

Review Article

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Abstract

Objective. Dignity therapy (DT) is a kind of psychotherapy that identifies the main concerns of end-of-life patients that affect their perception of dignity and helps them to find a new meaning in life. Most prior studies on DT analyze outcomes for palliative care patients. The aim of this systematic review is to explore the outcomes of DT in palliative care patients' family members.

Method. In June 2020, a bibliographic search was performed using the terms “Dignity Therapy” and “Palliative Care” in the following databases: *Cochrane library*, *TRIP database*, *PUBMED*, *Scopus*, and *Web of Knowledge*. Of the 294 articles found, 8 met the selection criteria and were considered in the present study. No articles were excluded based on their publication date.

Results. Family members generally believe that DT helps them to better prepare the patient's end-of-life and overcome the bereavement phase. The legacy document was considered a source of comfort, and most would recommend DT to other people in their situation. DT is generally considered as important as any other aspect of the patient's treatment.

Significance of results. There is evidence of the benefits of DT for palliative patients' family members. However, there are still few studies that evaluate these outcomes. The existing evidence is poorly generalized, and thus, further studies are needed to deeply explore the benefits of this therapy both for patients and their families.

Introduction

Family is usually involved in medical decisions and provides assistance in the patients' daily routine main activities in a palliative care context (Leow et al., 2014). Thus, palliative care is based on an interaction and communication flow in a caregiving triad: the patient, the healthcare professionals, and the family. The general aim is to improve the quality of life both of the patients facing a potentially deadly disease but also their families via the prevention and relief of suffering (Hauser and Kramer, 2004; Bennett et al., 2010; Nambisan, 2010).

In addition to physical suffering, psychological and spiritual distress are a major problem for palliative care patients and their families. It contributes to a decreased quality of life and increases patients' and families' suffering. Such distress is a huge challenge for healthcare professionals who care for these patients (Julião et al., 2013; Rego et al., 2018; World Health Organization, 2018). Psychological suffering for palliative care patients is also often framed in terms of loss of dignity (Chochinov et al., 2005). Dignity Therapy (DT) was developed by Chochinov et al. (2005) as a brief and individualized psychotherapy based on the dignity model. Its primary purpose is to help patients with advanced disease to free themselves from the usual psychological and emotional anxiety by providing them with an opportunity for creativity or legacy. The aim is to reduce their suffering and increase their dignity. It also aims to help these patients to find a new meaning of life (Chochinov et al., 2005; Fitchett et al., 2015).

DT first gives the patient a questionnaire that aims to be the guide of the forthcoming conversation with the therapist helping him/her to reflect upon the life moments that are more important and that they may want to convey to their loved ones: parts of their lives they feel that are or were more meaningful, stories that most would like to be remembered, or even some advice to their families or friends (Chochinov et al., 2005). This conversation is recorded, transcribed, and edited in a document as a final legacy. It is then delivered to the patient who, if and when he/she wishes, may share with the people he/she most cherishes. Alternatively, the document is delivered to patients' family members or other loved people but is always according to his/her specific will (Hall et al., 2011; Hall et al., 2015; Martinez, 2016).

Evidence shows that DT is effective in the reduction of several pathological issues related to the patient's end-of-life psychosocial experience: depression, anxiety, demoralization, dignity, wish of death, and suffering (Chochinov et al., 2011; Julião et al., 2013, 2014, 2017). However, its impact on the palliative patients' family members is less explored. As mentioned before, the

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welfare of family members of someone who faces a terminal diagnosis is closely linked to the patient's welfare (McClement et al., 2007; EAPC, 2013). Thus, worries about the dignity and the path of end-of-life healthcare are provided to palliative patients with implications for both of them and their families (in the palliative phase and in the bereavement phase) (McClement et al., 2007).

In this last phase — bereavement — families are challenged to adjust their daily lives without the physical, social, and psychological presence of their loved one. In addition to the end of the family as they knew it, each family member (with the death of the palliative patient), loses his individual relationship with him (Corless, 2001). DT has shown signs of being able to help in this difficult phase and is, therefore, of great importance for family members. In addition, the legacy document is usually delivered to the family members who, therefore (directly or indirectly), may experience the effects of DT (McClement et al., 2007). This systematic review emerges from that context with the aim of exploring and synthesizing existing evidence about the impact that DT may have on the palliative patients' family members.

Methods

A comprehensive systematic review using the PRISMA guidelines was conducted (Liberati et al., 2009; Shamseer et al., 2015).

Search strategy

In June 2020, a systematic review of the literature related to the terms “Dignity Therapy” and “Palliative Care” was undertaken in the following databases: *TRIP database*, *Web of Knowledge*, *Scopus*, *Cochrane library*, and *PUBMED*; no articles were excluded based on their publication date.

Selection criteria

The inclusion criteria were as follows: articles published in Portuguese or English focusing on adult family members (≥ 18 years old) of palliative care patients to whom DT (intervention) had been applied in comparison (whenever possible) to a group with the same characteristics but who had achieved standard palliative healthcare/without intervention. The measured outcome was the effect of DT on the family members' psychosocial and spiritual levels. Quantitative and qualitative studies were included. Studies performed on <18-year-old patients and/or family members were excluded as were ones that did not include the palliative patients' participating family members. Opinion articles, clinical cases, review articles, guidelines, news, and editorials were also excluded.

