Dignity Therapy Implementation in a Community-Based Hospice Setting

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Abstract

Background: Dignity Therapy is a brief, empirically supported, individualized psychotherapy designed to address legacy needs among patients at the end of life. To date, this psychotherapy has not been implemented in a “real-world” community-based hospice setting. This study was designed to offer information about the pragmatic aspects of implementing Dignity Therapy for patients receiving hospice care.

Method: Twenty-seven patients completed Dignity Therapy as part of a clinical service newly offered at a community-based hospice. Referral and enrollment procedures, as well as the logistics of therapy implementation were monitored. Patients’ legacy transcripts were also qualitatively analyzed to measure emergent themes.

Results: Patients were most commonly referred by social workers, and on average produced Dignity Therapy legacy transcripts approximately 3000 words/8 pages in length. The mean number of sessions spent with patients was 4, equating to an average of 380 minutes of clinician time per patient. Qualitative analyses revealed the most commonly discussed topics among patients were (in rank order): autobiographical information, love, lessons learned in life, defining roles in vocations or hobbies, accomplishments, character traits, unfinished business, hopes and dreams, catalysts, overcoming challenges, and guidance for others.

Discussion: This was the first study to implement Dignity Therapy in a community sample, with results highlighting the practical aspects of treatment as well as the most common themes discussed by clinical patients in a hospice setting. These findings provide useful data for clinicians or organizational leaders who may consider offering Dignity Therapy in their setting, and offer general insight regarding the legacy topics most frequently discussed by patients near the end of life.

Introduction

HOSPICE PALLIATIVE CARE “aims to relieve suffering and improve the quality of living and dying.”^{1(p11)} It is focused not only on physical care, but also on the emotional, psychosocial, and spiritual needs of patients and families.^{1,2} A particular emphasis is often placed on quality of life, respect, and dignity.³ The concept of “dignity” can be difficult to characterize, although in a palliative care context “it also includes the notions of being able to maintain feelings of physical comfort, autonomy, meaning, spiritual comfort, interpersonal connectedness, belonging, and courage in the face of impending death.”^{3(p330)}

Dignity Therapy is a brief, empirically-supported, individualized psychotherapy uniquely designed to address the emotional and existential needs of adults at the end of life. In so doing, the therapy allows patients to create a formalized “legacy”

document for potential dissemination to desired loved ones and family members.⁴ The treatment’s theoretical basis, content, and procedure have been clearly outlined and discussed previously.^{4–9} To date, studies have found Dignity Therapy to significantly decrease patients’ sense of suffering and depressed mood, with the majority of subjects noting satisfaction with the process and indicating that the therapy heightened their sense of dignity and purpose.⁵ Family members were found to echo these sentiments.¹⁰ These studies have led to the postulation that “Dignity Therapy is a feasible and effective new approach to address suffering and distress in patients near the end of life,”⁶ a belief corroborated by a separate literature review of all current manualized interventions for the treatment of existential distress among those with life-threatening illnesses.¹¹

In light of the mounting theoretical and empirical base, many hospice and palliative care clinicians have expressed interest in the use of this novel psychotherapy within their

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own community sites (H.M. Chochinov, personal communication, 2010). However the practicality of bringing this psychotherapy into clinical settings is unclear. Namely, what are the logistics of its implementation as a clinical service? What could one expect with regard to the most common referral sources, the mean cost of creating the patients' legacy documents, and the amount of clinician time required for service provision? Furthermore, when offered this psychotherapy as a service, what are the characteristics of the patients' actual legacy documents? What topics are most commonly discussed by patients when completing this type of treatment? This study begins to address these questions, thereby providing useful data regarding the initiation of such a service within a community-based setting. This type of study further helps to move the investigations about this treatment along the continuum of efficacy to effectiveness research.^{12,13}

Methods

The Institutional Review Board at the Institute for Palliative Medicine at the San Diego Hospice reviewed and approved the protocol for this study.

