

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

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A B S T R A C T

Purpose

This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

Patients and Methods

Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and postintervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a postintervention satisfaction survey.

Results

Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Postintervention measures of suffering showed significant improvement ($P = .023$) and reduced depressive symptoms ($P = .05$). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ($r = 0.480$; $P = .000$) and having a sense of purpose ($r = 0.562$; $P = .000$), accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P = .000$).

Conclusion

Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

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INTRODUCTION

One of the most confounding challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. Our prior studies of dignity and end-of-life care have shown a strong association between an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others, and overall poorer quality of life.¹⁻⁴ Yet, dying with dignity is usually only vaguely un-

derstood; hence, although the pursuit of dignity frequently underlies various approaches to end-of-life care, its therapeutic implications are frequently uncertain.

There is mounting evidence that suffering and distress are major issues facing dying patients. Some studies suggest that psychosocial and existential issues may be of even greater concern to patients than pain and physical symptoms.⁵⁻⁷ The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and

well-being among the key domains of quality end-of-life care. Similarly, patients deem a sense of spiritual peace, relieving burden, and strengthening relationships with loved ones among the most important facets of end-of-life care.⁵ Several studies have linked these issues, including a loss of sense of dignity, loss of meaning, and a sense of being a burden on others, with heightened requests for a hastened death.⁶⁻⁹ Clearly, palliative interventions must reach beyond the realm of pain and symptom management to be fully responsive to a broad and complex range of expressed needs.

The purpose of this study was to examine a brief, individualized psychotherapeutic intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Such distress has often been linked to the notion of suffering and described in terms of the challenges that threaten the intactness of a person.¹⁰ Others have suggested that meaning, or a paucity of meaning, defines the essence of existential distress.¹¹ Dignity therapy builds on the foundation of this work by engaging patients in a brief, individualized intervention designed to engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death.

Our empirically based dignity model of palliative care provides the framework for this novel intervention, informing its content and therapeutic tone (Table 1).¹⁻⁴ To decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose, and dignity, patients are offered the opportunity to address issues that matter most to them or speak to things they would most want remembered as death draws near. An edited transcript of these sessions is returned to the patient for them to share with individuals of

their choosing. This study was undertaken to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

PATIENTS AND METHODS

The outline of the dignity-therapy interview guide is based on themes and subthemes that arise from the dignity model (Table 2). Therapy sessions are transcribed and edited, and the resulting “generativity document” is returned to patients to bequeath to a friend or family member. Therapeutic sessions, running between 30 and 60 minutes, were offered either at the patients’ bedside for those in hospital or, for outpatients, in their residential setting (home or long-term care facility). A psychiatrist (H.M.C.) and palliative care nurse (in Winnipeg, Canada) or two palliative care nurses and a psychologist (in Perth, Australia) administered the manualized protocol. Before starting the study, pilot sessions were conducted to ensure intertherapist consistency in administering dignity therapy. To ensure protocol integrity, approximately one in four transcripts were selected randomly for review by the principal investigator (H.M.C.). Although no major breaches of the protocol were detected, this process enabled minor refinements and standardization of the interview format and editing process between therapists and across study sites.

Dignity therapy was offered to all patients meeting entry criteria who were registered with palliative care services in Perth or Winnipeg. In Australia, patients were recruited from two sites, including the Silver Chain Hospice Care Service (Osborne Park, Western Australia, Australia; Australia’s largest in-home specialist palliative care service) and The Cancer Council Centre for Palliative Care Cottage Hospice (Shenton Park, Western Australia, Australia; a 26-bed palliative care unit). In Canada, patients were recruited from the Winnipeg Regional Health Authority Palliative Care Program (Winnipeg, Manitoba, Canada). Similar to the

