

Resolving Anticipatory Grief and Enhancing Dignity at the End-Of Life: A Systematic
Review of Palliative Interventions

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Acknowledgements

The study is funded by the Singapore Ministry of Education (MoE) Academic Research Fund (AcRF) Tier 2 Fund (Ref : MOE-T2-1-061). MoE has played no role in study design, collection, analysis or interpretation of data, or preparation of manuscripts. The authors would like to extend their thanks to Ms. Yasmin Lynda Munro, Ms. Oindrila Dutta, Ms. Natalie Kang and Ms. Thurga Rajen for their support in this endeavour.

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Abstract

Anticipatory grief is the experience of grief symptomatology prior to loss. This study is a systematic review of empirical interventions or interventional components that were observed to lessen or adaptively direct the experience of anticipatory grief for patients at the end of life and their family members. A search of 5 major databases found 13,718 articles, of which 10 high quality randomized controlled trials were included for final review. Lebow's (1976) 'adaptational tasks of anticipatory mourning' was employed as a working model on the efficacy of the interventions. The interventions exhibited some positive outcomes but none addressed anticipatory grief directly.

Keywords: Anticipatory Grief, Intervention, Loss, End of life

Resolving Anticipatory Grief and Enhancing Dignity at the End of Life: A Systematic Review of Palliative Interventions

Anticipatory grief, though garnering substantial interest by clinicians and researchers over several decades, remains a poorly defined and little understood psychosocial construct. Nebulous assertions on the nature of the phenomenon led to divided extant literature, unclear operationalization, and uncertainty in proceeding with clinical situations where such grief makes itself apparent (Siegel & Weinstein, 1983). Although anticipatory grief has reached acceptance as a valid clinical phenomenon, limited conceptual and empirical underpinnings coupled with an accumulation of inconsistent information about its benign, adaptive, or emotionally malignant nature make intervention development and conduct particularly problematic (Fulton, Madden, & Minichiello, 1996). With multiple definitions subject to constant revision and perpetual shifting focuses from patients to their families, the current state of empirical literature thus begs the question of not whether anticipatory grief exists, but if the process is psychologically useful in facilitating adaptation to one's own mortality and the loss of a loved one (Clayton, Halikas, Maurice, & Robins, 1973; Shore et al., 2016; Cheung et al., 2018). To facilitate the future design and implementation of appropriate interventions that effectively address anticipatory grief, a review of existing, empirically robust therapeutic mediations is necessary.

A general consensus of the available literature posits that anticipatory grief is the grieving process in *anticipation* of impending or expectations of significant loss (Fulton et al., 1996). Lindemann (1944) described the case of a homecoming veteran who discovered his wife no longer loved him and wanted a divorce. Lindemann (1944) suggested that the soldier's wife had so efficaciously mourned the absence of her spouse that she had inadvertently emancipated herself from him emotionally. The author described how the wife had surreptitiously experienced grief symptomatology; depression, heightened preoccupation

with thoughts about her spouse, fantasies of his passing, as well as her adjustment to his absence. Lindemann (1944) concluded that this anticipatory grieving served to safeguard against any sudden experience of death. This thesis of premature mourning through detachment, and by not yet being bereaved, is supported by a sizeable body of literature (Richmond & Waisman, 1955; Natterson & Knudson, 1960; Binger et al., 1969; Rando, 1986; Cheng et al., 2010; Shore et al., 2016).

However, the concept of anticipatory grief has also been challenged. Weiss (1988) criticized the concept of anticipatory grief completely, arguing for the exclusivity of grief only in instances of actual death, and not as an advanced experience. Rando's (1984) reconsideration of the term perhaps strikes a precipitous balance. Deeming it a misnomer in her seminal work on the topic, Rando (1984) posits that such grieving is not just for anticipated losses, but also extends to past and present losses. She described grief (for some) as the complete decathexis from a dying individual; as such, such grief encompasses an individual's hopes and expectations associated with that person in the future as well. She considered this period of 'forewarned loss' a complex and multidimensional set of processes; offering a holistic definition of:

...the phenomenon as encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future. (Rando, 1984, p. 209)

Moreover, Rando (1986) described anticipatory grief is not simply a social phenomenon of impending loss of another, but one that is experienced in part by individuals who are dying as well, grieving (psychoexistentially) not only their loss of life, but their losses in functioning, autonomy, hopes and dreams, and futures with their loved ones.

Aldrich (1974) highlighted this dual differentiation by forwarding several key differences

between anticipatory grief and conventional grief, in that the former is experienced by both a patient and the family, cannot be infinite because death is imminent, accelerates with time, is more easily denied, and is accompanied by an additional phase of hopefulness. Lebow's (1976) position on anticipatory grief is multidimensional in that it comprises cognitive, affective, social, and cultural reactions to expected death in addition to the temporal nature of the phenomenon. More recently, Rando (2000), cognizant of the caveats posed, has opted to employ the term 'anticipatory mourning' to highlight the clinical reality of what occurs before an anticipated death and how it undoubtedly has a profound influence on the dying experiences as well as bereavement outcomes.

Duke (1998) commented that studies of the social phenomenon of dying make anticipatory grief a key mitigating factor for bereavement at the point of its occurrence. Findings continue to be inconclusive. For individuals facing the impending death of a loved one, studies have observed lower rates of depression and numbness-disbelief (Welch, 1982; Jacobs et al., 1986) as well as adjustment to the loss (Parkes, 1975). Better outcomes due to anticipatory grief might not indicate more efficient emotional reconsolidation, but rather that families had more time to give up hope and understand the cause of death (Glick, Weiss, & Parkes, 1974). Contrary to the anticipatory grief hypothesis, a recent empirically rigorous systematic review and qualitative synthesis of 34 articles showed that high levels of pre-loss grief coupled with low preparedness actually resulted in poorer bereavement outcomes for caregivers (Nielsen et al., 2016).