Data collection and analysis process

Study quality and eligibility were performed individually by two researchers. Data extraction was done manually without any extraction software. The results were subjected to critical review by two researchers and a coordinator. Any differing opinions regarding the articles' relevance were solved by reaching a consensus among the authors. The evaluation of the quality and evidence level (EL) of the included articles was discussed and decided by consensus among the authors. The EL and the strength of recommendation (RF) were assigned by the authors considering the criteria of the scale *Strength of Recommendation Taxonomy* (SORT) of the *American Family Physician* (Ebell et al., 2004).

Results

Identification of studies

We found 294 articles using the search terms “Dignity Therapy” and “Palliative Care” in databases: 40 in the *TRIP database*, 117 in the *Web of Knowledge*, 50 in the *Scopus*, 25 in the *Cochrane library*, and 62 in *PUBMED*. Of these, 126 were duplicates and were excluded. Another 137 were excluded due to title and abstract readings leaving a total of 31 articles to be evaluated on a full reading basis. Out of this reading, 23 articles were excluded for not respecting the previously defined inclusion criteria. The PRISMA flow diagram of study selection is shown in [Figure 1](#).

Risk of bias assessment

The risk of bias was determined to evaluate the quality of the selected studies. The EL was assigned by the authors according to the SORT scale criteria (Ebell et al., 2004). The article-by-article evaluation is detailed in [Table 1](#).

The characteristics of the studies evaluated in this review are summarized in [Table 2](#).

Context of the studies and characteristics of the samples

The studies selected samples of populations from Australia ($n = 3$; 37.5%), Canada ($n = 2$; 25%), the United Kingdom ($n = 3$; 37.5%), and Germany ($n = 1$; 12.5%). In addition, $n = 2$ (25%) were carried out in elderly care homes (Chochinov et al., 2012; Goddard et al., 2013), $n = 1$ (12.5%) in palliative healthcare units (PHU) (Mai et al., 2018), $n = 1$ (12.5%) with patients under palliative healthcare teams (not having been specified in which context that healthcare was carried out) (Hall et al., 2013), and $n = 1$ (12.5%) in terminal patients in the community (Johns, 2013); the place of the study was not clearly specified in three studies (37.5%) (McClement et al., 2007; Bentley et al., 2014; Aoun et al., 2015). The patients involved in the studies mostly had oncological pathologies (McClement et al., 2007; Hall et al., 2013; Johns, 2013; Mai et al., 2018) or motor neuron disease (MND) (Bentley et al., 2014; Aoun et al., 2015). In two of the studies, the patients were frail elderly people in care homes (Chochinov et al., 2012; Goddard et al., 2013).

The number of family members in the samples varied between 6 and 60: $n = 6$ (Johns, 2013); $n = 9$ (Hall et al., 2013); $n = 14$ (Goddard et al., 2013); $n = 18$ (Bentley et al., 2014); $n = 18$ (Aoun et al., 2015); $n = 24$ (Chochinov et al., 2012); $n = 30$ (Mai et al., 2018); and $n = 60$ (McClement et al., 2007) ([Table 2](#)). In the studies in which this information was available, they were mostly female constituting from 64.3% up to 72% of the sample (McClement et al., 2007; Goddard et al., 2013; Bentley et al., 2014; Aoun et al., 2015), except for one in which they were mostly men (53%) (Mai et al., 2018). This information is not present in $n = 3$ (37.5%) of the studies (Chochinov et al., 2012; Hall et al., 2013; Johns, 2013). Most studies (62.5%) showed that the family members were mostly composed of the patients' spouses (McClement et al., 2007; Hall et al., 2013; Bentley et al., 2014; Aoun et al., 2015; Mai et al., 2018), except for one of the studies in which most family members were patient's children (12.5%) (Goddard et al., 2013). This information was not available in $n = 2$ (25%) of the articles (Chochinov et al., 2012; Johns, 2013). Three of the studies (37.5%) included not only family members but also friends (Goddard et al., 2013; Hall et al., 2013), care home staff designated by patients to be the recipients of the

