Empirical Foundations of Dignity Therapy: Comparing Dignity Therapy with Life Review for Palliative Care Patients

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ABSTRACT

Approaching end of life is a time of significant change. The physical impacts of an advancing illness can be overwhelming, and this can be closely followed by psychological, social, existential, and spiritual contributors to distress and suffering. Palliative care patients also typically need to navigate complex healthcare systems, and face difficult decisions relating to medical, personal, family, and financial matters. Not surprisingly, sense of demoralisation and expressions of desire to die are particularly prevalent in this patient population. In order to meet these complex biopsychosocial needs, palliative care relies on active cooperation and coordination of a variety of health professionals, volunteers, and community representatives. Its key guiding principle is to help patients maintain sense of dignity throughout the dying process.

However, there is evidence that palliative care clinicians may not have sufficient skills and confidence in optimally assessing and treating psychosocial, existential, and spiritual domains of distress. Furthermore, there is a need to better understand the acceptability, feasibility, and effectiveness of psychotherapeutic interventions that are specifically tailored to palliative care patients. Dignity Therapy is one such promising intervention, as it is based on an empirical model of dignity in this patient population. It aims to address dignity-related distress by facilitating a creation of a lasting legacy document that is then typically shared with family or friends, and archived for future generations. Systematic reviews to date have found that Dignity Therapy has very high acceptability and satisfaction rates, variable feasibility, and generally uncertain effectiveness. Similar interventions such as Life Review also have the potential to demonstrate clinically meaningful patient outcomes but the relative lack of empirical evidence is a key barrier to their inclusion into standard palliative care practice.

The overarching aim of this project was to conduct research that examined the efficacy of Dignity Therapy for palliative care patients by comparing this intervention to Life Review and a Waitlist Control Group. In order to achieve this aim, the first study involved developing a brief measure of Erik Erikson’s concepts of generativity and ego-integrity that is suitable for use in palliative care settings. The second study was a Randomised Controlled trial that compared the efficacy of Dignity Therapy vs Life Review vs Waitlist Control Group on a range of outcome measures, including the newly-developed generativity and ego-integrity measure from the first study. The third
study utilised qualitative research methods to further explore and better understand similarities and differences between Dignity Therapy and Life Review.

The first study ($N=143$) demonstrated that the newly-developed measure of Erikson’s concepts generativity and ego-integrity is suitable for use with middle-aged and older adults. In the second study, Dignity Therapy was able to positively impact a sense of generativity and ego-integrity in a sample of 56 palliative care patients, when compared to Life Review and Waitlist Control groups. Creating a tangible legacy document seemed to bolster the sense of productivity, purpose, meaning, and acceptance. These outcomes were not replicated in recipients of Dignity Therapy after the waitlist period, though this group also had higher functional well-being and lower physical and psychological distress at baseline, and more frequently engaged in other memory/legacy activities. Dignity Therapy also had consistently positive therapeutic outcomes, as rated by patients and their families. This included improvements in the sense of dignity, meaning, and purpose; assistance with unfinished business; and helpfulness to family. Life Review had similarly high patient satisfaction ratings. The study did not demonstrate any meaningful changes in dignity-related distress; or physical, social, emotional, or functional well-being; following either intervention.

Further qualitative analyses in the third study ($N=56$ palliative care patients who also participated in Study 2) showed that both Dignity Therapy and Life Review facilitated the reflection and affirmation of a variety of meaningful and important aspects of participants’ lives. Legacy documents were particularly facilitative of exploration of themes involving hope, resilience, and legacy. Themes involving interpersonal regrets, unfinished business, and aftermath concerns were less prevalent in Dignity Therapy compared to Life Review sessions, despite controlling for interview questions, session length, and therapist influences.

Overall, this project introduced a new measure of generativity and ego-integrity and provided preliminary evidence of its suitability for use with patients receiving palliative care. Whilst previous studies have had challenges in demonstrating change on standardised outcome measures following Dignity Therapy, the newly developed generativity and ego-integrity measure showed differential improvement in patients receiving Dignity Therapy compared to Life Review. Qualitative analyses provided further insight into how each patient’s individual needs, vulnerabilities, preferences, and family circumstances may help to determine whether Dignity Therapy and/or Life Review might be appropriate and beneficial to them. Expanding the evidence base for
such systematically developed psychotherapeutic interventions is essential in meeting complex psychosocial and emotional needs of palliative care patients.
STATEMENT OF ORIGINALITY

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Dean Vuksanovic

11 September, 2018
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ABBREVIATIONS

CBT..................................................Cognitive-Behavioural Therapy
CCC..................................................Client Centred Care
CNS..............................................Clinical Nurse Specialists
DS..................................................Demoralisation Scale
DS-II............................................Demoralisation Scale-II
DSM-5........................................Diagnostic and Statistical Manual of Mental Disorders, 5th edition
EAPC................................................The European Association for Palliative Care
FACT-G..............................Functional Assessment of Cancer Therapy-General
GCH..................................................Gold Coast Hospital
GCUH................................................Gold Coast University Hospital
LREF................................................Life Review Experiencing Form
MCGP..............................................Meaning-Centred Group Psychotherapy
NMBA..............................................Nursing and Midwifery Board of Australia
NSAP..............................................National Standards Assessment Program
PCA..................................................Palliative Care Australia
PCOC..............................................Palliative Care Outcomes Collaboration
PDI..................................................Patient Dignity Inventory
RCT................................................Randomised Controlled Trial
SEGT..............................................Supportive-Expressive Group Therapy
UDHR..............................................United Nations Universal Declaration of Human Rights
LIST OF PUBLICATIONS FROM DOCTORAL RESEARCH


LIST OF ADDITIONAL PUBLICATIONS AND PRESENTATIONS


STATEMENT OF ETHICAL PROTOCOL

I confirm that ethical clearance was granted by the Griffith University Human Research Ethics Committee (GU Ref No: PSY/08/12/HREC) and the Gold Coast Hospital and Health Service Human Research Ethics Committee (HREC/11/QGC/83). I confirm that the research was conducted in accordance with the approved protocols.

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Section 9.1 of the Griffith University Code for the Responsible Conduct of Research (“Criteria for Authorship”), in accordance with Section 5 of the Australian Code for the Responsible Conduct of Research, states:

To be named as an author, a researcher must have made a substantial scholarly contribution to the creative or scholarly work that constitutes the research output, and be able to take public responsibility for at least that part of the work they contributed. Attribution of authorship depends to some extent on the discipline and publisher policies, but in all cases, authorship must be based on substantial contributions in a combination of one or more of:

- conception and design of the research project
- analysis and interpretation of research data
- drafting or making significant parts of the creative or scholarly work or critically revising it so as to contribute significantly to the final output.

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Researchers are expected to:

- Offer authorship to all people, including research trainees, who meet the criteria for authorship listed above, but only those people.
- Accept or decline offers of authorship promptly in writing.
- Include in the list of authors only those who have accepted authorship.
- Appoint one author to be the executive author to record authorship and manage correspondence about the work with the publisher and other interested parties.
- Acknowledge all those who have contributed to the research, facilities or materials but who do not qualify as authors, such as research assistants, technical staff, and advisors on cultural or community knowledge. Obtain written consent to name individuals.

Included in this thesis are papers in Chapters 5, 6, and 7 which are co-authored with other researchers. My contribution to each co-authored paper is outlined at the front of the relevant chapter. The bibliographic details for these papers including all authors, are:


Appropriate acknowledgements of those who contributed to the research but did not qualify as authors are included in each paper.