Table 1. Dignity Themes, Definitions, and Dignity-Therapy Implications^{1,2}

Dignity Theme	Definition	Dignity-Therapy Implication
Generativity	The notion that, for some patients, dignity is intertwined with a sense that one’s life has stood for something or has some influence transcendent of death	Sessions are tape-recorded and transcribed, with an edited transcript or “generativity document” being returned to the patient to bequeath to a friend or family member
Continuity of self	Being able to maintain a feeling that one’s essence is intact despite advancing illness	Patients are invited to speak to issues that are foundational to their sense of personhood or self
Role preservation	Being able to maintain a sense of identification with one or more previously held roles	Patients are questioned about previous or currently held roles that may contribute to their core identity
Maintenance of pride	An ability to sustain a sense of positive self-regard	Providing opportunities to speak about accomplishments or achievements that engender a sense of pride
Hopefulness	Hopefulness relates to the ability to find or maintain a sense of meaning or purpose	Patients are invited to engage in a therapeutic process intended to instill a sense of meaning and purpose
Aftermath concerns	Worries or fears concerning the burden or challenges that their death will impose on others	Inviting the patient to speak to issues that might prepare their loved ones for a future without them
Care tenor	Refers to the attitude and manner with which others interact with the patient that may or may not promote dignity	The tenor of dignity therapy is empathic, nonjudgmental, encouraging, and respectful

Table 2. Dignity Psychotherapy Question Protocol

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, other(s))?
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 that you would like included?

Australian site's program, this program offers a broad range of inpatient and outpatient end-of-life care services.

Patient eligibility criteria were as follows: (1) a terminal illness associated with a life expectancy of < 6 months; (2) minimum age of 18 years; (3) English speaking; (4) a commitment to three to four contacts over approximately 7 to 10 days; (5) no cognitive impairments, based on clinical consensus; and (6) willingness to provide verbal and written consent. The ethics review boards at both the University of Manitoba, Winnipeg (Winnipeg, Manitoba, Canada), and Edith Cowan University (Perth, Western Australia, Australia) approved this study.

Once consent was obtained, patients were asked to complete a psychometric battery covering a broad range of physical, psychological, and existential outcomes to discern possible areas of therapeutic influence. Because this was a feasibility study and we wished to examine possible areas of influence across a broad range of outcomes, these were confined to single-item screening instruments for depression, dignity, anxiety, suffering, hopefulness, desire for death, suicide, and sense of well-being (consisting of a seven-point ordinal scale: 0, not a source of distress; 1, minimal distress; 2, mild distress; 3, moderate distress; 4, strong distress; 5, severe distress; 6, extreme distress).⁸ Wilson et al⁸ have shown that such screening approaches yield excellent inter-rater (0.92 to 0.97) and test-retest (0.50 to 0.90) reliability and correlated highly with their visual analog equivalent (0.78 to 0.90).⁶ The protocol also contained a two-item quality-of-life instrument¹² and a revised Edmonton Symptom Assessment Scale, which included a will-to-live visual analog scale.¹³

Once patients completed the baseline psychometrics, participants were reminded that the following session would consist of being asked to speak about things that mattered most to them, on audiotape, including things that they would want to say and be known to the people closest to them. They were provided the standard framework of questions (Table 2), thus giving them ample time to reflect on and shape their eventual responses. A time for the tape-recorded session was then scheduled at their earliest convenience, usually within 1 to 3 days.

The taped sessions began with the question, "Tell me a little about your life history, particularly the parts that you either remember most or think were most important"? The question framework provided a flexible guide for the therapist to shape the interview, based on the level of interest and elicited response. The therapist followed the patients' cues, helping them to structure and organize their thoughts (eg, by asking logical questions based on time sequences or how events were causally related to each

other; facilitated disclosure of thoughts, feelings, and memories). Similarly, providing encouragement and asking for details enabled even patients particularly close to death to participate (eg, "Imagine that you and I are looking at a picture book of your life; tell me in as much detail as you can about some of the pictures we might see"). Most patients were able to complete this process with one recorded session; occasionally a second (and, rarely, a third) session was required to complete the generativity document.

Once the taped session was completed, over the course of the next 2 to 3 days, the patient's recorded dialogue was reshaped into a narrative. The interview was first transcribed verbatim. This transcript then underwent a formatted editing process, including (1) basic clarifications (eliminating colloquialisms, nonstarters, and portions of the transcript not related to generativity material [eg, needing to change a colostomy bag, interruptions that occurred during the course of the session such as visitors, care providers, and so on]); (2) chronological corrections (it was common for patients to say things out of sequence or present their thoughts in an illogical order); (3) tagging and editing any content that might inflict significant harm or suffering on the transcript's recipient(s) (these were always discussed and reviewed with the patient); and (4) finding a statement or passage within the transcript that provided an appropriate ending (given that this was a generativity, legacy-making exercise, the ending needed to be appropriate to the patient's overall message [eg, "Life has been good"; "I wish my family all God's blessings"; "I wouldn't have changed a thing"]), resulting in manuscripts that patients would feel captured their intent and achieved the appropriate final tone.

