²² and good correlation with clinical outcomes for those with lung cancer.²³ QOL was also measured for all participants using the *Linear Analogue Self-Assessment*,²⁴ a reliable and valid brief survey of QOL domains using a 10-point visual analog scale.

Spirituality was measured with the *FACIT-Sp-12* (Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being; The 12-item Spiritual Well-Being Scale),²⁵ containing 3 subscales: meaning, peace, and faith. It has demonstrated good internal consistency (α , 0.81–0.88) and moderate to strong correlations with other measures of spirituality and religion (r , 0.25–0.48). We measured purpose in life with the *Purpose in Life Test–Short Form*, which has a 5-point Likert response format. The validity of this shorter version of the original measure was supported by confirmatory factor analysis and moderate to strong correlations ($r=0.47$ – 0.63) with other meaning/purpose measures. Internal consistency reliability by Cronbach α was reported as 0.84.²⁶

Demographic data including age, sex, race/ethnicity, marital status, educational level, time since diagnosis, and occupational status were collected at baseline. We also collected longitudinal descriptive data regarding subsequent chemotherapy and/or radiation therapy, evidence of disease progression, and overall survival data from the EHR.

We collected and managed data using REDCap (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research.²⁷ Data were analyzed with SPSS software (IBM SPSS Statistics for Windows, Version 21.0). Descriptive statistics and raw numbers were used to report demographic data. Descriptive statistics and 1-sample, 2-sided t tests were used if data were normally distributed to compare baseline (T1) outcomes of distress, dignity, QOL, spirituality, and purpose in life with values at T2 and T3. Wilcoxon tests were used if data were not normally distributed. The level of significance was set at $P .05$.

Results

Of 20 patients who enrolled, 2 who began the study later withdrew: 1 was lost to follow-up and 1 sustained injuries from a car accident, which prevented further participation. Eighteen patients completed all study procedures, with equal representation ($n=9$) from each cancer group. Complete enrollment data are reported elsewhere.¹⁵ In general, participants were middle-aged, with similar characteristics between cancer groups, except that the pancreatic cancer participants were predominantly women (89%) and approximately 1 month since diagnosis, and the lung cancer participants were predominantly men (78%) and almost 4 months after diagnosis (Table 1). At the time of writing, 1 patient with pancreatic cancer was alive (38.3 months since diagnosis), 7 had died (mean survival, 17 months), and 1 patient was lost to follow-up. Five patients with lung cancer were alive (mean survival, 28.2 months since diagnosis) and 4 had died (mean survival, 20.3 months).

We pooled the data for patient-reported outcomes from all 18 participants. There were no significant changes from T1 to T2 or T3 on measures of QOL, spirituality, purpose in life (Table 2), or dignity (Table 3), with the exception of distress. Distress levels measured 3 months after DT/LP were significantly lower than at baseline (Wilcoxon signed rank, $z = -2.078$; $P=.04$). Six patients reported distress levels of 7 or greater during the study and were referred to their oncology provider for further evaluation, per national distress management standards¹⁹; no additional psychosocial interventions were provided, as documented in the EHR.

Discussion

The purpose of this pilot study was to conduct a preliminary exploration of the influence of the combined DT/LP intervention on patient-reported outcomes of distress, QOL, spirituality, dignity, and purpose in life for those with pancreatic or advanced lung cancer undergoing chemotherapy. There were no significant improvements in these outcomes, with the exception of improved distress scores at 3 months. Although these findings were statistically nonsignificant, they should be viewed in the context in which they occur. All participants had advanced pancreatic or lung cancer, had received their initial diagnoses within the previous year, and were undergoing active disease-modifying treatment. The distress experienced during treatment of advanced lung or pancreatic cancer is due to not only the disease but also adverse effects of treatment, especially frequent and severe pain, as well as fatigue.¹⁹ Distress in all its forms is prevalent in these populations²⁸ and is greater for both of these cancer groups than for other cancers and can remain high during treatment, often affecting not only the person with cancer but also the family caregiver.²⁹ Therefore, being able to maintain QOL and other psychosocial outcomes during active treatment for advanced cancers should be viewed as a positive outcome.

Our discovery that QOL was maintained in these seriously ill participants is noteworthy because QOL can no longer be dismissed as an optional outcome associated with cancer treatment. Poorer QOL has been shown to be prognostic of shorter survival for those with lung cancer undergoing chemotherapy, particularly in those with poorer physical functioning and pain.³⁰ QOL decreases over time for patients with pancreatic cancer, with meaningful

decreases noted at 5 to 6 months.³¹ Better overall QOL has also been associated with longer survival for those with pancreatic cancer.³⁰

Findings from this study are similar to those reported by Vergo and colleagues,¹⁴ in which DT was provided to patients with advanced colorectal cancer undergoing treatment for recurrent disease. In that study, most participants reported no change between baseline and 2 subsequent evaluations of QOL, depression, anxiety, distress, and general wellness. Also, participants in our study reported the study timing as appropriate,¹⁵ which should allay fears by oncology clinicians that DT may actually cause more distress for these patients with advanced cancer. In addition, we intervened earlier in the cancer treatment process than other research teams have done¹⁴; most of our participants were within 1 to 5 months after diagnosis and were undergoing primary cancer treatment rather than treatment for disease progression. Not all patients may be interested in DT, however; we suspect that patients or their families who may have anticipated emotional burden opted out of the study.