(Signed)……………………………………(Date): 11/09/2018

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Finally, I would not have been able to accomplish this research without the love and support of my family, particularly my wife Penelope. I am grateful for the patience, encouragement and understanding that you have all shown throughout. Thank you!
Chapter One provides an introduction to the thesis, explores the nature of comprehensive multidisciplinary palliative care, presents its key historical developments, and outlines its core tenets as well as contemporary standards and outcomes. Key challenges that face palliative care health professionals are presented, along with research priorities and needs that psychologists are well placed to contribute to. The need to further progress psychotherapeutic research and better understand psychotherapeutic outcomes in palliative care patients is explored. This chapter concludes with the aims, significance, and structure of the thesis.

1.1 Thesis Introduction

People approaching end of life are faced with having to adjust to significant biopsychosocial changes associated with their advancing illness. As such, there is an elevated risk of experiencing psychological/emotional distress, existential and spiritual concerns, perceived loss of dignity, mood disorders, and expressions of desire to die (Chochinov, 2012; Chochinov et al., 2009; LeMay & Wilson, 2008). While psychosocial care is an integral part of the overall care of people with advanced disease, the feasibility, efficacy, and acceptability of psychotherapeutic interventions in this population are topics of ongoing research. This thesis provides an overview of the role of dignity near end of life, and presents quantitative and qualitative research on the effects of Dignity Therapy and Life Review interventions on people with advanced cancer and their families/carers. As part of measuring outcomes of these interventions, this thesis also outlines the development of a novel psychotherapeutic outcome measure involving sense of generativity and ego-integrity for use in palliative care settings.

1.2 What is Palliative Care?

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation, 2015)

Palliative care is an active, holistic, and multidisciplinary care of people with life-threatening or advanced illnesses (Billings, 1998). The key goals of palliative medicine
and the broader palliative care are to assist with symptom management in context of an
advancing disease; identify and manage sources of distress or suffering; improve
psychological, social, and spiritual well-being; and ultimately help people maintain
sense of dignity throughout the dying process (Chochinov, 2002; Kelley & Morrison,
2015). It aims to meet the complex needs of patients and their families or carers and as
such, it requires the cooperation and coordination of a variety of health professionals
from disciplines such as medicine, nursing, other health professionals, religious
representatives, and volunteers. The proportion of care that is palliative in intent tends
to increase when a patient’s illness is no longer considered to be curable. However, they
may also continue to receive other treatments that aim to control the progression of
disease and assist with symptom management such as additional surgery,
hemodialysis, and palliative chemotherapy and radiation therapy. Therefore, palliative
care is not an alternative to other models of care but rather an integral part of a
comprehensive health care system whose core principles remain consistent across a
variety of demographic factors and patient settings including hospitals, hospices,
nursing homes, and patients’ own homes (Billings, 1998).

Contemporary palliative care has its roots in rich human traditions of caring for
the sick and dying and its focus on after-death experiences. Various religious
movements such as the Knights Hospitallers in the Middle Ages were known to have
hospice-type facilities that provided a refuge for travellers as well as care for the sick
and dying (Connor, 1998). One influential example is the founding of Our Lady’s
Hospice in Dublin in 1845 by Mary Aikenhead and the Irish Religious Sisters of
Charity in response to significant challenges in caring for people dying with
tuberculosis, cancer, and other diseases (Kerr, 1993). In the 20th century, Dame Cicely
Saunders has been widely recognised as a central figure in studying, articulating, and
promoting key tenets of modern hospice and palliative care (Lutz, 2011). She began her
work with dying patients as a nurse and social worker in the late 1940s and
subsequently earned her medical degree before founding St Christopher’s Hospice in
London in 1967. In contrast to the usual approaches to end-of-life care at the time, she
placed significant emphasis on: (a) the concept of “total pain” that includes physical,
psychological, and spiritual distress, (b) appropriate and timely use of opioids in
management of physical pain, (c) attention to the complex needs of family or carers of
dying patients, and (d) provision of care regardless of diagnosis, religious affiliation, or
socio-economic status (Lutz, 2011). These guiding principles were influential in the
development of modern palliative care and continue to be reflected in its formalised
definitions and aims (e.g., the World Health Organisation definition of palliative care
quoted above).

1.3 Palliative Care Standards and Outcomes

As a medical subspecialty, palliative medicine is a rapidly evolving field that is
increasingly recognised as being guided by evidence-based practice and research
(Currow et al., 2009). The accreditation to practise as a palliative care physician in
Australia or New Zealand requires medical graduates to undertake a three-year
Palliative Medicine Advanced Training Program. This involves work-based learning,
coursework, conducting research, achieving assessment requirements, and receiving
supervision from a practising palliative care physician at an accredited training site
(RACP, 2017). Whilst certain aspects of comprehensive palliative care are inherently
discipline-specific, there are also core competencies and standards of education that are
relevant to all clinicians and other team members involved in the provision of palliative
care. The European Association for Palliative Care (EAPC) has reached a consensus on
and published a series of White Papers on palliative care and hospice standards and
norms (Radbruch & Payne, 2009), outcome measurement (Bausewein et al., 2015), and
palliative care education and core competencies that all health professionals and other
team members need to consider in the provision of comprehensive palliative care
(Gamondi, Larkin, & Payne, 2013).

Gamondi et al. (2013) also published a White Paper that outlined the following
three-tier framework of palliative care to help guide the required level of training and
education: (a) Palliative Care Approach in general settings of care such as internal
medicine and aged care where palliative care methods and procedures can be integrated
as required, (b) General Palliative Care provided by primary care clinicians who have
good basic palliative care skills and knowledge in treating patients with life-threatening
diseases such as oncologists, nephrologists, and other specialists, and (c) Specialist
Palliative Care provided by professionals working solely in palliative care settings and
managing complex end-of-life problems that require specialised skills and
competencies. In this framework, the required specialisation of palliative care guides the
extent of academic and clinical education ranging from undergraduate learning and
continuing professional development to specialist post-graduate programs, expert
supervision, and training. Furthermore, this White Paper identified ten core
competencies relevant to all health professionals working with patients with life-
limiting illnesses, regardless of the palliative care specialisation of their workplace. These competencies are outlined in Table 1.1.

Table 1.1: Core competencies in working with palliative care patients, as outlined in the Gamondi et al. (2013) White Paper

| 1. Application of core constituents of palliative care in the place of the patient/family’s choice, whenever possible |
| 2. Enhancement of physical comfort throughout the disease process |
| 3. Meeting patients’ psychological needs |
| 4. Meeting patients’ social needs |
| 5. Meeting patients’ spiritual needs |
| 6. Responding to the needs of family or carers in relation to patient care goals |
| 7. Responding to challenges of clinical and ethical decision-making |
| 8. Provision of comprehensive care coordination and interdisciplinary teamwork |
| 9. Development of effective interpersonal and communication skills appropriate to the nature of palliative care |
| 10. Practice of self-awareness and commitment to continuing professional development |

The proposed competencies were intended to complement and be integrated with existing skills and attitudes acquired through clinical practice and experience, particularly given the range of palliative care specialisation as outlined above by the three-tier framework. The ultimate goals of these competencies and guidelines are to promote service development, improve the quality and efficiency of multidisciplinary palliative care, enhance patient outcomes, and minimise risk to patients and clinicians (Gamondi et al., 2013). However, the impact of these consensus guidelines on service delivery and quality of palliative care remains to be empirically demonstrated. There is an urgent need to design educational interventions with the aim of improving end-of-life care in nursing homes (Anstey, Powell, Coles, Hale, & Gould, 2016), and end-of-life care competencies among General Practitioners (Giezendanner et al., 2017).

