

Innovations

Dignity Therapy in Terminal Illness: A Systematic Review

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Abstract

Terminal illness is a very challenging burden to live with. Most people who go through this usually experience psychological, social, spiritual and physical distress which may lead them to suicidality. Palliative care is a health care system that aims to help patients with terminal illnesses relieve and prevent their suffering. This study aimed to determine whether a novel palliative care technique, dignity therapy, is effective for alleviating distress in terminally ill patients through a systematic review of available literature in eight databases- Pub Med, Scopus, Google Scholar, Cochrane, Ajol, Mendeley, and Pro-quest. A total of 35 studies were identified but 17 met the selection criteria (Total sample size = 610, Mean = 60.51). Dignity Therapy showed a significant effect on well-being, sense of purpose, communication, self-expression, connection with loved ones, anxiety, depression, demoralization, and hopelessness. DT was also widely accepted by both participants and family members. In conclusion, DT is valuable as a palliative treatment of terminally ill patients and should be explored as a treatment alternative for depression and anxiety in other Patient groups.

Keywords: *Dignity therapy, terminal illness, palliative care*

Introduction

Living with a terminal illness can be very distressing (Li et al, 2019) and lead to psychosocial problems like depression and anxiety (Juliao et al., 2014). The care for such individuals and their families or caregiver may determine how individuals cope or live through the illness (Bell et al, 2017). Hence the World Health Organisation (WHO) has over the years emphasised a holistic approach to end-of-life care that includes both the psychological and spiritual needs of the Patients (Li et al, 2019). Individuals with terminal illness experience distress going through their illnesses. Psychological distress may also lead to a low or decreased quality of life, which is a challenge for patients, families, and healthcare professionals (Juliao et al, 2014).

Terminally ill patients tend to worry about family relationships, inability to do the things they did prior to physical decline, and worry about family care (Gonzalez-Ling et al, 2021). According to Vuksanovic et al. (2017), palliative care professionals lacked the ability to cope with psychological distress, and there is no standard for what constitutes good spiritual and existential care. In recent years, there has been a systematic development of evidence-based manualized psychotherapy aimed at addressing these issues.

Dignity refers to the universal value system which is used to indicate the value of human beings and the right to be respected by others which comes as a result of interaction between individuals, communities and culture (Yu-Chi et al, 2020). Dignity is a concept that dates back over 2500 years, when the Romans defined it as a 'status of honour and respect,' bestowed solely on those who were deserving of the honour and respect due to their status, a concept they called 'Dignitas hominis' (Vehling et al, 2017).

The evidence for the use of dignity therapy (DT) as a psychological intervention in palliative care is gaining more popularity. As patients experience worsening symptoms of their illness and the end of life approaches, they experience heightened emotional anguish which has an impact on their sense of dignity. Chochinov, a psychiatry professor at the University of Manitoba, developed dignity therapy (DT) in 2005, which he described as "a brief psychotherapy based on an empirical model of dignity that helps us reflect on why some terminally ill patients would wish to die and why others will choose to enjoy their final days on earth" (Martinez et al, 2017). Dignity therapy is more concerned with boosting purpose, the meaning of life, and the feeling of dignity than with acquiring knowledge and skill building, and it is brief and adaptable, developed expressly for palliative care patients (Vuksanovic et al, 2017).