Our findings regarding other outcomes also mirror inconclusive findings from other studies, especially for distress, dignity, and spiritual well-being and when baseline distress is high.¹³ To our knowledge, ours was the first study to directly use the distress thermometer to evaluate overall distress; other researchers have used various other measures to measure components of distress.^{12,32} Anecdotally, for some participants in our study, *distress* may have been too nebulous a term, and they may not have understood the concept. One participant based his distress rating on the discomfort of the chairs in the clinic lobby. The concept of *distress* may need to be categorized into individual components, such as symptom distress, spiritual distress, and physical distress, to be meaningful for assessment and interventions.

Purpose in life may be an important aspect of dignity, based on Chochinov's model of dignity.^{10,11} We believed that asking participants to make a list of life goals, or LP, might influence purpose in life, but this did not change over time with the intervention. The DT/LP intervention may not be sufficient to affect such a deeply-rooted component of self that evolves over one's entire lifetime.

The findings of this study are limited by the use of a small, nondiverse convenience sample, primarily from one geographic region in the United States. There was not sufficient power to derive any conclusions about effectiveness of the combined DT/LP intervention. Future studies should continue to explore the mechanisms by which DT influences components of patient dignity and to determine which patient-reported outcomes it is most likely to affect.

Conclusions

This study was innovative in its use of DT/LP for those still receiving active cancer treatment and not at the impending end of life, in accordance with guidelines to provide palliative care interventions simultaneously with cancer treatment. Even though the DT/LP intervention did not lead to improvements in the psychosocial outcomes we measured, patients receiving active treatment typically experience worsening outcomes during advanced cancer and active treatment. Maintaining these outcomes from baseline can be

viewed positively, because the intervention may be preventing further morbidity in an advanced cancer population. Further work is needed to evaluate the effects of DT/LP and to address the concept of providing this intervention combination earlier in the cancer disease course.

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Abbreviations

DT	dignity therapy
EHR	electronic health record
LP	life plan
QOL	quality of life

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Figure.

Dignity Therapy (DT)/Life Plan (LP) Procedures. T1 indicates baseline; T2, immediately post intervention after the third DT session; T3, 3 months post intervention.

Table 1

Patient Demographics

Characteristic	Group ^a	
	Pancreatic Cancer (n=9)	Lung Cancer (n=9)
Age, y	63.2 (11.5)	64.0 (13.1)
Women	8 (89)	2 (22)
Race		
White	8 (89)	9 (100)
American Indian	1 (11)	
Ethnicity		
Hispanic or Latino		1 (11)
Other	9 (100)	8 (89)
Marital status		
Married	6 (67)	8 (89)
Divorced	2 (22)	
Widowed	1 (11)	1 (11)
Education		
High school graduation or less	2 (22)	2 (22)
College, 1–4 years	5 (56)	3 (33)
Graduate school	2 (22)	4 (44)
Time since diagnosis, wk	4.3 (2.4)	23.0 (14.1)
Occupation status		
Retired	5	5
Medical leave	3	2
Employed	1	2

^aValues are mean (SD) or No. of patients (%).

Modified from Dose et al¹⁵; used with permission.