Once the edited transcript was completed, another session was arranged for the therapist to read the document in its entirety to the patient; this was often emotionally evocative, because patients heard their words, thoughts, and feelings spoken aloud. Patients were invited to make any editorial suggestions, including identifying errors of omission or commission. In some instances, these errors were minor in nature (eg, an elderly immigrant who stated "Not Bavaria. . .but Bulgaria!"); in other instances, the errors were major (eg, a middle-aged woman who felt she needed to say more about one of her two children). Depending on the patients' preference or health status, editorial changes were addressed within the transcript-review session or, occasionally, at the earliest possible follow-up time. Throughout the protocol, an ethos of immediacy and short time frames acknowledged the patients' limited life expectancy and reinforced the importance of what the patient needed to say and the significance of creating the generativity document. At the conclusion of the intervention,

quantitative measures were readministered, along with a dignity-therapy satisfaction survey, which included an opportunity for patients to reflect on the experience of engaging in the therapy.

Pre- and postintervention comparisons and item correlations were tested by using Wilcoxon's signed rank-sum test and Spearman's rank correlation, respectively. Given the uniformly positive responses reported in the qualitative data and the lack of any significant adverse effects reported across the study sample, we hypothesized a postintervention improvement on all psychosocial measures; hence, in those instances, a one-tailed Wilcoxon test was carried out (the use of a one-tailed test provides more sensitivity and power than the corresponding two-tailed test, reducing the risk of a type II error while maintaining the risk of a type I error at .05). The results of a post-dignity-therapy intervention survey were also tabulated.

RESULTS

Over a 2-year period (2001 to 2003), 100 patients completed the study across both sites: 50 patients from Australia and 50 from Canada. One hundred eighty-one patients agreed to have their names released to the study nurse; of those, 21 either deteriorated or died before entering the study. Thirty-one patients (19.6%) subsequently refused to take part in the study. Within the remaining group of 129 participants, the study completion rate was 78% (14 patients died and 15 deteriorated before completing the protocol). There were no differences between those completing the protocol versus those not completing the protocol on dimensions of age, sex, or disease-site distribution. Of those completing the study, 18% had breast cancer, 17% had lung cancer, 15% had gastrointestinal cancer, 13% had genitourinary cancer, 5% had primary brain tumors, 5% had hematologic malignancies, 19% had various solid tumors, 5% had tumors of unknown primary, and 3% had nonmalignant conditions. The mean age of participants was 63.9 years (range, 22 to 95; standard deviation, 14.2), and 44 were women. Thirty-seven percent had less than a high school education, 23% had graduated from high school, and 39% had some college or postgraduate training. Sixty-four percent of the patients were married or cohabiting with someone, with the remainder being divorced (11%), never married (4%), widowed (14%), or separated (5%). The patients' religious affiliations were Protestant (34%), Catholic (23%), Jewish (2%), other (16%), and no religious affiliation (24%). The median length of survival from the time of the initial interview to the time of death was 51 days (range, 3 to 377), and the median survival from the time that the generativity document was received to the time of death was 40 days (range, 0 to 371).

Qualitative Findings

Of the 100 patients who completed the study, 91% reported feeling satisfied or highly satisfied with the intervention (a rating of ≥ 4 on a seven-point ordinal scale),

with 86% reporting that the intervention was helpful or very helpful. Seventy-six percent indicated that it heightened their sense of dignity. With regard to the issue of hopefulness, 68% indicated that dignity therapy increased their sense of purpose, and 67% indicated that it heightened their sense of meaning. Forty-seven percent of participants indicated that dignity therapy increased their will to live; one 62-year-old woman with metastatic breast cancer went so far as to say, "I see [taking part in this study] as one reason why I am alive." It is particularly noteworthy that 81% of those who completed the protocol reported that this novel therapeutic intervention had already helped, or would help, their family.

