

## Feasibility, Acceptability and Effectiveness of Dignity Therapy among Palliative Cancer Patients: A Pilot Study in Tamil Nadu, India

**Saranya Sindarraju**

PhD Research Scholar Department of Psychology Annamalai University, Tamil Nadu

**R. Sanker**

Assistant Professor, Department of Psychology Annamalai University Tamil Nadu India

### Abstract

Dignity therapy is a transient, individualized intervention designed to engender a sense of meaning and purpose among patients with terminal un-healthiness, thereby reducing distress among end of life patients with palliative care. The aim of the present paper is to evaluate the effectiveness and feasibility of Dignity therapy in improving the dignity of palliative cancer patients and to reduce the symptoms experienced by the palliative care cancer patients in Tamil Nadu. The data for the present study was collected by using Purposive Sampling techniques across different Palliative care centres in Tamil Nadu. A total number of 30 patients were contacted and were exposed to pre and post experimental conditions. The feasibility and the effect of dignity therapy were assessed by The Palliative Performance Scale - version 2 (PPSv2) and The Patient Dignity Inventory Chochinov et al. (2008). The data was tabulated and analysed by SPSS version 20 through paired t-test in experimental design. The results of this study revealed that there is significant mean difference between the mean scores of palliative cancer patients in pre and post experimental conditions. The pre-test condition are having mean score of (M=103.10, N=30) while after the intervention of dignity therapy the mean scores dropped significantly (M= 42.30). The magnitude of effect size has been estimated through Cohen's eta square which revealed large effect of dignity therapy in reducing the symptoms and improving the conditions of palliative patients.

**Keywords:** Dignity therapy, palliative cancer patients, intervention.

### Introduction

Cancer is a leading cause of death worldwide and accounted for 8.2 million deaths in 2012 (Torre, Bray, Siegel, Ferlay, Lortet-Tieulent, & Jemal, 2015). Approximately 6.5 million cancer patients are in PC worldwide (Ministry of Health and Welfare, 2014). More than 70% of the cases present in advanced stage account for poor survival and high mortality. It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV (Seamark, Ajitha kumari, Burn, Devi, Koshy, & Seamark, 2000). Furthermore, a significant portion of these cases requires specialized palliative care (PC).

Cancer patients develop severe physical and psychological symptoms as a result of their disease and treatment. Their families commonly suffer great emotional distress as a result of caregiving. It is the most feared of all illnesses, and its diagnosis is usually associated in the patient's mind with premature and unpleasant death. Pain, anorexia, weight loss, tiredness, malaise, shortness of breath, and confusion are some of the other many symptoms that cancer can cause as it spreads to vital organs. Added to the physical distress of advancing cancer, is the emotional distress and eroding sense of dignity, caused due psychosocial, existential, and spiritual challenges (Chochinov, 2007; Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2002; Hack, Chochinov, Hassard, Kristjanson, McClement, & Harlos, 2004).

In 1969, Kubler-Ross described five stages of grief, namely denial, anger, bargaining, depression and acceptance, which includes information and communication, emotional support and guidance and direction and proved interviewing patients helps the patients. Steinhauer *et al.* (2001) have investigated the preferences of patients nearing the end of life and have reported that overwhelmingly issues of 'preparation' are felt to be important. Patients report that they want to have time to express their wishes both verbally and in writing, to name someone to make decisions, to put their financial affairs in order and to make their funeral preparations.

The emotional distress and dignity can be upheld by measures such as symptom control (Pringle, Johnston, & Buchanan, 2015) promoting independence, privacy, social support and a positive tone of care (Johnston *et al.*, 2015), listening, giving appropriate information, having a caring bedside manner (Beach *et al.*, 2015); and showing respect, empathy and companionship (Rajagopal, 2010) enabling management of finances, facilitating activities such as reading or watching television, allowing the patient to spend time with their family, providing choices regarding the place of death, remembering the dignity of the family after the death of the individual, and offering emotional support (Sridhar, Renuka, & Bonanthaya, 2012).

The concepts of respect, autonomy, empowerment and communication have been identified as the key attributes of dignity (Griffin-Heslin, 2005). Communication about end-of-life care and decision making during the final months of a person's life are very important. Research has shown that those who have open and honest conversation about choices for end-of-life care early in the course of their disease resulted in decrease of stress and their ability to cope with illness increases. It is found that dignity is correlated with lack of energy, anxiety, sadness, pain, shortness of breath, irritability, thirst, tiredness and psychological symptoms (Oechsle, Wais, Vehling, Bokemeyer, & Mehnert, 2014). Therefore, it is felt that assessing the symptoms among the palliative cancer patients and understanding the effect of DT would be interesting.

Many interventions like palliative care for dignified dying (Doorenbos, Jansen, Oaks, & Wilson, 2009), have proved to be effective in reducing the distress and thereby help in maintaining dignity. It is found that life review for those with advanced cancer goes beyond simple reminiscence (pleasant cognitive process of past life events), to examine and review one's life to obtain deeper meaning and ease death anxiety (Keall, Clayton, & Butow, 2015). Dignity therapy (DT) is one form of life review. In this context, Chochinov (2002) developed a brief psychotherapy based on an empirical model of dignity that begins with reflection on why some patients with advanced disease wish to die, while others find serenity and a desire to enjoy their last days.