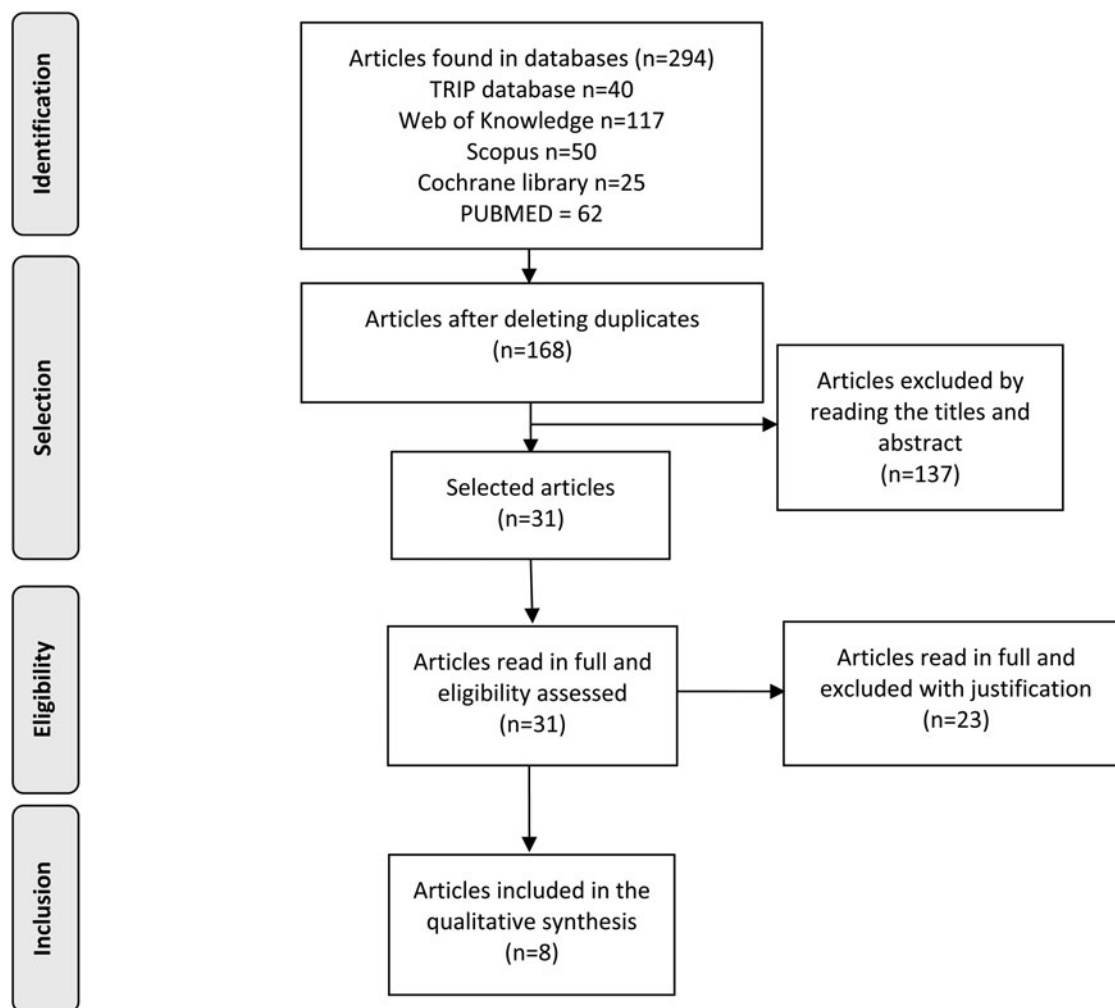


Fig. 1. PRISMA flow diagram showing the literature method search. *n*, the number of articles.

“generativity” document (Goddard et al., 2013), or even “others” — not specified (Mai et al., 2018) (Table 2). Finally, the median age was 57 with a minimum age of 54 years old and maximum age of 61 years old in relation to the analyzed family members’ age. This information was not provided in three articles (37.5%) (Chochinov et al., 2012; Hall et al., 2013; Johns, 2013).

Data collection method

All studies analyzed the effect of DT from the family members’ viewpoint. This includes their perception about the therapy effects on themselves and on the rest of the family as well as the perception of its effects on the ill family members. The family members’ feedback was obtained in all articles through a satisfaction questionnaire only varying the time in which it was applied: one week (Bentley et al., 2014; Aoun et al., 2015), 1 month (Johns, 2013), or 2 months after the administration of DT to the patient (Chochinov et al., 2012) or 9–12 months after his/her death (Mai et al., 2018). In three of the articles, there was no reference to the moment in which the questionnaire was applied (Goddard et al., 2013; Hall et al., 2013; Mai et al., 2018). In most studies, the questionnaire was sent by e-mail or by mail (Hall et al., 2013; Bentley et al., 2014; Aoun et al., 2015). In one study, it was carried out in the form of an interview (Goddard et al., 2013). In the remaining

ones, there was no reference to the way it was applied (McClement et al., 2007; Chochinov et al., 2012; Johns, 2013; Mai et al., 2018). In addition to the satisfaction questionnaire, interviews with the family members were also conducted in two of the studies (Hall et al., 2013; Mai et al., 2018): This was by phone call in one of them (Hall et al., 2013); no details were given in the other case.

Main outcomes: Acceptability and effectiveness

In the selected studies, the effects of DT on palliative patients’ family members psychosocial and spiritual levels were analyzed in terms of acceptability and effectiveness. Acceptability is based on family members’ perception about the usefulness of the intervention in several areas: the impact of care on the stress level, the impact on hope, preparation of the patient for end of life, and the impact on bereavement. Effectiveness was evaluated using validated scales in terms of the caregiver’s burden feeling (through the application of the “Zarit Burden Interview – ZBI-12”) as well as in terms of anxiety and depression [quantified by the scale of *Anxiety and Depression* (HADS)]. One of these articles assessed the effectiveness independent of these two aspects and further analyzed the parameter “hope” that was determined via the *Herth Hope Index* scale.