The generativity documents contained innumerable affirmations of love and expressions of regret, and the foremost was the recounting of memories. Many patients raised issues related to the theme of generativity; for example one 36-year-old woman dying of metastatic breast cancer said, "I'm very happy to have participated in this project. It's helped bring my memories, thoughts, and feelings into perspective instead of all jumbled emotions running through my head. The most important thing has been that I'm able to leave a sort of 'insight' of myself for my husband and children and all my family and friends." Others spoke to issues that helped them reaffirm their sense of continued self-worth. For example, a 49-year-old woman with end-stage breast cancer stated that "dignity therapy was a lovely experience. Getting down on paper what I thought was a dull, boring life really opened my eyes to how much I really have done."

A 61-year-old woman with a recurrent rectal cancer captured the essence of hopefulness as it relates to issues of ongoing meaning and purpose: "This experience has helped me to delve within myself and see more meaning to my life. I really look forward to sharing it with my family. I have no doubt that it will be enlightening to them." The wife of a 72-year-old man with end-stage lung cancer described the transcript as "magnificent," indicating that her husband "wanted to contribute; the interview gave him a 'second chance' to do something to help."

Quantitative Outcomes

Postintervention measures of suffering showed significant improvement ($z = -2.00$; $P = .023$ [one-tailed Wilcoxon test]), as did self-reports of depressed mood ($z = -1.64$; $P = .05$ [one-tailed Wilcoxon test]); the postintervention improvement in dignity approached significance ($z = -1.37$; $P = .085$ [one-tailed Wilcoxon test]). Hopelessness, desire for death, anxiety, will to live, and suicide all showed nonsignificant changes favoring improvement. It is not surprising that, given that patients were moving toward death, the level of well-being and current quality of life diminished slightly, albeit nonsignificantly.

Patients reporting more initial psychosocial despair seemed to especially benefit from dignity therapy. Specifically, preintervention distress on measures of current quality of life ($r = -0.198$; $P = .049$), satisfaction with quality of life ($r = -0.203$; $P = .042$), and level of dignity ($r = 0.230$; $P = .021$), suffering ($r = 0.226$; $P = .025$), and suicidality ($r = 0.250$; $P = .012$) all correlated significantly with finding the intervention helpful and/or satisfactory. Even patients reporting less satisfaction with pain relief before the intervention were more likely to report that dignity therapy yielded an increased sense of purpose ($r = -0.254$; $P = .04$); this finding could not be accounted for by any changes in pain reports before versus after the intervention.

Initial psychosocial distress, reflected by scores on measures of quality of life ($r = -0.220$; $P = .028$), satisfaction with quality of life ($r = -0.237$; $P = .018$), and desire for death ($r = 0.192$; $P = .055$) were significantly correlated with reports of finding that the intervention increased their sense of meaning. Consistent with the latter finding, patients who indicated that dignity therapy had increased their will to live were significantly more likely to report a heightened sense that their current life was more meaningful ($r = 0.480$; $P < .0001$) and an enhanced sense of purpose ($r = 0.452$; $P < .0001$).

Finding dignity therapy helpful was significantly correlated with reporting that it had made life currently feel more meaningful ($r = 0.566$; $P < .0001$), heightening sense of purpose ($r = 0.547$; $P < .0001$), lessening suffering ($r = 0.267$; $P = .008$), and increasing will to live ($r = 0.290$; $P = .004$). The latter was also significantly correlated with a sense that the intervention had engendered a sense of heightened purpose ($r = 0.444$; $P < .0001$) and diminished suffering ($r = 0.401$; $P < .0001$); the effect of dignity therapy on sense of purpose and suffering were also highly correlated ($r = 0.444$; $P < .0001$). A lessened sense of suffering resulting from the intervention correlated highly with finding life more meaningful ($r = 0.343$; $P = .001$) and having a heightened sense of purpose ($r = 0.444$; $P < .0001$). Finally, a belief that dignity therapy had helped or would be of help to their family correlated significantly with life feeling more meaningful ($r = 0.480$; $P < .0001$) and having a sense of purpose ($r = 0.562$; $P < .0001$) and was accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P < .0001$).

DISCUSSION

There are few nonpharmacologic interventions specifically designed to lessen the suffering or existential distress that often accompanies patients toward the end of life. The rationale of most interventions is to make the sufferer less aware of his or her suffering. Thus, strategies are invoked to render patients less aware of their suffering or distress until

it either improves or, more commonly, death ensues. As such, they offer the equivalent of emotional analgesia without necessarily addressing the source or cause of the underlying psychic pain.