Dignity therapy is a transient, individualized intervention designed to engender a sense of meaning and purpose among patients with terminal unhealthiest, thereby reducing distress among end of life patients with palliative care. Dignity therapy aims to alleviate psycho-emotional and existential distress and to enhance the experiences of patients whose lives are vulnerable by illness. This therapy offers patients a chance to reflect on problems that are important to them or other things that they might wish to recall or transmit to others. Care of the psychological and religious aspects of a person during illness are recognized as essential components of patient-centered care. Dignity therapy model includes religious as well as psychosocial and physical elements to promote maintenance of dignity for patients facing serious illness (Chochinov, 2008). Many trials of Dignity Therapy among cancer patients conducted in different cultures and population has reported high level of satisfaction with the therapy, heightened sense of dignity, an increased sense of purpose, heightened sense of meaning and it had been or would be of help to their family. Post-intervention measures of suffering and depressive symptoms showed modest, albeit significant improvement

(Chochinov *et al.*, 2005). Family members of patients also found dignity therapy helpful, it was comforting to them in their time of grief, and majority would recommend Dignity Therapy for other patients and families (McClement *et al.*, 2007).

DT has been largely explored in the Anglo-Saxon contexts of the United States, Canada, Australia and the United Kingdom. In studies on adapting the therapy to other cultures, some have noted cultural influences that may require an adaptation on the way that the therapy is offered (Akechi *et al.*, 2012; Houmann, Chochinov, Kristjanson, & Groenvold, 2014; Lindqvist, Threlkeld, Street, & Tishelman, 2015). Such differences do not mean that the therapy is not applicable, but rather that it needs some adjustments in its application (Houmann, Chochinov, Kristjanson, & Groenvold, 2014). On the one hand, different cultures interpret and accept certain words differently. On the other hand, the way that a population faces terminal condition can in itself be an obstacle for adapting the therapy because in the Japanese population, being 'unaware of death' is considered culturally appropriate. If participating in DT is offered in a way that confronts them with death and dying, it is likely to be rejected (Miyashita, Sanjo, Morita, Hirai, & Uchitomi, 2007). So, creating a legacy is for the patients in their end of life are important (Akechi *et al.*, 2012).

It is therefore necessary to test the feasibility of DT in Indian cancer care setting and explore the extent to which adjustments might be necessary, prior to moving into a more formal and extensive usage in India.

### **Research question**

1. Whether it is feasible and acceptable to adapt the dignity therapy developed by Chochinov and colleagues in an Indian setting?
2. Whether dignity therapy will be effective in improving dignity and reducing symptoms for palliative care cancer patients?

### **Objectives**

1. To assess the feasibility and acceptability of Dignity Therapy (DT) among palliative care cancer patients in Tamil Nadu
2. To assess the effect of Dignity Therapy on the dignity and symptom experienced of palliative care patients and their symptoms before and after intervention of dignity therapy.

### **Hypotheses:**

Researches on Dignity Therapy among cancer patients conducted in different cultures and population has reported high level of satisfaction with the therapy, heightened sense of dignity, an increased sense of purpose, heightened sense of meaning and it had been or would be of help to their family (Chochinov *et al.*, 2005; McClement *et al.*, 2007). Therefore, for the present study, alternate hypotheses are framed.

1. Dignity therapy will be effective in improving the dignity of the palliative care cancer patients in Tamil Nadu
2. Dignity therapy will be effective in reducing the symptoms experienced by the palliative care cancer patients in Tamil Nadu.

### **Method**

#### **Research design**

Using Quantitative analysis the effect of Dignity Therapy on the dignity and symptoms will be assessed using pre-post experimental design. The acceptability and feasibility will be assessed through qualitative methods using dignity therapy question protocol.

#### **Participants**

In order to fulfil the objectives of the pilot study 30 Patients are selected using Purposive Sampling techniques across different Palliative care centres in Tamil Nadu. The patient-caregiver-triad will be adopted as to understand the feasibility of dignity therapy, based on findings of emotional interdependence and interactive coping between the patient

and caregiver (Berg & Upchurch, 2007; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008) with the support of the health care practitioner (HCP).

#### **Inclusion criteria**

- Age  $\geq 18$  years and  $< 75$  years.
- Both genders
- Advanced cancer patients with the life expectancy of  $> 3$  months according to the treating oncologist.
- Those who can comprehend either in English or Tamil
- Patients who have the knowledge about their cancer diagnosis and its advanced nature.
- Those who score 30% and above in Palliative Performance Scale (PPS-V2) with full conscious level and without any confusion or drowsiness
- A commitment to three to four contacts over approximately 4-5 days
- Willingness to participate in the study

#### **Exclusion criteria**

- Any current or previously diagnosed psychological illness
- Any cognitive deficit or attention problem that could interfere with the ability of patients to answer questionnaires or understand the study aims (according to the investigator).
- Any comorbid condition that would interfere with patient safety, compliance with the study, or the interpretation of the results according to the investigator.

#### **Tools used for the study**

To assess the feasibility and the effect of dignity therapy the following tools are used.

