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**Published version**

RODRIGUEZ, Alison, SMITH, Joanna and MCDERMID, Kirstine (2018). Dignity therapy interventions for young people in palliative care: a rapid structured evidence review. *International journal of palliative nursing*, 24 (7), 339-349.

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# **Dignity Therapy and related meaning making interventions for young people in palliative care: A rapid structured evidence review**

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## **Abstract**

**Background:** Dignity Therapy is becoming established in adult settings, with research supporting its effectiveness. The article summarises and synthesises the research that has explored Dignity Therapy and related meaning making interventions in palliative care with young people.

**Methods:** A rapid structured review was undertaken. Quality appraisal was based on the Randomized Control Trial or Cohort Study CASP tool.

**Results:** Four studies met the inclusion criteria; one focused on young people (7-17 years), the other three included young people but mean ages were 50-70. Dignity Therapy was found to improve aspects of well-being and was perceived as helpful for the family.

**Conclusions:** Dignity Therapy is well received with improvements in measures of well-being. However, few studies have included young people (24 years and below). There is a clear gap in the literature, suggesting the need to develop and evaluate a Dignity Therapy or related meaning making intervention to support young people.

## Introduction

There is growing evidence that emotional suffering and psychological distress are significant concerns for individuals receiving palliative care. Research has found that psychosocial and existential issues may be of greater importance than physical pain and disease symptoms (Hall et al 2009). Dignity Therapy (DT) aims to address psychosocial and existential distress by engaging patients in a brief, individualised psychotherapeutic intervention designed to engender a sense of meaning and purpose (Chochinov et al 2005). DT has evolved from the Dignity Conserving Model of Care (DCMC), developed from detailed qualitative work that explored what constitutes dignity and how it can be achieved or maintained through experiences, cares and interactions (Chochinov 2002). The DCMC and subsequent DT has been found relevant to many Life Threatening (LTCs) and Life Limiting Conditions (LLCs), despite the original focus being on adults with cancer (Chochinov et al 2005; Chochinov 2012).

During DT, trained professionals undertake a one to one semi structured interview, usually lasting no more than an hour with the patient, based on questions developed from key tenets of the DCMC. Patients are encouraged to think about and discuss what they perceive to be their most valued memories, accomplishments, roles and life lessons, and are guided to articulate the hopes or dreams they may have for their significant others. The questions are structured in such a way that it is envisaged patients will feel a reinforced sense of self and a heightened sense of meaning and purpose (Chochinov 2002, Figure 1).

### Figure 1: Databases and sources searched

Cinahl (Ebsco) 1981-present
ClinicalTrials.gov
Cochrane Database of Systematic Reviews (Wiley): Issue 12 of 12, March 2017
Cochrane Database of Abstracts of Reviews of Effect (Wiley): Issue 2 of 4, April 2015
Cochrane Central Register of Controlled Trials (Wiley): Issue 3 of 12, March 2017
Embase Classic+Embase (Ovid)<1947 to 2017 March 30>
Ovid MEDLINE(R) 1946 to March Week 4 2017
Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations March 29, 2017
PsycINFO 1806 to March Week 3 2017
Scopus (Elsevier) 1823 – present
Sciences Citation Index Expanded (Thomson Reuters Web of Science) 1900-present
Conference Proceedings Citation Index- Science (Thomson Reuters Web of Science) 1990-present

The interview is digitally recorded, transcribed, edited and returned to the patient, who can then make any changes before the document is finalised and structured into either a question or answer format or storied narrative. The document is then labelled as a generativity document or written legacy (Chochinov 2012). Generativity documents are evolving; for example, DT with older adults has resulted in producing picture books, including cherished photos alongside briefer key commentaries (Johnston et al 2016). Many patients share their generativity documents with family and friends prior to their death, providing opportunity for meaningful family conversations that can assist with the bereavement process (McClement et al 2007).