Dignity therapy introduces a novel, brief, psychotherapeutic approach based on an empirically validated model of dignity in the terminally ill. This model informs the structure, content, and tone of its delivery, thus ensuring its feasibility at the bedside of patients nearing death. Unlike most other symptom-focused interventions, the beneficial effects of dignity therapy reside in being able to bolster a sense of meaning and purpose while reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible, even for those proximate to death.

The low refusal rate (19.6%) and similarly low withdrawal rate (22%; the latter primarily because of deterioration or death before protocol completion) speak to the feasibility and value of this intervention for patients with advanced, life-limiting diseases. One of the patients most proximate to death, a 55-year-old woman with end-stage liver cancer, died within days of completing her generativity document. Despite profound illness and severely compromised respiratory status, she was able to “whisper” the derivation of her child’s name, based on a beloved character from a favorite foreign film.

The survey responses indicate how favorably the vast majority of participants received dignity therapy. These clear endorsements on measures of satisfaction (93%), helpfulness (91%), sense of dignity (76%), purpose (68%), and meaning (67%), suggest that beneficial effects were obtained irrespective of whether patients indicated initial significant psychosocial/existential distress. This explains one of the challenges of trying to document quantitative improvements, given that even in the context of low initial distress, patients almost invariably reported having benefited from the intervention. It is also interesting to note that 81% of patients felt that dignity therapy had helped, or would be of help to, their families and that this perception was related to a heightened sense of purpose and meaning along with a diminished sense of suffering and heightened will to live. This distinguishes dignity therapy as a unique end-of-life care intervention in that it benefits the patients and their family members—with real potential for multi-generational impact.

In reflecting on the quantitative findings, it is important to note that we selected a broad range of outcomes to detect areas of possible therapeutic influence. As such, many brief measures were applied rather than selecting fewer, more detailed, and lengthy measures. It should also be borne in mind that patients were moving closer toward death during the study, thus making the task of showing improvement on measures of distress even more challenging. Nonetheless, depressed mood and suffering seem

particularly responsive to dignity therapy. This is noteworthy, given that other studies have shown that distress usually worsens as death draws near.^{14,15} However, the role of dignity therapy as a treatment, or adjunctive treatment, for major depression has not been explored yet.

Patients who are initially more distressed (as reflected on measures of quality of life, dignity, suffering, and suicidality) seemed to be those most likely to find the intervention beneficial. The data also suggest that although quality of life and sense of well-being inevitably deteriorate as physical decline ensues, suffering, depression, and sense of dignity (all facets of the patient's internal psychological and spiritual life) may have a resilience, or the capacity to improve, independent of bodily deterioration.

It is interesting to examine the ways in which therapeutic improvement seems to be mediated. For example, the beneficial effects of dignity therapy are associated with an enhanced sense of meaning and purpose, both of which are intertwined with a diminished sense of suffering, lessening desire for death, and increased will to live. In palliative care, the patient and family are often referred to as the "unit of care."¹⁶ With that in mind, it is noteworthy that patients who felt that the intervention had or might have some benefit for their family were most likely to report a heightened sense of meaning and purpose, along with a lessening of suffering, and a heightened sense of will to live. For dying patients, the salutary effects of safeguarding the well-being of those who they are about to leave behind seems to extend to the end of life itself.

We recognize several limitations of the study. This study took place primarily among older patients with end-stage malignancies. It would be premature to assume that this intervention could be applied successfully within all age

groups and across all terminal conditions. (We are currently conducting a small study of dignity therapy in patients with amyotrophic lateral sclerosis; although this group presents special logistical challenges in terms of protocol administration, it seems to be enjoying a highly favorable response.) Most importantly, this trial was conducted as a feasibility study.

Despite these limitations, it would seem that dignity therapy is a feasible and effective new approach to address suffering and distress in patients toward the end of life. As evidence mounts (and with appropriate training), we envision this being a form of treatment that could be administered by individuals with skill and expertise in psychosocial oncology. Health care practitioners should also note that evidence from this trial speaks to the importance of using every clinical encounter as an opportunity to acknowledge, reinforce, and, where possible, reaffirm the personhood of patients charged to their care. An international randomized controlled trial of dignity therapy, which will take place in Winnipeg, New York, and Perth has recently been funded by the National Institutes of Health. We hope that this randomized controlled trial will generate additional evidence to support the application of this novel therapeutic approach to suffering and distress, so commonly seen in patients nearing death.

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Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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