#### **Palliative Performance Scale**

The Palliative Performance Scale - version 2 (PPSv2) is a validated and reliable tool developed by Anderson et al. (1996) to assess a patient's functional performance and to determine progression toward end of life. The PPSv2 uses five observers rated domains: ambulation; activity & evidence of disease; self-care; intake; and conscious level. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient who is then assigned as the PPS% score. The items are read from the left column and downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

#### **The Patient Dignity Inventory:**

The Patient Dignity Inventory (PDI) is one of the few available instruments for measuring dignity, developed by Chochinov et al. (2008) in accordance with his model of dignity conserving care in the terminally ill patients. The PDI consists of 25 items aimed at investigating three primary domains of the model: 1) illness-related concerns, comprising level of independence and symptoms distress; 2) dignity conserving repertoire, consisting of dignity conserving perspectives and practices; and 3) social dignity inventory. For each item, the person indicates his/her degree of concern on a five-point scale, with 1 representing "not a problem" and 5 representing "an overwhelming problem."

Cronbach coefficient alpha for the PDI was 0.93; the test-retest reliability was  $r = 0.85$ . This questionnaire was validated in many languages and was also applied in oncologic settings, such as cardiology units<sup>34</sup> and severely ill outpatient settings. The validation studies demonstrated similar good internal consistency and the existence of more than one factor, with the exception of the Italian study in oncology which evidenced only one factor. The preliminary validation study in an acute psychiatric ward highlighted three factors supported by all but two items of the PDI, which represented the main domains of dignity,

excellent internal consistency and statistically significant positive correlation with the Hamilton Scales for both Depression and Anxiety.

**Edmonton symptom assessment system (revised)**

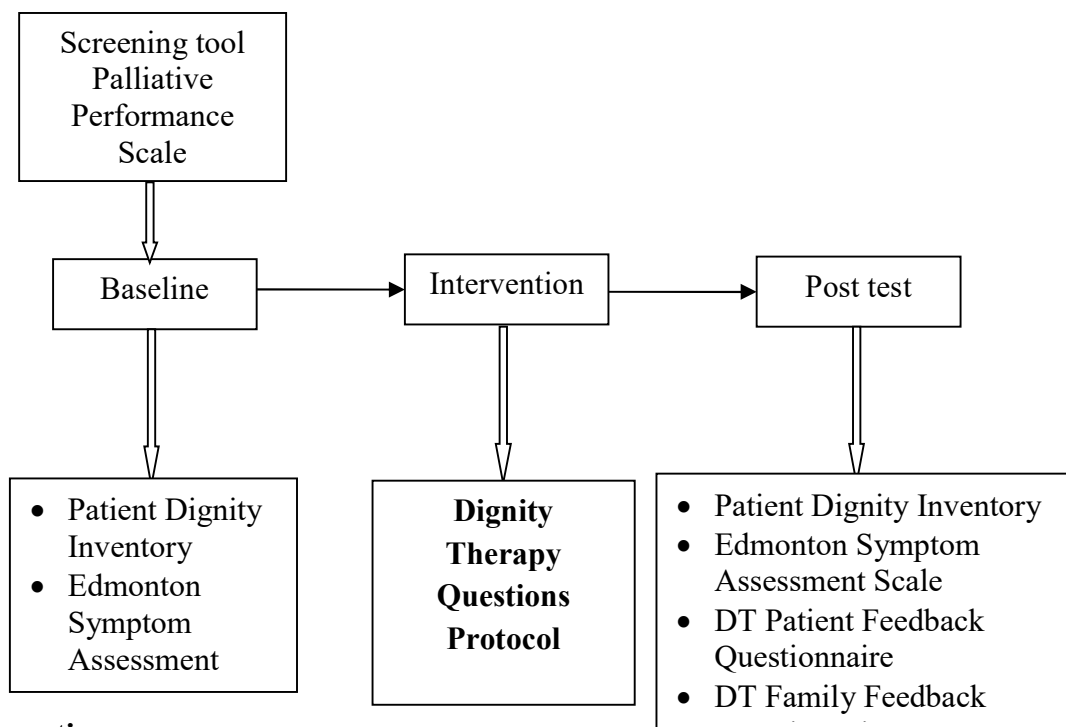
The ESAS-r (Watanabe et al., 2011) is intended to capture the patient’s perspective on symptoms. The ESAS provides a clinical profile of symptom severity over time. It consists of a visual numeric scale with scores of 0 to 10 to assess ten symptoms, including pain, fatigue, drowsiness, nausea, depression, anxiety, and loss of appetite, feeling of wellness, breathlessness, and insomnia (Bruera, Kuehn, Miller, Selmsler & Macmillan, 1991). The patient circles the most appropriate number to indicate where the symptom is between the two extremes. For example, for the pain symptom, the scale is as follows.

No pain                      0 1 2 3 4 5 6 7 8 9 10                      Worst possible pain

**Objective indicators**

1. Pain-grimacing, guarding against painful maneuver
2. Tiredness-increased amount of time spent resting
3. Drowsiness-decreased level of alertness
4. Nausea-retching or vomiting
5. Appetite-quantity of food intake
6. Shortness of breath-increased respiratory rate or effort that appears to causing distress to the patient
7. Depression-tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern
8. Anxiety-agitation, flushing, restlessness, sweating, increased heart rate (intermittent), shortness of breath
9. Well-being- how the patient appears overall

The Cronbach’s alpha value obtained was 0.77 (Yesilbalkan, Karadakovan, Turgut, & Kazgan, 2008) and 0.79 (Chang, Hwang, & Feuerman, 2000).



