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DIGNITY THERAPY IN PALLIATIVE CARE: A BIBLIOGRAPHIC REVIEW

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“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

- Dame Cicely Saunders

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INDEX

ABSTRACT 5

RESUM 6

1. INTRODUCTION 7

2. THEORETICAL BACKGROUND 7

  2.1. Palliative care and palliative patient description 7

    2.1.1. History and evolution of the development of palliative care 7

    2.1.2. Principles in Palliative Care 12

    2.1.3. Basic instruments in Palliative Care 13

    2.1.4. Palliative care in the actuality 13

    2.1.5. Spirituality in palliative care 14

    2.1.6. Ethical Frame in Palliative Care 15

  2.2. The role of nursing in palliative care 16

    2.2.1. Patient necessities and diagnostics 18

    2.2.2. Nurses' attitudes forward-facing death 19

    2.2.3. Nursing principal difficulties facing end-of-life issues 20

  2.3. Dignity Therapy 21

    2.3.1. Description and goals 21

    2.3.2. Dignity Therapy Protocol 22

    2.3.3. Effectivity evaluation 23

  2.4. Dignity at the End-of-life 23

    2.4.1. Concept Definition 23

    2.4.2. Related dimensions to the end-of-life dignity 24

    2.4.3. Dignity models 26

      2.4.3.1. The Dignity Model 27

        2.4.3.1.1. Illness-Related Concerns of Palliative Patients 28

        2.4.3.1.2. Dignity Conserving Repertoire in Palliative Patients 29

2.4.3.1.3. Social Dignity Inventory 30
2.4.4. Dignity measurement 31
3. OBJECTIVES 32
4. METHODS AND MATERIAL 33
4.1. Selection criteria 33
4.1.1. Inclusive Criteria 33
4.1.2. Exclusive Criteria 33
4.2. Search Strategy 34
5. RESULTS 36
6. DISCUSSION 52
6.1. Limitations 54
7. CONCLUSION 55
7.1. Overall Effectiveness and Applicability 56
8. BIBLIOGRAPHY 57
9. ANNEXES 65
9.1. Dignity Therapy Protocol 65

ABSTRACT

Background: Palliative care and dignity at patients' end-of-life are nursing competences. Many therapies and guides have been developed to assure the preservation of dignity in patients with life-threatening illnesses and in the last stages of these ones. In 2002, Harvey Max Chochinov developed the Dignity Therapy with the aim of promoting end-of-life dignity.

Aim: Analyse the effectiveness of Dignity Therapy on the improvement of patients with advanced life-threatening diseases and establish if its use in the clinical practice should be recommended. The specific objectives are: analyse the effectiveness of Dignity Therapy to improve psychological distress, anxiety, depression and psychological fatigue; analyse its effectiveness in improving physical distress and symptomatology; know the effectiveness of Dignity Therapy to increase the palliative patient's sense of dignity; analyse the benefits of Dignity therapy in the treatment of psychosocial and existential distress; and assess the feasibility of Dignity Therapy focusing on both patients and family relatives acceptability and satisfaction.

Methodology: Conduction of a bibliographic review. PUBMED, COCHRANE, CINAHL and CUIDEN databases were queried during the first half month of March 2019. The selection of articles was limited to the use of Dignity Therapy in adult patients admitted to palliative care units with the sufficient physical and mental capacity to undergo the intervention. Data extracted was synthesised and analysed following the study objectives.

Results: Fourteen papers encountered the selection criteria and were assessed for eligibility. The results obtained demonstrate that the Dignity Therapy is an effective instrument for the treatment and improvement of patients with life-limiting illnesses especially in the last stages of it. Therefore, its use in palliative care is recommended. Results on psychological distress lead to controversial conclusions. Four studies suggested benefits on physical distress. The overall light turns out to be positive in terms of sense of dignity, psychosocial distress and existential distress. Finally, in terms of feasibility, both patient and family's opinion in relation to acceptability and satisfaction have been found to be positive.

Conclusion: The results found throughout this review conclude firmly and affirm Dignity Therapy's effectiveness in terms of patients' dignity and consequently overall status. In palliative care settings, where de defence and preservation of patients' dignity is an undeniable obligation, patients could clearly benefit from Dignity Therapy. Dignity Therapy has demonstrate to be a useful instrument for patients to solve, close or clear out their personal believes and questionable issues before leaving. This paper emerges a positive light for future research and the application of the Dignity Therapy in palliative care settings.

Key Words: "Dignity Therapy", "Dignity", "End of Life", "Palliative Care", "Effectiveness".

RESUM

Introducció: Les cures pal·liatives i la dignitat al final de la vida de les persones són competències de la professió d'infermeria. S'han elaborat diverses teràpies i guies per tal de garantir la preservació de la dignitat de les persones afectades d'una malaltia incurable, en els darrers estadis de la mateixa. L'any 2002, Harvey Max Chochinov va desenvolupar la Teràpia de la Dignitat amb l'objectiu de promoure la dignitat al final de la vida.

Objectiu: Analitzar l'efectivitat de la Teràpia de la Dignitat en la millora dels pacients admesos a cures pal·liatives i establir si el seu ús a la pràctica clínica hauria d'estar recomanat. Els objectius específics han sigut: analitzar l'efectivitat de la Teràpia de la Dignitat en la millora de l'estrès psicològic, ansietat, depressió i fatiga emocional; analitzar l'efectivitat de la teràpia en la millora del malestar físic i simptomatologia física; conèixer l'efectivitat de la teràpia per incrementar el sentit de la dignitat dels pacients pal·liatius; analitzar els seus beneficis en el tractament del malestar existencial i psicosocial; i estudiar la viabilitat de la teràpia enfocant l'estudi a la acceptabilitat i la satisfacció expressada per part dels pacients i familiars.

Metodologia: Realització d'una revisió bibliogràfica. Les bases de dades PUBMED, COCHRANE, CINAHL i CUIDEN s'han consultat durant la primera meitat del mes de març de 2019. La selecció dels articles s'ha limitat a l'ús de la teràpia de la dignitat en pacients adults admesos a unitats de cures pal·liatives amb la suficient capacitat tant física com mental per completar la intervenció. Les dades extretes s'han sintetitzat i analitzat seguint els objectius de l'estudi.

Resultats: Catorze estudis complien els criteris de selecció i han estat inclosos a la revisió. Els resultats obtinguts demostren que la teràpia de la dignitat és un instrument efectiu en el tractament i millora dels pacients amb malaltia incurable i concretament, en els estadis avançats d'aquesta. Per tant, el seu ús està recomanat. Els resultats obtinguts en relació al paràmetre de malestar psicològic, donen lloc a conclusions controvertides. Pel que fa al malestar físic, quatre estudis defensen la teràpia com a beneficiosa per la seva millora. En termes de sentit de la dignitat, estrès psicosocial i existencial, els resultats generals han estat positius. Per últim, la opinió global de pacients i familiars en relació a l'acceptabilitat i satisfacció de la teràpia ha estat positiva.

Conclusions: Els resultats trobats al llarg de la present revisió conclouen firmament i afirmen l'eficàcia de la Teràpia de la Dignitat en termes de la dignitat en el pacient i conseqüentment de l'estat general. En l'àmbit de les cures pal·liatives, on la defensa i preservació de la dignitat dels pacients és una obligació innegable, els pacients podrien beneficiar-se clarament de la Teràpia de la Dignitat. Dignity Therapy ha demostrat ser un instrument útil per tal que els pacients puguin resoldre, tancar o aclarir les seves creences personals i aspectes qüestionables abans de marxar. Aquest estudi estableix una llum positiva per a futures investigacions i per l'aplicació de la Teràpia de la Dignitat en entorns de cures pal·liatives.

Paraules Clau: "Teràpia de la Dignitat", "Dignitat", "Final de la vida", "Cures Pal·liatives", "Efectivitat".

1. INTRODUCTION

Throughout the history of nursing, palliative care and dignity at the end-of-life have been gaining importance. Nowadays, the main objective of nursing palliative care is to assure a dignified death. Many therapies and models have been developed in order to guide health care providers in life-threatening circumstances.

After years of research and concluding that emotional suffering increases and sense of dignity is easily shaken when the end of progressing illnesses approaches, Harvey Max Chochinov a Canadian academic and psychiatrist developed in 2002 the Dignity Therapy with the aim of promoting and assuring dignity at the end-of-life. (1)

This psychotherapy is acknowledged in a wide range of countries. However, here in Spain and more specifically Catalonia, only a few health care providers know about its existence. Therefore, it is not systematically used and the health care system cannot benefit from its purpose.

The principal aim of this bibliographic review is to analyse the effectivity and feasibility of this therapy as to make this therapy known in this health care context and justify its usage.

2. THEORETICAL BACKGROUND

2.1. Palliative care and palliative patient description

2.1.1. History and evolution of the development of palliative care

Death is an expected part of life known by all and fought by many. (2) Since prehistoric times, there has been a consistently preoccupation with the after death circumstances. However, it has not been until recent time that dedication to the care of the dying has gained attention and human awareness. (3)

Over the past thousand years, there has been a complex unorganized progression from the origins of hospice until what is known nowadays as palliative care. (3)

The word “hospice” has its etymological origins in the Latin word *hospes* which meaning refers to both traveling guest and traveller’s host. The care for the dying was first established in houses set up to manage care for crusaders and travellers who became ill. (3)

It is believed that crusaders in the 11th century build up homes in order to take care of the incurably ill. In the same way, the Knights Hospitaller in the 14th century set up a hospice-type facility to provide refuge and care for both travellers and the terminally ill. (3)

Throughout the middle age, hospices increased tied to religious organizations. This tie continued during the 18th and 19th centuries. However, the further development of hospice and palliative care had less emphasis on travellers and centred its care on patients with 1 or 2 diagnoses in common. (3)

In 1879, the Irish Religious Sisters of Charity founded the Our Lady's Hospice in Dublin for those dying from tuberculosis or cancer. Similar hospices were open in other countries thanks to the Sisters of Charity. (3)

It was not until the 20th century when Cicely Saunders appeared. (3) In the later part of this century, palliative care emerged as a social movement and medical speciality with Dr Cicely Saunders as a referent. (4) Cicely Saunders was a nurse and social worker from Britain who centred her professional life on the care of those who were terminally ill and could not benefit from lifesaving treatments. (2,3)

She started as a volunteer in the St Luke's Home for the Dying Poor in England and it was in 1957 when she received a medical degree that gave her de opportunity to develop her ideas in palliative care. Playing a predominant role, she introduced in palliative care her ideas developing the principles followed worldwide in palliative care. (3) These were:

- The "total pain" concept that included physical, spiritual and psychological discomfort.
- The proper use of opioids.
- Attention to the family members and friends.

She also founded the first modern hospice in 1967, known as St Christopher's in London. This hospice attended all kind of patients with no distinction on the diagnosis, religious affiliation and social class. (3,4)

During decades, she continued to introduce new tenets on palliative care. She defended the holistic care taking care of the physical, social, psychological and spiritual domains with an aggressive symptom control during the last days of life. (3,4)

“Palliative” comes from the Latin word *pallium* meaning “to cloak”. This stands for symptoms that are eased while the main illness cannot be cured. (2) Therefore, palliative care appeared to solve the inadequacies in the management of these type of patients. (5)

The fist definition given to Palliative medicine was in 1987 in the U.K. It stated the following: “The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality-of-life ”. (2)

Palliative Care is the name given to the management of patients in these situations. It is a new medical field proven crucial for patients with serious chronic diseases.(6) The World Health Organization defines palliative care as an approach that improves the quality-of-life of patients and families facing a life-threatening illness and the problems it has associated. (7) It is an interdisciplinary care that includes many health professional specialities. (8)

The principal aim of palliative care is the improvement of the quality-of-life of patients of any age who are living with a serious illness. (8) Palliative care focuses in what we know as patient-centred outcomes including quality-of-life, symptom burden, emotional and spiritual well-being, caregiver distress and bereavement. (6,8)

Furthermore, in palliative care health care decisions it is of great importance the prognostication of life expectancy. (9) The correct identification of those in utmost need is vital when the aim is to provide appropriate, value driven and patient-centred care to the seriously ill population. (10) Clinical experts rely on their experience and intuition when estimating survival. However, numerous systematic models can be used. For example, the Palliative Prognostic Score (PaP score) is one of the most validated models. (11)

Therefore, when talking about prognostication in palliative care it is essential the awareness of the following concepts:

- Serious illness: health conditions that carries a high risk of mortality and either negatively effects a person's daily functions, quality-of-life and excessively strains their caregivers. (10)
- Terminally ill: Life expectancy of less than six months. (9)

- End-of-life: final period when it is clinically obvious that death is imminent (in hours, days, weeks or months) or a terminal state cannot be prevented.(9)
- Actively dying: last hours or days of life. (9)
- Transition of care: changes on the place, level and goals of care. (9)

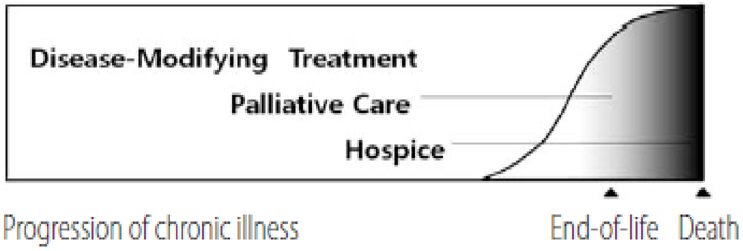


Figure 1. Conceptual frame of disease-modifying treatment, palliative care, and hospice.

Fig. 1: Conceptual frame of disease-modifying treatment, palliative care and hospice.

Source: (12)

It is also important to understand when palliative care is introduced. As the evidence determines, palliative care is initiated concordantly with other curative treatments. However, its main appearance occurs when the disease-directed therapies are starting to be limited and clinicians and patient forgo curative treatments. (Figure 1) Transition of care is the name given to the changes regarding the care given to patients with chronic serious illnesses. The principal differences in between curative and palliative care include changes in the place of care, level of care and goals of care. In the first stage, the main goal of the curative care is the eradication of the illness by administrating and providing active treatments. On the other side, palliative care focuses on the patients quality-of-life and comfort, by controlling and treating physical and psychological symptoms.(6) Moreover, curative care is mainly present in hospitals meanwhile palliative care can be present in both hospital and home care. (9)

Palliative care has strong historical bonds with the care of oncologic patients. (12) However, in the actuality, the provision of palliative care is based on need and not on diagnoses. (13) The need of palliative care depends on the psychological, spiritual and physical necessities each patient has rather than on the diagnosis. (6) It has been demonstrated that non-malignant illnesses have similar symptom burdens and it is for this reason that palliative care such be based on need. (12) However, it is important to mention that not all patients with a certain diagnosis will be candidates of palliative care. (6)

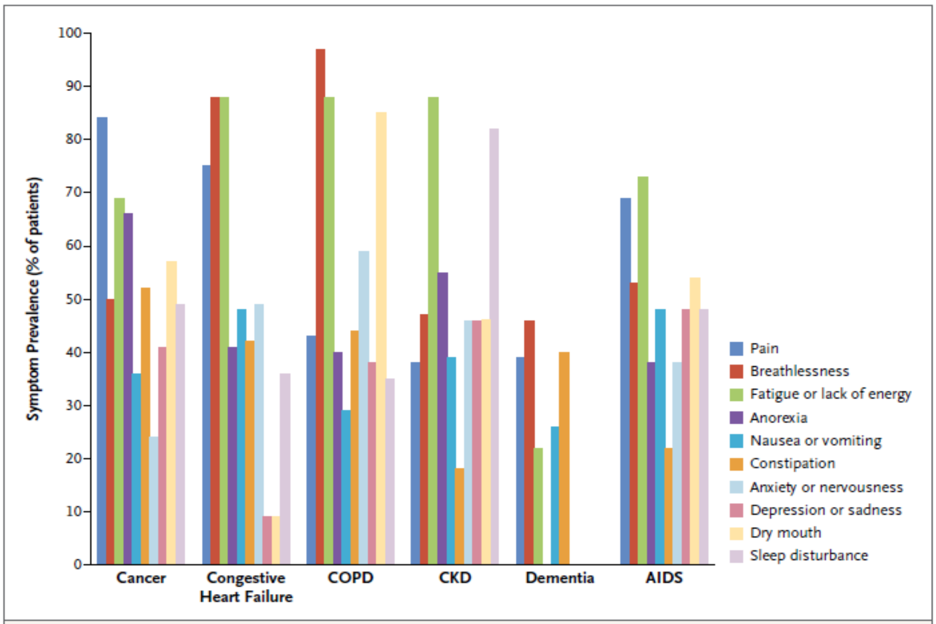


Figure 1. Symptom Prevalence in Advanced Illness.