Table 1. Evaluation of the risk of bias

Artigo/Ano	Factors that decrease the risk of bias	Factors that increase the risk of bias	SORT
Aoun et al. (2015)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Authorized by an ethics committee; - Well-defined patient range; - Well-characterized diagnosis; - Researcher independent of therapist; - Adequate follow-up; - Well-defined inclusion and exclusion criteria; - Questionnaires sent and returned by e-mail; - Authors declare to have no conflicts of interest. 	<ul style="list-style-type: none"> - Not specified how the sample was calculated; - Without comparative group; - Small sample; - Low response rate after the call. 	2
Chochinov et al. (2012)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Authorized by an ethics committee; - Well-defined inclusion and exclusion criteria. 	<ul style="list-style-type: none"> - Participants not selected by the researchers; - Heterogeneous patient range; - Questionnaire applied directly by the researcher; - Small sample; - Not specified how the sample was calculated; - Therapist was part of the research team; - Low response rate after the call; - Without comparative group; - Significant follow-up losses; - No reference to conflicts of interest. 	2
Goddard et al. (2013)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Authorized by an ethics committee; - Adequate follow-up; - Well-defined inclusion and exclusion criteria; - Authors declare to have no conflicts of interest. 	<ul style="list-style-type: none"> - Heterogeneous patient range; - Not specified how the sample was calculated; - Therapist was part of the research team; - Questionnaire applied directly by the researcher; - Without comparative group; - Small sample. 	2
McClement et al. (2007)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Adequate follow-up; - Participants without contact with the research team; - Well-defined patient range; - Considerable number of participants; - Well-characterized diagnosis. 	<ul style="list-style-type: none"> - Inclusion and exclusion criteria not explained; - Not specified how the sample was calculated; - Not specified how the questionnaire was delivered; - Without comparative group; - Without reference to approval by the ethics committee; - No reference to conflicts of interest. 	2
Mai et al. (2018)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Adequate follow-up; - Well-defined inclusion and exclusion criteria; - Researcher independent of therapist; - Well-defined patient range; - Well-characterized diagnosis; - Authors declare to have no conflicts of interest; - Authorized by an ethics committee. 	<ul style="list-style-type: none"> - Low response rate after the call; - Unclear how the questionnaire was delivered; - No comparative group; - Not specified how the sample was calculated; - Small sample. 	2
Bentley et al. (2014)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - Authorized by an ethics committee; - Well-defined inclusion and exclusion criteria; - Questionnaires sent and returned by e-mail or by an independent researcher; - Well-defined patient range; - Well-characterized diagnosis; - High response rate after the call; - Adequate follow-up; - Authors declare to have no conflicts of interest. 	<ul style="list-style-type: none"> - Small sample; - Not specified how the sample was calculated; - Without comparative group; - The therapist was part of the research team. 	2
Hall et al. (2013)	<ul style="list-style-type: none"> - Intentional sampling; - Several researchers; - With comparative group; - Randomized; - Authorized by an ethics committee; - Well-defined inclusion and exclusion criteria; - Researcher independent of therapist; - Participant selection process explained; - Well-defined patient range; 	<ul style="list-style-type: none"> - Small sample; - Not specified how the sample was calculated; - Performed only descriptive analysis. 	2

(Continued)

Table 1. (Continued.)

Artigo/Ano	Factors that decrease the risk of bias	Factors that increase the risk of bias	SORT
	<ul style="list-style-type: none"> - Adequate follow-up; - Well-characterized diagnosis; - Authors declare to have no conflicts of interest. 		
Johns (2013)	<ul style="list-style-type: none"> - Intentional sampling; - Researcher independent therapist; - Well-defined patient range; - Well-characterized diagnosis; - Adequate follow-up. 	<ul style="list-style-type: none"> - Only one researcher; - Poorly defined inclusion and exclusion criteria; - Few participants; - It is not clear how the questionnaire was delivered; - No comparative group; - Not specified how the sample was calculated; - Female sample only; - No reference to conflicts of interest; - Without reference to approval by the ethics committee. 	2

Acceptability

Acceptability was analyzed in all of the studies. The final document was considered a source of comfort by the palliative patients' family members, and most of them would recommend DT to other people in the same situation as theirs (McClement et al., 2007; Chochinov et al., 2012; Goddard et al., 2013; Johns, 2013; Bentley et al., 2014; Aoun et al., 2015; Mai et al., 2018). Furthermore, the family members believe that DT helped them to better prepare for the end of life of the palliative patient (Aoun et al., 2015). Some even mentioned that the intervention helped them to overcome the bereavement in a better way (McClement et al., 2007; Goddard et al., 2013; Mai et al., 2018). In addition, the family members considered DT to be as important as any other aspect of the patient's treatment (McClement et al., 2007; Johns, 2013; Aoun et al., 2015; Mai et al., 2018). The influence of DT in the stress level of care was studied in two articles (25%) (Bentley et al., 2014; Aoun et al., 2015): The results were more heterogeneous and contribute to this reduction (Aoun et al., 2015). This was not seen in the other study (Bentley et al., 2014). Finally, in the only article that evaluated the impact of DT on hope in terms of acceptability, 33.3% of the families felt that DT helped to improve their hope (Aoun et al., 2015).

Effectiveness

Effectiveness of DT was analyzed in only two of the included articles: Bentley et al. (2014) and Aoun et al. (2015). In terms of effectiveness, there were no significant changes pre-/post-DT for the family members in terms of the caregiver's burden feeling (ZBI-12), anxiety, and depression (HADS) (Bentley et al., 2014; Aoun et al., 2015). One of those articles, apart from these two aspects, further analyzed the hope parameter via the *Herth Hope Index* scale. There were no significant differences (Bentley et al., 2014).