Table 2

Patient-Reported Outcomes

Scale/Item	T1 Score (n=18)			T2 Score (n=18)			T3 Score (n=16)		
	Mean (SD)	Median (Range)		Mean (SD)	Median (Range)	P Value ^a	Mean (SD)	Median (Range)	P Value ^a
Distress	5.12 (2.69) (n=17)	6 (0–10)		4.89 (2.85)	4 (1–10)	.86	3.63 (3.14)	2.5 (0–9)	.04
QOL: FACT									
Physical well-being	20.89 (4.57)	19.5 (12–28)		20.06 (4.66)	21 (8–26)	.64	20.38 (4.80)	21.5 (12–28)	.59
Social/family well-being	20.14 (5.35) (n=14)	22.5 (6–24)		21.31 (4.39) (n=16)	23 (8–24)	.31	20.53 (4.82) (n=15)	22 (7–24)	.09
Emotional well-being	17.28 (3.30)	17.5 (12–23)		17.72 (4.36)	17.5 (9–24)	.63	18.00 (4.49)	18.5 (9–24)	.22
Functional well-being	18.47 (4.57) (n=17)	19 (9–27)		18.82 (5.96) (n=17)	18 (8–27)	.90	19.38 (5.30)	20.5 (7–27)	.27
QOL: LASA overall	7.39 (1.79)	7 (4–10)		7.11 (1.81)	7 (3–10)	.55	7.25 (1.81)	7 (2–10)	>.99
Mental well-being	7.83 (2.07)	8 (3–10)		7.61 (1.98)	8 (3–10)	.69	8.06 (1.88)	9 (4–10)	.46
Physical well-being	6.72 (1.60)	7 (4–9)		6.28 (1.74)	6 (3–9)	.40	6.88 (1.71)	7 (3–10)	.33
Social activity	7.00 (2.25)	8 (1–10)		6.44 (2.28)	7 (0–9)	.35	7.13 (2.75)	7.5 (1–10)	.55
Emotional well-being	7.11 (2.08)	8 (2–10)		7.17 (1.98)	7 (2–10)	.89	7.38 (2.34)	8 (2–10)	.50
Spiritual well-being	8.39 (2.25)	9.5 (3–10)		8.11 (2.06)	8.5 (4–10)	.32	8.38 (2.58)	10 (2–10)	.87
Spirituality: FACIT-Sp-12	39.22 (7.21)	41 (24–48)		38.28 (9.48)	41.5 (19–48)	.47	40.47 (6.73) (n=15)	41 (27–48)	.17
Peace	12.28 (2.89)	12 (7–16)		12.06 (3.46)	13 (5–16)	.78	12.44 (3.12)	12 (7–16)	.38
Faith	12.39 (3.93)	13 (2–16)		12.39 (4.31)	14.5 (4–16)	.86	12.31 (4.36)	14.5 (3–16)	.92
Meaning	14.56 (1.82)	15 (10–16)		13.83 (3.05)	15 (4–16)	.12	15.00 (1.46) (n=15)	16 (12–16)	.21
Purpose in life	17.39 (2.40)	18 (12–20)		17.39 (2.30)	18 (13–20)	.72	17.69 (2.21)	18.5 (12–20)	.95

Abbreviations: FACIT-Sp-12, Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being; The 12-item Spiritual Well-Being Scale; FACT, Functional Assessment of Cancer Therapy; LASA, Linear Analogue Self-Assessment; QOL, quality of life; T1, baseline; T2, immediately post intervention after the third DT session; T3, 3 months post intervention.

^aWilcoxon signed rank tests.

Table 3**Select Patient Dignity Inventory Items^a**

Item	T1		T2		T3	
	Score (n=18)	P Value	Score (n=18)	P Value	Score (n=16)	P Value
Not able to perform tasks of daily living	1.44 (0.78)	.16	1.17 (0.51)	.16	1.44 (0.73)	>.99
Not able to attend to bodily functions	1.00 (0.00)	>.99	1.00 (1.00)	>.99	1.06 (0.25)	.32
Physically distressing symptoms	1.83 (0.71)	.20	2.11 (0.68)	.20	2.19 (0.66)	.16
Feeling how I look has changed	1.39 (0.50)	.18	1.56 (0.71)	.18	1.63 (0.72)	.26
Feeling depressed	1.94 (1.00)	.42	1.72 (0.58)	.42	1.56 (0.73)	.11
Feeling anxious	2.22 (1.06)	.08	1.89 (0.76)	.08	1.81 (0.91)	.09
Feeling uncertain	2.33 (1.14)	.19	2.00 (0.97)	.19	2.19 (0.54)	.25
Worried about future	2.28 (0.90)	>.99	2.28 (1.07)	>.99	2.25 (1.00)	.66
Unable to think clearly	1.56 (0.62)	.41	1.67 (0.69)	.41	1.56 (1.03)	.76
Not able to continue usual routines	1.89 (0.83)	.29	2.11 (0.76)	.29	1.94 (0.77)	>.99
Feeling no longer who I was	1.89 (0.83)	.45	1.72 (0.90)	.45	1.75 (0.86)	.45
Not feeling supported by friends or family	1.00 (0.00)	>.99	1.00 (0.00)	>.99	1.06 (0.25)	.32
Not feeling supported by health care providers	1.17 (0.71)	.66	1.06 (0.24)	.66	1.00 (0.00)	.32
Not feeling able to mentally fight my illness	1.28 (0.58)	.10	1.50 (0.71)	.10	1.25 (0.58)	.56
Not being able to accept things as they are	1.67 (0.69)	.10	1.44 (0.62)	.10	1.63 (0.72)	.48
Not being treated with respect	1.11 (0.32)	.56	1.06 (0.24)	.56	1.06 (0.25)	.56

Abbreviations: T1, baseline; T2, immediately post intervention after the third DT session; T3, 3 months post intervention.

^aValues are mean (SD). Scoring: 1 indicates issue is not a problem; 2, a slight problem; 3, a problem; 4, a major problem; 5, an overwhelming problem.