Data are from representative studies of symptom prevalence among patients with cancer,[8-12] congestive heart failure,[13,14] chronic obstructive pulmonary disease (COPD),[15] chronic kidney disease (CKD),[13,14] or dementia[16,17] and among patients who received highly active antiretroviral therapy for the acquired immunodeficiency syndrome (AIDS).[18] Self-reported data regarding some symptoms were unavailable for patients with dementia.

Fig. 2: Symptom Prevalence in Advance Illness

Source: (8)

Based on the evidence, the main illnesses, in between others, that can be in need of palliative care because of the symptom burdens at de end-of-life are cancer, chronic lung disease, heart failure, chronic kidney disease, liver failure, dementia and AIDS. (6,8,13) However, all does patients with similar symptomatology at the end-of-life stage can be in need of palliative care despite of its diagnosis. Each condition presents its own special difficulties in end-of-life care. (13) For these reasons, it is important to know which symptoms determine together with the prognosis, the need of palliative care. The common symptoms described throughout the bibliography are the following: pain, anorexia, anxiety, constipation, depression, delirium, dyspnoea, nausea and fatigue. (6,8,12,13) (Figure 2)

In addition, palliative care it is the care given to those patients with advanced, progressive, incurable and serious illnesses to live as well as possible until they die regardless of their diagnosis and based on each patient needs and conditions.(6)

2.1.2. Principles in Palliative Care

The principal aim in palliative care is to improve the quality-of-life and guarantee comfort to those who are experiencing a life-threatening illness. In order to achieve these goals, the professionals must follow some tenets. These include the following:

- Give the patient a holistic care through an interdisciplinary team of professionals. Give support in all the domains: physical, emotional, social and spiritual; with an individualized and continued care. (14,15)
- Demonstrate an active and positive attitude. (14,15)
- Give great importance to communication and emotional support in the different stages of the adaptation to the terminal illness. (15)
- Control the symptoms especially pain, if possible, with healing, supportive and preventive treatments.
- Recognize the patient and its family as a whole. The family is a fundamental basis of support for the patient and it requires specific measures of support and education. (14,15)
- Respect the values, principles, ideals, preferences and elections of the patient. (15)
- Promote the patients autonomy and dignity. (14)
- Create an atmosphere of respect, comfort, support and communication. (14)
- Consider the global necessities of the patient and mitigate its isolation by offering security of non-abandonment and keeping it constantly informed. (15)

- Recognize the caregiver’s preoccupations and give support on its necessities. (15)
- Help implementing domiciliary care. (15)
- Promote actions to help the patient die in peace. (15)
- Give support to the family after the death of the patient. (15)
- Offer legal and ethical advice and support. (15)
- Develop institutional infrastructures that support the best practices and models of palliative care. (15)

2.1.3. Basic instruments in Palliative Care

Taking into consideration all the points mentioned above, the quality-of-life and comfort throughout the patient’s last stages of life are assured by applying the basis and elementary instruments of palliative care. These include:

- Correct Symptom control by recognising, evaluating and treating properly the different symptoms that appear and affect directly the comfort of the patients. While some such as pain or dyspnoea can be controlled, others no and require the adaptation of the patient to them. (14)
- Offer emotional support and correct communication to the patient and its family stablishing an honest relationship. (14)
- Change the organization and assure a flexible adaptation to the changing necessities the patient has. (14)
- Palliative care cannot be conceived without an interdisciplinary team taking care of the patient. (14)

2.1.4. Palliative care in the actuality

At the present time, advances in technology and science continue to prolong life expectancy. (16) The introduction of new medical treatments for instance antibiotics and immunizations, and the improvement of medical practices where decisive when dropping the morbidity and mortality and increasing life expectancy.(6)

Consequently, people are not only aging but also suffering from serious illnesses. (6) The natural progression of these serious and chronic illnesses comprise exacerbations and during the years leading to death, multiple hospitalizations. (17) Chronic conditions are not life-threatening but affect in a very significant way the person’s welfare and health care needs. (6)

Nowadays, the majority of the elderly die from chronic illnesses with a progressive period of deterioration and disability. Therefore, it is important to provide a patient-centred end-of-life care to these type of patients. (6)

2.1.5. Spirituality in palliative care

As Cecily Saunders (1960's) detailed, in palliative care, health care providers must offer a holistic care in order to confront the what she defined as 'total pain' which, includes a wide range of somatic, emotional, social and spiritual elements. (18)

All human beings have a biological dimension and a spiritual dimension. The Spanish Palliative Care Society (Sociedad Española de Cuidados Paliativos (SECPAL)) defines the spirituality concept as the profound and intimate aspiration of the human being, the desire of a life and reality vision which integrates, connects, transcends and gives sense to the existence. In other words, spirituality is a constant search of meaning, connexion and transcendence without forgetting the ethical values al human beings poses. (18)

Religion is nothing more than an expression of spirituality within concrete canons. However, spirituality is not a prerogative exclusive of those who are believers. It can be expressed as a religious practice or totally detached from it. (18)

Spiritual concerns are common in people with life-threatening situations and the majority of patient want to discuss spirituality with their health care providers. (6,8) For these reasons, spirituality has been defined as core domain for quality-of-life in terminally ill patients. Also, a lack of spiritual well-being can denote holistic suffering. (19) Health care professionals should provide spiritual care as many studies highlight the importance in addressing spiritual needs. (8)

The main spiritual necessities defined by the SECPAL (2008)(18):

- Be recognized as a person.
- Reread their life.
- Find meaning in existence and becoming: search of meaning.
- Get rid of any feeling of guilt.
- Reconciliation.
- Establish their life beyond their self.

  - Continuity.
  - Authentic hope without illusions.
  - Express religious feelings and experiences.
  - Love and be loved.

Furthermore, many instruments can be used as to make an adequate spiritual evaluation of the patient including: scale of spiritual well-being FACIT-Sp-12, Religious confrontment scale Brief-R Cope, Ortega spiritual suffering scale, Reed spiritual perspective scale, GES questionnaire and Meaning in life scale. (18)

2.1.6. Ethical Frame in Palliative Care

Ethics is considered the science of morality and its etymological origin comes from the Greek word *ethos*, which has two meanings. One refers to the way of being, character, to the inner reality from which human acts originate and the second indicates customs, habits or habitual actions. (20)

The ethical care and respect is very important in palliative care as to improve the quality-of-life and promote wellness of individuals, families, communities and humanity in general. (21) The International Council of Nurses Code of Ethics (2012) offer nurses guidelines to provide a health care, which recognises and respects the intrinsic value, dignity and integrity each patient has. (22,23)

Ethics in health care, also referred to as bioethics, has its origins in the 1979 Belmont report. This document highlights three fundamental principles (respect, beneficence and justice) and was developed with the purpose of minimizing ethical conflicts arising from biomedical science research. (20,21)

Later on, Beauchamp and Childress (1985) developed in their study “Principles of biomedical ethics” the concepts of autonomy, beneficence, non-maleficence and justice creating four guiding principles that must be applied to all health care actions. These principles that should be taken into account in the biomedical field do not obey any hierarchical order and have a strong foundation in health nowadays. (20,21)

- Autonomy: promotes the individual’s self-determination and their ability to decide whether to consent or refuse a clinically indicated medical treatment. Previously, mentally competent individuals must be adequately informed. (21,24)

- Beneficence: refers to positive actions implying knowledge and technical skills to minimize risks, maximize benefits, and regard for the patients' welfare and suffering relieve. (21,24)
- Non-Maleficence: based on the Hippocratic statement of "do not harm", considering risks and harms of interventions refers to help or at least not cause any damage to individuals. (21,24)
- Justice and Equity: refers to the equitable and fairly distribution of resources in health based on the right of each individual to receive the standard of care regardless of any type of discrimination. (21,24)

Palliative care has a fundamental ethical frame. Dignity resides in the centre of it. For these reasons, the Catalan Letter of Rights and Dues states that people have the right to live the dying process in concurrence with their dignity concept. (25)

The different statements established in this affirmation are:

- The person has the right to live the process that takes place until the end-of-life according to his conception of dignity.
- The person has the right to reject any treatment, even though this is of vital support, as long as it is a competent and well-informed decision.
- The person has the right to receive quality care that promotes the relief of suffering being either physical, psychological, social or spiritual. Care must be provided in the ideal environment (domicile, hospital, etc.), and taking into account the person's preferences.
- When situations of unbearable suffering occur, health professionals have to assist with the necessary treatments to facilitate a worthy death without suffering, always within the current legal framework.
- The accompaniment of the relatives, in a suitable social context allowing intimacy has to be ensured. (25)

2.2. The role of nursing in palliative care

The American Nurses Association (ANA) and the Hospice and Palliative Nurse Association (HPNA) describe palliative nursing as a holistic philosophy of care provided to patients in diverse settings, with a diagnosis of life-threatening illness.

(26) Nursing has taken an important role throughout the development of palliative care. (27)

Because of their closeness to the patient and its family, and their constant presence during these stages, nurses are a very important figure in palliative care. During the last stages in life, an adequate nursing practice is based on the respect of the patients' dignity and the assurance of a good death. A good death is defined in literature as unique and transcendent moment in each persons' life where all principles like dignity and ethics are taken into consideration always assuring the respect of the patient and family's wishes and the relieve of pain and distress offering an holistic care. (28)

Nurses must apply a biomedical model of service delivery with a holistic approach, which requires a therapeutic relationship. Such relation must be based on values such as compassion, respect, empathy and self-awareness. Pathophysiology and skills are also required to critically assess patients' needs across all domains of biomedical care. (29)

Furthermore, nurses have the commitment of honouring the patient's dignity throughout all stages in life. The intrinsic value of all patients must be recognized. In palliative care the patient's dignity is always present. (30)

Deontological nursing codes have been developed to ensure the good quality of care given to patients. The honouring of dignity is taken into consideration as a very important aspect in nursing care. For these reason, each nurse has its own deontological responsibilities when talking about honouring dignity. Some of them related to end-of-life issues include: (30)

1. Treat patients with respect.
2. Ensure the maintenance of their dignity and integrity.
3. In decision-making, take into account without judgment or impartially their spiritual beliefs, their values and customs, as well as their social and economic situation.
4. Nurses have to encourage compromised patients to clearly communicate their wills.
5. When a patient is terminally ill or about to die, nurses must: promote comfort, alleviate suffering, advocate for adequate relief of discomfort

and pain and help achieve goals of culturally and spiritual believes. This includes adopting a palliative approach for the duration of their life and throughout the continuum of care, support to the family during the last moments and after the death, as well as the care of the person after his death. (30)

2.2.1. Patient necessities and diagnostics

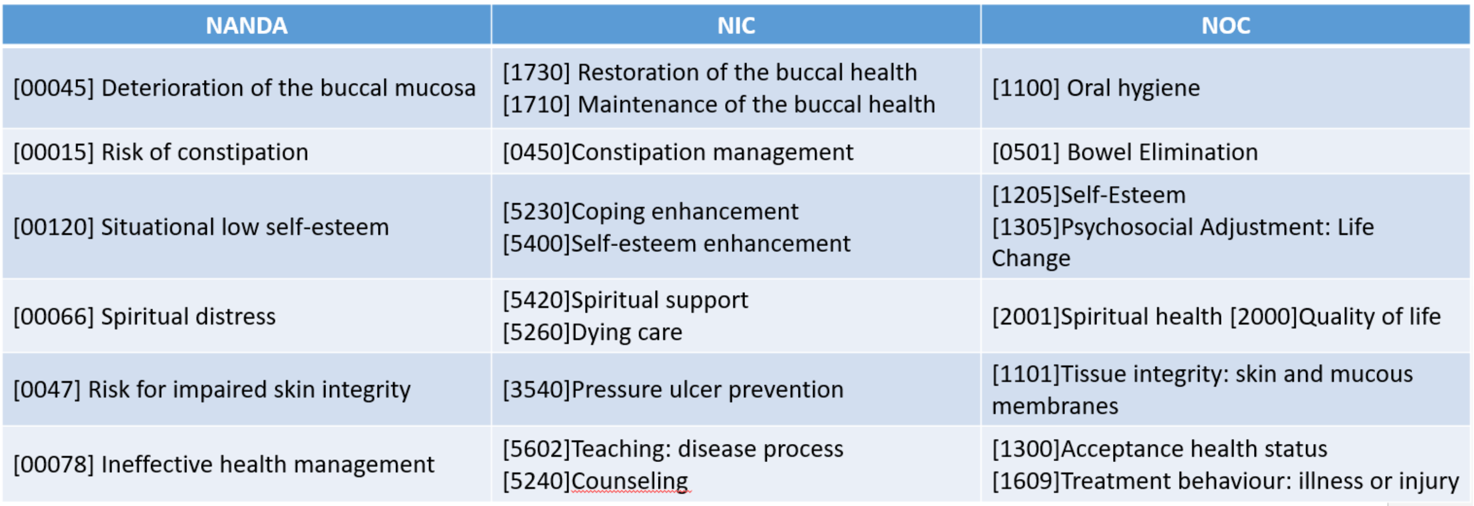
Nurses are the health professionals in charge of providing wellness and assuring an adequate communication in-between the different professionals that take part in the attention given to these type of patients. (31) Nursing roles in palliative care include a complex management of physical aspects and psychological symptoms providing a person-centred and family focused care. The role of a nurse providing end-of-life care is very complex and requires psychological preparation, flexibility and strength in order to take care of all the symptoms including: pain, anxiety, confusion, delirium, fatigue dyspnoea, insomnia, nauseas, constipation, diarrhoea, pruritus, depression, xerostomia, rales and terminal asthenia. (26,32)

The emotional impact the patient and family suffer is also of great relevance. Nurses must focus on the suffering and emotional impact the patient experiences. (31)

Moreover, there are specific nursing cares that must be taken into consideration, as they are basic to ensure the increase of quality-of-life and comfort. These include skin, buccal, nutrition, elimination, physical activity, rest and sleep and family cares. (31)

When following the nursing taxonomy, the main NANDA diagnosis, NIC activities and NOC outcomes are detailed in table 1 followed by the collaboration diagnosis and NIC activities, table 2. (33)

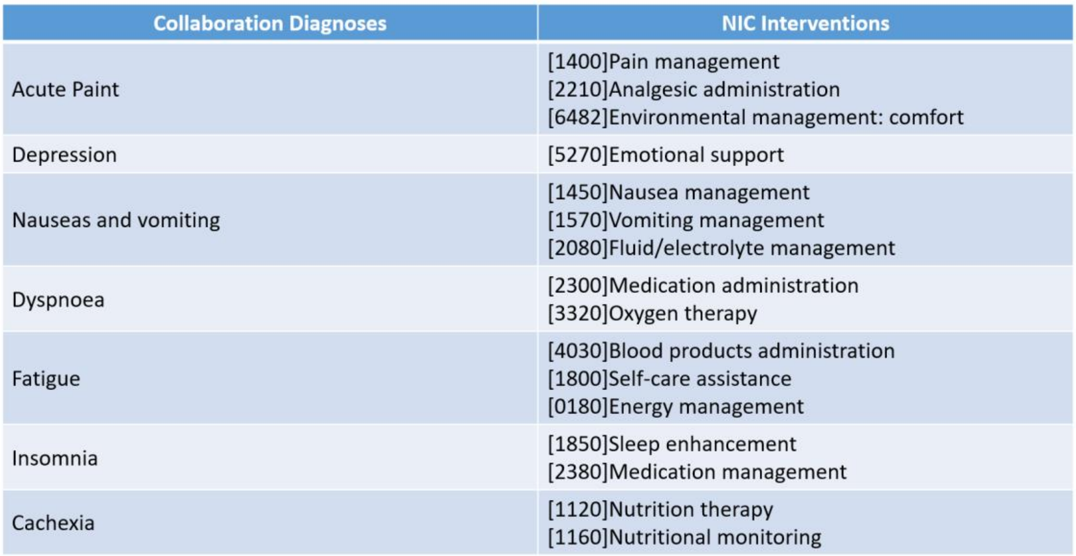
Table 1: Common nursing diagnosis, interventions and outcomes in palliative care



NANDA	NIC	NOC
[00045] Deterioration of the buccal mucosa	[1730] Restoration of the buccal health [1710] Maintenance of the buccal health	[1100] Oral hygiene
[00015] Risk of constipation	[0450]Constipation management	[0501] Bowel Elimination
[00120] Situational low self-esteem	[5230]Coping enhancement [5400]Self-esteem enhancement	[1205]Self-Esteem [1305]Psychosocial Adjustment: Life Change
[00066] Spiritual distress	[5420]Spiritual support [5260]Dying care	[2001]Spiritual health [2000]Quality of life
[0047] Risk for impaired skin integrity	[3540]Pressure ulcer prevention	[1101]Tissue integrity: skin and mucous membranes
[00078] Ineffective health management	[5602]Teaching: disease process [5240]Counseling	[1300]Acceptance health status [1609]Treatment behaviour: illness or injury

Source: (33)

Table 2: Common collaboration diagnosis and interventions in palliative care.