As a psychotherapeutic approach there is international interest in DT and its potential to improve the wellbeing and overall quality of life of patients at the end of life, and their families. Studies in adult populations are emerging in North America, China, Japan, Taiwan, New Zealand, Australia and Western Europe (Chochinov et al 2005; Chochinov 2012; Martinez et al 2017). It is likely that DT and related meaning making interventions will have similar benefits for young people. A national survey undertaken in the United States of America identified that young people with LTCs and LLCs are engaging in meaning making activities. However, these activities are not necessarily reported or evaluated in the peer reviewed literature or openly discussed as interventions that directly support young people facing shortened lives and the family bereavement process (Foster et al 2012). This is a missed opportunity to support young people and their families to engage in meaningful discussion about dignity, legacy and end of life care in a structured way.

Unlike many adult palliative care populations, young people with LTCs or LLCs can be receiving active and palliative treatment concurrently and live for years with deemed to be terminal conditions (Liben et al 2008). Young people in receipt of palliative care and their families can live with anticipatory grief for some time (Rodriguez and King 2009; Rodriguez and King 2014). There is often less certainty around prognosis and time lines for these young people; yet there has to be assumptions made with respect to longevity, given the necessity to identify the services (such as child or adult hospice/palliative care) that best meet their needs (Together for Short Lives 2017).

Improving the young person's quality of life and well-being throughout their shortened life journey should involve attending to their psychological and existential needs. This could be achieved using structured and focused interventions in order to provide holistic care. The frequent situation of the young person 'not knowing' the potential eventuality of their condition or the more likely scenario of the family perception of 'them not knowing' can heighten psychological and existential distress for the young person (Aldridge et al 2017). However, in considering Chochinov's DT protocol (Chochinov et al 2005), it may be that for some young people a one to one DT interview may be challenging because of their cognitive and oral communication abilities, and that a written narrative document may be less meaningful to them.

To determine whether DT and related meaning making interventions are suitable for young people who are experiencing the realities of their conditions, there is a need to identify and summarise the current evidence base and evaluate what interventions may be acceptable and efficacious for those aged 12-24 years and their families.

#### Aim

This review aimed to summarise and synthesis research that has explored DT and related meaning making interventions with young people (aged 12-24 years) to answer the following questions:

What DT and related meaning making interventions have been used, and evaluated, with young people in palliative care?

What are young people's experiences and perceptions of DT and related meaning making interventions in palliative care?

#### **Methods**

A rapid structured review was undertaken using systematic methods to summarise and synthesis research findings within the constraints of a given timeframe and limited resources. A rapid structured review differs from a systematic review in relation to the extensiveness of the search and methods used to undertake the analysis (Centre for Reviews and Dissemination (CRD) 2009). Rapid structured reviews are appropriate to identify future research priorities or, as in the case of the review presented, to identify the suitability of a DT type intervention for young people prior to undertaking research in a related area.

The methods used to undertake the review were informed by guidance for undertaking systematic reviews developed by the United Kingdom Centre for Reviews and Dissemination (CRD 2009).

Primary research studies were selected based on the following criteria:

#### Inclusion criteria

1. Sample included young people (12-24 years of age);
2. Interventions or young people's exercise related to Dignity Therapy or meaning making;
3. Health care context was either palliative or end of life care;
4. Studies were included if either quantitative or qualitative or mixed method designs.