Researchers have also investigated anticipatory grief in individuals facing impending death. Cheng, Lo, Chan, Kwan, and Woo (2010) noted that patients displaying anticipatory grief may evoke the traditional grief responses as postulated by Kübler-Ross (1969)—denial, anger, depression, bargaining, and acceptance. Grumann and Spiegel (2003) observed that terminally ill patients with unresolved issues, anxiety, pain, and fatigue were distressed by

thoughts about their own death. Chunlestkul, Carlson, Koopmans, and Angen (2008) reported that women with metastasized breast cancer who acknowledged their grief by making their death preparations, being psychologically prepared, seeking support and information, and preparing their family were more likely to describe peaceful feelings and self-growth for themselves as well as their families. Similarly, dignity therapy saw participants at the end of life having enhanced dignity and improved quality of life as they actively addressed issues of anticipatory grief by discussing key aspects of their lives, experiences, and future hopes during the intervention (Chochinov et al., 2011). The experience of anticipatory grief is thus, expressed differently in patients and their families, and should be addressed as such.

Interventions to Address Anticipatory Grief

Despite the inconsistencies in conceptualizations of anticipatory grief, professionals have advocated for the development of interventions during terminal illness in order to facilitate an adequate grieving process in anticipation of impending death and related losses, both for patients and their families (Fulton et al., 1996; Lebow, 1976; Sweeting & Gilhooly, 1990). Sweeting and Gilhooly (1990) proposed that the primary aims of successful interventions should encourage efficacious closure of the relationship, reduce guilt, and reduce chances of awkwardness, pain, and excessive stress when the death occurs. Shore et al. (2016) stated that addressing anticipatory grief in patients and their families is part of best-practice care. Efficacious facilitation of anticipatory grief is suggested by Lebow (1976) through interventions that promote 'adaptational tasks of anticipatory mourning'. These involve familial interactions that encompass:

- a) Remaining involved with the patient—responding to their experience and sharing those of the rest of the family;

- b) Remaining separate from the patient—believing in oneself as an individual who can and will exist in a future without the patient;
- c) Adapting suitably to role changes—assuming immediate new duties and anticipating future new responsibilities;
- d) Bearing the affects of grief—acknowledging and expressing the feelings aroused by terminal illness;
- e) Coming to terms with the reality of impending loss—being able to tolerate thoughts of the future and making practical plans required to deal with it;
- f) Saying goodbye—acknowledging the end is near and communicating a verbal or non-verbal farewell.

Although Lebow's (1976) tasks are dated, her observations and proposals of the therapeutic goals when working with anticipatory grief remains the most complete, structured, and clearly defined resource for remedial facilitation. The objective would not be to alleviate anticipatory grief but to facilitate and guide the grieving process for adequate functioning and support at the end of life (for patients and families) and post-bereavement (for families).

Assessment of anticipatory grief and its interventions remain difficult without standardized guidelines and operationalization of constructs and variables. Existing scale measures can be viewed as disease specific, caregiver-focused (Theut, Jordan, Ross, & Deutsch, 1991) or do not capture the breadth of the construct. Anticipatory grief is typically assessed by proxy, via the use of validated scale measures for psychological and psychosocial distress such as depression, anxiety, and other commonly measurable symptomatology. A recent systematic review focusing on caregiver anticipatory grief (Coelho et al., 2018) emphasized the need for manualization of interventions and the creation of guidelines for therapeutic practice, highlighting the complex grief dynamics in with regards to differing end-of-life trajectories.

We consider the currently available literature on empirically rigorous interventions that may address anticipatory grief for terminally ill adults at the end of life and their families. A systematic review of interventions will address how the anticipatory grieving process can be efficaciously facilitated to ensure a smooth end of life transition for patients and their families with minimal complication of grief symptomology and distress. We drew upon Lebow's (1976) 'adaptational tasks of anticipatory mourning' when considering the interventions; providing guidelines on how anticipatory grief issues might be reconciled within their participants.

Method

A systematic review of data comprising randomized controlled trials (RCTs) of interventions addressing anticipatory grief for individuals at the end of life or family members of such individuals was conducted. The review was guided by the Preferred Reporting Items for Systematic Review and Meta-Analyses ([PRISMA] Liberati et al., 2009). Only RCTs were selected in an effort to assess studies about interventions with adequate research rigor.

Inclusion and Exclusion Criteria

Studies were limited to those in English, had samples above the age of 18 years, and were published from 2000-2017. The eligibility criteria specified that each study be an original RCT published in a research journal that addresses the care, treatment, or therapy of individuals at the end of life and/or their families with regards to reducing grief reactions, other deleterious psychological states, psychosocial disconnect, or health related outcomes caused by pre-bereavement.

Data Sources and Search Strategy

Five major academic databases spanning various disciplines (MEDLINE, EMBASE, Academic Science Complete, PsychArticles, and PsycINFO) were subject to a rigorous

search strategy with the aid of a medical librarian. The PICOS (Patient, Intervention, Comparison, Study Type) framework was employed in the design of a search strategy, being a reliable tool endorsed by the Cochrane Collection (Higgins & Green, 2013). Key concepts and terms employed in the search were: Intervention (counseling, therapy, support, casework, approach, psychosocial, caregiver support, family coping, strategies); Anticipatory grief/grieving (pre-death grief, pre-loss grief, attitudes towards death, pre-bereavement, anticipatory mourning, losses, bereavement risk, experience, premature grieving); End of life (terminal care, palliative care, terminally ill, death and dying, prognosis, hospice care, critical path, cancer, dementia, HIV); and Patients and/or caregivers (family members, spouse, family, elderly, adults, healthcare professionals, hospital, hospice, nursing home, relationship). Due to the diverse terminology surrounding the conceptualization of anticipatory grief, interventions that sought to address existential or psycho-existential grief and end of life distress were included.