In Australia, the national peak body for palliative care, Palliative Care Australia (PCA), has developed and published the Standards for Providing Quality Palliative Care (PCA, 2005a). Currently in their fourth edition and under review at time of writing, the 13 standards have been designed for use primarily by acute specialist palliative care services but include elements relevant to all service providers. They were also
developed to assist national accreditation programs though they are utilised on a voluntary basis where they complement existing health legislation, benchmarks, and accepted protocols. Some of the key aspects of these standards include the need to acknowledge and respect the uniqueness of each patient and their family/carers, consider their holistic needs, maximise comfort, preserve dignity, ensure access to bereavement care and support, ensure effective collaboration with community agencies, and engage in ongoing research, education and self-care strategies. Similar to the EAPC three-tier framework (Gamondi et al., 2013), this document makes the distinction between general and specialist palliative care, and further outlines criteria for different levels of specialist care based on the ability to conduct quality research, education/teaching, and multidisciplinary staff resourcing.

Subsequently, PCA implemented the National Standards Assessment Program (NSAP) - a quality improvement initiative available to all specialist palliative care services. The program offers self-assessment and audit tools, and provides reports with basic performance comparisons with other services based on the 13 standards. Between 2010 and 2015, 178 centres across Australia have participated in the NSAP with a total of 297 assessment cycles. The standards involving patient-centred decision-making, bereavement support, and commitment to quality improvement and research had the highest ratings of priority. In general, services indicated high performance across most of the standards with the following elements identified as having potential need for improvement: advanced care planning, use of validated clinical assessment instruments, formal agreements with other service providers, assessment of community needs and involvement in community programs, education programs for staff to develop effective coping strategies, incorporating NSAP in education or training programs, and provision of bereavement follow-up.

A key disadvantage of the NSAP is that the outcomes based on self-assessments preclude any direct comparisons of performance and benchmarking between local, regional, or interstate services. Additionally, the use of mortality data or other simple process indices do not readily facilitate service performance improvements. One national program in Australia that aims to overcome these issues is the Palliative Care Outcomes Collaboration (PCOC), funded by the federal Department of Health. This voluntary program improves the understanding of palliative patient outcomes by (a) facilitating routine and systematic collection of patient outcomes through use of validated clinician-rated tools, (b) providing regular outcomes reports and workshops
that assist with service benchmarking, and (c) facilitating research through the use of a longitudinal database (Currow et al., 2015). The outcomes report (PCOC, 2017a) for the July to December 2016 time period revealed the following data from 113 participating specialist palliative care services:

- 83 services provided care in a hospital or hospice setting whilst the remaining 31 services provided care in the home
- 25,320 episodes of care were provided to 20,089 patients
- 74.5% of patients had a malignant diagnosis
- There were 10,212 patient deaths, of which 76.3% occurred in hospital
- The national benchmarks for timeliness of care and responsiveness to urgent needs were met by 80% and 53% of services respectively

The report also showed mixed results for pain management (six benchmarks), other symptom management (nine benchmarks), and family/carer problems (three benchmarks) although most services met at least one of these benchmarks, respectively. Long-term national results of participating specialist palliative care services from 2009 to 2016 are indicative of gradual improvements across all benchmarks and outcomes (PCOC, 2017b), and this trend is likely to continue in the near future. Of note is that PCOC does not incorporate any patient self-report measures despite the availability of a range of validated tools for suitable palliative care patients. Given the evidence that health professionals tend to underestimate rather than overestimate symptom intensities of cancer patients (Laugsand et al., 2010), these outcomes require careful interpretation. It is essential to continue to expand the evidence base for improved health outcomes, and also conduct further research into why comparable specialist palliative care services can have differing patient outcomes (Currow et al., 2015). This includes psychological, social, and spiritual outcomes following psychotherapeutic interventions tailored for use with palliative care patients.

### 1.4 Palliative Care Challenges

Australian life expectancy at birth is among the highest in the world, with 80.4 years for males and 84.5 years for females (Australian Bureau of Statistics, 2016). However, the increasing life expectancy is also associated with increasing rates of chronic diseases, and it is expected that up to 50% of deaths in Australia will be attributed to various chronic diseases (PCA, 2005b). Subsequently, it is expected that end-of-life care needs will continue to increase over time, even though not all people
approaching death require specialist palliative care (PCA, 2005b). Given also the relatively rapid development of palliative medicine as a medical subspecialty and multidisciplinary end-of-life care in general, there are a number of significant challenges for palliative care clinicians.

Public and professional misunderstanding of palliative care and discrepancies in the meanings of terms such as “hospice”, “end-of-life”, and “terminal” can make it difficult to draw conclusions from the growing research literature and apply that research evidence to local settings. The term “palliative care” itself had not entered the healthcare vocabulary until 1974 when Dr Balfour Mount coined this term in order to avoid perceived negative connotations of the term “hospice” in French culture (Loscalzo, 2008). There is also limited research into cost effectiveness of providing palliative care and inconsistent use of outcome measures in economic studies, which increases the likelihood of inefficient and inequitable funding decisions (Gardiner, Ingleton, Ryan, Ward, & Gott, 2017; Johnston, Normand, & May, 2017). Whilst voluntary in nature, national programs such as the PCOC are vital in demonstrating outcomes and cost-effectiveness given the finite state and federal health funding. Cultural considerations relevant to palliative care may also be poorly understood, guided, and resourced, despite the increasing cohort of patients from diverse cultural and linguistic backgrounds in Australian specialist palliative care units (Green, Jerzmanowska, Thristiawati, Green, & Lobb, 2018; Johnstone, 2012).

Significant barriers that impede palliative care research include funding limitations, poor infrastructure and research capacity, patients’ physical and psychological decline due to multi-systemic illness, the associated ethical issues, and possible gatekeeping by clinicians or carers (Chen et al., 2014; Kaasa, Torvik, Cherny, Hanks, & de Conno, 2007; LeBlanc, Lodato, Currow, & Abernethy, 2013). Palliative care health professionals are less likely to discuss research trial participation with eligible patients if they perceive these trials to be complex, inconvenient, involve possible side-effects, or impose a financial burden (White, Gilshenan, & Hardy, 2008). This is despite (a) the risk of denying patient autonomy, (b) the risk of hindering the completion of trials that may guide improvements in patient care, and (c) suitable palliative care patients being as interested in participating in research as other patient groups such as oncology patients (White & Hardy, 2010). There is also a need to better understand and evaluate supportive interventions for family members or carers of terminally ill patients that extend beyond practical assistance and bereavement support
This is especially the case for home-based palliative care services, given that psychosocial needs in particular can be more difficult to identify and manage in these settings (Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2014). Additionally, it remains to be seen whether the traditional focus on advanced cancer patients can be extended in practice to non-malignant conditions, with key barriers being relatively less certain illness trajectories, unclear clinician roles, and lack of interdisciplinary collaboration (Oishi & Murtagh, 2014). Rosenwax, McNamara, Blackmore, and Holman (2005) developed a method for estimating the total population that could benefit from receiving palliative care in the last year of their life, and they applied these estimates to the Western Australian (WA) population. The most conservative estimate of palliative care needs included about 50% of all patient deaths from the following 10 conditions: cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neurone disease/amyotrophic lateral sclerosis, Parkinson’s disease, Huntington’s disease, Alzheimer’s disease, and HIV/AIDS. Other estimates of palliative care needs in high-income countries are even higher, with up to 82% of all deaths (Murtagh et al., 2014). However, a retrospective study of all deaths in WA in 2009 and 2010 found that only 14% of all deceased patients with non-malignant conditions had accessed hospital and community specialist palliative care services in the last year of their life (Rosenwax, Spilsbury, McNamara, & Semmens, 2016). It was noted that this was still an increase of 6.1% compared to the equivalent patient population one decade prior. Patients with chronic obstructive pulmonary disease and end-stage liver disease were most likely to receive palliative care input, followed by renal and heart failure. Further progress is required in understanding best clinical practice and care needs for people with terminal non-malignant conditions, and incorporating the evidence base into healthcare policy and funding in order to provide appropriate palliative care for all (Oishi & Murtagh, 2014; Rosenwax et al., 2016).