#### Exclusion criteria

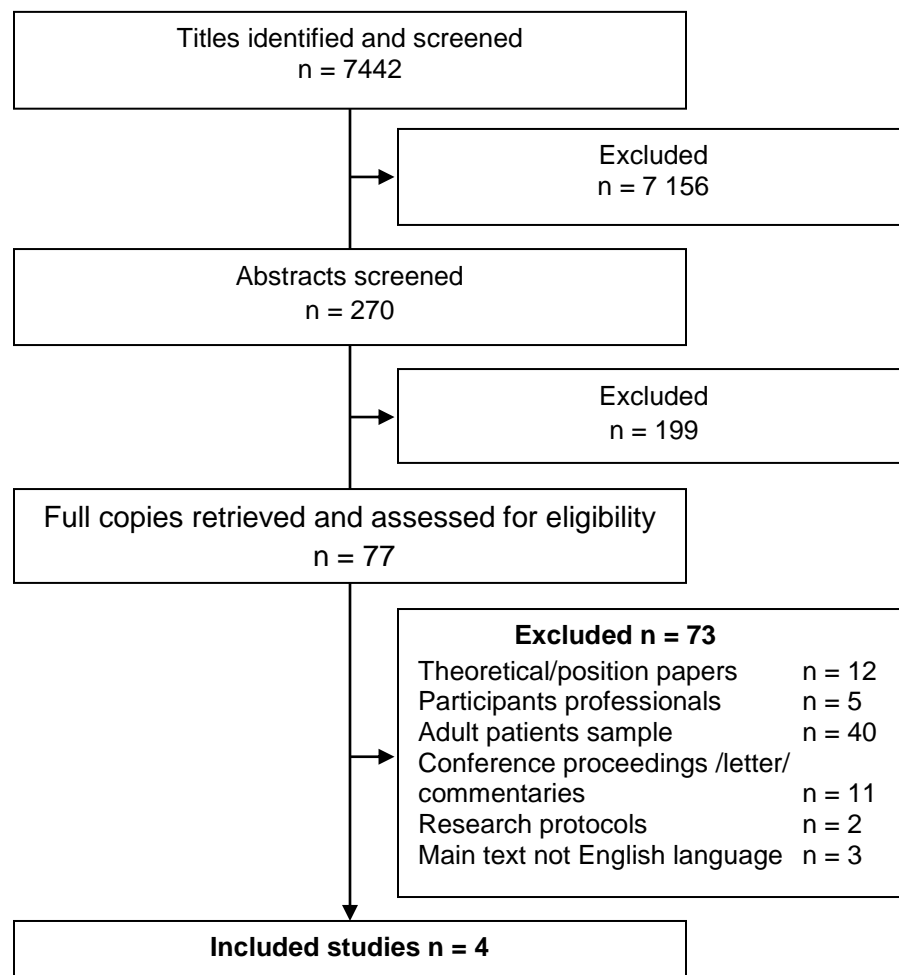
1. Sample did not include young people (12-24 years of age);
2. Interventions or experiences were related to bereavement support;
3. Experiences focused on 'well' children or young people;

4. Conference proceedings, discussion and opinion, theoretical, and clinical and case study publications;
5. Not published in English language.

#### Search methods

In December 2016 with the support of an information scientist (KM), we (AR & JS) assembled a robust search to capture literature on the DT and related meaning making interventions, which assist people facing end of life. The search terms were based on the two concepts of DT and end of life care, and related terms. The electronic searches identified 13,173 records, which were managed by using Covidence software (Covidence 2017) and reduced to 7468 after duplicates were removed. Figure 2 summarises the databases and sources searched December 2016.

**Figure 2: Flow chart of study selection process**



In December 2017 an update search was run to identify any new studies since the last searches. 9186 references were retrieved by the update searches and were de-duplicated against the original EndNote Library, giving an extra 1720 results since the last search. The references were screened and no additional articles were identified for review. Figure 3 summarises the databases and sources searched December 2017.

Insert Figure 3 –

AR undertook title screening, with selection bias reduced by both AR and JS undertaking abstract and full article screen. Following abstract screening, 92 full papers were accessed and reviewed with 4 meeting the inclusion criteria, the reasons studies were excluded and the selection process is presented in Figure. The reference lists of included studies were reviewed and citation searches run on key papers in an attempt to identify further relevant studies, none were identified. Authors were contacted where there were uncertainties as to whether young people (24 years of age and under) participated in the study.