Screening and Data Extraction

The screening process was conducted with the aid of the online Covidence platform. After the initial search, the titles and abstracts of all retrieved articles were reviewed by the authors as per the prescribed inclusion criteria. Full-text review was conducted for studies that were deemed fit by a research team comprising three members. A study was included only if two of the three team members arrived at this conclusion independently. In the event of a conflict, the third team member would make the decision to include or exclude the study. Team members were asked to state exclusion criteria for excluded materials to ensure that there was no disparity in the decision.

The included studies were subject to data extraction to a spreadsheet for assessment. The extracted information included measures such as sample size, type of intervention, intervention components, length of intervention, patient demographics, outcome measures,

and findings. Studies were grouped according to intervention type and were also scored against whether they had addressed any of Lebow's (1976) adaptational tasks with their samples. Scoring was conducted by two members of the research team to ensure intercoder reliability. The team members aligned the intervention description from the studies into thematic categories enunciated for the tasks. A task was considered fulfilled if both members agreed upon the conditions. In the event of conflict, a third team member would provide their input.

Results

After removal of duplication, 13,718 articles were generated from the five major databases searched. A total of 291 articles were selected for full text review post title and abstract screening and 281 of these studies were excluded on the grounds that they did not use an RCT based methodology, were pilot or studies or study protocols. Ten studies were high quality RCTs and were subject to data extraction and analysis (Figure 1).

Eight of these studies were directed solely towards patient populations (Ando, Morita, Akechi, & Okamoto, 2010; Bakitas et al., 2009; Breitbart et al., 2012; Chochinov et al., 2011; Juliao, Barbosa, Oliveira, Nunes, & Carneiro, 2013; Juliao, Oliveira, Nunes, Carneiro, & Barbosa, 2014; Steinhäuser et al., 2017; Vuksanovic, Green, Dyck, & Morrissey, 2017), with one catering to families of end of life patients (Lautrette et al., 2007). Only one study was directed to both patients and families (Kissane et al., 2006).

Eight studies were of psychotherapeutic interventions. These were specialized therapeutic interactions or treatments that were contracted between a trained professional and patient or group that included theory driven therapy session. Half of these interventions were dignity therapy ($n = 4$), one was of short-term life review, one employed individual meaning-centered psychotherapy, one used Outlook intervention, and one practiced family-focused grief therapy. The remaining interventions were patient-education based approaches that

focused on providing information, increasing knowledge and preparedness, enhancing decision-making, and encourage problem-solving. One study employed a nursing-led intervention called Project ENABLE II, and the last study provided a conference and brochure-based intervention. All interventions were aimed at improving psychological health and well-being for patients at the end of life as well as their family members. A description of these interventions and their outcome measures can be seen in Table 1.

Psychotherapeutic Interventions

Dignity therapy. Four studies employed dignity therapy (Chochinov et al., 2011; Juliao et al., 2013; Juliao et al., 2014; Vuksanovic et., 2017) to varying degrees of success. Dignity therapy involved four sessions of brief therapeutic intervention based on Chochinov et al.'s (2002) empirical model of dignity conserving care. The aim of dignity therapy is to decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose, and dignity. During sessions, patients are offered the opportunity to address issues that matter most to them or speak of things they would most want remembered as death draws near. Therapy sessions are transcribed and edited. The resultant 'generativity document' would be prepared by the therapist and bequeathed to the patient at the close of the therapy (Chochinov et al., 2002).

Chochinov et al. (2011) did not find significant differences in distress between their groups, but observed that dignity therapy was perceived as helpful, improved quality of life, increased sense of dignity, changed familial perception, improved spiritual wellbeing, and lessened sadness and depression. In both studies with their Portuguese samples, Juliao et al. (2013) and Juliao et al. (2014) found lower rates of depression and anxiety. Vuksanovic et al. (2017) observed that dignity therapy led to greater generativity and ego-integrity in their experimental group.

Short-term life review. The study by Ando et al. (2010) used a short-term life review intervention of two sessions. The first session comprised eliciting responses from patients through questions directed at reminiscence and autobiography. After transcribing the responses, the therapist created an album via collage of the key terms and memories shared. The second session saw the therapist and patient view the album together, where the therapist attempted to enunciate with the patient the continuity of self from past to present and a sense of satisfaction with their lives. Findings indicate increased spiritual wellbeing, hope, life completion, and preparation for death in the intervention group compared to the control group (Ando et al., 2010).

Individual meaning-centered psychotherapy (IMCP). Breitbart et al. (2009) practiced IMCP with their sample of participants. IMCP is a 7-week manualized intervention meant to assist patients at the end of their lives to sustain or enhance their sense of meaning, peace, and purpose. IMCP was adapted from a group therapy intervention developed by the authors in order to increase the flexibility of the treatment. IMCP employed didactics, experiential exercises, and psychotherapeutic techniques, and promoted the use of sources of meaning for coping. Identity, legacy, hope, illness, and the finite nature of life are themes addressed in the sessions. The authors found that IMCP promoted greater spiritual wellbeing and meaning, as well as quality of life. Moreover symptomatology, and symptom-related distress were observed to have lessened in participants (Breitbart et al., 2009).