Adequate palliation must also include psychological, social, psychiatric, existential, cultural, and spiritual factors of patient distress in addition to the traditional focus on pain and symptom management (Chochinov, Hack, Hassard, & Kristjanson, 2004; Chochinov et al., 2009; Huang, Yates, & Prior, 2009; Steinheuser et al., 2000). Patients with life-threatening or terminal illnesses may need to adjust to multiple changes in domains such as physical and cognitive functioning; symptom frequency and
severity; interpersonal or role functioning; perceptions of self, others, and the future; and beliefs about life’s meaning and purpose (Chochinov et al., 2009). There is often a need for palliative care patients to navigate typically complex healthcare systems and face difficult decisions relating to treatment, personal, family, and financial matters (Gaston & Mitchell, 2005). Not surprisingly, terminally ill patients are at significant risk for experiencing psychological and existential distress, depression, and suicide, with expressions of desire to die being particularly associated with depressive and anxiety disorders in this population (Wilson et al., 2016).

There is evidence that primary health-care providers in palliative care settings may not have sufficient training and confidence in optimally assessing and treating emotional and existential distress, depression, and anxiety (Lawrie, Lloyd-Williams, & Taylor, 2004; Lloyd-Williams & Payne, 2003; Rabow, Hauser, & Adams, 2004). There are also no specific standards of what constitutes adequate spiritual care (Puchalski, Kilpatrick, McCullough, & Larson, 2003). Ellis et al. (2009) examined the determinants of referrals to specialised psychosocial care in a sample of 326 advanced cancer patients. They found that the majority of patients who scored above the cut-off for depressive features and hopelessness were not referred to psychosocial care at any point during their clinical follow-up. This was particularly likely to occur with increasing age of patients and was irrespective of levels of distress. Possible reasons for inconsistent psychosocial care include lack of consensus about which multidisciplinary team member is best positioned to provide care; clinicians lacking specialised knowledge and skills to assess and treat complex psychosocial issues; difficulties differentiating clinical depression from the spectrum of normal responses such as grief, sadness, loneliness, and fear; difficulties defining existential or spiritual distress; the usual diagnostic cues for mental disorders being confounded by medical symptoms; and the stigma and apprehension stemming from a belief that palliative patients cannot tolerate antidepressant treatment or in-depth exploration of these issues (Block, 2000, 2006; King, Heisel, & Lyness, 2005; O’Connor & Fisher, 2010).

1.5 Psychotherapy Research Opportunities in Palliative Care Settings

The various challenges faced by palliative care clinicians also give guidance to the research priorities, needs, and opportunities in this area of practice. Psychologists working in health and acute medical settings are traditionally oriented towards health promotion, disease prevention, and application of psychological research to illness assessment, treatment, adjustment, and rehabilitation. Key issues that can occur near
end-of-life such as death anxiety, demoralisation, decision making, psychosocial aspects of pain and other symptoms, and complex grief and bereavement have been the subject of considerable psychological research (American Psychological Association, 2005). By utilising their comprehensive skill set and embracing the multidisciplinary and holistic palliative care perspective, psychologists and other mental health professionals working in palliative care settings are able to: (a) identify and outline research priorities and gaps relevant to psychosocial care, (b) contribute to intra- and inter-disciplinary education and clinical training programs, (c) assist with team development, self-care and management of team dynamics that can occur in emotionally demanding workplaces, (d) assist in developing best practice models of multidisciplinary psychosocial care and contribute to policy development at a local, state and federal level, (e) assist with team evaluations of compliance with palliative care standards, benchmarking, and outcomes, (f) evaluate the comparative effectiveness of various individual, group, and family psychological therapies in the palliative care population, and (g) directly assist patients and their families/carers with psychological, emotional, and social adjustment to the wide-ranging impacts of the terminal disease (Kasl-Godley, King, & Quill, 2014).

The establishment of an evidence base for systematically developed psychotherapeutic interventions aimed at addressing psychosocial and existential distress near end of life is particularly important in meeting complex psychosocial and emotional needs of palliative care patients (LeMay & Wilson, 2008). Akechi, Okuyama, Onishi, Morita, and Furukawa (2008) conducted the first systematic review of randomised controlled trials (RCTs) that compared psychotherapeutic approaches with treatments as usual for depression among incurable cancer patients. Out of the six studies used for meta-analyses, four utilised Supportive Psychotherapy, and there were single studies of Cognitive-Behavioural Therapy (CBT) and a structured problem-solving approach. Unlike treatments as usual, all psychotherapies were associated with significant decreases in depressive scores in mildly to moderately distressed patients, comparable to the effects of antidepressant pharmacotherapy in general psychiatry settings. The findings for general distress and anxiety were similar, though improvements in anxiety did not reach statistical significance. There was insufficient available research to be able to evaluate the efficacy of psychotherapy for patients diagnosed with clinical depression such as major depressive disorder (Akechi et al., 2008).
Findings from the systematic review by Akechi et al. (2008) were consistent with a more recent systematic review and meta-analysis of psychotherapeutic treatments for depression among advanced incurable cancer patients by Okuyama, Akechi, Mackenzie, and Furukawa (2017). Psychotherapies such as CBT and Supportive-Expressive Group Therapy were associated with moderate significant decreases in depression scores in mildly to moderately distressed patients. However, there was a notable lack of quality studies that included clinically depressed individuals, quality of evidence across the included studies was rated as low, and sample heterogeneity was high. No conclusions could be reached about superiority of any particular psychotherapeutic modality, and the effect sizes for group approaches were similar to individual therapies. The latter systematic review used inconsistent eligibility criteria for psychotherapy RCT inclusion. For example, two studies of meaning-making interventions were incorporated in the review, but trials of similar psychotherapeutic interventions such as Dignity Therapy were excluded. Okuyama et al. (2017) concluded that more well-designed clinical trials of a wider range of psychological interventions in clinically depressed palliative care patients were required in order to better our understanding of the psychotherapeutic effectiveness in this patient population.

A number of other, relatively novel psychotherapeutic interventions tailored to the psychosocial and existential concerns of palliative care patients have been developed, outlined, and evaluated in the literature. LeMay and Wilson (2008) conducted a review of the rationale, structure, therapeutic stance, and empirical evidence for eight manualised psychological interventions aimed at addressing existential concerns and suffering near end of life. Both individual and group approaches were reviewed, including Dignity Therapy, Supportive-Expressive Group Therapy, and the Meaning-Making Intervention. Methodological considerations and challenges were evident across most included studies, such as issues with recruitment and attrition, insufficient detail of sample characteristics, limited follow-up assessments, presence of confounding variables, and the need for inclusion of other therapeutic primary outcomes that palliative care patients may consider more meaningful to them. Whilst the initial outcomes of the included studies were deemed to be encouraging, there was insufficient evidence to suggest any one psychotherapeutic intervention was superior to others. Additional well-designed clinical trials are required to clarify the utility and effectiveness of these interventions in palliative care settings (LeMay & Wilson, 2008).
One of these promising novel interventions, Dignity Therapy, is a brief individualised psychological therapy which aims to address dignity-related distress by facilitating a guided life-review process. The aim of the process is to create a lasting legacy document that includes important and meaningful aspects of a patient’s life, words of wisdom, personal values, hopes and dreams, and other matters that may need to be expressed to their loved ones. In contrast to other psychotherapeutic approaches, Dignity Therapy is tailored to palliative patients by (a) being grounded in an empirical model of dignity that is based on palliative care patients’ own perceptions of their sense of dignity (Chochinov et al., 2002a), (b) being relatively brief, flexible, task-oriented, and facilitative of family or carer involvement, (c) placing less emphasis on insight, interpretation, and skill-building, and (d) instead focusing on the process of enhancing meaning, purpose, and sense of dignity. As a result, this approach has the ability to positively influence both patients and their families, and it can be suitable for patients who are unwell and proximate to death as long as they are able to maintain sufficient cognitive ability. A systematic review found that evaluations of Dignity Therapy to date have shown consistently high acceptability and satisfaction rates among patients and their families/carers, variable feasibility due to issues with recruitment and retention, and generally uncertain effectiveness given the limited effects on primary outcome measures immediately after interventions (Fitchett, Emanuel, Handzo, Boyken, & Wilkie, 2015).