Dignity Therapy begins by giving the patients nine standard questions that are options for the patients' consideration and reflection about what they want to say. The questions now guide a conversation with DT-trained healthcare professionals. The session is recorded, transcribed and edited, and then a legacy document is produced and delivered to the patient (Martinez et al., 2017). DT assists patients in analyzing the aspects of their lives that they regard to be the most essential and wish to communicate (Nunziante et al, 2021). A study conducted by Yu-Chi, Yin-Hsun, Shu-Ching, and Hsui-Hung in Taiwan in 2020 on the effectiveness of dignity therapy on cancer patients was to determine the effectiveness of dignity therapy for end-of-life cancer patients. It was revealed that after receiving dignity therapy, patients had a considerable improvement in dignity and a decrease in demoralization and sadness (Yu-Chi et al, 2020). Between 2017 and 2018, Beata, Malgorzata, Marta, Iwona, Anna, Ewa, and Philip conducted a study in Poland that looked at dignity therapy as a coping strategy for patients with chronic obstructive pulmonary disease (COPD) who were nearing the end of their lives. The study's goal was to determine the feasibility and overall advantages of dignity therapy in patients with advanced COPD, and the findings revealed that DT had a favourable impact on the patient's well-being (Beata et al, 2019). The purpose of this study is to see how dignity therapy affects terminally ill individuals.

1.2 Statement Of Problem

Evidence in research on the efficacy of dignity therapy for distress related to dignity is limited which raises the question of the reliability of the therapeutic technique (Li et al, 2020). This study aims at understanding the effect dignity therapy has on terminally ill patients.

1.3 Research Objective

1. To investigate the effectiveness of dignity therapy among terminally ill patients.
2. To determine if Dignity therapy will be accepted by terminally ill patients and their families.
3. To find out the psychological variables dignity therapy influences.
4. To determine the extent of research done in Africa on dignity therapy.

1.4 Research Questions

1. Will dignity therapy be effective among terminally ill patients?
2. Will dignity therapy be accepted by patients and their families?
3. What are the psychological variables that dignity therapy influences?

2.0 Methods

2.1 Research design

The systematic review was conducted and reported in accordance with the published protocol and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.

2.2. Search Strategy

Articles that fit the selection criteria were selected from 7 databases (Pub med, Scopus, Google Scholar, Cochrane, Ajol, Mendeley, and Pro-quest,). The search produced a total of 610 articles with the keywords dignity, dignity therapy and terminal illness, after which eliminations were made based on selection criteria.

3.0 Screening and selection

Inclusion criteria: The articles were selected for inclusion based on their title, abstract, and then full-text availability. Other requirements for qualifying included: Study design- Randomized control trials, pretest-posttest design, quasi-experimental design and Qualitative descriptive design, Types of participants: Men and women (18 years and above), those who experience terminal illnesses such as cancer, dementia and neurocognitive deterioration.

Type of intervention: Dignity therapy

Exclusion Criteria

Articles that did not meet the inclusion criteria and articles with no full-text access were excluded from the review.

Data Extraction

The online search for articles produced 610 articles (Pubmed=50, Scopus=20, Google scholar=110, Cochrane=20, Mendeley=170, proquest=240, Ajol=0,) of which 35 met the inclusion criteria and were retained for review. The following information was extracted from each of the articles: publication details (name of authors and the year of publication), the sample size in the studies, the study design, the age range of participants, and research findings. The details of the selection and screening process are illustrated in Figure 1 below.

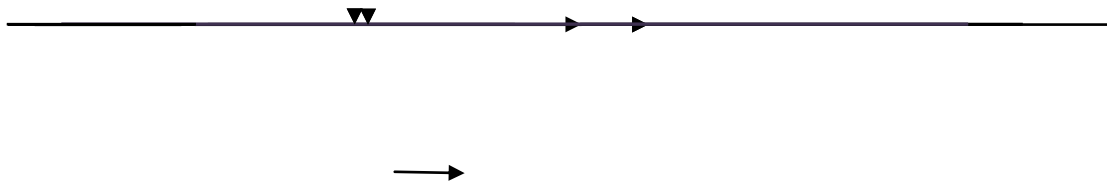


Fig 1: Flow chart of screening and selection of articles.

3.2. Process of Synthesis

3.2.1 Research Design

In 6 studies reviewed randomized control trial design was used, preliminary pretest-posttest design was used in 7 studies, Quasi experimental design was used in 3 studies and qualitative descriptive design was used in 1 study.