Family focused grief therapy. Kissane et al. (2009) implemented family focused grief therapy for their intervention group. The intervention was 4-8 sessions and attempted to prevent the complications of bereavement by enhancing the functioning of the family, through exploration of its cohesion, communication (of thoughts and feelings), and handling of conflict. Moreover, this story of illness and its related grief is shared in the process. The researchers found a reduction in distress at 13 months, as well as significant improvement in

depression and distress for individuals with high baseline score, compared to controls. Hostile families, as categorized by the authors, did not enjoy any benefits of the intervention (Kissane et al., 2009).

Outlook. Steinhauser et al. (2017) evaluated their Outlook intervention that sought to assist patients at the end of life with emotional and existential needs. Outlook focuses on preparation and life completion, including issues such as regret, a sense of burden, and concerns about family being prepared, attention to life review, resolving conflicts, sharing important time, gifts, wisdom with loved ones, legacy, and coming to peace. It pays special attention to life review and emotional self-disclosure. In their study, the authors found that the intervention was linked to higher scores of death preparation and life completion compared to the control group (Steinhauser et al., 2017).

Educational Interventions

Project ENABLE. Bakitas et al. (2009) employed a 4-session chronic care model based, multicomponent psychoeducational intervention called Project ENABLE (Educate, Nurture, Advise, Before Life Ends) run by palliative care nurses using a case management approach that sought to encourage patient activation, self-management, and empowerment. Patients signaling distress on areas such as practical problems (e.g., work or school), family problems, emotional problems, spiritual or religious concerns, and physical problems received specified aid regarding that issue through a specialist module covered by the nurse. The authors found benefits to quality of life, symptom intensity, and depressed mood (Bakitas et al., 2009).

VALUE conference. Lautrette et al. (2007) provided the intervention of a VALUE conference for families that hoped to value and appreciate what the family members said, to acknowledge the family members' emotions, to listen, to ask questions that would allow the caregiver to understand who the patient was as a person, and to elicit questions from the

family members. Results showed that, compared to controls, participants in the VALUE conference rather than standard family conference situations spent more time talking, had longer conferences, had lower symptoms of post-traumatic stress disorder post-bereavement, and lower anxiety and depression.

Adaptational Tasks

In order to assess the extent to which each intervention addressed anticipatory grief, the goals, descriptions, and delivery of the interventions as stated by the study authors were checked against Lebow's (1976) adaptational tasks. These tasks, in turn, had minor modifications made for the purposes of the current study, unifying *a posteriori* knowledge of anticipatory grief from studies following Lebow's (1976) work. Thematic categories were generated to facilitate analyses; as contemporary literature has observed that patients experience anticipatory grief as well, both patients and families were included for all tasks, and a shift from future focus to present autonomy for patients is posited for task (ii), as seen in Table 2. Although the interventions reviewed accomplished their forwarded objectives to varying success, none completely fulfilled every one of the adaptational tasks. Most achieved at least three tasks (with the exception of Bakitas' (2009) Project ENABLE, which was participant directed, with task fulfilment context-dependent).

Lebow's (1976) adaptational tasks were employed as a working framework for assessing interventions addressing anticipatory grief. Ando et al.'s (2010) short-term life review, though compact, failed to garner exploration in greater depth about patients' role within the family and their changing life role. Additionally, it did not consider aiding in the expression of grief or leave-taking. The therapist-made collage album, however, provides an interesting, colorful, and novel approach to legacy documentation, allowing for the expressions of life completion and continuation for family members. The re-creative nature of the collage method remains a potentially beneficial area of further study for populations at

the end of life. Steinhauser's (2017) Outlook intervention was similar in structure, but also allowed for open expressions of grief and dealing with negative emotions. A major strength of the intervention was the facilitation of reconciliation and forgiveness. However, Outlook also lacked the inclusivity of the family unit, additionally failing to respond to the present role changes that a patient might be going through.

Breitbart et al.'s (2009) IMCP allowed for a detailed and in-depth exploration of key psycho-existential issues, focusing heavily on meaning and life completion. Similar to the previous interventions, it did not allow for compensation of the grief experience as a family. IMCP showcased many strengths, taking an intimate and honest therapeutic approach focusing on patients' own legacy building. Kissane et al.'s (2006) family focused grief therapy captures the essence of addressing the mutual connection between patients and families, but focuses on short-term conflict resolution and in-the-moment coping with difficult emotions without work that could promote continuing relationships and transcendence.

Though comprehensive, dignity therapy (Chochinov et al., 2011; Juliao et al., 2013; Juliao et al., 2014; Vuksanovic et., 2017) did not allow for the structured consideration and expression and facilitation of difficult grief-based emotions as well as familial involvement. Major strengths of the intervention include a chronological approach, allowing a patient to address the breath of their life progress and eventual transcendental values. Dignity therapy is witnessed as being largely patient-centric, with the sessions also allowing patients to discuss their place in their families; family members, however, themselves were not always present.

The educational interventions have a heavier focus on the practicalities of end of life care and experience, which is highly commendable as many individuals and their families may not be literate in what might entail the dying and bereavement process. Bakitas et al.'s (2009) Project ENABLE II has a wide breadth and scope, with clinicians being able to

address medical issues. The nurse-practitioners working with patients, however, will only explore issues that the patients highlight they are distressed about. Issues such as generativity and creating lasting legacies are not defined, and there might also be a bias in self-reporting of what is distressing to the patients. Project ENABLE II itself does consist of modules directed at leave-taking or enunciating individual autonomy. Lautrette et al.'s (2007) singular family conference as well, might simply not have the adequate amount of time to consider the holistic nature and sheer number of issues that would likely be presented in such a situation. However, the intervention does provide an all-important facilitated platform for individuals and their families to address the concerns that they might have, an opportunity many that families do not currently have, but consequently might need.