Collaboration Diagnoses	NIC Interventions
Acute Paint	[1400]Pain management [2210]Analgesic administration [6482]Environmental management: comfort
Depression	[5270]Emotional support
Nauseas and vomiting	[1450]Nausea management [1570]Vomiting management [2080]Fluid/electrolyte management
Dyspnoea	[2300]Medication administration [3320]Oxygen therapy
Fatigue	[4030]Blood products administration [1800]Self-care assistance [0180]Energy management
Insomnia	[1850]Sleep enhancement [2380]Medication management
Cachexia	[1120]Nutrition therapy [1160]Nutritional monitoring

Source: (33)

2.2.2. Nurses' attitudes forward-facing death

Nurses experience the process of death in their professional routine. This is a complex situation as care provided at the end-of-life entices ethical dilemmas linked to personal values and beliefs. When dealing with patients in this phase of their life make nurses feel extremely distressed and emotionally exhausted. They may also experience insecurity, frustration and helplessness.(34)

Not only patients and families have a psychosocial implication, nurses also experience emotional implication as in this stages of the illness they have to deal in a more direct or indirect form with their own death or loved ones. (35) This can have a positive or negative influence on the professionals' attitude. The development of positive attitudes are of great importance as to offer better quality of care. (36)

Attitudes towards caring for palliative patients are more negative when the fear of death is bigger and the avoidance behaviours are more present generating higher indices. However, greater professional preparation reduces anxiety and ensures a better attention. (36)

On the other hand, other factors that influence the attitudes of nurses forward-facing death are personal experiences. When experiencing situations of proximity with death, personal resources are skilled and professionals are more prepared to confront these negative circumstances. (36)

In addition, professionals experience death differently and nurses' attitudes are different according to the meanings they attribute to death and this type of situations. (34)

Death and the last days of life must be conceived as a process and not an end where nurses and all professionals offer attitudes, which promote the understanding, listening and respecting of the patient. (34)

It is also important that nurses change their attitude facing palliative care, as they must accept that patients will not recover from their illness. The Nursing Process must refocus facing the specific aspects of palliative care offering a warm, supportive and favourable attitude. (37)

As all points mentioned above are of great importance for nursing in palliative care, the Dignity Therapy can offer a holistic management of all issues present in end-of-life care. For this reason, the inclusion of dignity therapy in nursing care should be considered.

2.2.3. Nursing principal difficulties facing end-of-life issues

To improve end-of-life care it is critical to identify the obstacles that have the most impact on patients and families in order to eliminate them as far as possible. (38)

Recent research findings indicate that the main difficulties and obstacles experienced by health providers caring for patients at the end-of-life stages count the following: lack of time for professional car and staff shortages; challenges in communication in between health professionals, patients and relatives; intensive treatment decisions made in spite of patients' wishes and needs; and lack of knowledge and skills. (38)

Two other items perceived by nurses as the most intense obstacles include the succeeding statements: the nurses' opinion on immediate patient care is not valued and the family has no access to psychological help after being informed about the situation. (38)

Dealing with angry patient's family members, patient's relatives having inadequate understanding of the circumstances and no time for conversations with patients focusing on their concerns and wishes of end-of-life issues are also identified as obstacles in nursing care. (38)

Moreover, the lack of acceptation of the end-of-life process by the family is identified as an obstacle for the nursing care as happens with the necessity of support and the psychical charge. (28)

Lastly, other difficulties and obstacles include the fact that some physicians avoid conversations with the patients and their relatives on diagnosis and prospects and the institutional difficulties related to the deficit of human, structural and physical resources and the high demand of patients. (38,39)

2.3. Dignity Therapy

2.3.1. Description and goals

Based on the Model of Dignity in the Terminally Ill, which, will be explained later in the next headland, Dignity Therapy is a clinical intervention and psychotherapy that involves the creation of a carefully constructed and edited document designed mainly to address generativity and aftermath concerns in a dignity-conserving atmosphere. (1)

The Dignity Model was created to inform clinical decisions and define dignity-conserving pathways in palliative care targeting dignity as an achievable outcome. Guiding therapeutic approaches, the Dignity Model led to the creation of the Dignity Therapy by counting some of its elements in each facet of the therapy including the *form, tone* and *content*. (1,40)

- Form: Generativity/Legacy is the most important theme in the Dignity Model that influences the overall form of the Dignity Therapy. The principal aim of this therapy is creating a document, which transcends the patient's death prolonging its influence across time. Reflecting who they are and what feelings they have had along their meaningful life, this generativity document is created. (1)
- Tone: as explained in the Dignity Model, the care tone has a profound influence in the patient's sense of dignity. Practitioners of the Dignity Therapy must be mindful of their tone of care and the influence it has on its patients. Based on the Carl Rogers' Client-Centred Therapy (CCT, 1942), the three main critical attitudes therapist must assure while Dignity Therapy is taking place are: genuineness (show themselves as real), unconditional positive regard (demonstrate acceptance and non-judgemental care) and empathic understanding (connect with the patient). (1)
- Content: the Dignity Therapy is facilitated by a series of questions. Influenced by the Dignity Model, the question framework is designed to elicit information highlighting the importance of two specific themes and each of its subthemes: dignity-conserving perspectives and aftermath concerns. The first questions are more biographical and evocative of the life story while the rest are more emotionally challenging. (1)

It is important to state that as the field of palliative care defines as a unit of care the patient and its family, in the Dignity Therapy, the family plays an important part.

2.3.2. Dignity Therapy Protocol

After the patient selection, Dignity Therapy usually requires four or more patient contacts and a multidisciplinary team behind including therapists and transcriptionists. In the first meeting, which usually lasts twenty minutes, the therapist explains the intervention, gets some basic information and plans the therapy itself. The second, is the recorded Dignity Therapy interview, and lasts about one hour depending on the energy level and degree of engagement the patient has. After the recorded interview has been transcribed, the third meeting takes place. It usually lasts twenty minutes and the patient offers its review and states changes that would like to be made. Lastly, the fourth contact consists on the presentation of the final generativity document. (1) (See annex 9.1)

2.3.3. Effectivity evaluation

The Dignity Therapy's efficacy can be evaluated by measuring a wide range of physical, psychological and existential issues and concerns. In previous clinical trials, the efficacy of the therapy has been measured by asking patients to fill in different questionnaires before and after the intervention. (1)

The main issues and feeling studied include depression, anxiety, suffering, hopelessness, desire for death, suicide, sense of well-being, sense of burden to others, quality-of-life and will to live. In relation to the physical matters, physical symptom distress is an important parameter to be studied.(1)

Validated measuring instruments must be used so as to ensure all results are real and objective. There is a broad range of standard measures, including the Spiritual Wellbeing Scale (FACIT-Sp); Patient Dignity Inventory (PDI); Hospital Anxiety and Depression Concerns; and The Edmonton Symptom Assessment Scale. (1)

2.4. Dignity at the End-of-life

Dignity at the end-of-life involves a wide range of concepts that have a direct relation with Dignity Therapy. Dignity is a complex and essential part of the person and many aspects relate to it. It also gives sense to Dignity Therapy as a whole defending and justifying its objectives, methodology and evaluation. For this reason, in order to understand completely the therapy these aspects must be interiorized.

2.4.1. Concept Definition

In end-of-life care, the preservation of dignity has increasingly gained great importance. (41) The tenets of palliative care can be summarized by using two basic concepts: improvement of the quality-of-life and maintaining the dignity of the dying person. For this reason, the human dignity is an essential component of the International Council of Nurses Code of Ethics and must be embedded in nursing practice. (23) It is essential the understanding of the 'human dignity' concept in order to provide a suitable healthcare.

Human dignity is a very important aspect in social and health care and throughout history of health care, it has been defined in many different ways. In the actuality, after numerous research on the meaning of dying with dignity and aspects of dignity in end-of-life care, it is known that dignity is a multifaceted and complicated concept. (23)

In end-of-life care, defined as the quality of being worthy, honoured or esteemed, dignity is considered a complex and textured construct. (1) Dignity is an attribute of a good death for terminal patient and it is a basic requirement when caring for dying patients. (23)

After analysing several articles, Guo, Q. and Jacelon, C. (2014) clarified the meaning of dying with dignity and all the aspects related. (23)

2.4.2. Related dimensions to the end-of-life dignity

As dignity is a multidimensional concept. When talking about dying with dignity, it is important to understand the different themes involved in it. An integrative review of dignity at the end-of-life after analysing several studies reported the following themes (Table 3).

Table 3: Meanings given to the concept of: dying with dignity.

Themes
A human right
Autonomy and independence
Relieved symptom distress
Respect
Being human and being self
Meaningful relationships
Dignified treatment and care
Existential and spiritual satisfaction
Privacy
Safe and calm environment

Source: (23)

To start with, dying with dignity is defined as a human right that cannot be taken away nor lost and applies equally to everyone. (23)

Secondly, although people usually use autonomy and independence to conceptualize dignity, it is important to remark that it is not a synonym but an attribute of dignity. Autonomy refers to the sense of control over actions and decisions patients have including both functional and cognitive attributes. Related to autonomy, the level of independence is also important. Defined as the degree of reliance a person has on others, it has been demonstrated that maintaining the independence of a patient promotes its physical and psychological integrity and dignity. (23)

The relief of the symptom distress is also an important aspect of the end-of-life dignity. Symptom distress is defined as the discomfort and anguish the patient experiences in relation to the progress of its illness including both psychological and physical distress.

Another important theme is respect. Respect includes self-respect and other-respect on the person’s identity, thoughts and values. Also, respect on the privacy and choices, wishes and needs of the dying person and family. (23)

Having meaningful relationships is another important matter. The relationship the patient has with its family, health providers and other important relatives, has a great influence on its sense of dignity. These meaningful relationships include being listened, understood, trusted, loved, included in decision making and not being burden to the family. (23)

Offering a dignified treatment and care is also an important theme to take into consideration when talking about end-of-life dignity. Invasive interventions of futile examinations and treatments must be avoided and a dignified care must be offered by demonstrating empathy and sensibility on the patient’s values, choices and needs. Symptom distress, change in appearance, the increase loss of functionality, uncontrolled symptomatology and management without empathy and sensibility can weaken their sense of dignity. On the other hand, the increasing need of help because of the illness progression can also diminish patient’s sense of dignity. (23)

Existential/spiritual satisfaction is another attribute of dignity at the end-of-life. Preserving the patient’s hope and helping them to find the meaning in life and death is important in care. It helps them feel completion and satisfaction during the dying process by helping them get ready to detach from the physical world. (23)

Moving on, privacy regarded as privacy of their body, personal space or information confidence must be always taken into consideration. (23)

An honest communication and keeping the patient fully informed is also essential to preserve the patient’s dignity as it gives them a sense of being valuable and maintaining the control.(23)

Finally yet importantly, a safe and calm environment must be offered in order to dignify the dying process. This includes assuring a death without fear in a calm and private environment and not leaving the patient to die alone. (23)

2.4.3. Dignity models

Understanding dignity requires more than knowing and associating the different end-of-life issues. For this reason, models have been developed. (1)

Theoretical dignity models have been created throughout the history of palliative care in order to remind the healthcare providers the importance of preserving the patients’ sense of dignity and guide them throughout the caring process. (1,6,23)

Chochinov et al. (2002) developed The Dignity Model that included three primary resources that affect the patients’ sense of dignity. Illness related concerns (physical and psychological symptoms); dignity-conserving repertoire (internal resources that brought the patient to the illness based on past experiences and psychological and spiritual states); and social dignity inventory (including social factors that have a direct influence on the patients’ dignity). (23)

Furthermore, Plescheberger created the Dignity Conceptual Model based on the intrinsic and extrinsic components of human dignity. In here, dignity was differentiated in two types of dignity, the personal dignity (beliefs, values, wishes and body aspects) and the relational dignity (social relationships and environment). (23)

Other models are the Dignity-Driven-Decision-Making Model and the Model of Preservation of Dignity. (23)

2.4.3.1. *The Dignity Model*

The Dignity Model or also called the Model of Dignity in the Terminally Ill (Chochinov H, et al. 2002) is a patient data based model that documents a complex landscape of how dignity relates to the widest range of issues important for those who are facing life-threatening challenges. (1)

The Dignity Model indicates there are three main sources that can influence patients' concerns. (Figure 3)

These are:

- Illness-Related Concern: factors that arise directly from the illness itself and that include physical and psychological replies. (1)
- Dignity-Conserving Repertoire: it refers to psychological and spiritual factors that influence patients' sense of dignity. (1)
- Social Dignity Inventory: includes all those external factors and challenges that affect the patients' sense of dignity. (1)

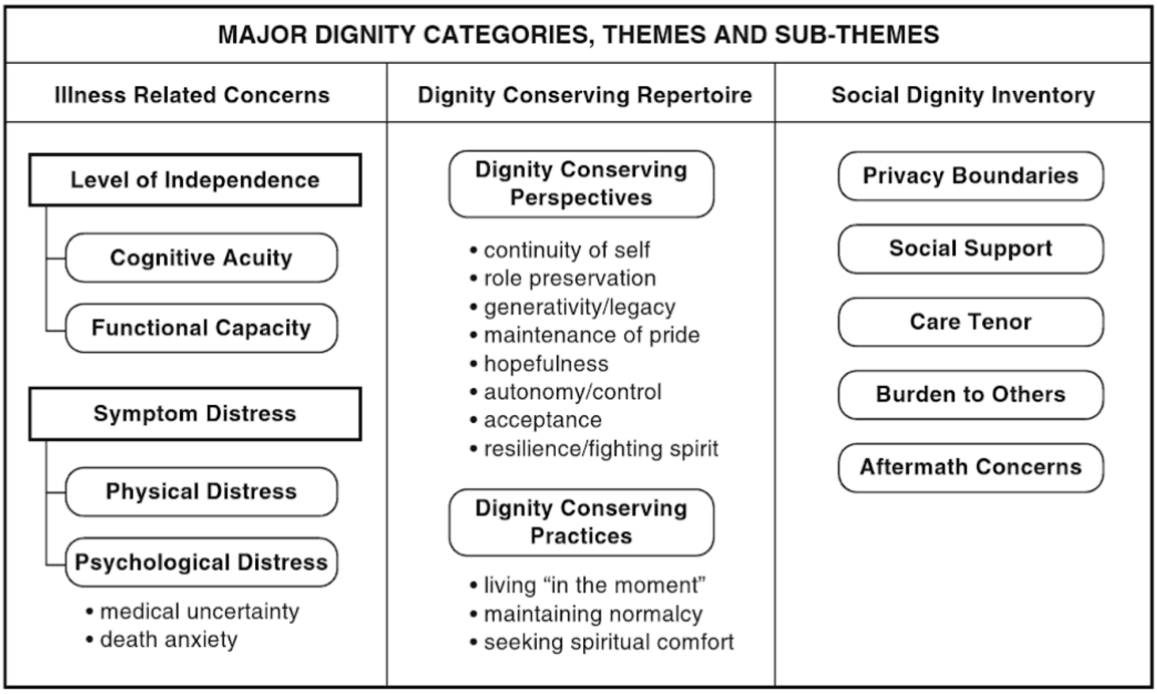


Fig. 3. The Dignity Model categories, themes and subthemes

Source: (1)

