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Dignity Impact as a Primary Outcome Measure for Dignity Therapy

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Abstract

Background: Feasibility of Dignity Therapy (DT) is well established in palliative care. Evidence of its efficacy, however, has been inconsistent and may stem from DT's primary effects differing from the outcomes measured in previous studies. We proposed that DT effects were in the spiritual domain and created a new outcome measure, Dignity Impact Scale (DIS), from items previously used in a large RCT.

Objective: The purpose of this secondary analysis study was to examine properties of a new measure of dignity impact.

Design: Using the DIS, we conducted reanalysis of posttest data from a large 3-arm, multi-site RCT study.

Setting/subjects: Participants were receiving hospice/palliative care (n=326, 50.6% female, mean age=65.1, 89.3% White, all with a terminal illness with six months or less life expectancy). They had been randomized to either standard palliative care [n=111], client-centered care [n=107], or DT [n=108].

Measurement: The 7-item DIS was derived from selected items in a post-test DT Patient Feedback Questionnaire. The DIS had strong internal consistency ($\alpha=0.85$).

Results: The DT group mean DIS score (21.4 ± 5.0) was significantly higher than the usual care group mean score (17.7 ± 5.5 ; $t=5.2$, $df=216$, $p<.001$) and a client-centered intervention group mean score (17.9 ± 4.9 ; $t=5.2$, $df=213$, $p<.001$).

Conclusion: We found that compared to both other groups, patients who received DT reported significantly higher DIS ratings, which is consistent with the DT focus on meaning making, preparation for death, and life-completion tasks. We propose that the DIS be used as the primary outcome measure in evaluating the effects of DT.

Introduction

Dignity therapy (DT) is an individualized psychotherapy designed to address the emotional and spiritual needs of patients with a serious illness as they approach the end of life.¹ DT offers patients an opportunity to create a legacy document that focuses on a review of their life, highlighting important memories and events. Patients have specifically reported DT being beneficial in improving their quality of life, sense of dignity, and how they are seen by their family members.² DT is generally well accepted by patients,³⁻⁹ but its effects on patients' distressing physical or emotional symptoms of life-threatening illness have been inconsistent across studies¹⁰ with statistically significant findings in some¹¹⁻¹⁴ and not statistically significant in others,^{4,15} including a large multisite trial.²

It is possible that the outcomes used in previous studies (distressing physical or emotional symptoms) were less responsive to DT² than other outcomes such as preparation for death, life-completion tasks, and meaning-making. Although there may be several ways to categorize these outcomes, we believe they reflect some of the major spiritual tasks associated with the end of life. For example, Leget¹⁶ identifies five spiritual questions that are central as the end of life comes into view: Who am I and what do I really want? How do I deal with suffering? How do I say goodbye? How do I look back on my life? and What can I hope for? Although defining spirituality can be challenging¹⁷ we believe outcomes such as preparation for death, life-completion, and meaning-making are consistent with the emphasis on meaning and purpose and connections with others and the sacred that are part of the definition of spirituality developed by the Consensus Conference on spiritual care as a dimension of palliative care.¹⁸ Because we believe these outcomes reflect common spiritual issues associated with the end of life we suggest that DT may be viewed as an intervention that affects the spiritual domain in palliative care. The purpose of this study was to examine properties of a new measure of the spiritual impact of DT.

A recent systematic review of the DT literature highlighted two important findings.¹⁰ First across studies, DT does not have consistent effects on distressing physical or emotional symptoms experienced by patients with life-threatening illness. One possible explanation, noted by Hall and colleagues,¹⁵ is that DT does not directly affect physical symptoms. Thus, it may not be appropriate for DT research to focus on physical symptoms or related outcomes as primary indicators of success. Second, patients who receive DT provide uniformly higher ratings of satisfaction and benefits for themselves than patients who receive usual care or another client-centered intervention. These findings are important, but

still needed is a sensitive outcome measure that detects the intended DT effects and guides mechanism-driven research.

Considering the prior findings and the focus of DT on meaning making, preparation for death, and life-completion tasks, we propose that DT effects are likely in the spiritual domain. The specific aim of this secondary analysis study was to examine properties of a new measure of dignity impact. Specifically, we examined face validity, reliability, and responsiveness to the intervention.

Methods

Design/Setting

We conducted reanalysis of posttest data from a large 3-arm multi-site randomized controlled trial (RCT) of 326 Canadian, Australian, and United States hospice/palliative care patients.² The original study, completed in 2009, was approved by the institutional review boards of the participating organizations.

Sample

A consecutive sampling approach was used to evaluate eligibility of potential participants who were identified by the clinical team. Potential participants were contacted by telephone or in person by the research staff who described the study to the patient and obtained informed consent. Eligibility requirements included: age 18 years or older, diagnosis of a terminal illness (life expectancy ≤ 6 months), receiving palliative care in a hospital or community setting (hospice or home) at an affiliated recruitment site, and agreed to commit to the duration of the study. Patients were excluded if they did not speak English, were cognitively impaired, or unable to complete requirements of the study. Of the 1,513 patients who were assessed for eligibility 630 were ineligible and 442 declined to participate. There were 441 participants randomized and a total of 326 who completed the original study and included in this reanalysis.²

Procedure

As reported previously,² in the DT group, the patients were randomly assigned to trained dignity therapists (e.g., psychologists, psychiatrists, experienced palliative care nurses). DT sessions (~60 min) were audio-recorded and later transcribed for creating a generativity document, a written narrative of the person's life, which was given to the patients who gave it to significant others. Patients in the client-centered care group were randomly assigned to a research nurse-therapist who encouraged and assisted patients to focus on personal issues related to their current stage of illness, associated symptoms, and treatments. Patients randomized to the standard palliative care group received palliative care at home and had access to typical support services from palliative care physicians and nurses, chaplains, and psychologists. In the client-centered or standard palliative care groups, as part of the intervention, no records were made from the discussions with therapists, nor was any generativity document given to the patients or to the family. The primary outcomes were measured at baseline and immediately after the study completion. A detailed description of procedures and measures was reported previously.² The items included in the Dignity

Impact Scale (DIS) were not measured at pretest, but were included in the measures at posttest.