Discussion

Our systematic review of studies of interventions for dealing with anticipatory grief and its components of psychoexistential suffering and distress in patients at the end of life as well as their families shows there is scant evidence of interventions with sufficient quality. No study addressed the phenomenon of anticipatory grief directly. However, all of the interventions exhibited some positive outcomes, such as lower depression and anxiety scores as well as improved quality of life in their intervention groups. Moreover, decreased suffering, lower distress, improved preparation for death, and greater spiritual well-being are other additional measures that were reported. All the interventions from the reviewed studies were developed from theories, conceptualizations, and frameworks based on populations in the West, including Ando et al.'s (2010) Short-term life review which was carried out in a sample of participants from Western Japan. It is unclear if Ando et al. (2010) tailored their intervention to be culturally-specific to their participants. No other studies from Asia met the criteria to be included in this review.

Anticipatory grief is still a vaguely defined phenomenon, with no standardized, specific measure to differentiate between normal and pathological anticipatory grieving processes (Shore et al., 2016). As such, the studies reviewed have employed a variety of validated measures that can be inferred as proxy for the varied symptomatology of anticipatory grief. Depression and anxiety measures, quality of life, and spiritual well-being scales were commonly employed to evaluate the interventions. Though these measures are reliable and valid, they do not readily capture the holistic, dual-agent (patient and family) experience of anticipatory grief as posited by existing literature (Aldrich, 1974; Knott & Wild, 1986; Lebow, 1976; Rando, 1984). We require instruments that are grief-specific than merely psychiatric aberrations (Neimeyer & Hogan, 2001) and that are generated from more nuanced quantitative and qualitative approaches to capture the breadth and depth of the experience.

Though the research team practiced a comprehensive and structured search and screening strategy, working through a vast number ($N = 13,718$) of articles, there is a chance that some key studies were overlooked. Moreover, the search strategy did not include ancillary terms such as 'psychoexistential' or 'existential' grief or distress, as these component terminologies only surfaced as the search narrowed substantially. Additionally, studies were from only six countries (United States, Australia, Portugal, Japan, France, and Canada) only studies published in English were included in the review, which limits the generalizability of findings. A more refined search strategy for the next iteration is warranted.

Though it is heartening that there are studies that show a high standard of research rigor in the development of interventions for such a population in need, it is also worrying that there is no multi-faceted mainstream intervention that might specifically address an issue that has been present in clinical literature for over half a century. There is a need to develop a comprehensive, time-sensitive intervention that includes both patients and their families

when addressing anticipatory grief. Among other things, this intervention should attempt to provide a sense of dignity for patients at the end of life, mold the pre-emptive grief ritual into an adaptive platform that encompasses the celebration of life completion, coordinate preparation for loss, facilitate open communication, and provide patients and families a sense of peace and continuing relationship even after the loved one passes. Such an intervention would run parallel to the World Health Organization (2016) guidelines for holistic palliative care as well as being able to aid in the alleviation of the ‘total pain’ faced by dying individuals (Saunders, 1967).

A promising novel intervention for Asian palliative patients and their families is the Family Dignity Intervention ([FDI] Ho et al., 2017). Borrowing from standardized dignity therapy, and being aligned with Lebow’s (1976) adaptational tasks, the FDI seeks to also include families of patients at the end of life in the therapeutic dialogue. As there is currently no empirically developed and rigorously tested culture-sensitive intervention in Asia, the FDI might be a unique and important addition to the field at large. However, one caveat to note about grief interventions is that those targeted at individuals with marked difficulties adapting to loss were more successful (Currier, Neimeyer, & Berman, 2008). Researchers studying anticipatory grief interventions would be wise to focus on the efficacious and accurate screening of individuals and families who face issues with anticipatory grief-based distress.

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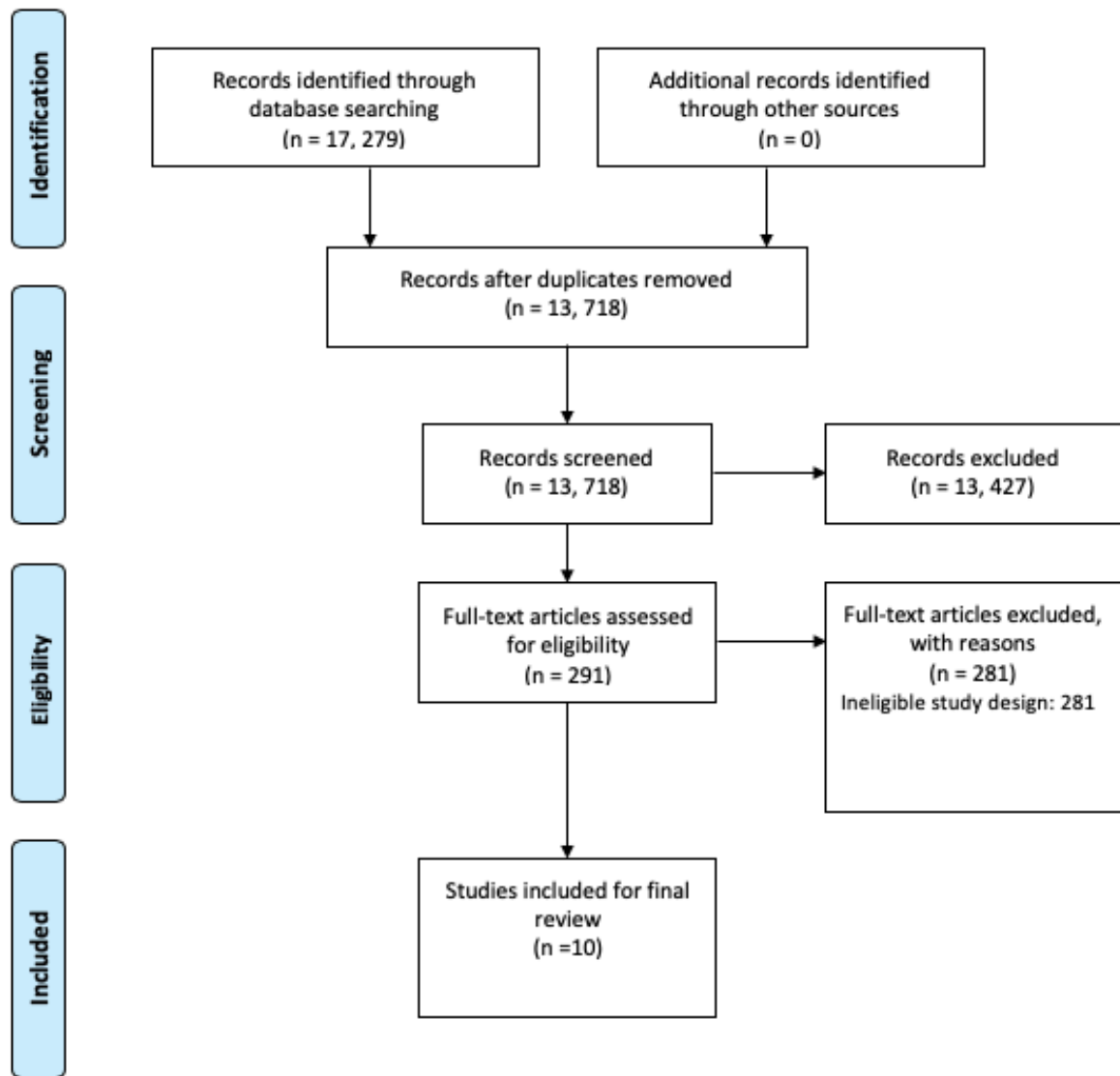