3.2.2 Regional Representation

A total of 11 countries were represented in this review – USA (3), China (3), Italy (2), Australia (1), Brazil (1), Taiwan (1), Canada (1), Poland (1), Kenya (1), Malta (1), Iran (1) and South Africa (1).

S/N	STUDY	AGE	SAMPLE	STUDY DESIGN	INSTRUMENTS	INTERVENTIO N	RESULT
1	Vuksanovic et al, (2017) AUSTRALIA	≥18years	56 participants diagnosed with a lifetime disease with life expectancy of 12 months	Randomized controlled trial	The Brief Measure of Generativity and Ego-Integrity10Patient Dignity Inventory (PDI)Functional Assessment of Cancer Therapy-General, version 4 (FACT-G12 Treatment Evaluation Form (15 items)Family Evaluation Form (15 items)	Dignity Therapy	Although the DT intervention improved generativity and ego integrity, no significant changes in dignity-related distress or physical, social, emotional, or functional well-being were seen. Despite the fact that participants' families/caregivers indicated a high degree of approval,
2	Yu-Chi et al (2020) TAIWAN	≥54years ≤80	30 participants	quasi-experimental study design	Demoralization Scale Mandarin Version- DS-MV	Dignity Therapy	Result showed significant improvement in

				with a nonrandomized controlled trial	and Patient Health Questionnaire-9		dignity and significant reduction in demoralisation and depression among participants.
3	Nunziante et al, (2021). ITALY	41 years to 89 years	37 participants	Pretest-posttest assessment technique	Patient Dignity Inventory and the Dignity Therapy Patient Feedback Questionnaire	Dignity Therapy	The patients gained a sense of purpose and self-continuity as a result of the DT intervention. The participants' and their families' relationship improved as a result of the intervention. The participants found DT to be beneficial and satisfactory.
4	Brozek et al, (2019) POLAND	60 to 87 years	10 participants (Chronic Obstructive Pulmonary Disease)	Pretest posttest assessment	Hospital Anxiety and Depression Scale (HADS) and Edmonton Symptom Assessment System (ESAS) questionnaires assessing their psycho-physical status, and The Spiritual Needs Questionnaire (SpNQ)	Dignity Therapy	The result indicated that DT had a positive effect on the patients mental well-being. The therapy helped the patients to express themselves more and connect well with family also.
5	Korman et al, (2020). CANADA	≥ 18 years	15 participants (Brain Tumour)	Pretest posttest analysis	open-ended, self-report survey	Dignity Therapy	Report showed that DT was beneficial in terms of

							communication and advanced care planning. Dignity therapist reported that DT had a positive impact on the patients and it was satisfying. In comparison to other treatments, the DT therapists were also inspired by their patients' ability to build meaning out of their lives despite the circumstances. Participants also reported a high level of acceptance after therapy.
6	Dose et al, (2018). USA	51 years to 77 years	18 participant (Advanced pancreatic and lung cancer)	phase I/II pilot study	Distress Thermometer Patient Dignity Inventory FACT-Hep (Functional Assessment of Cancer TherapyHepato biliary) FACT-L (Functional Assessment of Cancer Therapy-Lung) (Functional Assessment of Chronic Illness	Dignity Therapy	Report showed that after 3 months of the pilot study there were no significant changes in quality of life, spirituality, dignity, and purpose in life, except for less distress. There was no improvement in patients who experienced worsening

					Therapy – Spiritual Well-Being; The 12-item Spiritual Well-Being Scale)		symptoms.
7	Beck et al, (2018) USA	≥21 years	11 participants (Advanced stage of cancer)	Pretest posttest assessment method	Self developed questionnaire	Dignity Therapy	Abbreviated DT was found to improve self-expression, connection with loved ones, sense of purpose, and self-continuity in this study. Participants observed that leading the development of their legacy projects promoted independent reflection, autonomy, and opportunities for family interaction when reviewing and discussing the projects
8	Bluck et al, (2021) USA	55 to 75 years	25 participants (older cancer patient)	Pretest posttest analysis	Patient Dignity Inventory (PDI) 14-item version of the Religious/Spiritual Struggles Scale (RSSS) 14-item version of the Religious/Spiritual Struggles Scale (RSSS)	Dignity Therapy	Dignity therapy helped all the patients to make meaning. Patients who made meaning had higher psychospiritual discomfort, greater dignity-related suffering, greater spiritual