Measurement for Reanalysis

Dignity impact was measured using a 7-item Dignity Impact Scale (DIS; Table 1) derived from selected items in a post-test DT Patient Feedback Questionnaire.^{2,19} Two factors helped inform the selection of the items: a) they assessed spiritual issues associated with end of life, and b) four of the seven items showed significantly higher levels among those who were in the DT groups compared to those in the other two study arms. Each item was scored on a 5-point scale from 'strongly disagree' (1) to 'strongly agree' (5). The DIS score is the mean of the item scores with higher scores representing better dignity impact. The items have been used in many DT studies with evidence of their face validity in the target population.^{2,11,20} The Cronbach's α for the 7-item DIS was .85 in our sample, which indicates high reliability and that the large sample of subjects completed the scale items in an internally consistent manner.

Analysis

Independent t-tests were used to test differences in mean DIS scores between the DT group and the client-centered group, and between the DT group and the standard palliative care group.

Results

The primary study sample characteristics² are presented by group in Table 2. The majority of participants across all three groups was White (89.3%) and just over half were female (50.6%). The average age of participants was 65.1 years (SD 14.4), and 58.9% of the sample was married or with a life partner. With respect to education, 9.2% had less than a high school education, 32.8% completed high school, and 57.7% had college or post-graduate training.

The DT group mean DIS score (21.4 ± 5.0) was significantly higher than the usual care group mean DIS score (17.7 ± 5.5 ; $t=5.2$, $df=216$, $p<.001$) and a client-centered intervention group mean DIS score (17.9 ± 4.9 ; $t=5.2$, $df=213$, $p<.001$; Figure 1). Based on these DIS scores, the DIS shows responsive to DT effects at posttest with a large effect size of 0.7.

Discussion

These findings point to the initial validity and reliability of the DIS and suggest that the DIS may be a more sensitive and relevant measure for detecting the effect of DT than other tools that have been used in previous DT studies. The 7-item DIS scale showed significant differences between those who received DT and those who did not. Furthermore, the DT group difference in dignity impact is not likely to be an artifact of the attention provided during individualized therapy because the client-centered intervention group did not show a DIS effect better than standard palliative care.

These findings about dignity impact are important to patients, especially those with life-threatening illness, such as cancer. In a recent study (N=56), investigators compared the DT intervention with life review (identical to DT except no legacy document) and a waitlist control group in adults with advanced terminal illness.²⁰ Findings from this study support the positive impact of the legacy document (DT group) on the patient's sense of concern for leaving a lasting legacy, positive meaning making, and preparation for death. However, no differences were noted among the three groups on dignity-related distress and quality of life outcomes suggesting further research is needed to understand the mechanism of action.²⁰

Despite the importance of our findings, a limitation of our study is the posthoc nature of the analysis of the DIS as an outcome measure in an already completed RCT, whose hypothesized outcomes were not statistically significant. Further, the sample for the original study was primarily White, well educated, and experienced low distress. Additional evidence of the DIS construct validity and stability over time is also needed as a focus of future research. Clearly, confirmation of these findings in a prospective RCT is necessary.

Conclusion

The DIS is an internally consistent (reliable) measure that shows evidence of being sensitive to the effects of the DT intervention. We recommend future DT studies use the DIS as an outcome measure for DT. Currently, we are conducting a prospective, 6-site, 3-arm, pre/posttest, randomized, controlled 4-step, stepped-wedge design study (5R01CA200867) to compare the effects of usual outpatient palliative care and usual outpatient palliative care along with either nurse-led or chaplain-led DT. In this study, the DIS is the primary outcome measure of the effects of DT among elderly patients with cancer. This study will also provide an additional opportunity to examine the psychometric properties of DIS, which has promise and is an important contribution to the DT and palliative care literature.

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Figure 1.
Mean Dignity Impact Scale (DIS) Scores by Study Group

Table 1.

Dignity Impact Scale items (Modified from the DT Patient Feedback Questionnaire, Chochinov et al 2011)

Specific Items	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The care I received during the past week has given me a sense of looking after unfinished business.	1	2	3	4	5
The care I received during the past week has increased my sense of dignity.	1	2	3	4	5
The care I received during the past week will be of help to my family.	1	2	3	4	5
The care I received during the past week has or could change the way my family sees or appreciates me.	1	2	3	4	5
The care I received during the past week has lessened my sense of sadness and depression.	1	2	3	4	5
The care I received during the past week has made me feel that life was more meaningful.	1	2	3	4	5
The care I received during the past week has given me a heightened sense of purpose.	1	2	3	4	5

Table 2.

Characteristics of Participants by Study Group (Chochinov et al., 2011)

RCT Study Group			
Demographics	Standard Palliative Care	Client Centered Care	Dignity Therapy
Group [N]	111	107	108
Female [N (%)]	61 (55)	52 (49)	52 (48)
Age yrs [M (SD)]	66.7 (14.2)	64.3 (14.3)	64.2 (14.6)
Married [N (%)]	65 (59)	67 (63)	60 (56)
White race [N (%)]	99 (89)	94 (88)	98 (91)
Education Level [N (%)]			
None-primary	11 (10)	8 (7)	11 (10)
High school	36 (32)	33 (31)	38 (35)
College	47 (42)	45 (42)	43 (40)
Post-graduate	17 (15)	20 (19)	16 (15)