2.4.3.1.1. Illness-Related Concerns of Palliative Patients

This major theme includes two important subthemes, which are level of independence and symptom distress. (1)

The *level of independence* is described as being able to avoid feeling reliant to others. Throughout life-threatening challenges, it is important for patients to accept that help is necessary as it leaves the self and the sense of personhood unharmed. (1)

There are two areas in the Dignity Model that are considered to be part of the level of independence. On the one hand, there is the cognitive acuity that refers to the maintenance of the acute mental processes. On the other, there is the functional capacity that centres in the capability of carrying out various personal tasks. (1)

Changes in the level of independence in life-threatening processes can be challenging for patients. During the caring progression, it is important as a care provider to make the receiver feel that regardless of the level of dependency they are still in charge of how things are being done. (1)

Symptom distress is a profound challenge experienced by those who are ill and facing life-limiting situations. This theme includes both physical and psychological distress. (1)

The physical distress is the physical experience of a symptom and it cannot be detached of it emotional accompaniment. Every symptom is followed by an emotional response. For example, pain is linked to feelings of anxiety, depression and fear. (1)

Following on, psychological distress is deeply linked to the personhood. In the Dignity Model, psychological distress emerges from two subthemes. These are medical uncertainty and death anxiety. (1)

Many patients tend to fear what they do not know and sometimes the confirmation of a serious diagnosis provides more comfort than uncertainty. In a similar way, not knowing how death is going to be experienced also causes psychological distress. Some patients believe they might die in terrible pain or slow suffocation.

Care providers must clearly inform the patients and assure how distress or symptomatology will be managed and that they will never be abandoned. (1)

2.4.3.1.2. Dignity Conserving Repertoire in Palliative Patients

The way the person responds to life-threatening challenges is also influenced by their psychological and spiritual areas. The Dignity Conserving Repertoire describes the different components that influence on how people react to changing care conditions. It consists of both dignity-conserving perspectives and dignity-conserving practices. (1)

Dignity-Conserving Perspectives

Dignity-conserving perspectives are described as the way of seeing the world dominated by who is ill rather than by what ails them. These perspectives are explained by eight specific subthemes. (1)

- *Continuity of self* – being able to maintain their identity and sense of self despite the changing health circumstances. (1)
- *Role preservation* – illness can accumulate losses in roles and responsibilities. For patients it is important to accommodate minor losses as it maintains the sense of self. (1)
- *Generativity or legacy* – used to describe the guidance provided to the next generation. In life-threating circumstances, generativity becomes of great importance to patients. (1)
- *Maintenance of pride* – referred as a defensive or coping strategy to avoid the psychological and existential impact of health changing circumstances maintaining positive self-respect to safeguard the sense of self. (1)
- *Hopefulness* – in normal conditions it is described as future expectations predicated on the assumption there is going to be future. In health changing and life-limiting circumstances it is referred as what the disease may claim and what time is there still to offer. Hope usually anticipates a favourable prognosis and just a minority of terminally ill patients demonstrate a marked hopelessness. Hopelessness in these circumstances is an important clinical marker for suicidal ideation. (1)
- *Autonomy/Control* – ability of carrying out several functions. The difference between the level of independence and autonomy relies on the fact that

  the second theme is internally mediated and it depends more on the state of mind. (1)

- *Acceptance* – known as the ability to adapt to changing health circumstances making gradual adjustments in an ideally speed that can be tolerated. (1)
- *Resilience and fighting spirit* – having internal strength to face whatever comes ahead holding onto the hope of life-prolonging outcomes providing the encouragement needed to carry on. (1)

Dignity-Conserving Practices

Dignity-conserving practices are described as the activities and behaviours that help someone deal and manage the changing life circumstances. Includes three subthemes. (1)

- *Living the moment* – advanced knowledge or in other words, prognosis, forces the mind to look ahead into the future, which can be anticipated but never fully known. It makes people frightened and less engaged to the present. For this reason, living the moment here and now provides comfort. Enables the patient to experience moments of human contact, humour, love and celebration transforming the final stage of life into a time of living rather than a period of anticipating death. (1)
- *Maintaining normalcy* – upholding usual routines as long as possible assures psychological and existential comfort as the sense of self is not relinquished. (1)
- *Seeking spiritual comfort* – as people get closer to death, spirituality carries a wide range of different meanings. For some, it is fully linked to religiosity while for others it is understood in a nonreligious way. For the majority of patients experiencing life-threatening circumstances it is important to reach a sense of meaning and purpose in a manner of spirituality. (1)

2.4.3.1.3. Social Dignity Inventory

The Social Dignity Inventory focuses on the social issues and relationship dynamics that influence on the patient’s sense of dignity. In other words, it centres the whole attention on the extrinsic factors including the privacy boundaries, the social support, the care tenor, the burden to others and the aftermath concerns. (1)

- *Privacy Boundaries* – when facing health-changing circumstances the self-privacy also experiments challenges. Diminished privacy linked to a diminishing sense of control takes place when dependency increases. (1)
- *Social Support* – it is so important that palliative care as a discipline defines patient and family as a whole unit of care. Patients in these situations often experience a fear of abandonment and social support is of great importance. (1)
- *Care Tenor* – used to describe the tone of care that health care givers offer patients or the tone perceived by patients. Care providers have numerous ways to demonstrate dignity-conserving care tenor. These competencies are summarized in the A, B, C and D of dignity-conserving care consisting in A for Attitude, B for Behaviour (actions and conducts), C for Compassion (wish to relieve the suffering of the others) and D for Dialogue (exchange of extensive information). (1)
- *Burden to others* – refers to the patient perception of needing help without being able to offer anything in return. Burden to others is highly correlated to feelings of depression, hopelessness and sense of dignity. (1)
- *Aftermath concerns* – used to describe de subtheme of burden to others in a different stage of the process. It is the fear the patient experiences in what may be imposed following their death. This theme can be addressed in a variety of ways such as offering the patient advice, guidance or instruction. (1)

2.4.4. Dignity measurement

Successively, in order to prove the importance of following person-centred and dignity-centred care systems in end-of-life scenarios, several instruments have been developed. These instruments focus on those factors, which have great influence on dying patients' dignity. (23)

Chochinov et al. after developing the Dignity Model, created the Patient Dignity Inventory (PDI) providing health care professionals an instrument that enables the easy identification of many factors, which lead to distress among palliative patients. (1,23)

Moreover, other instruments developed by Periyakoil et al. (2009) were used to measure the patients' perception on the factors influencing the loss of dignity and the preservation of it at the end-of-life, these are the Dignity Card-Sort Tool (DCT) and the Preservation of Dignity Card-Sort Tool (p-DCT).(23)

Lastly, in order to evaluate the nursing care and nursing outcomes of dignified dying, two tools were developed. The Indicators for Dignified Dying and the International Classification of Nursing Practice (ICNP) Catalogue: Palliative Care for Dignified Dying.(23) The second one consists of a classification made by the International Council of Nurses which categorizes the different parameters and interventions that must be taken into consideration when caring for palliative patients during nursing practice. It is based on the Dignity Model as it is organized following the three categories: illness related concerns, dignity conserving repertoire and social dignity inventory. (42)

3. OBJECTIVES

General Objective:

Analyse the effectiveness of the Dignity Therapy on the improvement of patients with advanced life-threatening diseases and establish if its use in the clinical practice should be recommended.

Specific Objectives:

Objective 1: Analyse the effectiveness of the Dignity Therapy to improve psychological distress, anxiety, depression and psychological fatigue.

Objective 2: Analyse the effectiveness of Dignity Therapy to improve physical distress and symptomatology.

Objective 3: Know the effectiveness of the Dignity Therapy to increase the palliative patient's sense of dignity.

Objective 4: Analyse the benefits of the Dignity therapy in the treatment of psychosocial and existential distress.

Objective 5: Assess the feasibility of the Dignity Therapy focusing on acceptability and satisfaction of both patients and their family relatives.

4. METHODS AND MATERIAL

4.1. Selection criteria

4.1.1. Inclusive Criteria

The inclusive criteria includes:

- Scientific studies published within the last 5 years. From 2014 to 2019 both included.
- Articles published in Catalan, Spanish or English.
- Studies in which the Dignity Therapy has been applied to patients with life-threatening or life-limiting circumstances, palliative patients, with sufficient physical and mental energy to complete the intervention.
- Articles in which the parameters exposed in the objectives have been analysed including: psychological distress, anxiety, depression, physical distress, psychosocial and existential distress, acceptability, satisfaction, feasibility or relatives' opinion.
- Papers where the family relatives are contemplated.
- Sample included adult patients from 18 years old and over.

4.1.2. Exclusive Criteria

The exclusive criteria comprise:

- Articles published before 2014 year and written in other languages than Catalan, Spanish or English.
- Studies in which participants are not included in palliative care or do not have a life-limiting illness with a prognosis established and does who cannot participate in the Dignity Therapy because of their cognitive and physical state.
- Papers in which participants are in paediatric ages and/or under 18 years old.
- Publications in which the Dignity Therapy is not protocoled, case study publications and unfinished studies.

- Studies with no information on the objectives established including: psychological distress, anxiety, depression, physical distress, psychosocial and existential distress, acceptability, satisfaction, feasibility or relatives opinion.

4.2. Search Strategy

The following databases were queried to obtain the potential scientific articles for the review: MEDLINE PubMed, Cochrane, CUIDEN and CINAHL. The MESH terms and key words used included: “palliative-care”, “Dignity-Therapy”, “effectiveness”, “feasibility”, “family members”, “physical symptomatology”, “psychological distress”, “psychosocial distress”, “existential distress” and “satisfaction”. The Booleans operators used were: AND, OR and NOT. The search was made during the first half month of March 2019.

A total of 244 articles were identified in the search process. Of these 244, 193 were removed because of duplication and so 51 were screened by title. After the title screening, 19 papers were excluded and 32 articles were considered of great importance for the review. However, 29 full-text articles were assessed for eligibility. One was excluded because of the language (Chinese), an unfinished study also had to be excluded and the access to the remaining one was impossible. After a comprehensive lecture, 14 articles encountered the selection criteria and were included in the review. The articles excluded did not accomplish the selection criteria as some focused on different outcomes or studied other group of patients not admitted to palliative care. (Figure 4,5,6,7)

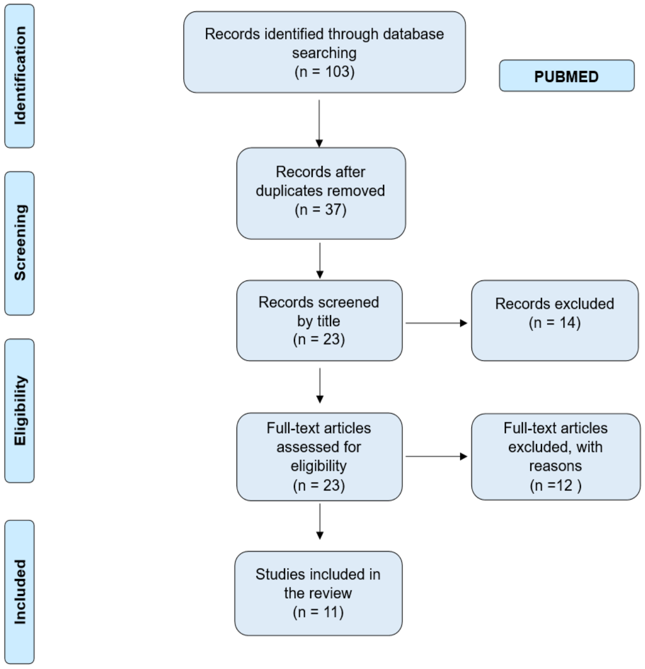


Fig. 4: Flow diagram selection process Medline PubMed

Source: Own elaboration

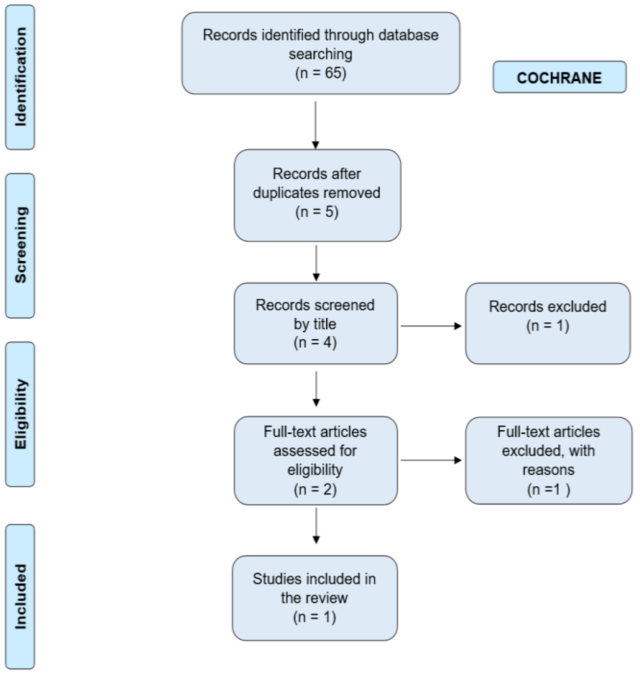


Fig. 5: Flow diagram selection process Cochrane.

Source: Own elaboration

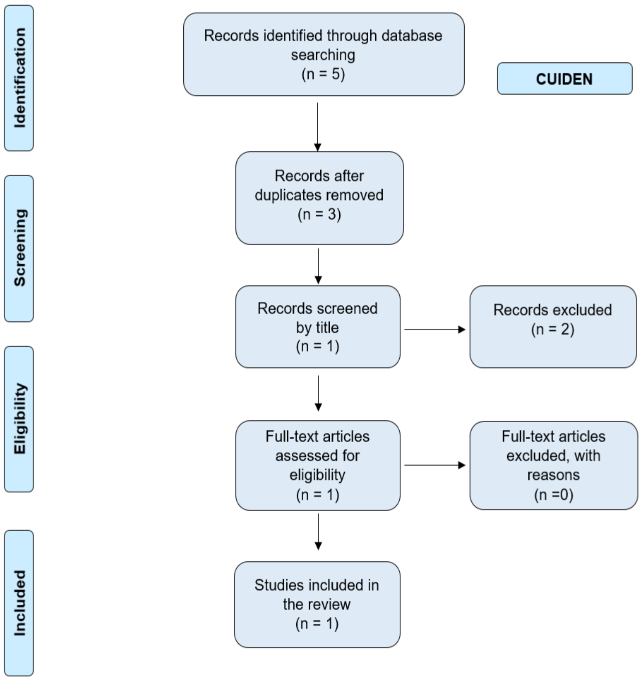


Fig. 6: Flow diagram selection process CUIDEN.