							distress, and inferior quality of life at the start of the study.
9	Chen et al, (2021) CHINA	37 to 60 years	66 participants (hematologic neoplasms)	A single-blinded, two-arm parallel randomized controlled trial	QOL The Chinese version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)	Dignity Therapy	In this study, dignity therapy was linked to a higher level of spiritual well-being and hope in the short term.
10	Weru et al, (2020) KENYA	18 to 65 years	144 participants (advanced cancer patient)	randomized control trial	Edmonton symptom scale (ESAS)	Dignity Therapy	DT intervention brought about improvement in appetite, lower anxiety and improved wellbeing respectively.
11	Barbara et al, (2021) MALTA	≥60 years	12 participants (Dementia)	one-group pretest-posttest pre-experimental study design	Herth Hope Index (HHI), Demoralization Scale-II (DS-II), and Zarit Burden Interview (ZBI-12)	Dignity Therapy	DT had a positive impact on demoralisation, hopelessness and caregiver burden in persons living with dementia
12	Espindola et al, (2017) BRAZIL	52 years old	1 participant (Cancer)	case study(pretest posttest assessment)	Beck Anxiety Inventory, Beck Depression Inventory, Patient Dignity Inventory	Dignity Therapy	The results showed that after receiving dignity therapy, the level of depression was reduced and the sense of dignity was improved. There was also an increase in anxiety. In addition, the

							therapy promoted the recovery of pleasant memories, the ability to repent and ask for forgiveness, and the presence of family members towards the end of life.
13	Lani et al, (2020) ITALY	61 to 88 years	35 participants (terminal illness)	Randomized Controlled Trial	The Functional Assessment of Chronic Illness Therapy-Spiritual Well-BeingScale (FACIT-SpDemoralization was assessed with the Demoralization Scale-II (DS-II Patient Dignity Inventory	Dignity Therapy	Patients in the DT intervention maintained similar levels of tranquility from pre-test to follow-up, according to the study's findings. It also found that during the same time span, patients in the control group had a drop in peace. In addition, there was no long-term influence on measures of meaning, faith, loss of meaning and purpose, discomfort and coping ability, existential, psychological, or physical pain.
14	Balbadhur et al, (2017)	31 to 81 years	12 participants	Qualitative descriptive design	post intervention patient feedback	Dignity Therapy and guided	Dignity Therapy and Guided Imagery

	SOUTH AFRICA		(Advanced diseases).		questionnaire	imagery	were found to be relevant, acceptable, and useful in improving patients' dignity, purpose, meaningfulness, will to live, and hope. DT aided in the improvement of family and healthcare provider relationships. Suffering, worry, and depression were also reduced as a result of DT.
15	Zaki-Nejad et al (2020) IRAN	>18 years	50 participants (patients with cancer)	Quasi experimental design Non-randomized controlled trial	European Organization for Research and Treatment of Cancer Quality of life-C15-Palliative (EORTC-QLQ-C15-PAL) Questionnaire	Dignity therapy	The outcome demonstrated that dignity therapy improved the intervention group's quality of life. In terms of physical and emotional functioning, there was also a substantial difference between the groups.
16	Xiao et al, (2022) CHINA	32 years to 72 years	120 participants (Lung Cancer)	randomized clinical trial	Patient Dignity Inventory, Patient Health Questionnaire-9, and Functional Assessment of Chronic Illness	Dignity Therapy	Patients in the intervention group had considerably lower levels of existential distress,

					Therapy – Spiritual Well-being Scale		sadness, and spiritual well-being than those in the control group.
17	Wang et al, (2021) CHINA	26 to 75 years	68 participants (haematologic malignancies)	Randomised control trial	Socio-demographic questionnaire Herth hope index (HHI) and functional assessment of chronic illness therapy - spiritual well-being scale (FACIT-Sp) Self-rating anxiety scale (SAS) and self-rating depression scale (SDS) Family adaptability and cohesion evaluation scale-II (FACES II)	Dignity Therapy	The family participatory dignity treatment program was found to be effective in enhancing patients' hope, spiritual well-being, and family cohesiveness and adaptation; it also reduced anxiety and depression among family caregivers while improving family cohesion and adaptability.

