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

1-4,6 Harvey Max Chochinov, MD Ph.D., 3,5 Thomas Hack, Ph.D., C.Psych., 4 Thomas Hassard Ph.D., 6 Linda J. Kristjanson Ph.D., 2,5 Susan McClement Ph.D., 7 Mike Harlos, MD.

1. Department of Psychiatry, Family Medicine. University of Manitoba. Winnipeg, Canada
2. Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, Canada
3. Patient and Family Support Services, CancerCare Manitoba
4. Community Health Sciences, University of Manitoba
5. Faculty of Nursing, University of Manitoba, Canada
6. Edith Cowan University, Perth, Australia
7. St. Boniface General Hospital, Winnipeg, Canada

Corresponding author: Dr. HM Chochinov, CancerCare Manitoba Rm. 3021-675 McDermot Avenue. Winnipeg, Manitoba R3E 0V9. Phone: 204-787-4933; Fax: 204-787-4937. e-mail: harvey.chochinov@cancercare.mb.ca

In Press: Journal of Clinical Oncology

Word Count: 3556
Abstract

Background: This study examined a novel, brief, individualized psychotherapeutic intervention, *Dignity Therapy*, designed to address psychosocial and existential distress among terminally ill patients. Dignity Therapy engages patients in discussion of issues that matter most to them, or that they would most want remembered. Sessions are tape-recorded, transcribed, and edited, with a final version returned to the patient to 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.

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

Findings: Ninety-one percent of participants reported being satisfied with Dignity Therapy; 76% reported a heightened sense of dignity; 68% an increased sense of purpose; 67% a heightened sense of meaning; 47% an increased will to live; 81% reported that it had already, or would be of help to their family. Post-intervention measures of suffering showed significant improvement (p=0.023), as well as reduced symptoms of depressive symptoms (p=0.05). Finding that Dignity Therapy had helped or would be of help to their family correlated with life feeling more meaningful (r=.480; p=.000), having a sense of purpose (r=.562; p=.000), accompanied by a lessened sense of suffering (r=.327; p=.001) and increased will to live (r=.387; p=.000).
Interpretation: Dignity Therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.
**Introduction**

One of the most confounding challenges end-of-life care providers face is helping patients achieve or maintain a sense of dignity as death approaches. Our prior studies of dignity and end of life care have shown a strong association between an undermining of one’s sense of dignity and depression, anxiety, desire for death, hopelessness, feeling a burden to others, and overall poorer quality of life.\textsuperscript{1-4} Yet, dying with dignity is usually only vaguely understood; hence, while 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.\textsuperscript{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.\textsuperscript{5} Several studies have linked these issues, including a loss of sense of dignity, loss of meaning, and a sense of burden to others, with heightened requests for a hastened death.\textsuperscript{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. Our empirically based dignity model of palliative care provides the framework for this novel intervention. Several key concepts, drawn from this model, inform its content and therapeutic tone (Table 1). This therapeutic approach, designed to decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose and dignity for patients approaching death, offers patients the opportunity to address issues that matter most to them, or speak to things they would most want remembered, as death draws nearer. Sessions are tape-recorded, transcribed, and edited, with a final version returned to the patient to bequeath to a friend or family member. This study was undertaken to establish the feasibility of Dignity Therapy, and determine its impact on various measures of psychosocial and existential distress.

**Methods:**

The outline of the *Dignity Therapy* interview guide is based on themes and sub-themes, which arise from the dignity model (Table 2). Therapy sessions are transcribed, edited, and the resulting *generativity document* is returned to patients, to bequeath to a friend or family member. Therapeutic sessions, running between 30 – 60 minutes, were offered either at the patients bedside for those in hospital, or in the instance of outpatients, within their residential setting (home, or long term care facility). Therapists, consisting of a psychiatrist (HMC) and palliative care nurse (in Winnipeg), and 2 palliative care nurses and a psychologist (in Australia), administered the manualized protocol. Before starting the study, pilot sessions were conducted to ensure inter-therapist consistency in administering Dignity Therapy. In order to ensure protocol integrity, approximately 1 in 4 transcripts were randomly selected for review by the PI [HMC]. While 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.

**Methods:** Dignity Therapy was offered to all patients meeting entry criteria, registered with palliative care services in Perth, Australia or Winnipeg, Canada. In Australia, patients were recruited from 2 sites, including the Silver Chain Hospice Care Service (Australia's largest in-home specialist palliative care service), and the Cancer Foundation of Western Australia Centre for Palliative Care Cottage Hospice (a 26-bed palliative care unit). In Canada, patients were recruited from the Winnipeg Regional Health Authority Palliative Care Program. Like the Australian site, 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 less than 6 months; 2) minimum 18 years of age; 3) English-speaking; 4) a commitment to 3-4 contacts, varying from 30 to 60 minutes in length, 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 the University of Manitoba, Winnipeg and Edith Cowan University, Perth each 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, in order 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 7-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=severe distress]. Wilson et al have shown that such screening approaches yield excellent inter-rater reliability (.92-.97), test-retest reliability (.50-.90) and correlated highly with their visual analog equivalent (.78-90). The protocol also contained a 2-item quality of life instrument, and a revised Edmonton Symptom Assessment Scale, which included a will to live visual analog scale.