**Intervention:**

**Dignity Therapy conduction procedure**

Dignity Therapy (DT) was developed by Chochinov and colleagues based on their previous research on the concept of dignity (Hack et al., 2004; Chochinov et al., 2002;

Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002). DT is based on an empirical model of dignity in the terminally ill, which delineates what influences an individual's sense of dignity. The purpose of DT is *"to decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose and dignity"* (Chochinov, 2005). Dignity Therapy employs a narrative approach and contains elements similar to Life Review and reminiscence, with its focus on letting the patient find meaning and reconciliation through examining past experiences and achievements, and making amends with or carry out unfinished business (Lewis & Butler, 1974; Linn & Linn, 1981; Linn, Linn, & Harris, 1982; Pickrel, 1989). It also contains elements from meaning-centered therapies, in terms of creating legacy (Breitbart, 2001; Greenstein, 2000; Greenstein & Breitbart, 2000; Lee, Robin, Edgar, & Laizner, 2006; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). Further, DT focuses on meaning-making, by inviting patients to reflect on what is important to them. The therapeutic stance of DT is one of unconditional positive regard, as per other supportive therapies (Classen *et al.*, 2001; Miller, Chibnall, Videen, & Duckro, 2005; Spiegel, Bloom, & Yalom, 1981). The strength of DT lies in the way it combines these elements in a fashion that is clearly described in a manual. Furthermore, DT is specifically tailored to patients living under conditions of severe illness, including heavy symptom burden, psychosocial and existential distress, and physical limitations. Guided by the Dignity Therapy question protocol (DTQP) (Chochinov *et al.*, 2005), DT constitutes a distinct and innovative approach that can be conducted at the bedside and completed within days, making it particularly suitable for the palliative care setting. Results from 100 patients, living in Canada and Australia, demonstrated significant reduction of depressed mood, sense of suffering and nearly significant improvement in sense of dignity (Chochinov *et al.*, 2005). In a study conducted at Denmark, between 81-91% of the patients found DT satisfactory and of help to their relatives, and 67-76% of the patients felt it heightened their sense of purpose, meaning and dignity. Interviews with the relatives' after the patient's death supported these findings. Furthermore, relatives reported great appreciation of the 'generativity document' (an edited transcription of DT), which had helped them during their grief (McClement, 2007).

### **Conduction of the Dignity Therapy**

A framework of questions (Table 1), based on an empirical model of dignity in the terminally ill, informs the basic content of the therapeutic process (Chochinov, Hack, McClement, Harlos, & Kristjanson, 2002; Chochinov, 2002). The DT questions will be asked by the trained researcher and the conversation based on each question will be guided by the researcher, and will be flexible so as to accommodate the patient's needs and choices regarding what they specifically wish to address. Dignity Therapy will be audio-recorded and transcribed. This transcript or 'generativity document' will be returned to the patient within approximately four days from their prior session, read to them completely to ensure that no errors of omission or commission needed to be addressed. This final session will take about 30 minutes). (Generativity, or the ability to guide the next generation, encompasses how patients might find strength or comfort in knowing that they will leave behind something lasting and transcendent of death), (Chochinov, Hack, McClement, Harlos, & Kristjanson, 2002). The final version of the generativity document will then be given to the patient, to be passed along to a designated recipient (the influence of Dignity Therapy on family recipients of generativity documents will be reported separately at the end of the intervention). At the conclusion of this session, participants will be asked to complete a feedback questionnaire.

Therapeutic sessions, running between 30 and 60 minutes, will be offered either at the patients' bedside for those in hospital, for outpatients at the centre, or in their residential setting. The therapy will be conducted by the researcher, who is trained in performing the DT.

**Table 1. Dignity Themes, Definitions, and Dignity-Therapy Implications**

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

Source: Chochinov et al. (2002)

**Ethics Committee Approval**

This study was approved by the ethics committee of Meenakshi Mission Hospital and Research Centre, Madurai.

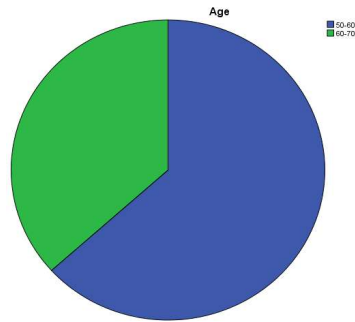
**Results and Discussion**

Prior to any specific statistical enterprise, the data were assessed for normality by examining the skewness and kurtosis of the distribution for each measure. All study measures were deemed normally distributed. The assumption of linearity and homoscedasticity were verified through the examination of the bivariate scatterplots between the study measures. These assumptions were met for all measures.