Life Review is a psychotherapeutic approach that is similarly flexible, brief, and suitable for use in palliative care settings. In this approach, a graduated review of the lifespan is conducted with the key goals of helping the person address or process key life experiences, explore life’s meaning and purpose, and ultimately achieve sense of acceptance (Stinson & Kirk, 2006; Trueman & Parker, 2006). Similar to Dignity Therapy, there is evidence that Life Review interventions are acceptable and feasible in palliative care settings though their efficacy remains uncertain due to limited empirical evidence and methodological issues such as high patient attrition rates and floor/ceiling effects of outcome measures (Keall, Clayton, & Butow, 2015). Further comparisons of these two psychotherapeutic interventions are presented in Chapter 3 of the Doctoral thesis.

1.6 Thesis Aims and Significance

The broad aim of this project was to conduct research that examined the efficacy of Dignity Therapy for palliative care patients by comparing this intervention to Life
Review and a Waitlist Control Group. This empirical component of the thesis comprises three separate though related studies (Chapters 5 to 7 of the Doctoral thesis).

The aim of the first study was to develop a measure of Erik Erikson’s (1963) concepts of generativity and ego-integrity that is suitable for use in palliative care settings and could also be used as an outcome measure in the subsequent RCT. In Erikson’s psychosocial theory of lifespan development, generativity refers to a person’s connection with the next generation, passing skills and knowledge to others, being productive, and leaving a lasting legacy. Ego-integrity refers to looking back on one’s life with a sense of meaning, acceptance of past life events, and the general absence of death anxiety. The lack of a suitable measure of these concepts in palliative care settings was a significant barrier in measuring and understanding the potential importance of these concepts near end of life.

The second study was an RCT that examined the efficacy of Dignity Therapy vs Life Review vs Waitlist Control Group on a range of outcome measures, including the Brief Generativity and Ego-Integrity Measure (Appendix A) that was developed and evaluated in the first study. The utilisation of a waitlist control group and the provision of Life Review in an identical way to Dignity Therapy with the exception of creating a legacy document allowed for an unprecedented evaluation of these interventions.

The third study utilised qualitative methods to further explore and better understand the similarities and differences between the transcripts of Dignity Therapy and Life Review interventions that were not possible by use of quantitative methods alone. These interventions were compared across three a priori themes - sense of generativity and ego-integrity based on Erik Erikson’s psychosocial theory, the empirical model of dignity, and personal or core values.

1.7 Organisation of Thesis

This thesis consists of eight chapters and is presented in a format where three of the chapters are papers that have been published in peer-reviewed journals. The current chapter (Chapter 1) presents an introduction to the thesis, provides an outline of the palliative care context, and its challenges and research opportunities, and describes the project aims and research questions. Chapter 2 is a literature review of the sense of suffering in palliative care patients and its key psychosocial contributing factors, namely existential and spiritual distress, demoralisation, mood disorders, and perceived loss of dignity. The most comprehensive model of dignity in palliative care patients (Chochinov et al., 2002a) is presented and its relevance discussed. Chapter 3 consists of
a literature review of Dignity Therapy, Life Review interventions, and their comparison with other psychotherapeutic modalities that have been utilised and evaluated in palliative care settings.

Chapter 4 provides an overview of the three studies that were conducted as part of this Doctoral research, and how they fit together as a larger body of research. Their rationale, aims, context, and methodological considerations are outlined. Chapter 5 is comprised of the first paper, titled “Development of a brief measure of generativity and ego-integrity for use in palliative care settings”. This paper was published in the peer-reviewed journal *Palliative and Supportive Care*. The development of this self-report questionnaire of Erikson’s concepts of generativity and ego-integrity enabled its use as a key outcome measure in the subsequent papers. Chapter 6 is comprised of the second paper, titled “Dignity therapy and life review for palliative care patients: A randomised controlled trial”. This paper was published in the peer-reviewed *Journal of Pain and Symptom Management* and it outlines the results of the main quantitative study conducted as part of the Doctoral research. Chapter 7 is comprised of the third paper, titled “Dignity therapy and life review for palliative care patients: A qualitative study”. This paper was also published in the *Journal of Pain and Symptom Management*. It outlines the results of qualitative comparisons between intervention groups, and discusses the clinical implications. Chapter 8 integrates the findings of the three studies into a general discussion, explores their implications in context of the previous literature, and provides recommendations for future research.
2.1 Sense of Suffering Near End of Life

Suffering in the palliative context is a broad multidimensional concept that extends well beyond concerns about physical symptoms. It can be conceptualised as a state of severe emotional distress that occurs when there is damage to the intactness or integrity of the person as a whole – a complex physical, social, psychological, and spiritual being (Cassell, 1982; Kearney, 2000). Consistent with Dame Cicely Saunders’ (1988) concept of “total pain”, suffering is an inherently subjective experience that is best understood by a careful consideration of its underlying multidimensional components and contributors. It is also apparent that the distinction between the various sources of suffering can become increasingly entangled and difficult to differentiate as people approach end of life (Chochinov, 2000). This complex interplay of the physical, psychosocial, existential, and spiritual factors helps explain why suffering can occur in the absence of pain and why patients with severe pain may not perceive themselves as suffering (Hebert, Arnold, & Schulz, 2007).

Whilst the palliative care literature generally recognises sense of suffering as a broad multidimensional concept, there is a lack of consistent frameworks that identify its core features and there is little consensus about the relative importance of its components (LeMay & Wilson, 2008). In order to provide a more nuanced understanding of this phenomenon, Best, Aldridge, Butow, Olver, and Webster (2015) conducted a systematic review of suffering in cancer patients with the specific goals of identifying and synthesising its various conceptualisations, and exploring its antecedents and consequences. One hundred and twenty-eight studies involving quantitative,
qualitative, and theoretical conceptualisations of suffering in adults with cancer were included in the analysis. Studies were limited to the English language and published in peer-reviewed journals between 1992 and 2012. The authors noted a wide range of synonymous descriptions and surrogate terms for the suffering phenomenon, including somatic pain, spiritual distress/angst/despair/crisis, existential anxiety, psychosocial-spiritual-suffering, death anxiety, and demoralisation (Best et al., 2015).

Regardless of the terminology used, a number of attributes of suffering were identified that were consistently referred to in the studies included in Best et al.’s (2015) systematic review. Suffering was observed to be a common human experience occurring in the context of the diminished ability to adjust to significant changes as well as real, perceived, or impending losses. It was frequently described as an intensely personal, unique, and dynamic experience that is all-encompassing in that it can pervade a person’s entire life. It was also characterised as an alienating and isolating experience, both from important others and the wider social context and community. It was noted that the sense of alienation can be further exacerbated by hospitalisations or hospice admissions, and the unintended consequences of understimulation, loneliness, and sense of imprisonment. This finding suggests that, in turn, suffering may also be at least partly alleviated by assisting palliative care patients in maintaining aspects of their family, social or cultural roles, and facilitating connectedness to their community.