Limitations

Some aspects of disagreement were sometimes mentioned despite the fact that most family members were favorable to DT. In this context, some family members viewed the reading of the final document as potentially being hurtful or causing more suffering in the family in the bereavement process itself. They further suggested that it may

sometimes portray the patient in an incomplete or imprecise way thus creating a distorted image of him/her. Finally, they considered the possibility of DT being physically/emotionally demanding for the patients not only due to the disease progression but also due to the implicit end-of-life message of this therapy (McClement et al., 2007; Goddard et al., 2013; Hall et al., 2013).

Discussion

DT is a psychotherapeutic approach based on a validated model of dignity in palliative patients (Chochinov et al., 2005). Unlike most of the other palliative healthcare interventions that are more focused on symptoms, the effects of DT lie in its potential to improve the life meaning of the patients to whom it is applied (Chochinov, 2007). In the field of DT, several studies have evaluated the psychosocial, spiritual, and physical effects of this intervention in palliative patients, but there are still only a few that have evaluated these outcomes on palliative patients' family members. While DT's main focus is on the patient, family members are also a very important part and a potential target for this therapy (Hauser and Kramer, 2004). Family caregivers often experience feelings of anxiety, exhaustion, and discouragement; they can potentially benefit from interventions that can mitigate these feelings such as DT (Adelman et al., 2004). Surprisingly, research on the effects of DT on family members is still rare. In addition, the literature has only a systematic review about these effects on family members based on different criteria (Scarton et al., 2018). Thus, further studies are needed to deeply explore the benefits of this therapy not only for the patients but also for their families.

In the studies that assessed the DT effects on palliative patients, it is clear from the literature that DT has a positive impact in terms of acceptability especially in patients' dignity (Chochinov et al., 2005; Chochinov et al., 2011; Houmann et al., 2014; Rudilla et al., 2015; Donato et al., 2016; Julião et al., 2017; Scarton et al., 2018), opinions about the benefits of the therapy (Chochinov et al., 2005; Chochinov et al., 2011; Hall et al., 2011; Fitchett et al., 2015; Martínez et al., 2016), decreased suffering (Chochinov et al., 2005; Chochinov et al., 2011; Hall et al., 2011, 2013; Martínez et al., 2016; Julião et al., 2017), will to live (Chochinov et al., 2005; Hall et al., 2013; Houmann et al., 2014; Fitchett et al., 2015; Donato et al., 2016;

Table 2. Systematic review results

Article	Type of study	Sample/Intervention	Main objectives	Results
Aoun et al. (2015)	Pre- and post-intervention design	<i>Sample:</i> Australian; $n = 18$ caregivers; $n = 27$ patients with MND. <i>Intervention:</i> One week after the application of DT, questionnaires were distributed to the participants, which were then sent by mail to the researchers.	To assess the acceptability, feasibility and effectiveness of DT for reducing distress in people with MND and their family.	<i>Demographic analysis:</i> Two-thirds of the patients were male ($n = 18$). The mean age was 64.3 years (SD 10.7). All family members ($n = 18$) were the patients' spouses; 72% were women ($n = 13$); average age: 59.9 years old (SD 11.8). <i>Acceptability:</i> 72.2% of family members state that the final document will continue to be a source of comfort (SD 0.62) and 77.8% will recommend DT to others in their situation (SD 0.69); 33.3% felt that DT helped to improve feelings of hope (SD 0.76) and reduced stress (SD 0.91); 50% reported that it helped them to better prepare the patient's end of life (SD 1.09); 61.1% of caregivers reported that DT was as important as any other aspect of the patient's treatment (SD 0.98). <i>Effectiveness:</i> There were no significant changes before/after DT for family members in terms of the caregiver's "burden," hope, anxiety, and depression feeling.
Chochinov et al. (2012)	Cross-sectional	<i>Sample:</i> Canadian; $n = 12$ cognitively intact and $n = 11$ cognitively impaired, frail elderly in long-term care; $n = 24$ family members. <i>Intervention:</i> Questionnaire to family members 2 months after intervention.	To evaluate the feasibility of DT in the elderly.	<i>Demographic analysis:</i> Of the $n = 23$ elderly participants, 18 were women and 5 were men; the mean age was 80 years. <i>Feedback from family members of elderly people cognitively able to participate in DT:</i> All were women. The majority (80%) felt that DT helped their relative with >50% in agreement with the fact that this is an important component of caring for their relative. All but one family member would recommend DT to others in the same situation. 40% believe that DT will continue to be a source of comfort for the family. However, most do not refer to these benefits in terms of dignity, reduced suffering, or preparation for the future. <i>Feedback from family members of elderly people cognitively unable to participate in DT:</i> Only nine gave feedback about DT ($n = 6$ women, $n = 3$ men, $n = 4$ spouses, $n = 4$ children, $n = 1$ sibling). Everyone would recommend DT to others in the same situation. Most (8/9) felt that DT will be useful for them and their remaining family giving them comfort. 6/9 believe that DT will change their opinion about the relative in question. Once again however, family members do not mention the benefits in terms of reducing suffering or improving dignity.
Goddard et al. (2013)	Qualitative Study	<i>Sample:</i> UK; $n = 27$ older adults living in care homes; $n = 14$ family/friend/staff of older adults living in care homes who received DT documents before patient's death. <i>Intervention:</i> Framework analysis of qualitative interviews conducted; interviews related to family views on the impact of DT for themselves and patient.	Explore the views and experiences of DT for older people in care homes from the perspective of family members.	<i>Demographic analysis:</i> Of the $n = 14$ participants in the study, nine were female and five were male. Regarding the relationship with the patient, six were children, two were nephews, two were friends, one was a grandson, one was a daughter-in-law, and two were staff members. The mean age of the family members who participated was 57 years old (46–76). <i>Views on the document:</i> Almost all participants felt that residents were very satisfied with their documents and were pleased to have had the opportunity to create them. <i>Impact on residents:</i> Almost all participants were positive about the interaction between the therapist and resident. Reappraisal and reminiscence also described as a positive benefit for patients. Despite several perceived benefits for the residents, concerns were raised by five participants on the feasibility of DT in care homes (i.e., memory loss and strain this may cause); six subjects were concerned with the impact of DT on patients who were not distressed or felt a loss of dignity. <i>Impact on family:</i> seven family/friends felt their knowledge regarding the patient increased. There was evidence that the document enhanced communication between the recipients and residents. Most participants felt that the document would be helpful during their bereavement.