**Table 2: Distribution of subjects with respect to age**

Variable	Sub Variable	Frequency	Percent
Age	50-60	19	63.3
	60-70	11	36.7
	Total	30	100.0

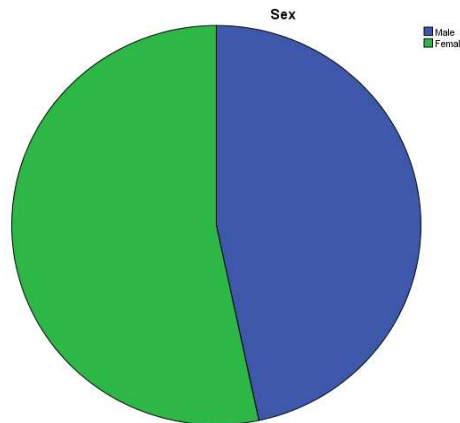
Fig 1 is showing graphical representation of data with regard to gender



**Table 3:** *Distribution of subjects with respect to gender*

Variable	Sub Variable	Frequency	Percent
Gender	Male	14	46.7%
	Female	16	53.3%
	Total	30	100%

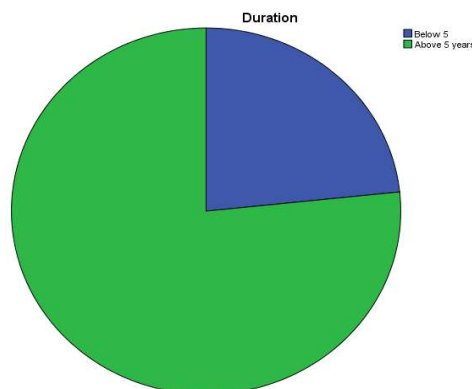
Fig 2 is showing graphical representation of data with regard to sex



**Table 4:** *Distribution of subjects with respect to duration of illness*

Variable	Sub Variable	Frequency	Percent
Duration of Illness	Below 5 years	7	23.3
	Above 5 years	23	76.7
	Total	100	100.0

Fig 3 is showing graphical representation of data with regard to duration of illness



**Table 5:** *Distribution of subjects with respect to locality*



Variable	Sub Variable	Frequency	Percent
Locality	Rural	17	
	Urban	13	38
	Total	100	100.0

Fig 4 is showing graphical representation of data with regard to duration of illness

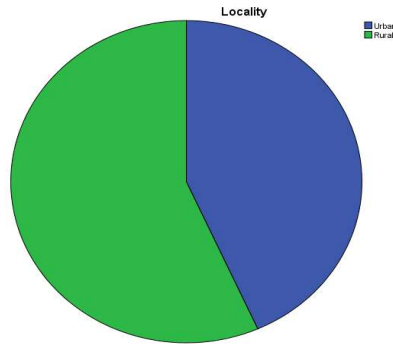
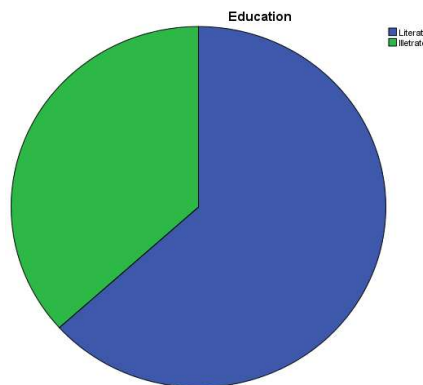


Table 6: Distribution of subjects with respect to education

Variable	Sub Variable	Frequency	Percent
Education	Literate	19	63.3
	Illiterate	11	36.7
	Total	30	100.0

Fig 5 is showing graphical representation of data with regard to duration of illness



The study was carried out with an objective to find the feasibility and effectiveness of dignity therapy among the palliative cancer patients. For that particular purpose an experimental design was used to see the impact of dignity therapy in reducing the symptoms and improving the quality of life. After the sample was exposed to pre-test and post-test conditions paired t-test of analysis were used. Paired t-test is a parametric static test that can be used when the sample is exposed to two different experimental conditions and the before and after effect can be examined. The assumptions for the paired t-test were tested and the results were shown below.

Table 7: Shows the means difference of scores of two groups before and after intervention

	Mean	N	SD	SE
Pre-test	103.10	30	8.376	1.52
Post-test	42.30	30	4.98	.910

The above table 4.5 shows the mean differences of scores of Palliative patients before and after the dignity therapy intervention. The table reflects there is significant mean difference between the mean scores in pre and post dignity therapy. The palliative cancer in pre-test condition are having mean score of (M=103.10, N=30) while after the intervention of dignity therapy the mean scores dropped significantly (M= 42.30). The table also reflects the standard deviation of the differences between the means and more important the standard error of the differences between participants' scores in each condition.

**Table8:** Shows the means difference of scores of two groups

	Mean	SD	SE	t	df	Sig
Pre Test-Post Test	60.80	7.64	1.39	43.53	29	.000*

The size of t is compared against known values based on the degrees of freedom. When the same participants have been used, the degrees of freedom are simply the sample size minus 1 (30-1=29). The degrees of freedom are used to calculate the exact probability that a value of t as big as the one obtained could occur if the null hypothesis were true (i.e. there was no difference between these means). Having established that there is significant difference between the mean scores of before and after experimental group, the above table shows that this mean difference is significant at .000 levels with t value (t= 43.53) and standard deviation of 7.64. The table statics reveals that the impact of dignity therapy is significant in reducing the symptoms of palliative cancer patients. Before the intervention of dignity therapy the patients had experienced negative symptoms that got reduced to lower level after the intervention of dignity therapy. Hence, our hypothesis which states that dignity therapy will be effective in improving the dignity of the palliative care cancer patients in Tamil Nadu stands supported. The intervention of dignity therapy has shown that patients have experienced high level of satisfaction with the therapy, heightened sense of dignity, an increased sense of purpose, heightened sense of meaning that carry positive.