Best et al. (2015) also found that suffering was frequently associated in the literature with sense of hopelessness, helplessness, inability to influence the progress of the illness, inability to attach meaning to the experiences, and loss of purpose in the remaining life. Of note is that some of the included studies considered loss of meaning to be an attribute or a consequence of suffering whilst others argued that loss of meaning is suffering. Additionally, it was noted that non-physical suffering can be difficult for patients to articulate due to inability or reluctance to express their deepest emotions and distress. This can potentially impact the ability of palliative care clinicians to assess, acknowledge, and manage the various manifestations of suffering and focus primarily on symptom management. Best et al. concluded their systematic review and synthesis of conceptualisations of suffering by proposing the term “holistic suffering”. They defined holistic suffering as “an all-encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality” (p. 981).
A key disadvantage of attempts to synthesise various conceptualisations of suffering into more comprehensive definitions (e.g., Best et al., 2015) is that the resulting definitions of suffering can become overly complex, over-inclusive, and difficult to apply to clinical settings due to individual patient variations. Suffering by its nature is a deeply personal and contextual experience although it is still possible to discern its underlying elements and sources (Hoffmaster, 2014). In other words, more effective understanding of suffering may involve asking “why” it occurs rather than “what” it refers to (Lindholm & Eriksson, 1993). Therefore, an alternative approach to conceptualising the sense of suffering is to de-emphasise the definitional approach and instead use this term as an “umbrella concept” for a number of its associated biopsychosocial factors. Given that suffering is contributed to by not just somatic issues but also emotional, existential, and spiritual sources of distress and perceived loss of dignity (Cassell, 2014), these psychosocial factors are explored next.

### 2.1.1 Existential and Spiritual Distress

Existential and spiritual distress are personal, dynamic, multidimensional concepts that are increasingly recognised in the empirical literature as being key contributors to the broader sense of suffering near end of life (Boston, Bruce, & Schreiber, 2011). Confronting existential or spiritual questions is not unusual towards the end of life. However, these concepts continue to lack consistent frameworks that define their core features resulting in conceptual misunderstandings, inadequate training for palliative care clinicians and medical practitioners in general, and inconsistent clinical management of these concerns (Berlinger, 2007; Boston et al., 2011; Dyson, Cobb, & Forman, 1997; LeMay & Wilson, 2008; McSherry & Cash, 2004).

There is a rich literature describing the existential themes of human existence starting with the early work of existential philosophers such as Soren Kierkegaard, Friedrich Nietzsche, and Jean-Paul Sartre. Engel (1967) introduced a “giving up-given up complex” in medically ill patients, which he saw as a state of pervasive discouragement and inability to cope with the impacts of medical illness, characterised by a sense of helplessness, hopelessness, subjective incompetence, loss of control, and loss of continuity between the past and the future. More specifically, he stated that:

- **with helplessness** the subject feels powerless to overcome the loss of gratification, but perceives the environment to be responsible and expects the environment to take over and provide the missing gratification; with
hopelessness the subject assumes he is responsible for the loss of
gratification and cannot be helped even if the environment takes action
(p. 553).

Engel noted that “giving up-given up” episodes do not only occur as a result of
somatic illness but can also contribute to the emergence of somatic issues as long as
necessary predisposing factors are also present.

Existential distress in psychiatric patients was conceptualised by Frank (1974) as
the experience of demoralisation. To Frank, demoralisation was the result of a persistent
failure to cope with external and internal stressors where there was an expectation to
cope by the person and by those close to him or her. He argued that when these
expectations are not met, the person’s self-esteem is damaged, and there are feelings of
powerlessness, rejection, impotence, isolation and despair. Furthermore, he stated that
the end result of the sense of demoralisation is expressed through the symptoms of
anxiety and depression.

Victor Frankl (1985) saw existential distress as resulting from failure to find
meaning in one’s existence, or experiencing the “existential vacuum”. He argued that
this typically involves seeing one’s existence as meaningless, empty, or futile, and
having a lack of purpose and direction. Based on his experiences in a Nazi
concentration camp, Frankl also emphasised the importance of maintaining hope for
the future even as the usual sources of meaning such as work, family, and small
pleasures in life were taken away from prisoners:

The prisoner who had lost faith in the future - his future was doomed. With
his loss of belief in the future, he also lost his spiritual hold; he let himself
decline and became subject to mental and physical decay... Usually it began
with the prisoner refusing one morning to get dressed and wash or to go out
on the parade grounds. No entreaties, no blows, no threats had any effect. He
just lay there, hardly moving. If this crisis was brought about by an illness,
he refused to be taken to the sick-bay or to do anything to help himself. He
simply gave up. There he remained, lying in his own excreta, and nothing
bothered him any more (p. 95).

Regarding the process of searching for meaning, Frankl (1975) also stated
that “meaning must be found and cannot be given” (p. 112) and it is “something to
discover rather than to invent” (p. 113). More specifically, he posited that meaning
emerges through actively experiencing something or someone we value, out of
concern for others, through creativity, and by changing one’s attitude towards suffering. Finding meaning in one’s existence or suffering is the ultimate goal of a form of psychotherapy called Logotherapy, which is explored further in Chapter 3 of the Doctoral thesis.

More recently, Kissane (2000) defined existential distress as “the distressed state of an individual confronting their own mortality, and arising from the consequent feelings of powerlessness, futility, meaninglessness, disappointment, remorse, death anxiety and the disruption of personal identity; the experience of life without meaning” (p. 1022). This conceptualisation further stated that each of these issues can lead to a spectrum of responses ranging from successful negotiation and adjustment to morbid complication and increasing distress. Kissane proposed that the features of successful negotiation and the subsequent perceptions of a good death include courageous awareness of the dying process, spiritual peace, sense of fulfilled life, allowing self to experience grief and sadness at saying good-bye, feeling supported by family and friends, accepting frailty and reduced independence, and feeling dignified despite the progression of the illness. On the other hand, he proposed that the risk of experiencing mental health disorders increases with fear and death anxiety, demoralisation due to sense of futility and meaninglessness, withdrawal, isolation, loss of control, symptom distress, and fears of being a burden to others.

Similarly, Murata and Morita (2006) conceptualised psycho-existential suffering as “pain caused by extinction of the being and the meaning of the self” (p. 17). They proposed that this type of suffering is caused by a series of losses such as (a) loss of relationships and sense of burdening others, (b) loss of autonomy including losses of independence, control, and continuity of self, and (c) loss of temporality or the future including poor sense of generativity, death anxiety, and sense of hopelessness about the future. The authors noted that this conceptual model of psycho-existential suffering requires further revisions through future studies and trials, and it is an initial step towards exploration of effective clinical approaches for this type of distress among palliative care patients.

Spiritual well-being is also a dynamic multidimensional concept that is fundamental to providing holistic end-of-life care (Dyson et al., 1997). Vachon, Fillion, and Achille (2009) systematically reviewed the empirical literature on end-of-life spirituality and defined this concept as a “developmental and conscious process, characterised by two movements of transcendence; either deep within the self or beyond
McSherry and Cash (2004) also suggested that there may be two main forms of spirituality: a traditional form that is based on religious and theocentric descriptors and a post-modern form that is based on phenomenological, existential, and humanistic descriptors. This therefore suggests that even though existential and spiritual distress can overlap and refer to similar patient experiences, they are not necessarily synonymous. In other words, spirituality can be seen as a “personal search for meaning and purpose in life, which may or may not be related to religion. It entails connection to self-chosen and or religious beliefs, values and practices that give meaning to life, thereby inspiring and motivating individuals to achieve their optimal being” (Tanyi, 2002; p. 506). Grech and Marks (2017) further outlined the following considerations in differentiating between existential and spiritual phenomena:

- Spirituality can have vastly different meanings for different people. Therefore, patients who experience existential distress or suffering may not consider themselves to be spiritual and may decline the need for a religious care worker such as a chaplain.