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart of study selection and results

Table 1

Summary of Included Studies

Study/ Year	Type of Intervention	Participant Description	Participants	Intervention	Sessions	Measured Outcomes	Summary of Results
Ando et al. (2010)	Psychotherapeutic	Cancer patients from the palliative care units of two general hospitals in Japan	Experimental: $n = 34$ Control: $n = 34$	Experimental: Short-Term Life Review intervention where patient's elicited narrative experiences were recorded and a simple collage album created by the therapist was presented. Control: General person-centred support by therapist on patient's physical/mental health and mood.	2 (30-60 minutes)	Meaning of life (<i>Functional Assessment of Chronic Illness Therapy- Spiritual</i>) Anxiety and Depression (<i>Hospital Anxiety and Depression Scale, Japanese Version</i>) Patient-Perceived Good Death (<i>Good Death Inventory - Hope, Burden, Life completion, and Preparation for death domains</i>) Psychological Suffering (<i>Author developed numeric scale</i>)	The Meaning of life ($p < .001$), Hope, Life completion, and Preparation scores in the intervention group showed significantly greater improvement compared with those of the control group (all $p < .001$). Anxiety and Depression ($p < .001$), Burden ($p < .007$), and Suffering ($p < .001$) scores were lower in the intervention group compared with the control group.
Breitbart et al. (2009)	Psychotherapeutic	Cancer patients with Stage III or IV solid tumour cancers or non-Hodgkins lymphoma from outpatient clinics in a cancer center in the United States	Experimental: $n = 64$ Control: $n = 56$	Experimental: Manualized Individual Meaning-Centred Psychotherapy (IMCP) that focused on sustaining or enhancing a sense of meaning, peace, and purpose utilizing didactics, experiential exercises, and psychotherapeutic techniques. Control: Therapeutic Massage by licensed massage therapist adapting Swedish massage techniques for frail patients	7 weekly (60 minutes)	Spiritual Well-Being (<i>Functional Assessment of Chronic Illness Therapy- Spiritual</i>) Overall quality of Life (<i>McGill Quality of Life Questionnaire</i>) Depression and Anxiety (<i>Hospital Anxiety and Depression Scale</i>) Hopelessness (<i>Beck Hopelessness Scale</i>) Symptom Burden and Distress (<i>Memorial Symptom Assessment Scale</i>)	Significantly greater treatment effect post-treatment for IMCP compared to control group for Spiritual Well Being, ($p < .001$), as well as for the Meaning ($p < .003$), and Faith subscales ($p < .03$) of Spiritual Well-Being. There was significantly greater improvement for IMCP participants compared with control participants in overall quality of life ($p < .013$), number of physical symptoms endorsed ($p < .001$), and physical symptom distress ($p < .001$).