Procedures

The patients in this study were all derived from The Institute for Palliative Medicine at the San Diego Hospice, which has a census of nearly 1000 patients.

Approximately two thirds of these patients are seen at home, with the rest residing in care facilities or receiving inpatient care within the San Diego Hospice's specially licensed acute care units (a total of 36 inpatient beds are available). Dignity Therapy has been offered as a clinical service at the San Diego Hospice since August 2009. The therapy was provided by a psychologist who completed formal training with the therapy originator, Dr. Harvey Chochinov. This psychologist launched the service by sharing general information about treatment at the quarterly meetings held for social workers, spiritual counselors, and acute care staff (including all interdisciplinary team members) and by attending rounds on the inpatient care unit to describe the service.

Per the Dignity Therapy protocol,¹⁴ an initial consult was completed between the patients and the psychologist to determine applicability and feasibility of treatment, as well as patient interest. If applicable for treatment, the patients were then provided with a copy of the interview questions from the published protocol⁴ prior to the initiation of service. This allowed individuals to review the questions and to make decisions about any questions they preferred not to answer for myriad reasons (e.g., discomfort regarding a specific topic, lack of energy or motivation to engage in certain discussions).

The Dignity Therapy interviews were transcribed using the hospice's currently existing medical dictation service (MX Secure). This service currently provides written transcripts of voice-recorded physician case notes; thus a contract was made for this HIPPA compliant service to transcribe the Dignity Therapy documents at a rate of 13 cents per line of text (the same rate charged for the physician dictations).

Participants

Between the dates of August 28, 2009 and May 28, 2010, 110 referrals were received for Dignity Therapy. Of these 110

referrals, 27 patients completed the full protocol (25%), 25 patients were unable to engage in treatment due to cognitive impairments or physical impairments which interfered with speaking (23%), 22 patients died before completion of their legacy document (20%), 21 patients declined treatment (19%), and 14 patients were lost to follow-up (13%). Notably, the 20% death rate in this community sample parallels the rate reported in a previous research study.⁶

Although not systematically monitored, patients did discuss varying reasons for declining Dignity Therapy as a clinical service. Examples of their stated rationales for declining treatment were: "I wouldn't have anything to talk about"; "I haven't done anything good in my life that I can share"; "I don't want to dredge up the past right now"; "I've done work on my legacy already, I don't need to create this document"; and "I just want to spend time with my family right now."

Given the nature of hospice care, patient needs are shared and addressed with the interdisciplinary team. Thus, after initially consulting with patients regarding their interest or applicability for Dignity Therapy, the clinician collaborated with the corresponding treatment team. This collaboration allowed for continuity of care and for follow-up as necessary, particularly if patients' reasons for declining treatment were indicative of more severe emotional distress.

Analyses

The following logistical data regarding Dignity Therapy implementation were analyzed utilizing frequency distributions provided in SPSS software¹⁵: average cost of patient transcripts, average number of pages/words in patient transcripts, average number of sessions and clinician minutes spent per patient, and the average number of questions the patients chose to include in their final document. In order to complete the qualitative analysis, two study investigators (the first and second authors) determined the most common themes present in the 27 patient documents. This analysis was completed utilizing a methodology of "Coding Consensus, Co-occurrence, and Comparison,"¹⁶ and was rooted in grounded theory.¹⁷ A randomly selected subset of six transcripts (22%) was chosen for initial review and was read separately by the two investigators in its entirety.

Coding was completed at the paragraph level, with disagreements in assignment or description of codes being resolved through discussion between the investigators and enhanced definitions of codes.

A final list of codes, constructed through consensus, consisted of a numbered list of all themes present in the patient documents. Using the final coding structure, the first and second authors separately coded the remaining 21 interviews in their entirety. Codes continued to be refined as necessary until a saturation point (when no new codes are gleaned from the transcripts) was reached after 9 interviews. The percent agreement among the codes ranged from 88 to 100 percent, with an average agreement of 96.8%.