#### Quality Appraisal

Quality appraisal involved both AR and JS assessing each study against predetermined criteria using an appropriate Critical Appraisal Skills Programme (CASP) tool; either the Randomized Control Trial or Cohort Study CASP tool (Critical Appraisal Skills Programme a & b 1998).

#### **Results**

Four studies met the selecting criteria and were included in the review; the aim, sample methods, and key findings of the studies are presented in Table 1.

**Table 1: Summary of included studies**

First author	Aim	Sample	Methods	Key findings
Akard 2015	Explore the feasibility of a digital story telling legacy-making intervention in children to improve and effects on their quality of life	28 child-parent dyads participated, children (7-11 years of age)  Mean age 11 years, 54% per female  15 children received a digital story telling legacy-making intervention; 13 children received usual care	Randomised control trial  Primary outcome measures were QOL using PedsQL v.4.0, Acute Version. Follow-up Child open-ended activity evaluation interviews  Electronic multiple choice parent survey on their views of the effects of intervention	Descriptive summaries of the PedsQL scores at baseline and end of study identify the intervention group had slightly better emotional and school functioning compared to the control group  Children perceived the intervention as fun and enjoyable  Parents reported that the intervention helped their children express feelings, provided emotional comfort to parents, facilitated communication and coping
Chochinov 2011	Compare DT with standard palliative care or patient centred care in relation to reducing psychological, existential and spiritual distress in terminally ill patients	326 participants (22-102 years of age)  Mean age 65.1 years, 49% men  108 patients received DT, 111 standard palliative care, 107 client-centred care	Randomised control trial  Intervention sessions lasting 30-60 minutes (based on a psychological interview protocol)  Primary outcome measures were psychological, existential and spiritual distress, assessing using Palliative Performance Scale, Chronic Illness Therapy Spiritual Well-being Scale, Patient Dignity Inventory, Hospital Anxiety and Depression Scale  ANOVA was used to compare groups where normal distribution was estimated, and if not Kruskal-Wallis test	There was no statistical difference in reported distress between groups  DT was better than client-centred care at improving spiritually well-being, which was statistically significant ( $\chi^2=10.35$ , $p=0.006$ )  DT was better than standard palliative care in lessening sadness or depression, which was statistically significant ( $\chi^2=9.385$ , $p=0.009$ )  Patients who received DT were significantly more likely to report improvement in quality of their lives and a sense of dignity  DT positively changed the families perception of and appreciation of their terminally ill relative assisted the family



<p>Chochinov 2005</p>	<p>Establish the feasibility of DT intervention and measure its effect on psychosocial and existential distress in terminally ill patients</p>	<p>100 patients completed the study from 181 recruited (22-95 years of age)  Mean age 63.9 years, 56% men</p>	<p>Pre-post intervention design, which followed a cohort of patients, who all received the DT intervention sessions lasting 30-60 minutes (based on a psychological interview protocol)  Primary outcome measures included measures of depression, dignity, anxiety, suffering, hopefulness, hopelessness, sense of well-being  Statistical analysis was primarily one-tailed Wilcoxon and correlation tests</p>	<p>DT is a feasible and effective approach to address suffering and distress in patients toward the end of life -91% of participants were satisfied with the dignity therapy intervention, with 76% reported a heightened sense of dignity  Post intervention measures found a significant improvement in suffering (<math>p=0.023</math>), and reduction in depressive symptoms (<math>p &lt; 0.05</math>)  Dignity therapy significantly correlated to finding life more meaningful (<math>r= 0.566</math>, <math>p &lt; 0.0001</math>), heightened sense of purpose (<math>r= 0.547</math>, <math>p &lt; 0.0001</math>), lessening suffering (<math>r= 0.267</math>, <math>p &lt; 0.008</math>)  Participants reported a belief that dignity therapy helped or would help their family in relation to life feeling more meaningful (<math>r= 0.480</math>, <math>p &lt; 0.0001</math>) and having a sense of purpose (<math>r= 0.5662</math>, <math>p &lt; 0.0001</math>)</p>
<p>Vaghee 2012</p>		<p>70 participants (20-70 years of age)  Mean age 49 years, 69.9% men  36 patients receiving dignity therapy, 34 standard care</p>	<p>Randomised control trial  Intervention group received the DT psychological intervention sessions lasting 45-60 minutes  Primary outcome measures hope and mental health status  Assessed by the Herth's Hope index questionnaire and Mini mental status examination score at the start of the study and 1 month later  Statistical analysis included Wilcoxon test Mann-Whitney tests</p>	<p>There was no statistical difference in reported hope between groups at the start of the study  For the DT intervention group, there was an increases hope level in of hope one month after DT, compared to the control group (1 month repeat measures), which were significant difference (<math>p=0.0,038</math>)  Mini mental status examination score were not reported</p>