- Spirituality can be subsumed within the larger existential domain but spirituality does not encompass all aspects of existential distress. Therefore, “all spiritual suffering is existential suffering, but not all existential suffering is spiritual suffering” (p. 94).

- The terms “spiritual” and “existential” may not be easy to recognise or acknowledge by palliative care patients. Therefore, explicitly naming the specific source of distress and reflecting the patient’s language characterising their suffering are likely to better facilitate these discussions.

Despite the inconsistencies in how palliative care providers conceptualise and identify existential and spiritual well-being, there is increasing evidence that people with advanced illnesses consider these aspects of care as critically important to them (Boston et al., 2011; Cohen, Mount, Tomas, & Mount, 1996). Mount, Boston, and Cohen (2007) conducted a phenomenological study examining in-depth experiences of existential and spiritual suffering and well-being in 21 adults with life-threatening illness. Participants in this study reflected on these themes occurring not just during their current illness but also throughout a variety of other life experiences. Participants generally attributed their existential and spiritual well-being and quality of life to being able to find a sense of meaning in the face of their illness, and particularly to being able to form “healing connections” and bonding with either the self, others, experiences, or
ultimate meaning. In contrast, sense of suffering, anguish, and poor quality of life were generally attributed to a sense of disconnection from the self, others and the wider world, and a crisis of meaning.

Winkelman et al. (2011) also found that spiritual concerns were relatively common among 69 religious and non-religious patients with advanced cancer, and associated with perceptions of poor quality of life and well-being. Most participants in this study viewed spiritual concerns to be either moderately or very important for medical and nursing staff to consider within the medical setting. The perspectives of palliative caregivers further affirm the importance of managing existential and spiritual themes in the provision of end-of-life care (Boston & Mount, 2006). In practice, the management of existential and spiritual sources of distress will be guided by each patient’s personal views of these themes and the ability of treating teams to identify and acknowledge these sources of distress. This ability can be further assisted by fostering rapport, maintaining sensitivity, and demonstrating unconditional receptiveness to discussing these sources of distress (Boston et al., 2011).

### 2.1.2 Demoralisation Syndrome

The broad conceptualisations of existential and spiritual distress described above are reflective of the complex and multidimensional nature of these constructs. However, there is a possibility that all psychological or emotional disturbances that occur near end of life may be subsumed by these definitions, and that existential distress is seen as a natural part of the human experience (Hauser & Walsh, 2009). In order to categorise the above-mentioned existential or spiritual issues and improve their clinical utility, Kissane, Clarke, and Street (2001) introduced the notion of a demoralisation syndrome. The proposed diagnostic criteria include a minimum of a two-week period of the loss of meaning and purpose in life, sense of hopelessness and helplessness, sense of failure, lack of motivation to cope differently, and social isolation or lack of support. Whilst there is inherent overlap between the demoralisation syndrome and major depression, the latter is associated with pervasive anhedonia or the loss of consummatory pleasure in the present while the former is primarily a disorder of meaning and hope (Kissane et al., 2001; Kissane et al., 2004; Lloyd-Williams, Reeve, & Kissane, 2008). Demoralisation symptoms can also fall on a continuum from non-pathological disheartenment and loss of confidence, through to despair, loss of hope, and full-blown demoralisation with loss of meaning, purpose, and the will to live (de Figueiredo, 2013).
The clinical utility of the demoralisation syndrome in the palliative care setting was further aided by the development of the Demoralisation Scale (DS) in 2004 and more recently the Demoralisation Scale-II (DS-II; Robinson et al., 2016). The DS-II is a 16-item self-report measure of sound psychometric properties comprising two 8-item factors: \textit{Meaning and Purpose} and \textit{Distress and Coping Ability}. The authors found that the Meaning and Purpose subscale had relatively stronger associations with desire and will to die and quality of life whilst the Distress and Coping Ability subscale yielded relatively stronger correlations with psychological symptom burden and distress. This association between demoralisation and increased physical symptoms appears to be at least partially mediated by the loss of dignity (Vehling & Mehnert, 2014). This suggests that higher physical symptom distress heightens the risk for perceived loss of dignity, which then raises the risk for experiencing demoralisation.

A systematic review of 10 studies that utilised the DS found that the prevalence of demoralisation in cancer or palliative care patients ranged from 13\% to 18\% (Robinson, Kissane, Brooker, & Burney, 2015). Clinically relevant demoralisation can also occur independently of mood disorders and was associated with higher suicidal ideation compared to depression in a sample of 430 cancer patients (Vehling et al., 2017). Nevertheless, the convergence between the demoralisation syndrome and the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) criteria for major depression and particularly adjustment disorder in palliative care settings is a key issue in establishing its divergent validity. For example, moderate levels of demoralisation are consistent with the DSM-5 criteria for adjustment disorder so a diagnosis of \textit{Adjustment Disorder with Demoralisation} may facilitate better description and understanding of patient experiences and guide psychotherapeutic interventions near end of life (Robinson et al., 2016). Further research is needed with large homogeneous samples and longitudinal study designs in order to better understand the relationships between demoralisation, mood disorders, and other biopsychosocial variables such as loss of dignity.

\textbf{2.1.3 Mood Disorders in Palliative Care Patients}

There is empirical evidence that anxiety and depressive disorders in palliative patients are associated with desire to die, existential and spiritual distress, lower performance status, social concerns, and also the physical symptoms of moderate to severe pain, weakness, and drowsiness (Wilson et al., 2007). Lloyd-Williams, Dennis, and Taylor (2004) found that depression in palliative care patients was significantly associated with perceived poor quality of life, pain, fatigue, and poor physical
functioning, but not with nausea and breathlessness. It appeared that the presence of psychological distress may have contributed to subjective magnification of the frequency, severity, and duration of physical symptoms, or that some physical symptoms were more likely than others to lead to psychological distress. However, the cross-sectional nature of the data did not allow assessment of whether either or both of these possible causal pathways was supported.

The prevalence of anxiety and depression in palliative care settings is difficult to estimate due to significant variations in study sample sizes, type and severity of illness, type of setting, patient characteristics, the quality and comprehensiveness of assessment methods, and the use of cut-off scores. Assessment methods can also significantly vary between studies in that they can include single question screens (e.g. “are you depressed”), clinician rating scales, self-report screening instruments, and gold-standard structured and semi-structured clinical interviews, each with their own inherent strengths and weaknesses and varying uptake levels. Distinguishing between clinical depression and concepts such as existential distress or suffering can be difficult for clinicians due to a lack of established guidelines for defining and assessing existential and spiritual concerns (Schuman-Olivier, Brendel, Forstein, & Price, 2008).

Mitchell et al. (2011) conducted a meta-analysis of 94 studies that utilised a psychiatric clinical interview in determining the prevalence of anxiety, depression and adjustment disorder in cancer and palliative care settings. They found that the pooled prevalence of depression in palliative care patients as per the criteria set by the Diagnostic and Statistical Manual of Mental Disorders or the International Classification of Diseases was 16.5%. Prevalence of adjustment and anxiety disorders were 14.4% and 9.8% respectively. However, it was noted that adjustment disorder is typically poorly studied and defined, and there were insufficient data to analyse the prevalence rates of specific anxiety subtypes such as post-traumatic stress disorder, panic disorder, and generalised anxiety disorder. Of note is that there was no difference in prevalence of depression between palliative and non-palliative cancer settings or disease stages, suggesting that depression is not a definitive consequence of disease becoming incurable or terminal.