In this study, if patients died before their legacy documents had been edited, they were deemed inappropriate for inclusion since it would unclear as to whether the themes emergent in their documents were based on their explicit intentions or perhaps would have been removed during the editing process per their request.

Results

Demographics

The 27 patients who fully completed Dignity Therapy as a clinical service had a mean age of 69 years, with a range from 33–98 years. On average, these patients completed Dignity Therapy approximately 2 months prior to their death (mean number of days elapsed between interview and death = 67.6). However, this variable did range with 1 patient completing the treatment within 1 week of death (5 days) and 1 remaining alive for approximately 7 months thereafter (219 days). At the time of this writing, 2 of the patients were still living. Additional demographic information is provided in Table 1.

Logistics of the clinical service

The majority (74%, $n = 20$) of the referrals were received from social workers. Eleven percent ($n = 3$) of referrals were from nurses, while the four remaining referrals were from a spiritual counselor, a physician, an aromatherapist, and a hypnotherapist (all members of the acute care interdisciplinary team).

The mean cost for the patients' transcripts was \$55.94 (range, \$27.00–\$143.75). The mean number of single-spaced pages in the documents was eight (range, 4–14, mode, 5) with a mean of 2993 words (range, 1387–6482 words). These totals included the questions asked by the interviewer as well. The mean and modal number of sessions spent with patients was 4 with a range from 2–7. The clinician spent a mean of 380 minutes or 6.3 hours per patient in order to complete the Dignity Therapy document with a range of 220–600 minutes

(3.6–10 hours). On average, patients' final documents contained their responses to five questions from the 12 question protocol (range, 2–12, mode, 3).⁴

Content analyses of patients' transcripts

Table 2 lists the most common themes and sub-themes emergent in the patients' transcripts, including how often

TABLE 2. MOST COMMON EMERGENT THEMES AND SUBCATEGORIES RANK ORDERED BY PERCENTAGE OF PATIENT ENDORSEMENT

Emergent themes	Theme frequency	% of patients endorsing theme
Autobiographical Information	852	100% ($n = 27$)
(Subcategories) Geographical Context	189	
Family	150	
Love	642	100% ($n = 27$)
Nostalgia	197	
Endearment	131	
Lessons learned	294	100% ($n = 27$)
Accept/acknowledge one's imperfections	106	
Celebrating/appreciating what you have	31	
Defining roles	288	96.3% ($n = 26$)
Career/Vocation	129	
Hobbies	110	
Accomplishments	178	92.6% ($n = 25$)
Pride for Children	74	
Character traits	133	92.6% ($n = 25$)
Giving/service to others	25	
Extrovert	12	
Adventurous	12	
Problem solver/logical	12	
Religious/spiritual	12	
Hard-working	11	
Unfinished business	173	88.9% ($n = 24$)
Regret	91	
Unresolved family conflict	28	
Hopes and dreams for others	86	77.8% ($n = 21$)
Hope they know how much I love them	16	
Hope for happiness	14	
Hope for education/career	10	
Catalysts	87	74.0% ($n = 20$)
Career/vocation/education change	18	
Desire to be with others	17	
Wanting adventure/change	15	
Need to meet others' expectations	13	74.0% ($n = 20$)
Overcoming challenges	93	
Hard work	28	
Pride	15	
Resilience	15	66.7% ($n = 18$)
Stretched my boundaries	15	
Guidance for Others	78	
Accept/acknowledge one's imperfections	16	
Just do it (even if it's hard)	10	
Find your passion	10	

TABLE 1. PATIENT DEMOGRAPHICS

Variable	%	n
Gender		
Male	56	15
Female	44	12
Ethnicity		
Caucasian	93	25
Hispanic	7	2
Marital status		
Married	48	13
Widowed	26	7
Divorced	18	5
Single	4	1
Unknown status	4	1
Religious affiliation		
Catholic	37	10
Christian	34	9
No affiliation	15	4
Agnostic or atheist	7	2
Other	7	2
Primary hospice diagnosis		
Cancer	70	19
Cardiac disease	14	4
Leukemia	4	1
Parkinson's disease	4	1
COPD	4	1
Debility unspecified	4	1

COPD, chronic obstructive pulmonary disease.

each code occurred in the patients' documents overall (theme frequency). All patients ($n = 27$, 100%) chose to discuss autobiographical information, love, and the lessons they had learned in life. Below are excerpts from patients in the love and lessons learned codes.