Although the results presented above tell us that the difference we obtained in the two sets of scores was unlikely to occur by chance, it does not tell us much about the magnitude of the intervention's effect. The magnitude effect can be calculated by calculating the effect size of statistic. We are using here Eta square (one of commonly used effect size static) to know the magnitude of intervention.

Eta square cab be obtained by the following formula

$$\text{Eta Squared} = \frac{t^2}{t^2 + t - 1}$$

While putting the values we get

$$\text{Eta Squared} = \frac{43.53^2}{43.53^2 + 43.53 - 1}$$

$$\text{Eta Squared} = 1.01$$

To interpret the eta squared values the following guidelines can be used (from Cohen, 1988): .01=small effect, .06=moderate effect, .14=large effect. Given our eta squared value of 1.01, we can conclude that there was a large effect, with a substantial difference in reducing the symptoms and improving the dignity of patients. Here the intervention provided by the experimenter improved the conditions as reflected by the effect size.

### Discussion

Dignity therapy is a brief Psychotherapeutic intervention that can be delivered at the bedside and may help both patients and their families. this pilot study is conducted as a

preliminary research showing if it is feasible to offer dignity therapy to patients in hospice setting, many of whom are likely to be in the terminal stage of their illness, whether it is acceptable to them and their families in India, if it is likely to be effective in Indian setting.

The result of this pilot study revealed that patients scored a mean score of 103. Indicating lower dignity after the intervention scored a mean score of 42.25 indicating improved dignity. However on analysing the individual themes on physical, psychosocial, existential and spiritual domains of concern or distress, physical domain did not differ significantly in the prepost trail as the therapy couldn't contribute to lessen the suffering of the patient. The 't' value was found to be. 43.53 Which indicates it is highly significant at 0.01 level 'hence considered to be effective in Indian setting. The results of this pilot study are consistent with the previous researchers by Bentley et al (2014) on palliative care patients and few other studies done by chocinov et al (2012) some of the non-ran demised studies suggested statistically significant improvement in existential and Psychosocial measurements. However a exploratory study with greater sample size may further elaborate the effectiveness.

### **Conclusions**

Evidence suggests that dignity therapy is beneficial but this pilot study is conducted to test the acceptability, feasibility and effectiveness of dignity therapy in a Indian setting. The study aimed to break the language barriers through the process of translation procedure based on EORTC guidelines. This pilot study is conducted among a smaller sample size since participants conditions can fluctuate rapidly as they are terminally ill cancer patients. Flow ever significant results have led to a larger study with larger sample size and other demographic factors. The main outcome of the study is the patients' sense of dignity which indicates the potential effectiveness of enhancing dignity therapy among terminally ill cancer patients in Indian settings

### **Limitation of the study**

Though dignity therapy is a brief Psychotherapeutic intervention that are delivered along the bedside of the palliative care patients many of them hesitated to participate in the study giving the Physical distress and fatigue as a reason. If at all the patients were willing to participate the caretakers were bothered that this therapy might bring some emotional disturbance in the patient after the researchers explained the process and benefits of dignity therapy some of the patients wished to participate.

Since dignity therapy is a novel therapy and many health care providers and nurses are not aware of the benefits and effectiveness of the therapy. Many hospice setting deiced permission to conduct the therapy. It is very important to educate health care providers and nurses about the need of therapeutic approach parallel to the treatment session should be mandated in the treatment plan of the terminally ill suffering from life threatening illness. One another aspect is that it is not only the patient suffering the illness is under stress, pain and trauma but the caretaker who is watching the loved one whose is suffering is also under emotional stress hence along with dignity therapy few other therapies and counseling sessions to be conducted on the family and the caretakers of the patient in order to handle & cope up with bereavement.

All the above limitations emphasis on one major need that is a need a psycho oncologist who is skilled and are capable of handling the emotional taxing and grief on working with dying patient in a hospice setting and every Tertiary care centers to educate and create awareness among rural patient for early diagnosis and treatment availability.

The study also emphasizes not only Psychologist should be trained in conducting dignity therapy. The nurses working in palliative care centers should be trained in conduction of Dignity therapy among patients. Nurses can be better counselors as they spend a Quality time with the patient in building hope and enhancing dignity naturally.