Chochinov et al. (2011)	Psychotherapeutic	Patients with a terminal prognosis receiving palliative care in a hospital or community setting in Canada, United States, and Australia	Experimental: $n = 165$ Control Arm 1: $n = 140$ Control Arm 2: $n = 136$	Experimental: Standardized Dignity Therapy that sought to enhance generativity, a sense of meaning, purpose, continued sense of self, and overall sense of dignity. Control Arm 1: Standard palliative care that allowed access to complete range of palliative-care-support services. Control Arm 2: Client-centred care where therapist guides patient through discussions that focus on here-and-now issues such as illness, symptoms and coping with distress.	3 to 4 sessions (Experimental and Control Arm 2). Two instances of measure completion for Control Arm 1.	Physical Performance (<i>Palliative Performance Scale</i>) Spiritual well-being (<i>Functional Assessment of Chronic Illness Therapy- Spiritual</i>) Psychosocial and Existential Distress (<i>Patient Dignity Inventory; Structure Interview for Symptoms and Concerns</i>) Additional measures (<i>2 Item QoL scale; Edmonton Symptom Assessment Scale</i>)	No significant differences were noted in the distress levels before and after completion of the study in the three groups. Dignity therapy was significantly more likely than the other two interventions to have been perceived as helpful ($p < 0.0001$), improve quality of life ($p = 0.001$), increase sense of dignity ($p = 0.002$), change how their family saw and appreciated them ($p < 0.0001$), and be helpful to their family ($p < 0.0001$). Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing ($p = 0.006$), and was significantly better than standard palliative care in terms of lessening feelings of sadness or depression ($p = 0.009$).
Juliao et al. (2013)	Psychotherapeutic	Terminally ill patients from a specialized palliative medicine unit in Portugal	Experimental: $n = 29$ Control: $n = 31$	Experimental: Standardized Dignity Therapy that sought to enhance generativity, a sense of meaning, purpose, continued sense of self, and overall sense of dignity. Control: Standard Palliative Care by clinical team including daily interviews, physical exams and symptom management with existential and psychosocial support being extended to family.	3 to 4 sessions 30-60 minutes each	Depression and Anxiety (<i>Hospital Anxiety and Depression Scale</i>)	Dignity Therapy was associated with a significant decrease in depressive symptoms at day 4 and day 15 ($p = 0.001$ and $p = 0.022$, respectively), but not at day 30 ($p = 0.097$). Dignity Therapy was also associated with a significant decrease in anxiety symptoms at each follow-up ($p = 0.005$, $p = 0.006$, $p = 0.054$, respectively).
Juliao et al. (2014)	Psychotherapeutic	Terminally ill patients from a specialized inpatient palliative medicine unit in Portugal	Experimental: $n = 39$ Control: $n = 41$	Experimental: Standardized Dignity Therapy that sought to enhance generativity, a sense of meaning, purpose, continued sense of self, and overall sense of dignity. Control: Standard Palliative Care by clinical team including daily interviews, physical exams and symptom management with existential	3 to 4 sessions 30-60 minutes each	Depression and Anxiety (<i>Hospital Anxiety and Depression Scale</i>)	Dignity Therapy was associated with a decrease in depression scores across time points ($p < 0.0001$, $p = 0.010$, $p = 0.043$, respectively). Dignity Therapy was similarly associated with a decrease in anxiety scores across time points ($p < 0.0001$, $p = 0.001$, $p = 0.013$, respectively). There was sustained therapeutic effect over 30 days.

and psychosocial support being extended to family.

Kissane et al. (2006)	Psychotherapeutic	Australian patients and their relatives from an Australian hospital or engaged in one of three participating hospice home-care services were eligible if treating physician gave a prognosis of < 6 months	Experimental: 53 families (n = 233 individuals) Group: 28 families (n = 130 individuals)	Experimental: Family focused grief therapy that aims to prevent the complications of bereavement by enhancing the functioning of the family, through exploration of its cohesion, communication (of thoughts and feelings), and handling of conflict. Control: No formal psychological treatment beyond the standard palliative care provided by home-care programs, which did involve counseling when deemed clinically appropriate.	4 to 8 sessions averaging 90 minutes each	Family Functioning (<i>Family Environment Scale</i>) Familial Task Accomplishment (<i>Family Assessment Device</i>) Psychological Morbidity (<i>Brief Symptom Inventory</i>) Depression (<i>Beck Depression Inventory -Cognitive items only</i>) Social Functioning (<i>Social Adjustment Scale</i>) Bereavement Grief (<i>Bereavement Phenomenology Questionnaire</i>)	Intervention impact was modest, with a reduction in distress at 13 months. Significant improvements in distress and depression occurred among individuals with high baseline scores on the Brief Symptom Inventory ($p < 0.01$) and Beck Depression Inventory ($p < 0.01$). Global family functioning did not change. Sullen families and those with intermediate functioning tended to improve overall, whereas depression was unchanged in hostile families. The difference for between group change for the Family Environment conflict scale was -0.80 (95% CI= -1.25 to -0.33 , $p=0.001$)
Steinhauser et al. (2017)	Psychotherapeutic	Seriously ill patients with cancers, heart disease or end stage renal disease from a Veterans' Affairs Medical Center in the United States	Experimental: n = 75 Control Arm 1: n = 74 Control Arm 2: n = 72	Experimental: Outlook Intervention to assist patients at end of life to address emotional and existential needs focusing on preparation and life completion. Control Arm 1: Relaxation Meditation with guided imagery and music. Control Arm 2: Usual Care at institution, participants not contacted during intervention window.	3 sessions in one-month period lasting 40-45 minutes	Preparation and Life Completion (<i>four-item preparation subscale and the seven-item life completion sub-scales from the QUAL-E</i>) Anxiety (<i>Brief Profile of Mood States</i>) Depression (<i>Center for Epidemiological Studies - Depression scale</i>) Quality of Life (<i>The FACT - General FACT</i>) Spiritual Well-Being (<i>Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being</i>)	Compared with usual care, Outlook participants had higher preparation ($p = 0.02$) and life completion ($p = 0.04$) scores at the first but not second post-assessment. Compared with relaxation meditation, Outlook participants did not show significant differences over time. For subgroups with cancer and low sense of peace, Outlook participants had improved preparation at first and not second post-assessment, as compared with usual care ($p = 0.04$, $pp = 0.02$, respectively).