I often say I wish they'd bring back the scheduled double-header in baseball. Now they only have double-headers to make up for prior rain-outs. But when I was a kid, you could go to Yankee Stadium on Sunday in the summertime and spend the whole day there. That's what I would do with some of my friends from school. . . we would be up there for the whole day, it was really, really fun.

There are such great memories with my family. I even remember some of the small things too. Like being together to make "sour cream walnuts." The kids loved that. And then my cheese sticks. . . oh, and they always wanted me to make "hard sauce" for every kind of pie, it didn't matter. They loved it!

Thanks for being my partner in so many different ways. We've eaten out at probably every restaurant in town. We go to the theater often, three or four times a month. We hit the live theater and go to the symphony. I'm so lucky to have a person who has similar interests and is really a companion. Whenever I feel I need advice, I always go to you as a confidant. You are the tail to my kite, which always keeps me balanced. I remember being in a philosophy class and we were asked to define love. I don't think I got a very good grade on that paper because I hadn't met you yet. I didn't know how to describe love until I knew you. . .

I've learned to not be too hard on yourself. Realize that life flows and sometimes you have to go with the flow. If you make what you say are mistakes, you can't go back and remake the bed or put the milk back in the bottle. It's just life. . . so forgive yourself.

Over 90% of the patients discussed the defining roles in their lives, their accomplishments, their self-perceived character traits, and the times they felt important. These times included "brushes with fame" as exemplified in the following examples:

Anyway, they came around and the General introduced him to everybody saying it was Charles A. Lindbergh. Lindbergh asked, "Who's gonna fly with me?" No one said anything, so I said, "I would consider it a pleasure to fly with you sir." So we went up for 22 minutes and I flew around with Charles A. Lindbergh. . . what a wonderful feeling!

As Director of Opera auditions, I would go to Los Angeles for events, and then I got to go to New York and have lunch with Placido Domingo and Luciano Pavarotti. That's when it was all worth it. To me, it was a dream!

Nearly 90% of patients reflected on "unfinished business," with regret being the most common.

Part of this illness is my fault. I should have been getting preventive medicine and that kind of thing. I just went along thinking I was indestructible, and found out I was anything but indestructible. I might have been able to prevent this had they caught it early. . .

Unfortunately I did not teach music to my children—which I should have done. They all love music, but they don't play. I was not good as a teacher; I don't have the patience, plus I'm a perfectionist. I could have given them more of my time. I know I was difficult and was expecting so much of them. I just hope they remember the love.

More than 75% of patients discussed their hopes and dreams for their loved ones.

I would hope that they remember how deeply I love them. My hopes and dreams are that they live life to the fullest, that they find their passion and that no matter what they do in life, whether it's big or small, that it means something to them.

Nearly 75% of patients discussed how they had overcome challenges in their lives, or had survived catalyzing experiences. Such life challenges were typically resolved through hard work and seemed to generate a sense of pride, resilience, or stretching of boundaries.

I feel most proud of starting my business because it was something I didn't know I could accomplish. I didn't think I could do anything like that. I thought I wasn't good enough, I wasn't smart enough, I wasn't accomplished enough. . . but now looking back it was a good thing for me to do. I liked the challenge of doing it, and I like the way that feels. It was successful, and still is.

Finally, 67% of patients offered advice or guidance for their loved ones. These words of advice most commonly revolved around a desire for their loved ones to accept or acknowledge their imperfections, to address difficult situations even when they appear difficult, and to find their passion.