(Continued)

Table 2. (Continued.)

Article	Type of study	Sample/Intervention	Main objectives	Results
McClement et al. (2007)	Qualitative Study	<i>Sample:</i> Canadian and Australian; $n = 113$ patients, 97% with oncological diseases and 3% with non-malignant conditions; $n = 60$ family members; $n = 16$ (11.6%) refused to participate in DT evaluation phase. <i>Intervention:</i> assessment of family members about the benefit of DT, 9–12 months after the patient's death.	Explore DT impact on families and patients from a family point of view.	<i>Demographic analysis:</i> Mean age of the $n = 60$ family members who participated was 54.5 years old (SD 14.3). 70% of the family members were women — mostly the spouse (53.3%) or child (31.7%). <i>For the benefit of patients:</i> – 95% of family members reported that the TD helped the patient because it encouraged them to share their feelings. They would recommend it to other patients and families in the same situation; – 78% of family members report that the therapy increased the patient's sense of dignity and 72% the sense of life. – 65% indicated that DT helped the patient to prepare for death with the same percentage indicating that it was as important as any other therapeutic attitude; – 43% reported that DT reduced the suffering of the palliative family member. <i>For the benefit of family members:</i> – 78% of family members report that DT — especially the final document — helped them in the grieving phase with 76% indicating that the respective document will continue to be a source of comfort.
Mai et al. (2018)	Pre- and post-intervention design	<i>Sample:</i> German; $n = 72$ patients met the inclusion criteria. Of these, $n = 30$ participated in the study. All had oncological pathology; $n = 30$ family members.	Investigate the feasibility, applicability, and acceptability of DT in palliative care units both from the point of view of patients and family members.	<i>Demographic analysis:</i> Of the 30 patients who participated, 10 (33%) were men and 20 (67%) were women. Their median age was 63 years old (SD 9.9). Of the 30 family members who participated in the study, the average age was 54 years old (SD 12.83) with 53.3% men and 46.7% women. Most were spouses (56.7%) or children (20%), siblings (10%), parents (6.7%), or others — not specified (6.7%) less frequent. <i>For the benefit of patients:</i> Of the 30 family members who participated in the study, 26 gave feedback of which 23 (88.5%) rated DT as beneficial to the sick family member. Twenty (76.9%) reported that DT was as important as any other aspect of the patient's treatment; 24 (92.4%) would recommend DT to other patients and families in the same situation. <i>For the benefit of family members:</i> Of the 26 family members who responded, 13 (52%) are of the opinion that DT helped them during the grieving process and 16 (64%) believe that it will continue to be a source of comfort for the family.
Bentley et al. (2014)	Pre- and post-intervention design	<i>Sample:</i> Australian; $n = 29$ patients with MND from whom $n = 18$ family members were recruited. <i>Intervention:</i> The evaluation of the results of the family members was made initially and one week after the delivery of the final document.	To evaluate the feasibility, acceptability, and potential effectiveness of DT for family caregivers of people with MND.	<i>Demographic analysis:</i> Of the 18 family members, 13 were women and 5 were men. The median age was 61 (ranging from 38 to 80). All family members were spouses/partners of palliative patients. <i>Effectiveness:</i> Family members reported a significant increase in fatigue since the beginning of DT at the same time that the physical condition of the sick family member worsened; however, it became insignificant after controlling this state ($p = 0.024$). There were no significant changes in the parameter of hope ($p = 0.083$), anxiety ($p = 0.257$), or depression ($p = 0.860$). <i>Acceptability:</i> The benefits and acceptability reported by family members were very different: some reported that DT helped them ($n = 9$) while some were of the opposite opinion ($n = 4$). As to the benefit of DT in terms of the stress reduction as a caregiver, five agreed with it and six did not agree with it. However, 14 would recommend DT to other patients and families in the same situation. Thirteen subjects that the resulting document would continue to be a source of comfort for the entire family. <i>Viability:</i> In general terms, DT sessions in which the family members were present took longer. The number of days required to complete DT was an average of 46 in cases where family members were present and 39 in other cases.