3.0. Results

In this review, fifteen (88.23%) of the studies (n=15) included in the research found that DT had a significant favorable effect on the participants' well-being. Participants and family members in the 15 trials said dignity treatment increased their well-being, sense of purpose, communication, self-expression, and connection with loved ones. Anxiety, depression, and demoralization were also reported to have decreased. For example the result gotten from Li et al (2020), showed that dignity therapy improved dignity of the participants, and caused a decrease in demoralization and depression. According to Nunzainte et al (2021), the participants' sense of purpose, self-continuity, and familial connection all improved. Participants' spiritual well-being and level of hope improved after dignity therapy, according to Chen et al (2021).

On the other hand, two research studies (n=2) found that dignity-related distress, physical, social, emotional, and functional well-being had a low or non-significant impact. Also quality of life, spirituality, meaning and coping ability (Vuksanovic et al 2017, Dose et al 2018 and Lani et al 2020). This result shows that there is more evidence of dignity therapy having a positive effect on the terminally ill patients than no effect or a negative effect.

Among all the 17 studies reviewed 12 studies (n=12) 70.58% investigated the acceptance of DT among the participants and their family and there was 100% acceptance by the participants. Though some complained about time and length of the therapy but they reported they benefited from it and would recommend to family

and friends. Most of the participants reported DT helped them to convey precious memories, helped them with their feelings, helped them with telling the truth, helped them improve in their relationship with others and especially family members. DT therapist reported that it had more effect on the family because it leaves the family with a small token of the patient when they are gone (Korman, 2020). Chen et al, (2020), reported that 93% of the participants claimed they benefited from the therapy and 96% of the family members also claimed to be satisfied with the therapy process.

The remaining 5 studies (n=5) 29.41% did not investigate the acceptance of DT by the participants or family of the participants. This shows that DT was accepted based on the benefits derived from the therapy.

Among the 17 studies, 10 studies (n=10) (58.82%) reported dignity therapy had effect on 3 major psychological variables, hopelessness, depression and anxiety. 2 studies reported a decrease in the level of depression, 1 study reported an improvement in the hope of patients, 2 studies reported an improvement in hope and reduction in depression and anxiety, 4 studies reported a decrease in the level of anxiety and depression and 1 study reported no change in the level of depression and anxiety after dignity therapy intervention. For example Espindola et al (2017), reported a decrease in depression among the participants, Yu-Chi et al (2020), also reported a reduction in depression among the patients and Balbadhur et al (2017), reported a 92% reduction in depression and anxiety and a 100% improvement in hopelessness.

There were only 2 (11%) studies on dignity therapy from Africa discovered in this review, one from Kenya and the other from South Africa (Weru et al (2021) and Balbadhur et al 2017). There was no journal or article on dignity therapy found from the African Journals Online. This shows that there is a research gap on dignity therapy as a therapeutic intervention in the palliative care system in Africa.

4.0 Discussion

The purpose of this systematic review was to assess the effect of dignity therapy on terminally ill patients in relation to the acceptance of dignity therapy among the terminally ill patients and their caregivers, the psychological factors dignity therapy influences and the research gap in Africa (Nigeria). This review included studies that were conducted in different parts of the world with USA and China having the highest representation. Seventeen (17) papers were included in which all were published between 2017 and 2022.