Go for it! You only get one shot at life. One shot each day, one shot at each week, each month, each moment. . . so go for it! So many people spend their entire lives indefinitely preparing to live, so they never quite step up to the plate, you know? I want to get my voice out there somehow and shout to them, "What are you waiting for?" Jump in, and you'll figure it out!

Discussion

This study is the first to offer practical, logistical results of Dignity Therapy when provided in a clinical, community-based sample. These results add breadth to the previously reported international research samples^{5,6,10} by describing pragmatic referral processes, transcription costs and characteristics, as well as clinical time required for service provision.

A qualitative analysis of the most common themes found in patients' legacy documents showed that all of the patients used the opportunity to discuss their pertinent autobiographical information, the loves they had experienced in life, and the lessons they had learned along the way. The majority of patients also discussed their defining roles, accomplishments, character traits, unfinished business, hopes and dreams for others, and times they were important. Although this study utilized a different qualitative methodology than the one used in a research sample by Hack and colleagues,¹⁸ some overarching similarities were found in transcript content.

In the Hack et al.¹⁸ research sample, the most common values expressed were: family, pleasure, caring, sense of accomplishment, true friendship, and rich experience. In this study, patients frequently discussed their family constellation within an autobiographical context, commonly noted pride for children when discussing their life accomplishments, and spoke kind words of endearment for ones they had loved (including family members). All patients provided nostalgic stories, often underscoring their pleasurable and rich life experiences. Nearly all of the patients described themselves as offering service to others (caring).

Interestingly, in our sample, friendship was so rarely discussed that it was not listed as a major code. This is a departure from the Hack et al. study¹⁸ that found true friendship as one of the six most strongly endorsed values. However, given the differences in the two study populations and methods of qualitative analysis (constant comparative analysis versus content analysis), these differences deserve further exploration.

The limitations of this study include its rather homogenous sample of Caucasian, Christian, or Catholic individuals diagnosed with cancer. The study provides information on only the first 27 patients seen, all of whom completed the intervention with the same clinician. All of the patients were from the same geographic area. Finally, the socioeconomic status of each patient was unknown, and most patients were seen in an acute inpatient unit, potentially limiting the generalizability of the topics discussed to acute hospice care populations, given the higher degree of acuity in this population versus home-based patients.

Future directions

This study helps to describe the practicalities of implementing Dignity Therapy in a community-based hospice setting and sets the stage for other research studies as well. For example, the total cost of implementing the service is unknown with time spent charting case notes or gathering referrals not being determined in this study. A future study could evaluate the overall cost effectiveness of this treatment, particularly as compared to treatment as usual or general supportive therapy. Notably, this study found the cost to be reasonable and at a level that is readily sustainable for the organization.

Patients in this study did share some reasons as to why they elected to decline Dignity Therapy when it was offered as a clinical service. However, the data was not strictly monitored, with future studies being able to more systematically address the characteristics of who declines this treatment modality and why. Who seems to be interested in this service? Why is it appealing to them and not other patients? These questions could help address to whom this therapy is most applicable and why.

Future research can continue to broaden the sample with inclusion of more ethnic and religious minorities, as well as individuals from other parts of the United States. People of varying socioeconomic statuses may also differ in the legacy content discussed, offering further depth to how this treatment best suits the needs of diverse peoples. It would also be beneficial to conduct a similar study with home-based patients to enhance general applicability. These types of broader samples may also inform any future modifications of the treatment protocol, perhaps by measuring which questions elicit the greatest response from various types of patients. Such an analysis could help streamline the 12 questions even further so as to provide a "shortened" design for patients with greater limitations or imminently deteriorating health conditions.

Summary

This initial sample of patients undergoing Dignity Therapy in a community-based hospice setting provided useful data regarding referral processes, cost, time spent in treatment provision, and the most common themes present in patients' legacy documents. Such results may inform others who are considering introducing Dignity Therapy into their clinical

setting, particularly as this study provided promising information about the treatment's cost-effectiveness and potential for rapid organizational adoption. This study also further enhances our general knowledge of the topics most important to patients who create legacy documents at the end of life.

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Author Disclosure Statement

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