(Continued)

Table 2. (Continued.)

Article	Type of study	Sample/Intervention	Main objectives	Results
Hall et al. (2013)	Qualitative part of a bigger RCT study	<i>Sample:</i> UK; $n = 45$ adults with cancer referred to palliative care teams. Intervention (DT $n = 22$), Control (Standard Palliative Care $n = 23$); $n = 9$ family members of patients in the intervention group (DT). <i>Intervention:</i> Interviews with families ($n = 9$) of patients in DT group. Framework analysis.	To explore the views of study and control group participants concerning the benefits of taking part in DT.	<i>Demographic analysis:</i> Four family members were spouses, three were sisters, one was a daughter, and one was a friend. <i>Generativity:</i> Three family members felt that DT helped in what generativity issues were concerned. <i>Negative aspects of DT:</i> Five family members felt that the final document was incomplete and indicated negative aspects of the therapy. <i>Positive aspects of DT:</i> Three family members reported that participation in this study improved the feelings of importance, sense of life, and value of the patients in question. Two family members reported that DT made patients more optimistic about the future. Four family members reported that the final document improved communication in the family allowing them to talk about different topics in a more open way.
Johns (2013)	Pre- and post-intervention design	<i>Sample:</i> US; $n = 10$ patients with metastatic cancer; $n = 6$ family members. <i>Intervention:</i> Satisfaction questionnaires were applied 1 month after receiving the final document, having the satisfaction with the therapy been classified on an increasing scale of 0–4.	Evaluate the feasibility of applying DT in a university-based cancer center.	<i>Demographic Analysis:</i> All patients were women with a mean age of 50.5 years old (SD 14.4). All family members rated DT as an important help; 75% of the family members believe that DT reduced the patient's total suffering. All family members indicated that the therapy increased the patient's sense of dignity, meaning, and purpose in life. <i>Family members also classified DT according to the referred scale:</i> – As important as any other aspect of the patient's care: 2.7 (SD 1.0); – His/her final document will continue to be a source of comfort for the family: 3.3 (SD 0.5); – They would recommend it to other patients and family members in the same situation: 3.7 (SD 0.5).

Martínez et al., 2016; Julião et al., 2017; Scarton et al., 2018), and life purpose (Chochinov et al., 2005; Houmann et al., 2014; Fitchett et al., 2015; Donato et al., 2016; Scarton et al., 2018). The acceptability parameter was evaluated here, and the results of this review were similar to palliative patients' family members, suggesting that DT can have the same positive effects.

On the other hand, the effectiveness results with regard to palliative patients were less consistent in terms of depression and anxiety scores. The results were favorable in some studies (Julião et al., 2013, 2014); others were not statistically significant (Hall et al., 2013; Donato et al., 2016; Martínez et al., 2016). The same phenomenon occurred in this review for palliative patients' family members. There were no significant changes pre-/post-DT in terms of effectiveness for family members (Bentley et al., 2014; Aoun et al., 2015). In articles whose results in terms of effectiveness for patients were favorable, the study sample experienced high levels of depression and anxiety at baseline. The authors suggested that low base rates of distress and anxiety were a possible explanation for the inability to demonstrate DT's influence on this outcome in other studies (Julião et al., 2013, 2014). In fact, the studies in this review that analyze this outcome for palliative patients' family members found that there were no significant changes but do suggest that DT can decrease anxiety and depression in family caregivers who are experiencing moderate to high levels of distress (Bentley et al., 2014; Aoun et al., 2015). Similarly, a letter to the editor presented the effects of DT on 25 palliative patients' family members using the mental health inventory (MHI) in which the family members indicated moderate to high psychological well-being before the intervention: The results showed no significant differences before

and after the intervention — likely because of the high baseline MHI scores (Julião, 2017). Thus, further studies are needed to better explore this point — preferably with participants with high baseline levels of anxiety and depression.

The gender of the caregiver seems to influence the experience of caring for the palliative patient (Washington et al., 2015). In this review, most family members were female and the patient's spouse makes it difficult to extrapolate the results to the remaining family members. Examples include friends or other acquaintances (like care home staff) that are sometimes designated by the patients to be the receivers of the final document (Goddard et al., 2013; Hall et al., 2013; Mai et al., 2018) and that are often also involved in the care of these patients. In general, to fully evaluate the effect of DT in demographic terms, it would be necessary in all analyzed articles to characterize both the patient getting the therapy and his/her family members in a better way. It would also be helpful for future researchers to understand the wide range of recipients to whom DT documents are provided. This could ascertain its effectiveness according to the presented characteristics but also understand in which family members/friends/other acquaintances and with what characteristics the therapy may be more effective. The studies that analyze these parameters do not do it in a critical way — they present the results only quantitatively (McClement et al., 2007; Goddard et al., 2013; Hall et al., 2013; Bentley et al., 2014; Aoun et al., 2015; Mai et al., 2018).

Most patients in these studies had cancer (McClement et al., 2007; Hall et al., 2013; Johns, 2013; Mai et al., 2018), which is similar to the WHO report. Oncological pathologies are one of the main pathologies suffered by patients in need of palliative care (World Health Organization, 2018). It would be interesting to

study the impact of DT on family members of patients with other types of pathologies besides cancer and MND, i.e., chronic cardiovascular and respiratory disease.