Source: Own elaboration

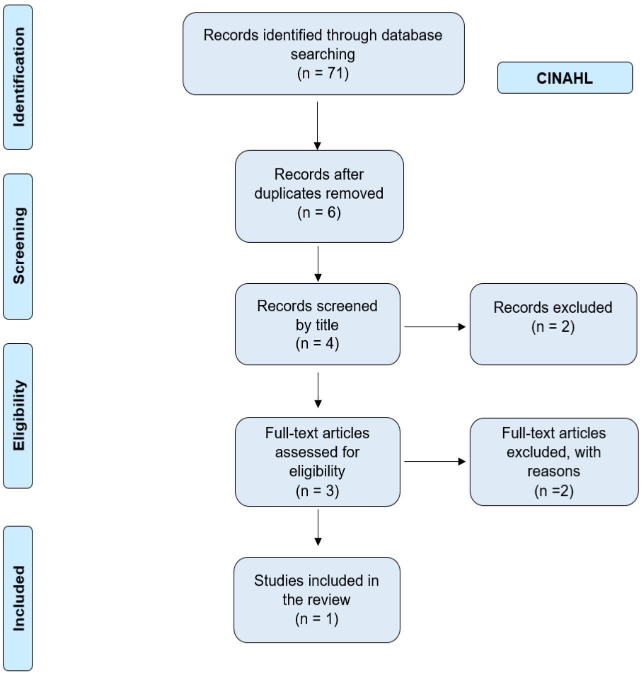


Fig. 7: Flow diagram selection process Cinahl.

Source: Own elaboration

5. RESULTS

After a comprehensive lecture of the articles included in the review, the following table was elaborated in order to expose the summary of the results found. The table is comprised by 4 columns in which information on the articles assessed can be red including (from left to right): title, authors, year, database from where it has been obtained and bibliographic reference; aim of the study; methods used; and finally the key outcomes extracted. Each row corresponds to each article, a total of 14. (Table 4)

Table 4: Bibliographic Review Results: Summarized Table

	Title, Authors, Year, Database and Bibliographic Reference	**Aim**	**Methods**	**Key Outcomes**
1	Efficacy of Dignity Therapy on Depression and Anxiety in Portuguese Terminally Ill Patients: A Phase II Randomized Controlled Trial. Julião M, Oliveira F, Nunes B, Vaz Carneiro A, Barbosa A. 2014 Medline Pubmed (43)	Report the efficacy data of Dignity Therapy on symptoms of depression and anxiety.	**Phase II randomized controlled trial**. Comprising two arms: an intervention group receiving both standard palliative care and Dignity Therapy; and a control group receiving only standard palliative care.	Patients assigned in Dignity Therapy scored a significant decrease on depression ratings on day 4 and 30 after the intervention. Dignity Therapy participants showed lower anxiety rating in all assessments.
2	Estudio comparativo de la eficacia del *counselling* y de la terapia de la dignidad en pacientes paliativos. Rudilla D, Barreto P, Oliver A, Galiana L. 2014 Cochrane (44)	Evaluate the efficacy of both interventions on the improvement of the quality-of-life of palliative care patients and explore the differences between the two.	Quasi-experimental comparative study with two randomized intervention groups each one for each therapy.	Focusing on the Dignity Therapy group: Slight differences in the pre and post intervention levels of depression, mental peace and social support. Medium grade statistical differences on anxiety. High level of improvement on the rest of magnitudes: suffering, symptom distress, existential distress, dependence distress and quality-of-life.

3	A feasibility study of Dignity Therapy in patients with stage IV colorectal cancer actively receiving second-line Chemotherapy. Vergo MT, Nimeiri H, Mulcahy M, Benson A, Emmanuel L. 2014 Medline PubMed (45)	Determine the feasibility of Dignity Therapy in patients who are undergoing active palliative chemotherapy and assess changes in death acceptance, distress, symptoms, quality-of-life, peacefulness and scenario-based end-of-life goals of care and treatment choices pre and post intervention.	Experimental quantitative and qualitative study.	Feasibility: Reported satisfaction, helpfulness (for both patient and family), and increase in the sense of dignity, meaning, purpose and will to live. Physical Symptomatology: No statistically significant changes in most of the symptoms with the exception of appetite, which improved. Emotional Symptomatology: no negative impact neither significant changes. Increase in death acceptance.
4	A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. Houmann LJ, Chochinov HM, Kristjanson LJ, Petersen MA, Groenvold M. 2014 Medline PubMed (46)	Assess and explore the interest in and the evaluation of the Dignity Therapy in Danish patients with incurable cancer.	Prospective (pre/post) evaluation study.	The majority of patients and families reported satisfaction, helpfulness. 25%-43% stated Dignity Therapy made life more meaningful, lessened suffering and expected it would change family's appreciation of him/her. Slight differences in depression pre and post parameters. Overall quality-of-life decreased. Decrease in sense of being a burden. An improvement in suffering, sense of dignity, hopelessness, feeling anxious, sense of being a burden, sense of purpose etc. was noted.
5	Care of the human spirit and the role of Dignity Therapy: a systematic review of Dignity Therapy research. Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. 2015 MedlinePubMed (47)	Provide a synthesis of the evidence from existing Dignity Therapy studies focusing on the feasibility, acceptability and effects. Also, propose further aims of research related to the Dignity Therapy.	Systematic review using a PubMed search with the key terms of "Dignity Therapy".	Consistent evidence on Dignity Therapy's acceptability. High rates of satisfaction and benefits for patients themselves and their families. Feasibility: recruitment and retention of participants were issues for nearly all studies and a major problem for some. Effectiveness: single group studies demonstrated significant changes in study outcomes after Dignity Therapy intervention. In randomized controlled trials, no statistically significant effects of Dignity Therapy have been reported.

6	Comparing counselling and dignity therapies in home care patients: A pilot study. Rudilla D, Galiana L, Oliver A, Barreto P. 2016 Medline PubMed (48)	Examine the effects of these two popular psychological therapies in palliative care in a Spanish home care patients' sample. Compare the effects of the therapies offering useful information on which intervention fits better.	Pilot randomized controlled trial. Patients included in two different groups.	Dignity Therapy group showed statistically significant differences in all variable evaluated pre and post intervention (symptom distress, existential distress, dependency, peace of mind, social support, anxiety, depression, spirituality, support, quality-of-life) except for resilience. Improvement in sense of dignity. Report fewer problems in symptom distress, existential distress, dependency, peace of mind and social support. Improvement in terms of anxiety but not depression. Spirituality, social support and quality-of-life also experienced improvement.
7	Effects of Dignity Therapy on terminally ill patients: a systematic review. Donato SCT, Matuoka JY, Yamashita CC, Salvetti MG. 2016 Cuiden (49)	Analyse the evidence published on the effects of Dignity Therapy on terminally ill patients focusing on the physical, spiritual and psychosocial effects of the therapy.	**Systematic review** of the literature using the search strategy in six databases (CINAHL, COCHRANE, LILACS, PubMed, SCOUPS and WEB OF SCIENCE). Election criteria included primary studies excluding reviews and conceptual articles. 10 articles included.	The acceptation of Dignity Therapy has been noted in almost all articles included. Five papers identified Dignity Therapy as satisfactory and 6 studies as useful. An increase in the sense of dignity was showed in 5 studies, quality-of-life in 4. A decrease in suffering was noted in 6 studies. In 3 studies, levels of depression decreased after the intervention.
8	Effect of Dignity Therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial. Julião M, Oliveira F, Nunes B, Carneiro AV, Barbosa A. 2017 Medline PubMed (50)	Study how Dignity Therapy affects demoralization syndrome, the desire of death and sense of dignity.	Phase II non-blinded randomized controlled trial, cohort of 80 terminally ill patients comprised in two study arms: intervention group (Dignity Therapy and standard palliative care) and control group (standard palliative care).	Patients in Dignity Therapy group noted a statistically significant decrease in all Patient-Dignity-Inventory items except for cognitive capacity, meaningful life and healthcare support demonstrating an overall improvement in their sense of dignity and dignity distress.
9	Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial.	Compare Dignity Therapy and life review and a waitlist control group on a range of outcome measures.	Randomized controlled trial with an enrolment of 70 participants to a Dignity	Dignity Therapy was rated as helpful and would be recommended by participants, high acceptability and satisfaction. It also heightened their sense of dignity and purpose. It improved

	Vuksanovic D, Green HJ, Dyck M, Morrissey SA. 2017 Medline PubMed (51)		Therapy, life review and control group.	patients' quality-of-life, spiritual wellbeing, depression and distress. Family members reported overall acceptability and satisfaction. Dignity Therapy was rated as helpful. It improved their sense of dignity, sense of purpose and depression.
10	'Dignity Therapy', a promising intervention in palliative care: A comprehensive systematic literature review. Martínez M, Arantzamendi M, Belar A, Carrasco JM, Carvajal A, Rullán M, Centeno C. 2017 Medline PubMed (52)	Analyse the outcomes of Dignity Therapy in patients with life-threatening diseases.	Comprehensive systematic review using PRISMA guideline. Sensitive search carried out in PubMed, Cinahl, Cochrane Library and PsycINFO databases. 28 articles were included.	In terms of effectiveness, controvert results have been found. The majority of the studies included report improvements. However, others show either statistically insignificant improvements or deteriorations. Focusing on acceptability and feasibility, overall results show a positive light and increased satisfaction of both patients and family relatives.
11	A Narrative Review of Dignity Therapy Research. Bentley B, O'Connor M, Shaw J, Breen L. 2017 Cinahl (53)	The aim to synthesis and summarize qualitative and quantitative findings and interpret them.	Narrative review of Dignity Therapy querying the databases of PubMed, Cinahl and PsychINFO.	In terms of efficacy, controversial exclusive results have been found between the different papers analysed. In relation to feasibility, a general both patients and relatives state a positive light on Dignity Therapy, an overall satisfaction and acceptability is noted.
12	Feasibility, acceptability and adaption of Dignity Therapy: a mixed methods study achieving 360° feedback. Mai SS, Goebel S, Jentschke E, van Oorschot B, Renner KH, Weber M. 2018 Medline PubMed (54)	Test the feasibility and acceptability of Dignity Therapy in an inpatient setting.	Clinical multicentre mixed method study comprising qualitative and quantitative research in palliative care units in Germany. Patients and relatives provided data on Dignity Therapy intervention.	Dignity Therapy is a feasible intervention for palliative care units in Germany and demonstrated high levels of acceptability among patients and their relatives. Dignity Therapy was rated as helpful and satisfactory. A high percentage of patients reported Dignity Therapy heightened their sense of dignity.

13	Dignity Therapy interventions for young people in palliative care: a rapid structured evidence review. Rodriguez A, Smith J, McDermid, K. 2018 Medline PubMed (55)	Summarise and synthesise that has explored Dignity Therapy focusing on interventions with young people (12-24 years old).	Rapid structured review using systematic methods. Including a total of four articles.	Feasibility and acceptability was showed in all papers. Patients found the therapy satisfying and helpful. Reported an increase in their sense of dignity and purpose and quality-of-life in two articles. Hopefulness experienced improvement in two studies. Dignity Therapy was perceived as beneficial to family relatives in two articles.
14	Effects of Dignity Therapy on Family Members: A Systematic Review. Scarton L, Boyken L, Lucero R, Fitchett G, Handzo G, Emanuel L, Wilkie D. 2018 Medline PubMed (56)	Provide a systematic literature review of the effects of Dignity Therapy on family members of patients receiving Dignity Therapy from patients and family perspectives.	Following PRISMA systematic review guideline, de PubMed database was queried. A total of 18 articles were included.	Feasibility and acceptability: one study reported that 50% of the family members agreed or strongly agreed Dignity Therapy was helpful to them. In another study, 6 of 9 family members reported that Dignity Therapy improved communication and 3 that improved comfort. Five quantitative studies stated that most family members felt Dignity Therapy was a source of comfort for both patients and family and would recommend the therapy to others. These studies also reported that most family members thought Dignity Therapy was an important part of care. Family members felt positive about Dignity Therapy, however, some concerns raised.

As detailed throughout the theoretical framework, the Dignity Therapy involves the creation of a carefully constructed and edited document in a dignity-conserving atmosphere. The main objective is to preserve patient’s dignity through the last stages of its life. For these reason, in order to analyse if the therapy is effective and feasible many trials and systematic reviews have been complete. Focusing on the main parameters that relate to its effectiveness and feasibility (emotional distress, depression, anxiety, sense of dignity, physical distress, psychosocial and existential distress, satisfaction and acceptability) the following results have been obtained after a comprehensive lecture of each paper included in the review.

Julião M et al. (43) conducted a phase II randomized controlled trial in which a total of 80 patients admitted into the palliative care unit were randomized into two different groups: intervention group (Dignity Therapy and standard palliative care) and control group (standard palliative care). The principal aim was to assess the effects of dignity on depression and anxiety in palliative care admitted patients. Depression and anxiety were assessed using the Hospital Anxiety and Depression Scale (HADS) at baseline, day 4, day 15 and day 30 post Dignity Therapy intervention. Of these 80 patients 10 were lost to day 4 follow-up, 18 lost follow-up at day 15 and only 36 finished day 30 follow-up. Clinical deterioration was the main cause of the losses.

Patients assigned to the intervention group showed a statistically significant decrease in depression ratings on days 4 and 30 post-Dignity Therapy. Statistically significant decrease on day 15 was not observed. On the other hand, there was an important increase in depression ratings within the control group between baseline and all follow-ups. Overall, the Dignity Therapy group reported significantly lower rates of depression in all assessments. In terms of anxiety, those participating in the Dignity Therapy group reported statistically significant lower anxiety ratings at all follow-up periods. There was a significant reduction between baseline and all assessments anxiety ratings. An increase in anxiety ratings was experienced in the control group however, it is not statistically significant. To sum up, Dignity Therapy resulted beneficial in improving patients’ psychological distress encountered end of life stages.

Rudilla D et al. (44) developed a comparative study testing the efficacy of both Dignity Therapy and counselling in palliative care patients. Two groups were included in this trial, a sample of 30 patients were randomly chosen for the groups receiving Dignity Therapy and counselling. Patients were evaluated pre and post intervention on the following areas: emotional distress using the emotional thermometer (visual analogue scale), anxiety and depression using the HADS, sense of dignity using the PDI and quality-of-life using the QLQ-C30 questionnaire.

Patients assigned into the Dignity Therapy group pre and post rates in anxiety experienced a medium improvement. Depression, mental distress and social support qualified a small improvement. Following with the rest of variables studied: psychological distress, quality-of-life, physical distress, existential distress and sense of burden to others reported an overall statistically significant improvement. No statistically significant differences were noted between the two therapies.

Vergo MT et al. (45) piloted an experimental qualitative and quantitative study assessing the feasibility of the Dignity Therapy by the success rate of enrolment and a satisfactory survey post-intervention. A 0-7 Likert scale was used to assess satisfaction by responding satisfaction and helpfulness. Death acceptance was also analysed using the TIA. Distress was assessed using the Distress Thermometer (0-10 Likert scale). Symptoms using the Edmonton Symptom Assessment System and quality-of-life using a 2-item quality-of-life scale were also assessed. A 6-point Likert scale was used to measure peacefulness. Finally, the Hypothetical Advanced Care Planning Scenario (H-CAP-S) was used to assess scenario-based goals of care and treatment preferences. These questionnaires were completed at baseline, at the end of the Dignity Therapy and one month after.

A number of 15 patients enrolled in the study. However, six were removed and only 9 completed it. In terms of feasibility and primary outcomes, 100% of patients were satisfied or very satisfied with the Dignity Therapy. Eighty percent reported it was helpful or very helpful and also agreed or strongly agreed the intervention increased their sense of meaning and would be helpful to their relatives. Seventy-eight percent agreed or strongly agreed their sense of dignity and purpose increased after Dignity Therapy. Sixty-seven percent reported their will to live increased after participating in the therapy. In relation to the secondary outcomes, for instance physical symptomatology (pain, tiredness, nausea, drowsing, appetite, dyspnoea) experienced no change after the intervention with the exception of appetite, which seemed to improve. In terms of psychological distress and emotional symptomatology (anxiety, depression, sense of well-being, quality-of-life rating, satisfaction with quality-of-life, distress) a negative impact was not reported and the majority of the patients experienced no change after the intervention. Peacefulness was not assed post-intervention as all patients reported high rates at baseline scores. There was a statistically significant increase in death acceptance after the therapy from 11% to 57% 1 month after.