## References

- Akechi, T., Akazawa, T., Komori, Y., Morita, T., Otani, H., Shinjo, T., Okuyama, T., & Kobayashi, M.(2012). Dignity therapy: preliminary cross-cultural findings regarding implementation among Japanese advanced cancer patients. *Palliative Medicine*, 26, 768–769.
- Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N.(1996). Palliative Performance Scale (PPS): A new tool. *Journal of Palliative Care*, 12, 5–11.
- Beach, M. C., Forbes, L., Branyon, E., Aboumatar, H., Carrese, J., Sugarman, J., & Geller, G.(2015). Patient and family perspectives on respect and dignity in the intensive care unit. *Narrative Inquiry in Bioethics*, 5(1A), 15A–25.
- Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133(6), 920-954.
- Breitbart, W. (2001). Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer*, 10 (4), 272-80
- Bruera, E., Kuehn, N., Miller, M. J., Selmsler, P., & Macmillan K. (1991). The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7, 6-9.
- Cameron, D., & Johnston, B. (2015). Development of a questionnaire to measure the key attributes of the community palliative care specialist nurse role. *International Journal of Palliative Nursing*, 21(2), 87–95.
- Chang, V.T., Hwang, S.S., Feuerman, M. (2000). Validation of the Edmonton Symptom Assessment Scale. *Cancer*. 88,2164-71.
- Chochinov, H. M. (2002). Dignity Conserving Care: A New Model for Palliative Care. *Journal of the American Medical Association*, 287, 2253–2260.
- Chochinov, H. M. (2013). Dignity in care: time to take action. *Journal of Pain and Symptom Management*, 46(5), 756–9.
- Chochinov, H. M.(2008). Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *Journal of the American Medical Association*, 287(17), 2253–60.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet*, 360 (9350), 2026-30. doi: 10.1016/S0140-6736(02)12022-8.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos. M. (2005). Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, 23 (24), 5520-25.
- Chochinov, H. M., Hack, T., McClement, S., Harlos, M., & Kristjanson, L.(2002). Dignity in the Terminally Ill: A Developing Empirical Model. *Social Science and Medicine*, 54, 433–443.
- Chochinov, H. M., Hassard, T., McClement, S., Hack, T., Kristjanson, L. J., Harlos, M., Sinclair, S., & Murray, A. (2008). The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of Pain Symptom Management*, 36(6), 559–71.
- Chochinov, H. M., Kristjanson, L. J., Breitbart, W., McClement, S., Hack, T. F., Hassard, T., & Harlos M.(2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology*, 12, 753–762. doi: 10.1016/S1470-2045(11)70153-X.
- Classen, C., Butler, L. D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., Fobair, P., Carlson, R. W., Kraemer, H. C., & Spiegel, D. (2001). Supportive-Expressive Group

- Therapy and Distress in Patients With Metastatic Breast Cancer: A Randomized Clinical Intervention Trial. *Archives of General Psychiatry*, 58 (5), 494-501. doi: 10.1001/archpsyc.58.5.494.
- Daaleman, T. P., Usher, B. M., Williams, S. W., Rawlings, J., & Hanson, L. C. (2008). An exploratory study of spiritual care at the end of life. *Annals of Family Medicine*, 6(5), 406–11.
- Dewolf, L., Koller, M., Velikova, G., Johnson, C., Scott, N., & Bottomley, A. (2009). EORTC quality of life group translation procedure. Brussels: EORTC Quality of Life Group.
- Doorenbos, A. Z., Jansen, K., Oaks, R. P., & Wilson, S. A. (2009). International Classification for Nursing Practice (ICNP) Catalogue: Palliative Care for Dignified Dying. Geneva: International Council of Nurses.
- Greenstein, M. (2000). The house that's on fire: meaning-centered psychotherapy pilot group for cancer patients. *American journal of psychotherapy*, 54 (4), 501-11.
- Greenstein, M., & Breitbart, W. (2000) Cancer and the experience of meaning: a group psychotherapy program for people with cancer. *American journal of psychotherapy*, 54 (4), 486-500.
- Griffin-Heslin, V. L. (2005). An analysis of the concept dignity. *Accident and Emergency Nursing*, 13(4), 251–7.
- Hack, T. F., Chochinov, H. M., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos M. (2004). Defining dignity in terminally ill cancer patients: A factor-analytic approach. *Psycho-oncology*, 13 (10), 700-8. doi:10.1002/pon.786.
- Hagedoorn, M. I., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134(1):1-30. doi: 10.1037/0033-2909.134.1.1.
- Ho, F., Lau, F., Downing, M.G., & Lesperance, M. (2008). A reliability and validity study of the Palliative Performance Scale. *BMC Palliative Care*, 7:10. doi:10.1186/1472-684X-7-10.
- Houmann, L. J., Chochinov, H. M., Kristjanson, L. J., & Groenvold, M. A. (2014). Prospective evaluation of dignity therapy in advanced cancer patients admitted to palliative care. *Palliative Medicine*, 28, 448–458.
- Jacelon, C. S., & Choi, J. (2014). Evaluating the psychometric properties of the Jacelon attributed dignity scale. *Journal of Advanced Nursing*, 70(9), 2149–2161.
- Johnston, B., Flemming, K., Narayanasamy, M. J., Coole, C., & Hardy, B. (2017). Patient reported outcome measures for measuring dignity in palliative and end of life care: a scoping review. *BMC Health Service Research*, 17(1), 574. doi: 10.1186/s12913-017-2450-6.
- Johnston, B., Larkin, P., Connolly, M., Barry, C., Narayanasamy, M., Ostlund, U., & McIlpatrick, S. (2015). Dignity-conserving care in palliative care settings: an integrative review. *Journal of Clinical Nursing*, 24(13-14), 1743–72.
- Keall, R. M., Clayton, J. M., & Butow, P. N. (2015). Therapeutic life review in palliative care: a systematic review of quantitative evaluations. *Journal of Pain and Symptom Management*, 49(4):747–761.
- Kubler-Ross, E. (1969). *On Death and Dying* (1st ed.). New York: Macmillan.
- Kuckartz U. (2014). *Qualitative text analysis: a guide to methods, practice and using software*. London: Sage.
- Kuliš, D., Bottomley, A., Velikova, G., Greimel, E., & Koller, M. (2017). on behalf of the EORTC Quality of Life Group. EORTC Quality of Life Group Translation Procedure. 4th ed. EORTC Quality of Life Group Publication, Brussels.