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 tape, including things 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 upon, and shape their eventual responses. A time for the tape recorded session was then scheduled at their earliest convenience, usually within 1-3 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. For example, 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 very 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”).

Once the taped session was completed, over the course of the next 2-3 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, non-starters, 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, etc.), 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]; 4) finding a statement or passage within the transcript providing an appropriate ending; given that this was a generativity, legacy-making exercise, the ending needed to be appropriate to the patient’s overall message (such as, “Life has been good”; “I wish my family all God’s blessings”; “I wouldn’t have changed a thing”), resulting in manuscripts that patients felt captured their intent and achieved the appropriate final tone.
Once the edited transcript was completed, a further session was arranged for the therapist to read the document in its entirety; this was often emotionally evocative, as 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 were minor in nature (e.g., an elderly immigrant who stated “Not Bavaria…but Bulgaria!”), in other instances, major (e.g., a middle-aged woman who felt she needed to say more about 1 of her 2 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 timeframes 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 re-administered, along with a Dignity Therapy satisfaction survey, which included an opportunity for patients to reflect on the experience of engaging in the therapy. Most patients were able to complete this process with 1 recorded session; occasionally a second (and very rarely a third) session was required to complete the generativity document.

Pre and post comparisons and item correlations were tested 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 post-intervention
improvement on all psychosocial measures; hence, in those instances, a one-tailed Wilcoxon test (*) was carried out.

The organizations funding this research played no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; nor preparation, review, or approval of the manuscript.

Findings: Over a 2-year period (2001-2003), 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 prior to 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, prior to completing the protocol). There were no differences between those completing the protocol, versus those not completing the protocol on dimensions of age, gender, or disease site distribution. Of those completing the study, 18% had breast cancer, 17% had lung cancer; 15% gastrointestinal cancer, 13% genitourinary cancer; 5% primary brain tumors, 5% hematological malignancies, 19% various solid tumors, 5% tumors of unknown primary, 3% non-malignant conditions. The mean age of participants was 63.9 years (range: 22-95; SD14.2), and 44 were woman. Thirty-seven percent had less than 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 the remainder being divorced (11%), never married (4%), widowed (14%), or separated.
Religious affiliation was 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 3-377) and the median survival from the time the generativity document was received to the time of death was 40 days (range 0-371).

*Participants’ Words:* It is important to place the study findings in the context of what people said during the course of Dignity Therapy. Generativity documents contained innumerable affirmations of love, expressions of regret, and foremost, the recounting of memories. Many patients raised issues related to the theme of generativity; for example one 36-year-old woman dying of metastasis 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, “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.”

**Qualitative findings:** Of the 100 patients who completed the study, 91% reported feeling either satisfied or highly satisfied with the intervention (a rating of 4 or greater on a 7-point ordinal scale), with 86% reporting 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.” Particularly noteworthy, 81% of those completing the protocol reported that this novel therapeutic intervention had already helped, or would help, their family.

**Quantitative Outcomes:** Post-intervention measures of suffering showed significant improvement ($z=-2.00; p=0.023^*$), are clinically significant, not just statistically significant, as did self reports of depressed mood ($z=-1.64; p=0.05^*$); the post intervention improvement in dignity approached significance ($z=-1.37; p = 0.085^*$). Hopelessness, desire for death, anxiety, will to live, and suicide all showed non-significant changes favoring improvement. Not surprisingly, given that patients were
moving towards death, the level of well-being and current quality of live diminished slightly, albeit non-significantly.

Patients reporting more initial psychosocial despair appeared to especially benefit from Dignity Therapy. Specifically, pre-intervention distress on measures of current quality of life ($r = -.198; p=0.49$), satisfaction with quality of life ($r=-.203; p=0.42$), level of dignity ($r=.230; p=.021$), suffering ($r=.226; p=.025$) and suicidality ($r=.250; p=.012$) all correlated significantly with finding the intervention helpful and/or satisfactory. Even patients reporting less satisfaction with pain relief prior to the intervention were more likely to report that Dignity Therapy yielded an increased sense of purpose ($r =-0.254, p=0.04$); 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 ($r=-.220; p=0.28$), satisfaction with quality of life ($r=-.237; p=.018$), and desire for death ($r=.192; p=.055$) 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 a sense that their current life was more meaningful ($r=.480; p<.0001$), and an enhanced sense of purpose ($r=.452; p<.0001$).