Chochinov M et al. (46) conducted a prospective evaluation study to explore the interest, evaluation and effectiveness of Dignity Therapy in Danish patients. The outcome measures were made at baseline point, immediately after patients received the generativity document and 2 weeks later as patients had time to share de document with relatives. The instruments used were: Structured Interview for Symptoms and Concerns (SISC) including dignity, communication, social connection, suffering, depression and hopelessness; 25 item PDI; European Organisation for Research and Cancer Treatment (EORTC) QLQ-C15-PAL assessing health-related quality-of-life; HADS; Palliative Performance Scale-Version 2; and Dignity Therapy Patient Feedback Questionnaire (9 items).

A total of 866 consecutive patients were admitted. Due to different criteria, only 341 were truly eligible. Only 101 accepted (30%). However, 21 deteriorated before starting the intervention and so, only 80 patients completed the Dignity Therapy (79%). Only 55 patients completed the first post-intervention assessment. Between 73% and 89% reported Dignity Therapy was helpful, satisfactory or of potential help to family. Among 47% to 56% reported that Dignity Therapy heightened their sense of purpose, sense of dignity and will to live. 25% to 43% stated Dignity Therapy made life more meaningful, improved suffering and expected the family’s perception of them would change. In this assessment, a small increase in depression was found however, improvements were assessed in suffering and feeling like a burden to others. For the third assessment, 2 weeks after, only 31 patients were able to complete it. Improvements were found in depression, sense of dignity, hopelessness, suffering, anxiety, sense of being a burden and other ratings. Overall quality of live decreased. Dignity Therapy turned out to improve emotional and psychosocial/existential distress and patients' sense of dignity. Positive evaluations raised in relation to feasibility in terms of satisfaction and acceptability.

Fitchett G et al. (47) carried out a systematic review and synthesised the literature found of the Dignity Therapy regarding its feasibility, acceptability and effectiveness. Following PRISMA guidelines, PubMed database was queried. Twenty-five articles were included in the review. A variety of measures was used to analyse primary and secondary outcomes. The variables studied were depression (9 studies), anxiety (6 studies), symptom (4 studies), quality-of-life (7 studies), hope (5 studies), spiritual well-being (2 studies), dignity (7 studies), function (3 studies) and other psychosocial or palliative care related concepts (5 studies). The instruments used for primary outcomes in efficacy studies included: PDI, HADS and other tools. For secondary outcomes: Dignity Therapy Feedback Questionnaire. Other five qualitative studies used coding consensus as analytic technique.

Acceptability evidence was proved clear and consistent. Patients provided high rates of satisfaction and benefits for themselves and their relatives. For instance, an experimental Canadian and Australian study including a sample of 100 participants reported a 91% of satisfaction or high satisfaction with Dignity Therapy, 76% stated it increased their sense of dignity and 47% their will to live. Similar ratings were found in several studies. In terms of feasibility, for many Dignity Therapy studies, recruitment and retention were issues or problems in conducting experimental trials. For example, in a Danish study only 21% patients were eligible and it took 2-year time to recruit a sample of 80 patients and only 31 (39%) completed the second follow-up. In a randomized controlled trial in UK, of 45 eligible patients only a 24% was recruit and of these, 60% completed the first follow-up and 44% completed the 1-month assessment. Similarly, in a Portuguese randomized controlled trial, among 60 eligible patients only 30 (50%) were included in the 30-day follow-up. Lastly, effectiveness rated by analysing multiple outcomes, is significant in single group studies. However, when Dignity Therapy is compared to standard care control groups, Dignity Therapy effects are not as statistically significant. For instance, one study detected small or moderate effects in study outcomes (n=441, 3 groups) no significant differences were measured for primary outcomes between the Dignity Therapy group and the two control groups. However, in a randomized controlled trial were Dignity Therapy was compared to standard care, participants receiving Dignity Therapy showed statistically significant lower rates of anxiety and depression. In 3 randomized controlled trials, satisfaction was reported in Dignity Therapy groups in comparison to control groups, higher levels of meaning in life, quality-of-life and spiritual well-being were assessed post-intervention.

Rudilla D et al. (48) undertook a pilot study comparing counselling and Dignity Therapy in home care patients. A total of 80 patients were assessed to eligibility and 75 met the inclusion criteria and were randomly assigned to both groups, Dignity Therapy and counselling, following the CONSORT criteria for nonpharmacological trials. Seventy patients completed the study, 35 in each group. Surveys were completed during and pre and post-intervention. Outcome measures included sociodemographic and clinical data, sense of dignity (PDI), emotional distress (HADS), emotional well-being (resilience (Brief Resilient Coping Scale), spirituality (GES questionnaire), social support (Duke-UNC-11 Functional Social Support Questionnaire) and quality-of-life (2-item EORTC quality-of-life C30 Questionnaire)).

Before the interventions, no differences were assessed in the measured variables. The *t* test measures in the Dignity Therapy group reported statistically significant differences for all variables studied except for resilience. An improvement of dignity was noted in five domains assessed in the Patient Dignity Inventory. Patients referred fewer problems in terms of symptom distress, existential distress, dependency, peace of mind and social support. Anxiety decreased after the intervention. However, depression did not experienced any improvement; levels were higher after the therapy. In relation to spirituality, social support and quality-of-life an improvement was noted with higher effects on the three dimensions of spirituality and social support and medium effect in quality-of-life. Post-counselling similar results were showed. Improvements in dignity, anxiety, spirituality, social support and quality-of-life were rated. Small improvements in resilience and no effects on depression were assessed. Comparing both interventions, counselling proved statistically significant better results in terms of anxiety, lower levels of anxiety were assessed.

Donato S et al. (49) carried out a systematic review with the objective to analyse the evidence on the effects of Dignity Therapy on terminally ill patients focusing on physical, spiritual and psychosocial effects. After a strict screening, 10 articles met the selection criteria and were included in the review.

In terms of feasibility and acceptability, Dignity Therapy turned out to be well accept by patients and was identified as satisfactory in five of the ten studies and useful in six. An improvement reported in dignity was noted in five studies, quality-of-life in four studies and suffering in six studies. Only two studies demonstrated an improvement in spiritual-related issues. Two studies compared Dignity Therapy versus counselling, and this last intervention turned out to have better results on psychosocial distress than Dignity Therapy. Other two studies evaluating the effect of Dignity Therapy on depression and anxiety reported an improvement in scores and other three studies showed a decrease in depression after the intervention enabling a controversial conclusion which states that although Dignity Therapy improves depression it does not have de same effect on anxiety.

Julião M et al. (50) conducted a II phase nonblinded randomized controlled trienni terminary inpatient palliative medicine unit in Lisbon with two study groups: intervention group (Dignity Therapy and standard palliative care) and control group (standard palliative care). The principal aim was to report the effect of Dignity Therapy on demoralization syndrome, desire of death and sense of dignity. To measure sense of dignity, the PDI was employed. The different assessments took place at baseline and day 4 post-intervention.

In a 36-month period, 150 were admitted in the palliative care unit of which 92 were assessed for eligibility. Eighty patients were finally included in this cohort study. Seventy-eight received Dignity Therapy and 10 lost follow-up in the 4-day post-intervention assessment. In relation to the PDI the baseline scores of most of the items (64%) had an average score >3 demonstrating an intense dignity-related distress. Dignity Therapy was associated with a statistically significant decrease in all PDI items with the exception of cognitive capacity, meaningful life and healthcare support. A reduction on 19 of the 25 items was assessed. On the other hand, in the control group, only five items related to bodily functions, physical symptoms, anxiety, sense of value and health care support were statistically significant improved.

Vuksanovic D et al. (51) piloted a randomized controlled trial with the aim to compare Dignity Therapy with life review and a waitlist control group that also received Dignity Therapy. The outcomes assessed to analyse the interventions included within others: dignity, perceived quality-of-life and patients/family satisfaction. To measure dignity-related concerns the PDI was used. The Functional Assessment of Cancer Therapy-General 4 (FACT-G) was used to assess quality-of-life as it measures physical well-being, social/family well-being, emotional well-being and functional well-being. Satisfaction was analysed by using the 15-item Treatment Evaluation Form for patients and the Family Evaluation Form for relatives. A total of 70 patients were assessed for eligibility. However, of them only 56 completed the study protocol. Participants were randomly assigned to one of the three groups: Dignity Therapy, life review or control group. Outcome assessments were made pre-intervention and post-intervention (two post-test in the waitlist control group, before and after receiving Dignity Therapy).

No statistically significant effects were reported in the PDI in none of the three groups. Dignity Therapy participants reported small improvements between pre and post-intervention assessments in terms of anxiety, depression and physically distressing symptoms. In comparison to life review intervention, Dignity Therapy ratings did not worsen and showed improvement although insignificant while life review assessments did not experienced any improvement. Similarly, the FACT-G scores did not change across the three assessments. In terms of the Treatment Evaluation, Dignity Therapy was significantly rated more helpful than life review in helping relatives now or in the future and in the way families saw and appreciated their relative. Both Dignity Therapy and life review interventions were similarly rated as helpful, helpful as other aspects of health care, made participants feel more valued, improved their sense of dignity, made them feel life was more meaningful and heightened their sense of purpose. Dignity Therapy had higher rates in the items of helping them prepare for the future, helping with unfinished business, quality-of-life, spiritual well-being, depression and suffering. In relation to family satisfaction and acceptability, 15 family members completed de Family Evaluation Form. 93,3% reported Dignity Therapy to be helpful. 66,7% that it changed the way they appreciated their relative. 100% reported it was helpful to them. 80% rated Dignity Therapy helpful as other aspects of health care. 60% stated that it helped with unfinished business. 60% that improved depression. 93,3% that it made the person feel more valued. 80% reported it improved sense of dignity. 86,7% said it made them feel life was more meaningful and heightened sense of purpose and 73,3% assured it helped them prepare for the future. Lesser improvement were reported in family ratings of patients' quality-of-life (46,7%), spiritual well-being (53,3%) and suffering (33,3%).

Martínez M et al. (52) conducted a comprehensive systematic literature review of studies in which Dignity Therapy was used for patients with life-threatening diseases. From the database research 121 articles were identified but 28 were included in the review. These studies had been conducted in the United Kingdom, United States, Canada, Australia, Denmark, Portugal, Sweden, Japan and Spain. The objective was to analyse the effectiveness, satisfaction, suitability and feasibility of the Dignity Therapy.

In terms of effectiveness, five randomized controlled trials turned out to be inconclusive about the effect of the Dignity Therapy on anxiety, depression, well-being, dignity-related distress, hope, quality-of-life and symptoms. Two randomized control trials were piloted with patients with high levels of psychological distress at baseline scores. One showed statistically significant decrease on anxiety and depression scores while the other reported decrease in anxiety but not on depression. In randomized controlled trials with low levels of baseline scores, depression, anxiety and hope measures improved but insignificantly. In non-randomized studies existential and psychosocial measurements including suffering and depression, statistically significant improvements were assessed with the exception of one study in which depression and anxiety scores increased. Focusing on acceptability and feasibility, overall results show a positive light. Patients, family and healthcare professionals' perspectives report that Dignity Therapy heightens participants sense of dignity, hope and purpose and consider it as a useful intervention. Family members in the studies revised also consider that Dignity Therapy helps and increases their perception of dignity and meaning in life and that it also improves suffering.

Bentley B, et al. (53) performed a narrative review of Dignity Therapy with the aim to synthesis and summarize qualitative and quantitative findings in order to interpret the evidence on this particular topic. The research was made through both 2014 and 2016 years. A total of 29 papers met the selection criteria and so, were included in the review. The research focused on the efficacy of Dignity Therapy, feasibility of Dignity Therapy and influence on families in-between other aspects.

Focusing on the assessments of interest for the present review, in terms of efficacy and feasibility, one article reported strong acceptability and satisfaction. Only one study assessed Dignity Therapy potentially decreased anxiety and depression. An international randomized controlled trial conducted in the USA, Canada and Australia with a sample of 326 participants reported no statistically significant differences in measures of distress between the three arms of study and a review shows very little evidence on Dignity Therapy's ability to improve distress and emotional symptomatology. Another phase II randomized controlled trial with 80 participants reported a decrease in anxiety and depression however placebo effect was questioned. Finally, in a Spanish randomized controlled trial, Dignity Therapy was compared to counselling therapy and both groups experienced improvements on anxiety, dignity, quality-of-life, and spirituality however counselling turned out to be more appropriate than Dignity Therapy as an increase on depression in the Dignity Therapy group was reported. Furthermore, palliative care patients reported in a randomized controlled trial satisfaction, helpfulness, increase sense of dignity, purpose and will to life after the participation on the Dignity Therapy concluding Dignity Therapy as feasible, satisfying and meaningful to patients. In relation to family members' evaluations, a general high satisfaction and acceptability ratings are reported in many papers with the exception of a low percentage of relatives who described negative experiences.

Mai SS et al. (54) developed a clinical multicentre mixed methods study in which participants and their relatives provided quantitative (feedback questionnaires) and qualitative (cognitive interviews) information on the Dignity Therapy intervention. The study took place in two German Palliative Care Units (Mainz and Würzburg). One of the principal aims of this mixed methods study was to test the feasibility and acceptability of the Dignity Therapy. Semi-structured cognitive interviews were conducted after the Dignity Therapy in order to analyse the qualitative data. In terms of quantitative assessments, although they include some free text comments, the Dignity Therapy Patient Feedback Questionnaire and the Dignity Therapy Family Feedback Questionnaire were employed. The outcome assessments were stablished after the intervention.

After the admission of 410 patients to the palliative care units from June to October 2015, 72 of them met the inclusive criteria and 30 of them were assessed to participate. Of the patients included 29 participated in the cognitive interviews. Positive remarks and ideas regarding the therapy were given. Patients stated Dignity Therapy leads to more openness in talking about cancer, it preserves pride, should be conducted in the presences of relatives and it is only successful if it is a helpful encounter. Other sceptical believes were collected in terms of effectiveness, usefulness and the fear of arising psychological challenges. Staring at the qualitative results, 19 patients completed the feedback questionnaires. Of all, 18 evaluated Dignity Therapy as helpful and satisfactory. Fourteen agreed it heightened their sense of dignity and made life more meaningful. Thirteen reported heightened sense of purpose and increased will to live. Eleven stated it lessened their sense of suffering and it could change the way they are appreciated by relatives. Finally, all 19 reported satisfaction with their psychosocial care. In relation to the family relatives, 30 were selected but only 26 provided the feedback questionnaires. Twenty-three evaluated the therapy as helpful for their relatives. Twenty agreed that it is as important as any other aspect of care. Sixteen believed it had a positive impact in their relative’s sense of dignity, purpose and comfort. Seventeen agreed it would be helpful in terms of death acceptance and fourteen agreed it would help mitigate the patient’s suffering. Thirteen thought it would have a good influence in their future grief. Lastly, 24 would recommend Dignity Therapy to other patients and their families. Dignity Therapy is feasible as both patients' and families' results demonstrate high levels of satisfaction and acceptability.

Rodriguez A et al. (55) conducted a rapid structured review using systematic methods to analyse and synthesise research findings related to Dignity Therapy effectiveness and suitability among young people from 12 to 24 years old. However, the review also analyses papers in which samples of adult patients have been included in the studies. Following the guidance of the United Kingdom Centre for Reviews and Dissemination the research was made and 4 articles were assessed for eligibility and included as the election criteria was met. Three of them were randomized controlled trials which, compared Dignity Therapy to usual care and the other one was a cohort study. All of them except one analysed adult patients.