## Design and methods

Three of the included studies were randomised control trials, which all compared a DT intervention with usual care (Chochinov et al 2011; Vaghee et al 2012; Akard et al 2015) and one cohort study (Chochinov et al 2005). The DT protocol developed by Chochinov (Chochinov et al 2005) based on psychological interviewing (Table 1) was used in three studies (Chochinov et al 2005; Chochinov et al 2011; Vaghee et al 2012) and adapted as the guiding framework for one study, which solely focused on children and young people (Akard et al 2015). In addition to the DT protocol, Akard et al's (2015) conceptual framework incorporated qualitative research (Foster et al 2009), which found a meaning making activity is most meaningful if perceived as mutually beneficial for both the parent and child. Videography was used to engage children in digital story making, and included photographs and music of the young person's choosing. Children had the flexibility to focus on issues of interest and meaningful to them and their legacies, for example some included a heightened focus on their illness journeys, others their hobbies.

## Setting and participants

Studies were undertaken in Canada (Chochinov et al 2005; Chochinov et al 2011), USA (Chochinov et al 2011; Akard et al 2015), Australia (Chochinov et al 2005; Chochinov et al 2011) and Iran (Vaghee et al 2012), with some studies undertaken in more than one country. Participants were receiving care in hospital (Chochinov et al 2005; Chochinov et al 2011; Vaghee et al 2012; Akard et al 2015) or community settings (home or hospice) (Chochinov et al 2005; Chochinov et al 2011; Akard et al 2015). Participants were from mixed demographic backgrounds, faiths and genders. Although, participant's ages ranged from 7-102, only one study focused solely on meaning making in young people, aged 7-17 years (Akard et al 2015), the mean age of participants for the other studies was 50-70, (Table 1). In addition, although many of the 77 studies reviewed in detail (Figure 4) included young people above 18 years of age in their sampling protocols, only three studies recruited young people 24 years of age or below, and were included in the review (Chochinov et al 2005; Chochinov et al 2011; Vaghee et al 2012), suggesting current research on DT represents an older population.

Participants in review studies included individuals with cancer (Akard et al 2015) and non-malignant conditions (Chochinov et al 2005), including organ failure and amyotrophic lateral sclerosis (Chochinov et al 2011) and chronic renal failure (Vaghee et al 2012). Sample sizes ranged from 28 (Akard et al 2015) to 326 (Chochinov et al 2011). A summary of the quality assessment is presented in Table 2. The research designs and methods were appropriate to meet the study aims.