Finding Dignity Therapy helpful was significantly correlated with reporting that it had made life currently feel more meaningful ($r=.566;p<.0001$), heightened a sense of purpose ($r=.547; p<.0001$), lessened suffering ($r=.267; p=.008$), and increased will to live
(r=.290; p=.004). The latter was also significantly correlated with a sense that the intervention had engendered a sense of heightened purpose (r=.444; p<.0001) and diminished suffering (r=.401; p<.0001) [the effect of Dignity Therapy on sense of purpose and suffering were also highly correlated (r=.444; p<0001)]. A lessened sense of suffering due to the intervention correlated highly with finding life more meaningful (r=.343; p=.001) and a heightened sense of purpose (r=.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=.480; p<.0001), having a sense of purpose (r=.562; p<.0001), accompanied by a lessened sense of suffering (r=.327; p=.001) and increased will to live (r=.387; p<.0001).

Discussion: There are very few non-pharmacological interventions specifically designed to lessen the suffering or existential distress that often accompanies patients towards 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 rendering patients less aware of their suffering or distress until it either improves, or more commonly, until 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 due to deterioration or death prior to protocol completion), speaks 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. In spite of 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 favourite 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 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 its benefits are felt among patients and may be transmitted to family members – with very 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 in order 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 towards death during the study, thus making the task of showing improvement on measures of distress even more challenging. Nonetheless, depression and suffering appear particularly responsive to Dignity Therapy. This is particularly noteworthy, given that other studies have shown distress usually worsens as death draws near.12,13

Patients who are initially more distressed (as reflected on measures of quality of life, dignity, suffering, and suicidality) appeared to be those most likely to find the intervention beneficial. The data also suggests that while quality of life and sense of well being inevitably deteriorate as physical decline ensues, suffering, depression and sense of dignity – all facets of the patients 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 appears 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 of desire for death, and an increased will to live. In palliative care, the patient and family are often referred to as the unit of care.\textsuperscript{14} With that in mind, it is noteworthy that patients who felt 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 they are about to leave behind, appears to extend to the very 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 successfully applied 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; while 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. As such, in spite of its initial promise, it needs to be evaluated utilizing a randomized control design. An international randomized controlled trial (RCT) of Dignity Therapy, which will take place in Winnipeg, Canada, New York, New York, and Perth, Australia, has recently been funded by the National Institute of Health. Hopefully, this RCT will generate the necessary evidence base, supporting the application of this novel therapeutic approach to suffering and distress, so commonly seen towards the end of life.
Acknowledgements: We thank our research nurses Kathy Cullihall, Joanne Hale, Jenny Clarke and Lynn Oldham. The work was supported by grants from the American Foundation for Suicide Prevention, the National Cancer Institute of Canada, with funding from the Canadian Cancer Society; Dr. Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research. Dr. Kristjanson is supported by The Cancer Council of Western Australia.

Contributors: HM Chochinov, T Hack, LJ Kristjanson, S McClement and M Harlos contributed to the protocol design; and HM Chochinov, T Hassard, T Hack, LJ Kristjanson and S McClement to the analysis and interpretation of the data. HM Chochinov and T Hassard had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The report was written by HM Chochinov, with critique and approval by the full research team.
References:


Table 1. Dignity Themes, Definitions and Dignity Therapy Implication

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<th>Dignity Theme</th>
<th>Definition</th>
<th>Dignity Therapy Implication</th>
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<tr>
<td>Generativity</td>
<td>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.</td>
<td>Sessions are tape-recorded and transcribed, with an edited transcript or <em>generativity document</em> being returned to the patient, to bequeath to a friend of family member.</td>
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<td>Continuity of Self</td>
<td>Being able to maintain a feeling that one’s essence is intact, in spite of advancing illness.</td>
<td>Patients are invited to speak to issues that are foundational to their sense of personhood or self.</td>
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<td>Role preservation</td>
<td>Being able to maintain a sense of identification with one or more previously held roles.</td>
<td>Patients are questioned about previous or currently held roles that may contribute to their core identity.</td>
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<td>Maintenance of Pride</td>
<td>An ability to sustain a sense of positive self-regard.</td>
<td>Providing opportunities to speak about accomplishments or achievements that engender a sense of pride.</td>
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<td>Hopefulness</td>
<td>Hopefulness relates to the ability to find or maintain a sense of meaning or purpose.</td>
<td>Patients are invited to engage in a therapeutic process, intended to instill a sense of meaning and purpose.</td>
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<td>Aftermath Concerns</td>
<td>Worries or fears concerning the burden or challenges that their death will impose on others.</td>
<td>Inviting the patient to speak to issues that might prepare their loved ones for a future without them.</td>
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<td>Care Tenor</td>
<td>Refers to the attitude and manner with which others interact with the patient that may or may not promote dignity</td>
<td>The tenor of Dignity Therapy is empathic, non-judgmental, encouraging, and respectful.</td>
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Table 2. Dignity Psychotherapy Question Protocol

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<td>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?</td>
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<td>Are there specific things that you would want your family to know about you, and are their particular things you would want them to remember?</td>
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<td>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?</td>
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<td>What are your most important accomplishments, and what do you feel most proud of?</td>
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<td>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?</td>
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<td>What are your hopes and dreams for your loved ones?</td>
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<td>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)]?</td>
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<tr>
<td>Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future?</td>
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<tr>
<td>In creating this permanent record, are there other things that you would like included?</td>
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