Focusing on the studies that took place in Canada, USA, Australia and Iran centred on the adult palliative care patients, in this review, Dignity Therapy was found to improve psychosocial wellbeing, emotional functioning, dignity and hopefulness. It was also found to be helpful for patients' family members. In terms of feasibility and acceptability, most of the adults patients involved in the Chochinov et al's (2005) study showed to be satisfied or very satisfied with the Dignity Therapy and also an increase in their sense of dignity, purpose and meaning. Many participants had also the belief that Dignity Therapy would increase their will to live and help their families. However, in this study not all patients included could finish all follow-up assessments. The same happened in a later Chochinov et al (2011) study demonstrating that Dignity Therapy feasibility can be effected by the type of patients it focuses on and its timing. In the Vaghee et al (2012) study, no drop-outs were reported. In relation to effectiveness, in Chochinov et al (2005) study measures of suffering significantly decreased in the intervention group, participants who reported higher levels of psychological despair before the intervention benefit the most from the Dignity Therapy experiencing an improvement. In Chochinov et al (2011), participants in the Dignity Therapy group assessed statistically significant higher rates of quality-of-life, dignity and treatment satisfaction and perceived the therapy as useful for their families. An improvement in spiritual wellbeing and depression was also noted. In Vaghee et al's (2012) study, levels of hopefulness were statistically significant increased in the intervention group.

Scarton L et al. (56) undertook a systematic literature review with the purpose to analyse the effects of Dignity Therapy on family members of patients who receive this intervention. Perspectives of both patients and family members were analysed. Following the PRISMA systematic review guideline, PubMed database was queried and of 59 articles identifies, 18 were include as they met the selection criteria, 8 type of studies were found. The total articles included both quantitative and qualitative studies were the impact of the Dignity Therapy on family members and caregivers was examined. The studies analysed included samples from 6 to 60 participants and took place in populations from Australia, Canada, United Kingdom and United States.

Focusing on feasibility and acceptability, one study reported that 50% of the family members (n=9) agreed or strongly agreed Dignity Therapy was helpful to them. In another study, six of nine family members, reported that Dignity Therapy improved communication and 3 that improved comfort. Five quantitative studies stated that most family members felt Dignity Therapy was a source of comfort for both patients and family and would recommend the therapy to others. Evidence on family members' perceptions of the benefits to their loved ones was positive. These quantitative studies also reported that most family members thought Dignity Therapy was an important part of care. For example, in a study, 68% of 60 family members, felt Dignity Therapy heightened their relatives sense of dignity and 71,7% their sense of purpose. In general, family members felt positive about Dignity Therapy, however, some concerns raised in relation to negative feelings when reading the final document and belief of incomplete documents.

6. DISCUSSION

Objective 1: Analyse the effectiveness of the Dignity Therapy to improve psychological distress.

Psychological distress has been evaluated in 11 articles (42–48,50–52,54). The results found lead to a controversial conclusion in terms of anxiety and depression. Dignity Therapy turned out to be useful in decreasing anxiety and depression in 3 of the 11 studies (43,44,51). On the other hand, in 2 articles, an increase in depression ratings after the intervention was noted in some assessments however, anxiety continued to improve (46,48). One article reported no changes in between the pre and post intervention ratings of both anxiety and depression (45). In relation to the systematic reviews, similar controversial results were found as some detail improvements in both anxiety and depression levels while others only state improvements of anxiety levels. (47,49,52,53,55).

Objective 2: Analyse the effectiveness of Dignity Therapy to improve physical distress and symptomatology.

In terms of physical distress, this item has been assessed in 4 studies(44,45,48,51). In the 2014 pilot study comparing the effectiveness of Dignity Therapy versus counselling, an overall statistically significant improvement was reported (44). The feasibility study of Dignity Therapy in patients with stage IV colorectal cancer documented no changes in physical symptomatology after the intervention with the exception of appetite which, seemed to improve (45). Small improvements were assessed in physically distressing symptoms in a randomized controlled trial (51). On the other hand, patients included in the 2016 pilot study comparing Dignity Therapy versus counselling referred fewer problems in terms of symptom distress. (48)

Objective 3: Know the effectiveness of the Dignity Therapy to increase the palliative patient’s sense of dignity.

Sense of dignity from patients’ perspectives has been present in the majority of the studies and reviews, 11 (44–54). In a total of 6 experimental studies, patients reported a heightening of their sense of dignity after participating in the Dignity Therapy (45,46,48,50,51,54). In relation to the systematic reviews, the overall light turns out to be positive in terms of patients’ sense of dignity (47,49,52,53,55).

Objective 4: Analyse the benefits of the Dignity Therapy in the treatment of psychosocial and existential distress.

Following on with psychosocial and existential distress, 11 authors talked about it in their studies (43–48,50–54). The terms used to refer to this items included: sense of burden, sense of meaning, sense of purpose, will to live, hopelessness, spiritual well-being, quality-of-life, peace of mind, dependency, meaningful life and sense of suffering. Patients included in experimental studies and results of all systematic reviews showed improvements and fewer problems in these dimensions after participating in Dignity Therapy.

Objective 5: Assess the feasibility of the Dignity Therapy focusing on acceptability and satisfaction of both patients and their family relatives.

Feasibility has been studied from acceptability and satisfaction perspectives. In a systematic review it has also been assessed in terms of patients' drop-outs. Both acceptability and satisfaction have been proved clear and evident. Different arguments have been used to describe both patient and family satisfaction and acceptability. Terms used include helpfulness, benefit, recommendation, usefulness and comfort. Ten articles talk about feasibility (45–47,49,51–56). Of these, 5 include family members' opinions (51–54,56). Patients describe Dignity Therapy as satisfactory, helpful and beneficial for them and their relatives. Family members believe Dignity Therapy has a positive impact on their relatives and that it is as helpful as other health care interventions. Relatives and patients would also recommend this therapy to others in their same situation. Both patients and relatives demonstrate high levels of satisfaction and acceptability making Dignity Therapy a feasible intervention. Nevertheless, three papers aroused negative issues in relation to Dignity Therapy's feasibility (47,55,56). Two studies suggested that feasibility can be affected by the type of patient it focuses on and the timing required (47,55). The recruitment and retention are notable problems issued when conducting this therapy. Lastly, related to family members, although the overall light is positive, some concerns were raised in relation to negative feelings appeared when reading the legacy document (56).

6.1. Limitations

The main limitations found were related to the access to some of the papers selected. However, thanks to the university's library services, the problem was solved and all the articles queried and eligible for comprehensive lecture were advised.

On the other hand, the lack of qualitative or mixt studies and homogeneity in-between trial groups complicates the extraction of overall conclusions. In further investigations, it might be interesting to develop reviews focusing on only one type of paper or either homogenising the randomized controlled trials focusing on the groups included.

7. CONCLUSION

After synthesising and analysing the evidence found, several aspects can be conclude. To start with, the first objective of the review was to know the effect of Dignity Therapy on psychological distress. Findings suggest controversial conclusions in terms of depression and anxiety. No clarifying neither conclusive results have been stated to determine the effectiveness of Dignity Therapy on this dimension. For these reasons, further research should be taken into consideration.

Following on, very few studies evaluate Dignity Therapy's impact on physical symptomatology. Besides, these results suggest that Dignity Therapy has a low statistically significant effect on some symptoms such as appetite. However, more research should be made to firmly conclude its effects on these aspects of palliative health care. Physical distress and symptomatology is a very important part of palliative care as both pharmacological and non-pharmacological treatment in this stage of the illnesses focuses on mitigating all distressing symptoms such as pain. For these reason, if Dignity Therapy is proved to mitigate this symptomatology, its use would increase as it would have a plus in considering it cost-effective. However, these clinical settings are highly influenced by the natural course of the life-limiting illnesses in question and so, efficacy of Dignity Therapy on physical improvement is difficult to determine and sustain.

Moreover, the principal aim of Dignity Therapy is to heighten patients' sense of dignity in life-limiting settings. The results found throughout the present review firmly conclude and affirm the efficacy of Dignity Therapy in terms of patient's dignity. In palliative care settings were patients' dignity defence is an undeniable must, patients could clearly benefit from Dignity Therapy.

When reaching the End-of-life stage, the personal psychosocial and existential spheres exacerbate and so, together with the physical and psychological issues, its management is important. Dignity Therapy has been proved a helpful instrument in terms of enabling patients to resolve, close and clear personal believes and questionable issues before leaving. The creation of a legacy document is seen as an opportunity to express issues left unsaid and to remember important things which make the patient and life meaningful improving so patients' psychosocial and existential distress.

Furthermore, in relation to patients and family members' point of views, feasibility has a positive light as both patients and relatives report high rates of satisfaction and acceptability. Family members are generally the recipients of the legacy document, for this reason, it is important to assess the impact it has on them. On the other hand, although benefits are highly assessed, when talking about health care professionals' points of view, the feasibility of Dignity Therapy is questioned. To start with, the recruitment and retention of Dignity Therapy participants is difficult as the type of patient to whom the therapy is addressed has a limited time and unforeseen denouements can occur.

7.1. Overall Effectiveness and Applicability

To sum up, this review synthesise the effectiveness and feasibility of Dignity Therapy and emerges a positive light for future research and the application of the Dignity Therapy in palliative care settings. This review demonstrates the strengths of Dignity Therapy and leads the way to further areas of research focusing on its limitations. Dignity Therapy turns out to be an overall effective and feasible psychotherapy in palliative care.

Moreover, professionals are also reticent to apply Dignity Therapy as the timing is very extended. Therefore, if the effectiveness and benefits of Dignity Therapy are reported, health care professionals' perspectives can improve in relation to feasibility.

8. BIBLIOGRAPHY

1. Chochinov HM. Dignity therapy: final words for final days. New York: Oxford University Press; 2012.

2. Merino MTG. Palliative Care: Taking the Long View. Front Pharmacol [Internet]. 2018;9(1140):1–5. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6198353/

3. The History of Hospice and Palliative Care. Curr Probl Cancer [Internet]. 2011;35(December):304–9. Available from: https://www.sciencedirect.com/science/article/abs/pii/S0147027211000924

4. Clark D, Graham F, Centeno C. Changes in the world of palliative care. Medicine (Baltimore) [Internet]. 2015;43(12):696–8. Available from: https://www.sciencedirect.com/science/article/pii/S1357303915002479

5. Brennan F. ‘ To die with dignity ’: an update on Palliative Care. Intern Med J [Internet]. 2017;47:865–71. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/imj.13520

6. Cruz-oliver DM. Palliative Care: An Update. Sci Med [Internet]. 2017;114(2):110–5. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6140030/

7. WHO | WHO Definition of Palliative Care [Internet]. WHO. World Health Organization; 2012 [cited 2018 Dec 10]. Available from: https://www.who.int/cancer/palliative/definition/en/

8. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. Campion EW, editor. N Engl J Med [Internet]. 2015 Aug 20 [cited 2018 Dec 10];373(8):747–55. Available from: https://www.nejm.org/doi/pdf/10.1056/NEJMra1404684

9. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for ‘actively dying,’ ‘end of life,’ ‘terminally ill,’ ‘terminal care,’ and ‘transition of care’: A systematic review. J Pain Symptom Manage [Internet]. 2014;47(1):77–89. Available from:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3870193/

10. Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The “Denominator” Challenge. J Palliat Med [Internet]. 2017;21(S2):7–16. Available from: https://www.liebertpub.com/doi/10.1089/jpm.2017.0548

11. Hui D, Park M, Liu D, Paiva CE, Suh SY, Morita T, et al. Clinician prediction of survival versus the Palliative Prognostic Score: Which approach is more accurate? Eur J Cancer [Internet]. 2016;64:89–95. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969216/

12. Bostwick D, Wolf S, Samsa G, Bull J, Taylor DH, Johnson KS, et al. Comparing the Palliative Care Needs of Those With Cancer to Those With Common Non-Cancer Serious Illness. J Pain Symptom Manage [Internet]. 2017;53(6):1079–84. Available from: https://www.jpsmjournal.com/article/S0885-3924(17)30159-8/fulltext

13. Traue D, Ross J. Palliative care in non-malignant diseases. J R Soc Med [Internet]. 2005;98:503–6. Available from: https://journals.sagepub.com/doi/10.1177/014107680509801111

14. Sociedad Española de Cuidados Paliativos. Guía de cuidados paliativos [Internet]. SECPAL. Madrid: SECPAL; 2002. p. 1–52. Available from: http://www.secpal.com//Documentos/Paginas/guiacp.pdf

15. León AR, Garcés R, Ernesto L. Los Cuidados Paliativos, una revisión documental. Qhalikay Rev Ciencias la Salud [Internet]. 2017;2:75–81. Available from: https://revistas.utm.edu.ec/index.php/QhaliKay/article/view/765/608

16. Chow K, Dahlin C. Integration of Palliative Care and Oncology Nursing. Semin Oncol Nurs [Internet]. 2018;34(3):192–201. Available from: https://www.sciencedirect.com/science/article/pii/S0749208118300354?via%3Dihub

17. Cardona-Morrell M, Hillman K. Development of a tool for defining and identifying the dying patient in hospital: Criteria for Screening and Triaging to Appropriate aLternative care (CriSTAL). BMJ Support Palliat Care [Internet]. 2015;5(1):78–90. Available from:

https://spcare.bmj.com/content/bmjspcare/early/2014/12/09/bmjspcare-2014-000770.full.pdf

18. Pérez-garcía E. Enfermería y necesidades espirituales en el paciente con enfermedad en etapa final. Enfermería Cuid Humaniz [Internet]. 2016;5(2):41–5. Available from: http://www.scielo.edu.uy/pdf/ech/v5n2/v5n2a06.pdf

19. Best M, Aldridge L, Butow P, Olver I, Price MA, Webster F. Treatment of holistic suffering in cancer : A systematic literature review. Palliat Med [Internet]. 2015;29(10):885–98. Available from: https://journals.sagepub.com/doi/abs/10.1177/0269216315581538?rfr_dat=cr_pub%3Dpubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&journalCode=pmja

20. Andrade J, Magalhaes M, Pinho-Reis C. Bioethical Principles and Nutrition in Palliative Care. Acta Port Nutr [Internet]. 2017;09:12–6. Available from: http://www.scielo.mec.pt/pdf/apn/n9/n9a03.pdf

21. Crippa A, Lufiego C, Gonçalves A, Carli GA De, Gomes I. Bioethical issues in publications about palliative care of the elderly : critical analysis Research article. Rev bioét [Internet]. 2015;23(1):148–59. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000100149&lng=pt&tlng=pt

22. Girbau M, Monedero P, Centeno C. Integration of the principles of palliative care in intensive care medicine. Cuad Bioética [Internet]. 2016;27(2):175–84. Available from: http://aebioetica.org/revistas/2016/27/90/175.pdf

23. Guo Q, Jacelon CS. Integrative review of dignity in end-of-life care. Palliat Med [Internet]. 2014;28(7):931–40. Available from: https://www.ncbi.nlm.nih.gov/pubmed/24685648

24. Kim DJ, Choi MS. Life-sustaining treatment and palliative care in patients with liver cirrhosis - legal, ethical, and practical issues. Clin Mol Hepatol [Internet]. 2017;23(2):115–22. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5497670/

25. CatSalut. Carta de Drets i Deures de la Ciutadania en relació amb l'Atenció

Sanitària [Internet]. Barcelona: CatSalut; 2015. p. 1–32. Available from: http://canalsalut.gencat.cat/web/.content/_Sistema_de_salut/Drets_i_deures/destacats/carta-drets-deures.pdf

26. Dahlin C. Palliative Care: Delivering Comprehensive Oncology Nursing Care. Semin Oncol Nurs [Internet]. 2015;31(4):327–37. Available from: https://www.sciencedirect.com/science/article/pii/S0749208115000686

27. Codorniu N, Guanter L, Molins A, Utor L. Competéncias enfermeras en cuidados paliativos. Monogr SECPAL [Internet]. 2013;(3). Available from: http://www.secpal.com/%5CDocumentos%5CBlog%5CMONOGRAFIA%203.pdf