- Lee, V., Cohen, S. R., Edgar, L., Laizner, A. M., & Gagnon, A. J. (2006). Meaning-making and psychological adjustment to cancer: development of an intervention and pilot results. *Oncology Nursing Forum*, 33 (2), 291-302.
- Lee, V., Robin, C. S., Edgar, L., Laizner, A. M., & Gagnon, A. J. (2006). Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social and Science Medicine*, 62 (12), 3133-45.
- Lewis, M. I., & Butler, R. N.(1974). Life-review therapy - Putting memories to work in individual and group psychotherapy. *Geriatrics*, 29 (11), 165-73.
- Lindqvist, O., Threlkeld, G., Street, A. F., & Tishelman, C. (2015). Reflections on using biographical approaches in end-of-life care: dignity therapy as example. *Qualitative Health Research*, 25, 40–50.
- Linn, B. S., Linn, M. W. (1981). Late stage cancer patients: age differences in their psychophysical status and response to counselling. *The Journal of Gerontology*, 36 (6), 689-92
- Linn, M. W., Linn, B. S., & Harris, R. (1982). Effects of counseling for late stage cancer patients. *Cancer*, 49 (5), 1048-55.
- McClement, S., Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L., & Harlos, M. (2007). Dignity therapy: family member perspectives. *Journal of Palliative Medicine*, 10 (5): 1076-82.
- Miller, D. K., Chibnall, J. T., Videen, S. D., & Duckro, P. N.(2005). Supportive-Affective Group Experience for Persons with Life-Threatening Illness: Reducing Spiritual, Psychological, and Death-Related Distress in Dying Patients. *Journal of Palliative Medicine*, 8 (2), 333-43.
- Ministry of Health and Welfare. (2014). Retrieved from: [http://www.mohw.gov.tw/EN/Ministry/Statistic.aspx?f\\_list\\_no=474&fod\\_list\\_no=3443](http://www.mohw.gov.tw/EN/Ministry/Statistic.aspx?f_list_no=474&fod_list_no=3443).
- Miyashita, M., Sanjo, M., Morita, T., Hirai, K., & Uchitomi Y.(2007). Good death in cancer care: a nationwide quantitative study. *Annals of Oncology*, 18, 1090–1097.
- Oechsle, K., Wais, M.C., Vehling, S., Bokemeyer, C., & Mehnert, A. (2014). Relationship between symptom burden, distress, and sense of dignity in terminally ill cancer patients. *Journal of Pain Symptom and Management*, 48(3), 313-21.
- Oosterveld-Vlug, M. G., Pasman, H. R. W., van Gennip, I. E., de Vet, H. C. W., Onwuteaka-Phillipsen, B. D.(2014). Assessing the validity and intra-observer agreement of the MIDAM-LTC; an instrument measuring factors that influence personal dignity in long-term care facilities. *Health Quality Life Outcomes*, 12, 17.
- Parker, D., & Hodgkinson, B. (2011). A comparison of palliative care outcome measures used to assess the quality of palliative care provided in long-term care facilities: a systematic review. *Palliative Medicine*, 25(1), 5–20.
- Pickrel, J. (1989). "Tell me your story": Using the life review in counseling the terminally ill. *Death Studies*, 13, 127-35.
- Pringle, J., Johnston, B., Buchanan, D. (2015). Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: a systematic review. *Palliative Medicine* 29(8), 675–94.
- Rajagopal, M. (2010). Disease, dignity and palliative care. *Indian Journal of Palliative Care*, 16(2), 59–60.
- Seamark, D., Ajithakumari, K., Burn, G., Saraswathi, D.P., Koshy, R., & Seamark, C. (2000). Palliative care in India. *Journal of the Royal Society of Medicine*, 93, 292-5
- Spiegel, D., Bloom, J. R., & Yalom, I. (1981). Group support for patients with metastatic cancer. A randomized outcome study. *Archives of General Psychiatry*, 38 (5), 527-33.

- Sridhar, P., Renuka, P. K., & Bonanthaya, R. (2012). End of Life and Life After Death - Issues to be Addressed. *Indian Journal of Palliative Care*, 18(3), 226–9.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., & Tulsky, J. A. (2001). Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of Pain Symptom and Management*, 22, 727–737.
- Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal A. (2012). Global cancer statistics, CA: A Cancer *Journal for Clinicians*, 65, 87-108.
- Watanabe SM, Nikolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multi-centre comparison of two numerical versions of the Edmonton Symptom Assessment System in palliative care patients *J Pain Symptom Manage* 2011; 41:456-468.
- Wills, G. B. (2005). *Cognitive Interviewing: A tool for improving questionnaire design*. London: SAGE.
- Yesilbalkan, O., Karadakovan, A., & Turgut, T & Kazgan, B. (2008). Validity and reliability of the Edmonton Symptom Assessment Scale in Turkish cancer patients. *Turkish Journal of Cancer*. 38. 62-67.
- Yun, Y. H., Kim, S. H., Lee, K. M., Park, S. M., Lee, C. G., Choi, Y. S., LEE, W.S., Kim, S.Y., & HEO, S. D. (2006). Patient-reported assessment of quality care at end of life: development and validation of quality care questionnaire- end of life (QCQ-EOL) *European Journal of Cancer*. 42, 2310–2317. doi: 10.1016/j.ejca.2006.04.010