**Table 2: Summary of critical appraisal of included studies**

<b>CASP appraisal tool criteria for randomized control trials studies</b>											
<b>First Author</b>	Did trial have a clear focus?	Were patients randomized?	Were all patients properly accounted for?	Were all patients / study personnel 'blind' to treatments?	Were groups similar at the start of study?	Except for intervention were groups treated equally?	How large were treatment effects?	How precise was estimate of treatment effects?	Can results be applied in other context?	Were clinical important outcomes considered?	Are the benefits worth the harms and costs?
Akard 2015	✓	✓	✓	X	✓	✓	?	?	✓	✓	✓
Chochinov 2011	✓	✓	✓	X	✓	✓	?	?	✓	✓	✓
Vaghee 2012	✓	✓	X	X	✓	✓	?	?	✓	X	✓
<b>CASP appraisal tool criteria for cohort studies</b>											
<b>First Author</b>	Did the study have a clear focus?	Was recruited acceptable?	Was bias minimize bias when measuring exposure?	Was bias minimize bias when measuring outcomes?	Have confounding factors been accounted for (design /analysis)?	Was follow up complete, and long enough?	What are results- are they clear? How precise are they?	Are the results believable?	Can results be applied in other contexts?	Do results 'fit' with other studies?	What are implications of study?
Chochinov 2005	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Refer to comment <sup>1</sup>

Notes:

✓ Yes; □ X No; ? Can't tell

<sup>1</sup>Dignity therapy has potential to reduce suffering and distress in patients with a terminal condition stress, and promote a sense of purpose and meaning

## Measures/approaches

A number of validated and well recognised measures were used to examine primary and secondary outcomes.

Tools used included PedsQLv4.0 Acute version (Varni et al 2001), which measures General Health related Quality of Life; Herth Hope Index (Herth 1992) which measures three dimensions of hope – cognitive temporal, affective behavioural and affinitive contextual. Single item screening instruments were also used to measure levels of depression, anxiety, suffering, hopefulness, desire for death, suicide and sense of wellbeing (Wilson et al 2004). A two item Quality of Life instrument was used (Graham and Longman 1987) and a revised Edmonton Symptom Assessment scale that included a will to live visual analogue scale (Bruera et al 1991). Further measures included the Palliative Performance scale (for physical performance, 100% = healthy, 0=death) (Anderson et al 1996), the Functional Assessment of Chronic Illness Therapy Spiritual Wellbeing Scale (spiritual wellbeing with two subscales – meaning or peace or faith) (Peterman et al 2002), the Patient Dignity Inventory (Chochinov et al 2008) and the Hospital Anxiety and Depression scale (Moorey et al 1991).

## Key findings

Across included studies, DT was found to improve aspects of psychosocial wellbeing, emotional functioning, dignity and hope, and was perceived as helpful for the family.

## Feasibility and Acceptability

A key finding in the Akard et al (2015) study was children's enjoyment in what they perceived to be a 'fun' activity. Parents reported that the activity had enabled their child to express their feelings and that it had been of emotional comfort to them as parents, assisting them with communication and coping. The intervention was perceived to have helped the children cope better and have improved emotional, social and spiritual functioning. In addition, most of the adult patients involved in Chochinov et al's (2005) study were also satisfied or highly satisfied with the DT intervention. They found the intervention was helpful and had increased their sense of dignity. In analysing data relevant to hopefulness, participants reported an increased sense of purpose and meaning, with a number of participants stating that their will to live had increased. Many participants perceived DT had also helped or had the possibility of helping their families. Participants were supportive of the generativity document, in that they felt it was important to leave for their loved ones but it had also been self-reaffirming and had highlighted to participants how wonderfully meaningful their lives had so far been.

In Akard et al's (2015) study, young people eligible for the study had cancer diagnoses, poor prognoses or had relapsed. Parents were approached first by a primary physician or nurse practitioner during a hospital stay or clinic visit. In their absence, the researcher approached potential participants following clinician approval to do so. Most of the children completed all study stages and these were young people at various disease stages, not only those considered terminal. One child died before the close of the research but had completed their digital story which was later played at their funeral, which supported their family through their time of bereavement. At follow up five parents had experienced the death of their child, some parents were contacted as soon as six weeks post child death, made possible by the strength of the already established relationships between families and the research team. This is in contrast to Chochinov's (2005) original protocol that recommends not contacting relatives within 3 months of the patient's death. Contacting parents or significant others within this time frame may be supportive for some families, however requires further investigation.