Vuksanovic et al. (2017)	Psychotherapeutic	Patients with advanced terminal disease from hospitals or home-care settings in Australia	Experimental: $n = 23$ Control Arm 1: $n = 23$ Control Arm 2: $n = 24$	Experimental: Standardized Dignity Therapy that sought to enhance generativity, a sense of meaning, purpose, continued sense of self, and overall sense of dignity. Control Arm 1: Life Review where protocol, recording and transcription, were identical to Dignity Therapy with the exception that the legacy document was not generated or provided to participants. Control Arm 2: Waitlist Control provided with Dignity Therapy after 10 days of waiting.	3 to 4 sessions of 60 minutes	Generativity and Ego-integrity (<i>Brief Measure of Generativity and Ego-Integrity</i>) Dignity Related Distress (<i>Patient Dignity Inventory</i>) Perceived Quality of Life (<i>Functional Assessment of Cancer Therapy-General</i>) Belief of Impact of Therapy (<i>Author devised Treatment Evaluation Form and Family Evaluation Form</i>)	Participants in the Dignity Therapy group had higher generativity factor scores ($p < 0.001$) and higher ego-integrity scores ($p = .01$) at completion of the study compared with baseline. The control group scored significantly higher on the functional well-being subscale compared with the other two groups ($p = 0.01$).
Bakitas et al. (2009)	Educational	Patients with life-limiting cancer within 8 to 12 weeks of a new diagnosis from a cancer center in New Hampshire or one of several outreach clinic in the United States	Experimental: $n = 161$ Control: $n = 161$	Experimental: A multicomponent, psychoeducational intervention (ProjectENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses. Control: Participants allowed to use all oncology and supportive services without restrictions including referral to the institutions' interdisciplinary palliative care service.	4 weekly sessions	Quality of Life (<i>Functional Assessment of Chronic Illness Therapy for Palliative Care</i>) Symptom Intensity (<i>Edmonton Symptom Assessment Scale</i>) Mood (<i>Center for Epidemiological Studies Depression Scale</i>) Resource use (<i>Chart Review process</i>)	The estimated treatment effects (intervention minus usual care) for all participants were significant for quality of life ($p = .02$), symptom intensity ($p = .06$), and depressed mood ($p = .02$). Intensity of service did not differ between groups.
Lautrette et al. (2007)	Educational	Family members of dying patients from 22 intensive care	Experimental: $n = 63$ Control: $n = 63$	Experimental: End of life family conference held in accordance to author developed standardized guidelines of the VALUE intervention to value and	Single Family Conference	Symptoms of Post-Traumatic Stress Disorder (<i>Impact of Events Scale</i>) Anxiety and Depression (<i>Hospital Anxiety and Depression Scale</i>)	Participants in intervention spent more time talking ($p < 0.001$) and had longer conferences ($p < 0.001$). Intervention group had significantly lower post-traumatic stress symptoms than the control group ($p = 0.02$) and a lower

units in
France

appreciate what the family members said, to acknowledge the family members' emotions, to listen, to ask questions that would allow the caregiver to understand who the patient was as a person, and to elicit questions from the family members. Informational brochure also provided for family.
Control: Usual care practice at institution.

prevalence of post-traumatic stress symptoms ($p = 0.01$). The anxiety and depression score was also lower in the intervention group ($p = 0.004$), and symptoms of both anxiety and depression were less prevalent ($p = 0.02$, $p = 0.003$, respectively).

PRE-PROOF

Table 2

Adaptational Task Fulfilment for Extracted Studies

Study/ Year	Intervention	Fulfilment of Lebow's (1976) Adaptational Tasks						Specific components
		(i) Remaining involved with the patient/family (<i>Mutual Connection</i>)	(ii) Remaining separate from the patient/family (<i>Individual autonomy</i>)	(iii) Adapting to role changes (<i>Changing responsibilities</i>)	(iv) Bearing the affects of grief (<i>Open Expression</i>)	(v) Coming to terms with the reality of impending loss (<i>Accepting Mortality</i>)	(vi) Saying goodbye (<i>Opportunity to say farewell</i>)	
Ando et al. (2010)	Short-Term Life Review	o				o		ii) Reminiscence regarding self v) Therapist enunciates life completion in second session vi) Discussion of what patients would like to say to family
Breitbart et al. (2009)	Individual Meaning- Centred Psychotherapy		o	o	o	o	o	ii) Understanding patient's personal journey and legacy iii) Encountering limitations iv) Life as a living legacy vi) Legacy project
Chochinov et al. (2011)	Dignity Therapy		o	o		o	o	i) Discussion about familial situation ii) Discussing own accomplishments v) Preparation for the future vi) Legacy project and instructions to family
Juliao et al. (2013)	Dignity Therapy		o	o		o	o	i) Discussion about familial situation ii) Discussing own accomplishments v) Preparation for the future vi) Legacy project and instructions to family
Juliao et al. (2014)	Dignity Therapy		o	o		o	o	i) Discussion about familial situation ii) Discussing own accomplishments

								v) Preparation for the future vi) Legacy project and instructions to family
Kissane et al. (2006)	Family Focused Grief Therapy	o		o		o		i) Exploration of family cohesion iii) Handling of conflict v) communication of thoughts and feelings
Steinhauser et al. (2017)	Outlook		o			o	o	ii) Exploration of personal life and accomplishments iv) Exploration of forgiveness v) Life completion and feeling at peace vi) Sharing a legacy
Vuksanovic et al. (2017)	Dignity Therapy		o	o			o	i) Discussion about familial situation ii) Discussing own accomplishments v) Preparation for the future vi) Legacy project and instructions to family
Bakitas et al. (2009)	Project ENABLE II	o		o	o		o	* Project ENABLE II sought to address issues from 5 key areas practical problems (e.g. work or school), family problems, emotional problems, spiritual or religious concerns, and physical problems.
Lautrette et al. (2007)	VALUE Conference	o		o		o		i) Appreciate what family said iii) Understanding family member as patient iv) Exploration of emotions v) Preparing for bereavement

Note. o Indicates the presence of the task. Thematic categories for each task are presented in (parentheses). The research team mapped these categories into descriptions of study interventions. *Interventionists would only explore issues if patient pointed out they were distressed in those areas.