When DT is provided in the last few weeks or months of life, patients and their families may experience it quite differently than when it is provided in the last few years of life. Two of the studies were about frail elderly people in care homes who may not be typically seen as terminal patients; their main objective was to assess the feasibility (Chochinov et al., 2012; Goddard et al., 2013), acceptability, and potential effectiveness (Goddard et al., 2013) of DT in older people in care homes. The findings of these two studies suggest that DT may be useful for enhancing the end-of-life experience for residents and their families. They introduce evidence that DT has a role to play among this population suggesting the need for further study in this area. Thus, existential issues facing the elderly likely approximate those facing people who are approaching end of life because of illness (Chochinov et al., 2012).

The time in which the final evaluation was applied, in the studies in which it was known, also varied between one week after the performance of DT and 12 months after the death of the patient in question. This later case involved family members already in the bereavement phase. Bereavement is a complex and multidimensional process that involves the physical, psychological, social, and spiritual domain (Sanders, 1999; Chochinov, 2005). The experience of losing someone close often comes up as a profound change in an individual's life path involving a lengthy process of restructuring the meaning of the loss in which the individual has to relearn how to live in a new world without the person lost (Puigarnau, 2010). The moment of application of the evaluation about the effects of the DT can thus depend on the moment it was applied and, consequently, on the stage the family is going through. This leads to different evaluations by the family members who are inherently at different stages in the course of the disease or the bereavement for the palliative patient in question (Kübler-Ross, 1969).

It is also necessary to consider how the respective evaluation of the therapy was carried out. Besides indicating a lack of standardization, this may also have influenced the family members' responses. For instance, family members who answered questions in person or on the phone with a member of the research team — especially in cases where they were the ones who applied the therapy — may have inhibited them from highlighting any potential negative aspects of the therapy thus constituting a limitation of the studies in question. This approach to evaluation can be seen in a positive way because this contact with the therapist/research team may give way to the creation of a therapeutic alliance and to a future feeling of ease for the family to address sensitive issues that they may need to face. Furthermore, the benefits of this therapy are complemented by a personalized description based on the participants' free comments introducing subjectivity (McClement et al., 2007; Goddard et al., 2013; Bentley et al., 2014; Mai et al., 2018). This heterogeneity and subjectivity can be beneficial from the viewpoint of reading each individual study. It can allow the benefits of the therapy to be addressed in a more broad, unique, and comprehensive way. However, the measures used in these studies may vary depending on the country, culture, socio-economic status, age, gender, marital, and familial status, i.e., single, have children or close family members, or if they have gone through a similar disease/situation of a family member (death in palliative care). The specific outcomes that could be affected include acceptability, the notion of benefit from the therapy, a feeling of reduced stress, improved parameters of hope, and better

preparation for the end of life. This impact is due to the subjective conceptual character and difficulty in generalizing these feelings.

A key limitation of most studies in this review was the low number of participants (Chochinov et al., 2012; Goddard et al., 2013; Hall et al., 2013; Johns, 2013; Bentley et al., 2014; Aoun et al., 2015; Mai et al., 2018). This makes it difficult to extrapolate the conclusions to the general population. This comparison was not made except for one of the articles in which there was a control group submitted to standard palliative care compared with another one that received standard care in addition to DT (Hall et al., 2013). To determine the effectiveness of this therapy for family members and patients, future prospective studies with suitable controls should be performed as in Julião et al. Here, DT improved depression and anxiety in the treated patients (Julião et al., 2013, 2014, 2017).

All of these findings raise important questions: Namely, whether the same would be true in patients with different characteristics from the patients analyzed in the studies in this review, whether the measures used are the most appropriate to assess the effects of this type of intervention, and whether the results would be similar in studies with a larger number of participants because most of these studies had small sample sizes.

Conclusion

The main objective of this systematic review was to explore the psychosocial and spiritual outcomes of DT on palliative patients' family members. The importance of family members in palliative care is recognized worldwide and is an integral part of the WHO definition of palliative care (World Health Organization, 2018). In this context, it is necessary to perform more studies involving the family members of palliative patients as participants with the aim of covering the entire care unit for patients at the end of their lives (Bennett et al., 2010; Nambisan, 2010). Without the perspectives of family caregivers, it is difficult to fully understand the needs for palliative care and develop effective interventions in this regard (Aoun et al., 2016).

The evidence suggests that family members generally believe that DT will better prepare patients for end of life and overcome the bereavement phase. In addition, the legacy document was considered to be a source of comfort, and most family members would recommend DT to others in their situation considering DT as important as any other aspect of the patient's treatment.

The results of this systematic review are encouraging but still reveal many aspects that need to be investigated further so that DT can be used in the most appropriate and beneficial way possible. Further studies are also needed to evaluate the effects of DT on family members. They should preferably be methodologically more uniform: not only in relation to the patient samples but also to the measures used to quantify the benefit of this therapy, forms of evaluation, as well as ways and times in which the therapy is applied. Thus, the conclusions can be more objectively useful and generalizable. It would also be interesting to perform studies with a larger number of participants and, whenever possible, with a control group. The results of such studies could have a significant impact on the way patients and family members deal with end of life and bereavement issues. This could improve the overall well-being of these patients and their families.

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