Chochinov et al (2005) offered DT to all patients receiving palliative care, who met the inclusion criteria. Inclusion criteria was similar to Chochinov et al's (2011) later study, in that participants had a terminal diagnosis, a life expectancy of less than 6 months and were at least 18 years of age, English speaking, committed to three to four contacts over seven to ten days, no cognitive impairment and willing to provide verbal and written consent. 181 patients initially agreed to participate. Later, 21 deteriorated or died prior to the study commencing, 31 later refused to participate. This left 129 participants, however the study completion rate translated to 78%. 14 died and a further 15 became too ill to complete the protocol. In Chochinov et al's study (2011), of the 1513 patients identified as meeting the study criteria, 326 patients agreed to participate. Thirty one participants later withdrew from the study, 28 patients died and the health of 87 patients deteriorated making them unable to participate. Consideration needs to be given for the timing of DT interventions in the future. Vaghee et al (2012) study did not report drop-out rates during the DT intervention or follow up.

### Effectiveness

Quality of life ratings before and after intervention were not significant in all of the domains in Akard et al's (2015) study. However, the intervention group did show improved emotional and school functioning compared to controls. In Chochinov et al's (2005) study, measures of suffering were significantly reduced for intervention participants. All participants had some benefit, with participants who had higher levels of psychological despair prior to DT benefiting the most, identified by pre DT quality of life, satisfaction and desire for death scores. Participants following DT who reported an increased will to live also stated their life was more meaningful and they had

a heightened sense of purpose. A heightened sense of purpose was supported by a lesser sense of suffering. In Chochinov et al's (2011) study, participant's reports of quality of life, dignity and treatment satisfaction were significantly higher for those in the DT group and were more likely to perceive DT to be of benefit to their families and had changed how their families viewed them. DT significantly improved spiritual wellbeing and was significantly better at improving sadness/depression scores. In Vaghee et al's (2012) study, levels of hope were significantly increased in the DT group.

## **Discussion**

In relation to our first question:

What Dignity Therapy and related meaning making interventions have been used and evaluated with young people in palliative care?

The review found one meaning making intervention study (Akard et al., 2015) that had evaluated a DT based approach solely with young people in palliative care. Participants engaged in digital story telling with the help of a professional videographer to document their experiences and stories through visual media. The three other included studies involved small numbers of patients aged 18 -24 years and they were involved in the one to one interviewed based DT (Chochinov et al 2005; Chochinov et al 2011; Vaghee et al 2012).

The literature on adult patients reports that there are very few interventions available to help patients with their psychological suffering and existential distress within palliative or end of life care that are not pharmacological in nature (Chochinov et al 2005). This review suggests that limited research has been focused on young people aged 12-24 years. No young person focused DT intervention studies were found to have been undertaken in the UK or Europe. There may be DT related meaning making activities engaged within in practice (Foster et al 2009; Foster et al 2012) but these do not appear to be reported or evaluated, suggesting a dearth of evidence in the peer reviewed literature that can guide structured meaning making interventions for young people.

In relation to our second review question:

What are young people's experiences and perceptions of DT and related meaning making interventions in palliative care?

DT is brief and designed on a validated model of dignity with adult patients who have terminal illnesses (Chochinov et al 2005; Chochinov et al 2011; Chochinov 2012; Vaghee et al 2012). There is uncertainty around whether the dignity needs of adults expressed by the model of dignity conserving care are equivocal for younger people. This poses uncertainty as to the suitability of

DT for those 18 years or younger. However, the willingness of young people to participate in DT and meaning making activities suggests the acceptability of the approach for this group. Attrition rates in the studies reviewed poses questions as to whether DT could be of more benefit if delivered earlier in the disease trajectory, or at different junctures/episodes of transition to aide meaning making and reflection on the journey so far.