28. Piedrafita-Susín AB, Yoldi-Arzoz E, Sánchez-Fernández M, Zuazua-Ros E, Vázquez-Calatayud M. Percepciones, experiencias y conocimientos de las enfermeras sobre cuidados paliativos en las unidades de cuidados intensivos. Enferm Intensiva [Internet]. 2015;26(4):153–65. Available from: https://www.elsevier.es/es-revista-enfermeria-intensiva-142-linkresolver-percepciones-experiencias-conocimientos-las-enfermeras-S1130239915000607

29. Robinson J, Gott M, Gardiner C. Specialitst palliative care nursing and the philisophy of palliative care: a critical discussion. Int J Palliat Nurs [Internet]. 2017;23(7):352–8. Available from: http://eprints.whiterose.ac.uk/120913/3/Robinson

30. Canada L des infirmières et infirmiers du. Code de déontologie des infirmières et infirmiers autorisés [Internet]. 2017. Available from: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-fr/code-de-deontologie-edition-2017-secure-interactive.pdf?la=fr

31. Caunedo Suarez J. Los cuidados de enfermería al paciente terminal en su domicilio. Rqr Enferm Comunitaria [Internet]. 2016;4(4):18–32. Available from: https://dialnet.unirioja.es/servlet/articulo?codigo=5769064

32. Martinez-Litago E, Martínez-Velasco MC, Muniesa-Zaragozano MP. Cuidados paliativos y atención al final de la vida en los pacientes pluripatológicos. Rev Clin Esp [Internet]. 2017;217(9):543–52. Available

from: https://www.sciencedirect.com/science/article/pii/S0014256517302102

33. Tejada F, Ruís M. Abordaje asistencial en el paciente en fase avanzada de enfermedad y familia. Enferm Glob [Internet]. 2009;15:1–13. Available from: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1695-61412009000100003

34. Mussolin Tamaki C, Meneguin S, Aguiar Alencar R, Bronzatto Luppi CH elen. Care to terminal patients. Perception of nurses from the intensive care unit of a hospital. Investig y Educ en enfermería [Internet]. 2014;32(3):414–20. Available from: https://europepmc.org/abstract/med/25504407

35. Pérez M, Cibanal L. Impacto psicosocial en enfermeras que brindan cuidados en fase terminal. Rev Cuid [Internet]. 2016;7(1):1210–8. Available from: http://www.scielo.org.co/scielo.php?pid=S2216-09732016000100009&script=sci_abstract&tlng=es

36. Fernández J, García L, García M, Fernández A, Lozano T, Rubio A. Actitudes y afrontamiento ante la muerte en el personal de enfermería. Tiempos enfermería y salud [Internet]. 2017;2(1):27–33. Available from: https://dialnet.unirioja.es/servlet/articulo?codigo=6319007

37. Contreras S, Sanhueza O. Los pacientes del programa alivio del dolor y cuidados paliativos: razones y significados para enfermeras/os. Cienc y Enfermería [Internet]. 2016;22(1):47–63. Available from: https://scielo.conicyt.cl/scielo.php?script=sci_arttext&pid=S0717-95532016000100005

38. Blaževičiene A, Newland JA, Čivinskiene V, Beckstrand RL. Oncology nurses’ perceptions of obstacles and role at the end-of-life care: cross sectional survey. BMC Palliat Care [Internet]. 2017;16(74):1–8. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5735910/

39. Cirilo JD, Silva MM da, Fuly P dos SC, Moreira MC. Nursing Care Management for Women With Breast Cancer in Palliative Chemotherapy. Texto Context - Enferm [Internet]. 2016;25(3):1–9. Available from: http://www.scielo.br/scielo.php?pid=S0104-

07072016000300325&script=sci_abstract

40. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. J Clin Oncol [Internet]. 2005;23(24):5520–5. Available from: https://www.ncbi.nlm.nih.gov/pubmed/?term=10.1200%2FJCO.2005.08.391

41. Mah L, Grossman D, Grief C, Rootenberg M. Association between patient dignity and anxiety in geriatric palliative care. Palliat Med [Internet]. 2012;27(5):478–9. Available from: http://journals.sagepub.com/doi/10.1177/0269216312

42. Doorenbos A, Jansen K, Oakes R, Wilson S. Palliative Care for Dignified Dying [Internet]. Geneva: International Council of Nurses; 2017. Available from: https://www.icn.ch/sites/default/files/inline-files/Palliative_Care.pdf

43. Juliao M, Oliveira F, Nunes B, Vaz A, Barbosa A. Efficacy of Dignity Therapy on Depression and Anxiety in Portuguese Terminally Ill Patients: A Phase II Randomized Controlled Trial. J Palliat Med. 2014;17(6):688–95.

44. Rudilla D, Barreto P, Oliver A, Galiana L. Estudio comparativo de la eficacia del counselling y de la terapia de la dignidad en pacientes paliativos. Med Paliat. 2014;1–8.

45. Vergo MT, Nimeiri H, Mulcahy M, Benson A, Emanuel L. A feasibility study of dignity therapy in patients with stage IV colorectal cancer actively receiving second-line chemotherapy. J Community Support Oncol [Internet]. 2014;12:446–53. Available from: https://www.ncbi.nlm.nih.gov/pubmed/?term=10.12788%2Fjcso.0096

46. Houmann LJ, Chochinov HM, Kristjanson LJ, Petersen MA, Groenvold M. A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. Palliat Med. 2014;28(5):448–58.

47. Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. Care of the human spirit and the role of dignity therapy : a systematic review of dignity therapy research. BMC Palliat Care [Internet]. 2015;14(8):1–12. Available from: https://0-www-ncbi-nlm-nih-

gov.cataleg.udg.edu/pmc/articles/PMC4384229/

48. Rudilla D, Galiana L, Barreto P, Oliver A. Comparing counseling and dignity therapies in home care patients: A pilot study. Palliat Support Care. 2016;14:321–9.

49. Donato S, Matuoka J, Yamashita C, Salvetti M. Effects of dignity therapy on terminally ill patients : a systematic review. Rev Esc Enferm USP [Internet]. 2016;50(6):1011–21. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342016000601014&lng=en&tlng=en

50. Juliao M, Oliveira F, Nunes B, Vax A, Barbosa A. Effect of dignity therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial. Palliat Support Care. 2017;15:628–37.

51. Vuksanovic D, Green HJ, Dyck M, Morrissey SA. Dignity Therapy and Life Review for Palliative Care Patients : A Randomized Controlled Trial. J Pain Symptom Manage [Internet]. 2017;53(2):162–70. Available from: https://www.ncbi.nlm.nih.gov/pubmed/?term=10.1016%2Fj.jpainsymman.2016.09.005

52. Martínez M, Arantzamendi M, Belar A, Carrasco JM, Carvajal A, Rullán M, et al. 'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review. Palliat Med [Internet]. 2017;31(6):492–509. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5405836/

53. Bentley B, Connor MO, Shaw J, Breen L. A Narrative Review of Dignity Therapy Research. 2017;52:354–62. Available from: http://0-web.b.ebscohost.com.cataleg.udg.edu/ehost/pdfviewer/pdfviewer?vid=3&sid=35bd7fd5-d117-4028-81b7-fafde522f7f7%40pdc-v-sessmgr05

54. Mai SS, Goebel S, Jentschke E, van Oorschot B, Renner K, Weber M. Feasibility, acceptability and adaption of dignity therapy : a mixed methods study achieving 360 ° feedback. BMC Palliat Care [Internet]. 2018;17(73):1–10. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5944046/

55. Rodriguez A, McDermid K. Dignity therapy interventions for young people in palliative care: a rapid structured evidence review. Int J Palliat Nurs [Internet]. 2018;24(7):339–49. Available from: https://www.ncbi.nlm.nih.gov/pubmed/30044704

56. Scarton LJ, Boyken L, Lucero RJ, Fitchett G, Handzo G, Emanuel L, et al. Effects of Dignity Therapy on Family Members: A Systematic Review. J Hosp Palliat Nurs. 2018;20(6):542–7.

9. ANNEXES

9.1. Dignity Therapy Protocol

The protocol therapist follow when the Dignity Therapy is taking place, is the following:

1. Patient selection.

Like any therapeutic modality, the first step is to determine which patients might benefit from Dignity Therapy. After research has been made, criteria has been defined to guide when to apply and not apply the therapy as it is of utmost importance. (1)

Eligibility Criterion

1. *Anyone facing life-threatening or life-limiting Circumstances.* (1)
2. *The patient is interested in Dignity Therapy and feels motivated to take part.* (1)
3. *The patient, and therapist and transcriptionist speak the same language.* (1)

Exclusion Criterion

1. *Anyone who is too ill and who is not expected to live more than about two weeks:* feeling too ill depletes patients of their physical and mental energy. Also, only patients expected to be alive within two-week period is important because it is usually the time needed to complete the entire intervention. (1)
2. *Patients with impaired cognitive ability, limiting the patient's capacity to provide meaningful and reflective responses:* counting delirium, cognitive clouding or cognitive failure, which are common among palliative patients. Also including pseudodementia, poverty of thought that can occur with severe depression. (1)

FIRST SESSION

2. Formally introduction of the Dignity therapy to the patient and family.

Dignity Therapy those not imply mental illness or that the patient is not coping well with the health changing situation. The wording used to introduce the therapy must depend on the patient’s degree of insight and openness in talking about their clinical situation. It is important that the therapist applies the palliative care communication skills. (1)

3. **Answer any questions the patient might have.**

Offering responses that promote a sense of comfort and trust, each question the patient has must be widely recognised and appropriately addressed. (1)

4. **Offer a copy of the basic Dignity Therapy question protocol.**

This provides the patient a clearer idea demystifying the process. It gives the patient the opportunity to deliberate how they wish to respond and consider which issue they would like to include that does not take part in the therapy question protocol. (1)

5. **Collect basic demographic information.**

Baseline information (patient’s name and how they would like to be addressed; age; marital status; who they live with and where; whether they have children or grandchildren (counting their age and names); the nature of their illness and for how long they have been sick; and how they understand the gravity of their illness). This information is useful, as it will help guide the content of the therapy. (1)

6. **Arrange an appointment with the patient to conduct the Dignity Therapy Interview.**

Based on the patient needs and wishes, schedule the interview session within one or ideally no more than three days in a place where privacy can be guaranteed. Arrange whether the patient wants to be accompanied during the sessions by a friend or family member. Determine who, within their family or broad social network, would be the most appropriate recipient or recipients of this generativity document. (1)

SECOND SESSION

7. **Answer remaining questions.**

Summarize Dignity Therapy and answer any question the patient or person accompanying the patient, might have. Answer openly and honestly providing them comfort, confidence and a sense of safety. (1)

8. **Arrange the therapeutic setting and audio recorder.**

Maximize privacy and comfort as much as possible. Seat as close as possible to the patient so that it is easy to speak and listen without raising the voice establishing a sense of intimacy and privacy. Offer the patient something to drink and assure facial tissue is on hand. The friend or family member must seat beside the patient opposite the therapist. Finally, test that the audio recorder is working properly and place it at a correct distance from the patient to ensure a clear and audible recording. Some patient might feel anxiety knowing their words are being recorded. Remind them that any change can be made to the transcript by adding, deleting or changing the information given. (1)

9. **Start the audio recorder and the Dignity Therapy Interview itself. (Table 5)**

Table 5: Dignity Therapy Question Protocol

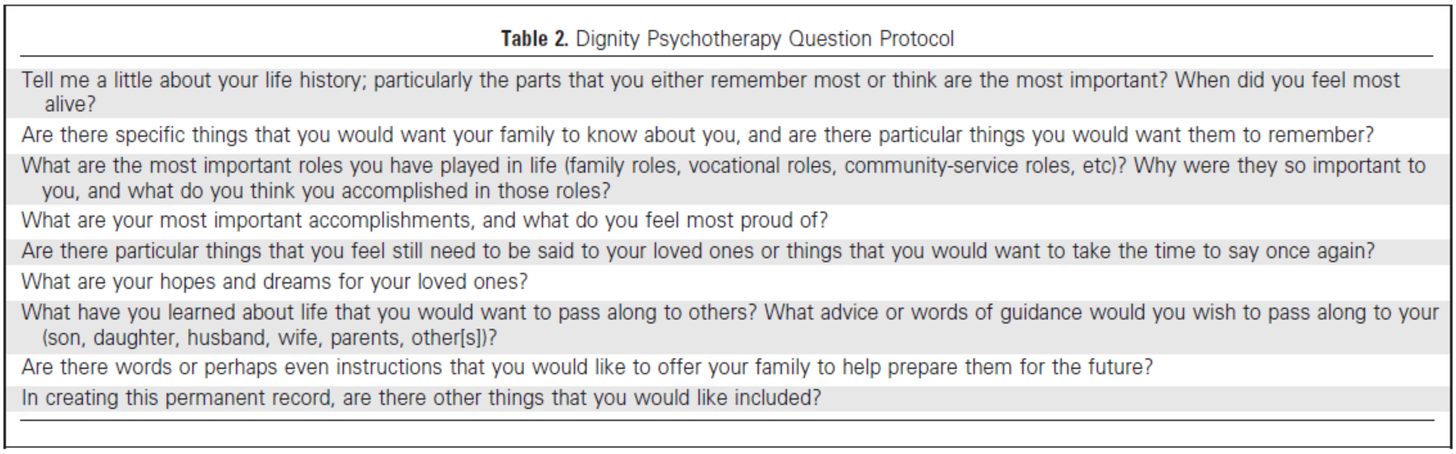


Table 2. Dignity Psychotherapy Question Protocol

Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
In creating this permanent record, are there other things that you would like included?

Source: (40)

GENERATIVITY DOCUMENT CREATION

10. **Transcribe the audio recorder interview.**

The transcription must be done in a time frame of one to three days and it is important to stress the following points:

- Overall approach: finding the needed time and feeling personally invested makes this task emotionally and intellectually gratifying.(1)

- Timing: transcriptionist must be completed as soon as possible within no more than three days.(1)
- Confidentiality: as it contains highly detailed and personal information, confidentiality must be assured by adhering to professional codes and legislation.(1)
- Generativity document layout: as the transcript will be read like a conversation between the therapist and the patient, the dialogue must be labelled correctly.(1)
- Equipment: good quality transcription equipment is essential as patients words are challenging to accurately discern because of the health condition of the patient.(1)
- Accuracy: transcribe as accurately as possible the document including periodic lapses, reconstruction the essence of patient's intended words and emotional tone.(1)
- Word processing and program compatibility: transcriptionists, editors and therapist must use the same word processing program as a quality assurance.(1)
- Electronic transcript transfer: therapist must receive an electronic version of the transcription in order to assure confidentiality when transferring the document by e-mail.(1)
- Debriefing: Transcriptionists' experience must be asked regularly, as it is a high emotional evocative work and it can be helpful. (1)

11. Edit the verbatim transcript.

The editing process includes four primordial tasks. The objective is to create a unique manuscript and make sure each word said by the patient and message will be heard and understand perfectly by the people they love. (1)

- Cleaning up the transcript: it consists in editing the manuscript so that it reads more like prose than a recorded conversation. (1)
- Clarifying the transcript: when speaking the patient may say something they perceive to be obvious, however, later readers might find it less clear. This task has the principal aim of clarifying this ambiguous information.(1)
- Correcting time sequences: when talking, patient may not explain information in a chronological way. Editors must correct time sequences.

Reading a non-chronological generativity document can be difficult to follow.(1)

- Finding a suitable ending: editors must search for a statement that makes an appropriate ending striking an aesthetical tone that is respectful to the process. (1)

THIRD SESSION

12. Patient final say.

After the recorded interview has been transcript and shaped to best of the therapist ability, the document is returned to the patient for a final approval. The entire manuscript is red allowing any corrections to be made. Information can be added, deleted or transformed to ensure it is satisfactory enough. (1)

13. Final corrections made.

The editor makes the final corrections with accuracy in relation to the patient's final say. (1)

FOURTH SESSION

14. Return of the final generativity document.

The final generativity document is returned to the patient and the recipients chosen. During this last session, it can be useful for further interventions to ask for some feedback. It is important to hear the opinions and feelings experienced by the patient and its family during the realization of the Dignity Therapy. (1)