Results from this review shows dignity is an important aspect of the human life especially when people are vulnerable or at their weakest points in life. Knowing one has few months or days to live due to a terminal illness is a challenging phase for any individual and most people live in despair, fear and regret at this stage of their life. From the findings in this review we discovered that terminally ill patients are usually demoralized, distressed, anxious, worried about their loved ones (family), some have regrets about life and find no meaning to it, some feel hopeless which most times lead to depression and deterioration in their health status and some also experience existential and spiritual distress. Baczewska et al., (2019) reported that when one is diagnosed of cancer they usually perceive it as an end to professional goals and personal achievements which usually leads to negative emotions such as anger sadness, hopelessness and regret.

The first research question found that dignity therapy had an effect on over 96 percent of the participants, based on 15 (88 percent) of the studies analyzed. Generativity, ego integrity, well-being, level of hope, communication, self-expression, connection with loved ones, feeling of purpose, anxiety, sadness, demoralization, and discomfort were all affected by dignity treatment. This is in line with a study on dignity therapy conducted by Rahimi et al., 2020, which found that dignity therapy was beneficial in assisting patients in developing hope. Hope has also been linked to reduced symptoms, decreased depression, and increased self-esteem, according to Nierop-van Baalen et al., 2020, which is consistent with the findings.

According to the findings of the second research question, Dignity therapy was completely accepted by patients and their family members in all investigations. In one of Vuksanovic et al (2017)'s investigations, dignity therapy had no significant effect on dignity distress, physical, social, or emotional functioning, or well-being in general,

but participants and their families found it to be highly acceptable and satisfying. DT was approved and recommended by both participants and family members in all 12 studies that assessed its acceptance level among participants and their family members. Bentley et al., 2017 also reported that dignity therapy was well accepted in most of the cases in her study. Likewise Stephanie Mai et al., 2018 reported that DT was feasible and had high level of acceptability among patients and relatives. This proves DT is widely accepted and it can be attributed to the technique used in carrying out the intervention and due to the high level of positive feedback gotten from participants.

Results from the third research question shows that the major psychological areas DT influences are anxiety, depression and hope. Most patients reported anxiety about their illness and losing hope due to the disease terminal nature and this makes them develop depression which makes their health deteriorate the more. DT helped patients develop meaning to life and this in turn gave them a sense of hope, for example in Wang et al., study DT gave the patient high hope, spiritual well-being and family cohesion which also reflected in lower anxiety and depression. This is in line with a study carried out by Zheng et al., 2017 in which DT reduced anxiety and depression after intervention. Another study carried out by Martinez et al., 2017 showed that DT helped in the decrease of anxiety and depression among patients with high level of psychological distress. Cuevas et al., 2021 also reported DT intervention helped in reducing anxiety and depression. This indicates that DT might be a useful psychological intervention tool in treating anxiety, depression and hopelessness.

4.1. Limitations of Study

One of the limitations of this study was that there were few research studies on the subject matter and the selection of material between the year 2017 and 2022 made it difficult to get a good number of studies on the research topic. Also only studies with full text access were reviewed which means some studies may have been missed. Most of the studies were from the western context.

Identified Gap and Recommendation

There is a gap in research on dignity therapy in African palliative care and more research needs to be carried out on this study to understand if there is a cultural difference in the effect of dignity therapy, especially in Africa. Dignity therapy should be introduced into the palliative care system in Africa, especially Nigeria to bring about improved care for individuals living with terminal illness. Dignity therapy should also be looked at as a possible psychotherapy treatment in dealing with some psychological problems among people with mental health issues such as depression, anxiety and hopelessness.

Conclusion

This research adds to existing studies on the effect dignity therapy has on terminally ill patients in the palliative care. The result shows dignity therapy to be effective in helping discover hope, meaning to life, resolving spiritual conflicts, reducing anxiety and depression and discovering dignity even in critical health situations. Helping patients who have terminally ill diseases live well through their challenge is a positive for the palliative care system and it brings about more fulfilments to the patients and caregiver.

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