Adult focused studies highlight the cost effectiveness of DT as a bed side intervention that can be undertaken by staff trained in DT. However, Chochinov et al (2011) suggests the costs incurred relate to the provision of tailored training, resources to deliver the intervention alongside existent roles and, the efficiency and cost of transcribing services. In addition, depending on the type of generativity document produced, the cost of production particularly if including photographic content needs to be considered. The digital story making intervention undertaken by Akard et al (2015) included the services of a qualified videographer. However, it may be possible that a less professional but acceptable and effective output could be achieved by practitioners or the child themselves, if monies were not available for this type of professional service.

#### Review strengths and limitations

While rapid evidence reviews use methods considerably more rigorous than a narrative literature review, they are not without limitations. In order to accelerate the 'rapid' review process we imposed some restrictions and only included English language papers, did not search the UK grey literature; did not include books, theses and conferences papers; and we did not undertake an extensive search of all reference lists of included studies. Consequently, there may be some interventions, studies or data that were missed in this review. However, correspondence with key authors in the field suggest this is a new area of research, particularly in the context of young people. The few studies included has limited our ability to make a judgment about effectiveness of DT and related meaning making interventions for young people.

One of the strengths of this review was the search of multiple electronic bibliographic databases which was exhaustive and we imposed no limits on year of publication. We are confident that this process was rigorous enough to identify the majority of publications within our search parameters.

This review focused on young people aged 12-24 years, therefore all included studies needed to involve young people. While we were able to identify 4 papers that clearly included this population, there were a high number we rejected because reporting in the paper or analyses used did not allow us to reasonably determine the possible effect of the intervention for the target age group. It is possible that some of these papers reported interventions that may in fact be of benefit to the target age group, but it was just not possible to determine this from the information available. Further interventions of interest may have been missed due to the specific search terms and inclusion criteria used in this review. These terms and criteria were necessary in order to identify the most relevant interventions for the target population and to make the search and

selection process manageable.

A final limitation of this review, and in fact of all reviews, is that the information reported here is time limited. High quality systematic reviews undergo regular updates to check for new studies. This analysis was completed in January 2018 and readers are advised that new evidence will emerge after publication of this report. We recommend that any new evidence is taken into consideration when selecting and implementing DT and related meaning making interventions for young people.

#### Future research directions

We have been unable to locate any UK or other wider European study that includes a younger population and that explores DT or related meaning making interventions. There may be cultural considerations that we need to explore, for example within the UK there is a truth telling hesitance and mutual protectiveness with children and young people in palliative care (Rodriguez and King, 2014). Therefore, the acceptability of a DT type intervention may meet some clinical and family barriers. To fully consider the appropriateness of a DT type intervention for young people with LTCs and LLCs in the UK, consultation with professionals, young people and families is needed. It is important to ascertain their perception of the need for structured meaning making intervention and at what time(s), and to explore further the DT protocol, its suitability and ideas for adaptation.

#### Conclusion

With medical and technological advancements we have progressed our understanding of diseases and how to manage pain and physical discomfort. Palliative care aims to support the whole person and yet we are somewhat lagging behind physical medicine advancements in terms of supporting patient's psychosocial, existential and spiritual wellbeing, especially towards the end of life (Chochinov 2012). The review identifies that DT is a unique, welcome and needed intervention that can improve measures of wellbeing and be of benefit to families. However, few studies have included young people aged 12-24 years, and those that have, have focused mostly on cancer conditions. No studies in the UK or across Europe have explored DT or related meaning making interventions with regard to acceptability, feasibility and effectiveness solely for young people with LTCs or LLCs. Given the reported positive outcomes for varied populations, this is an area of needed research for young people with palliative care needs and their families.

This review confirms that we are missing opportunities to support young people and their families to engage in meaningful discussion about dignity, meaning making and end of life care in a structured way.



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