2.2 Role of Dignity Near End of Life

Primary aims of palliative care can be summarised under the overarching goal of helping people die with dignity. Respect for patient dignity is of universal concern for palliative care clinicians and it is an essential component of nursing care (Baillie, 2009;
One of the earliest major documents that recognised the importance of the inherent sense of dignity was the United Nations Universal Declaration of Human Rights (UDHR) published in 1948. This carefully worded document provided the background for the modern human rights revolution. The opening sentence of the first article of the UDHR states that “All human beings are born free and equal in dignity and rights”. This statement established the basis for universal human rights on which the rest of the UDHR elaborated. Despite its initial prominent placement, the term dignity was only briefly mentioned two more times in the UDHR and no definition was provided (Mann, 1998). The need to maintain patient dignity has been included in the International Council for Nurses Code of Ethics, which states that “Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect” (ICN, 2012, p. 1). The Nursing and Midwifery Board of Australia (NMBA) Code of Conduct states that nurses must support “the rights, dignity and safety of others, including people and colleagues” (NMBA, 2018, p. 9).

Patient dignity has also been widely used in healthcare by policy makers. In the UK, health policies produced by the National Health Service have supported the need for dignified care of patients. Campaigns such as “Dignity in Care” were launched in response to the concerns that older people’s dignity was not always respected (Baillie, 2009). UK Government reports such as “Caring for Older People” and research reports such as “Not Because They Are Old” by the Health Advisory Service also highlight the problems with patient dignity. In the US, there is a similar societal and political consensus about facilitating dignity in aged and palliative care as evidenced by a number of government initiatives regarding “aging with dignity” and “dying with dignity” (Periyakoil, Kraemer, & Noda, 2009). There is a similar trend in Australia where, for example, preservation of dignity is specifically mentioned in two out of 44 outcomes that residential nursing homes must comply with at all times under the Aged Care Act 1997. The issue of human dignity has also been central in recent biomedical ethics documents including in international policy documents related to human embryo experimentation (Andorno, 2014). For example, the Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine utilises human dignity as a criterion to determine the permissibility of international biomedical developments.
Dignity is also a key concept in the debate on euthanasia and physician-assisted suicide where both supporters and opponents of these practices commonly express concerns about patient dignity to support their respective views. In this context, the term euthanasia refers to a physician acting directly to end a patient’s life, whereas the terms physician-assisted suicide and assisted dying involve a physician providing the means or assistance to a patient for them to end their own life. In Australia, concerns about patient dignity have been central in voluntary euthanasia bills that were introduced in most states over the last 15 years. In 2016, the Death with Dignity Bill 2016 was tabled in the House of Assembly of the South Australian Parliament and narrowly rejected by Members of Parliament after an initial tied vote. Subsequently, the Victorian Parliament passed the Voluntary Assisted Dying Bill 2017 after a conscience vote. As a result, Victoria became the first Australian state to legalise assisted dying for terminally ill patients.

The role of dignity in patient requests for euthanasia and physician-assisted suicide has been increasingly investigated since the 1997 enactment of the Oregon “Death with Dignity Act”. This legislation allowed terminally ill Oregonians to obtain prescriptions from their physicians for self-administered lethal doses of medication. Between 1997 and the start of 2017, a total of 1,749 people had prescriptions written under this act of which 1,127 people died from ingesting the medications (Oregon Public Health Division, 2016). In 2016, the most commonly stated end-of-life concerns for the 133 people that died were loss of autonomy (89.5%), decreased ability to participate in enjoyable activities (89.5%) and loss of dignity (65.4%). These findings were similar to previous years where loss of dignity consistently ranked highly among end-of-life concerns.

Several empirical studies of physician experiences and perceptions have supported the above findings. Rietjens et al. (2006) examined physician perceptions about terminal sedation and euthanasia in the Netherlands. Individual interviews were held with a nation-wide stratified sample of 410 physicians. They found that euthanasia requests were strongly associated with perception of suffering with no prospect of improvement and loss of dignity, while requests for terminal sedation were most often related to suffering with no prospect of improvement, severe pain, and dyspnoea. Similarly, Onwuteaka-Philipsen et al. (2012) examined the attitudes of physicians attending the 8,496 deaths by euthanasia or physician-assisted suicide in the Netherlands in 2010. They found that the most important reasons for physicians to grant euthanasia requests
were patient wishes (85%), no prospect of improvement (82%), no treatment options left (73%), and loss of dignity (61%).

Other empirical studies have shown that loss of dignity is associated with requests for euthanasia or physician-assisted suicide for a relatively smaller number of patients. Wilson et al. (2007) administered semi-structured interviews to 379 patients who were receiving palliative care for cancer. They found that less than 10% of patients were highly concerned about loss of dignity. There was no significant difference in perceived loss of dignity between patients who would immediately request hastened death if this was legally permissible compared to patients who were not actively expressing such requests. Desire for hastened death was most strongly associated with lower religiosity, diagnosis of major depression, reduced functional status, and greater symptom distress.

 Whilst the concept of dignity has been widely used in contemporary discussions, policies, and research in palliative care, patient needs and rights, and biomedical ethics, a number of significant issues have been identified that question its validity and utility. Phrases such as “right to dignity” and “death with dignity” have been criticised for becoming clichés due to their frequent overuse or misuse in advancing political or philosophical agendas. The inherent subjectiveness of the concept of dignity can be contradictory due to influences by various personal, cultural, social, and spiritual constructs (Periyakoil et al., 2009).

Macklin (2003) notably argued that the term “human dignity” in biomedical ethics has contradictory uses due to poor definitional specificity and that it therefore has no utility in this area of medicine. Furthermore, she suggested that this concept refers to nothing more than respect, voluntary informed consent, confidentiality, and the need to avoid abusive practices. This viewpoint had subsequently resulted in considerable debate (e.g., Chochinov, 2003; Killmister, 2010) with most responses acknowledging the issue of definitional specificity but nevertheless arguing that improved understanding of the concept of dignity and factors that preserve and undermine it has the potential to improve the quality of health care in palliative patients and assist in future planning of end-of-life services. Furthermore, improved understanding of the relationship between sense of dignity and variables such as psychosocial and spiritual distress, symptom management, and desire for hastened death is essential in guiding the multidisciplinary management of palliative patients (Chochinov et al., 2002a). A number of theoretical and empirical studies have attempted to address the above-
mentioned issues, and particularly the issue of the imprecise meaning of dignity and factors that enhance and erode it. These studies are presented in the following section.

2.3 Dignity - Theoretical and Empirical Foundations

Tadd, Bayer, and Dieppe (2002) suggested three possible approaches to defining dignity: (a) searching for a rigorous and universal definition despite its complexity and the resulting differing interpretations, (b) accepting its inherent ambiguity and allowing differing definitions depending on individuals, health-care settings and cultures, and (c) using it as an “umbrella concept” for a number of associated biopsychosocial factors and examining how it functions and how it is expressed in various patient settings.

Universal explanations of dignity can be traced to at least classical Greece where dignity was assigned to individuals of high social status (Jacobson, 2007). In Christianity, dignity was seen as a quality innately possessed by humans due to their unique relationship to God (Imbach, Düwell, Braarvig, Brownsword, & Mieth, 2014). Most dictionary definitions of dignity make references to respect, worthiness, honour, and social rank. Nordenfelt (2003) and Nordenfelt and Edgar (2005) proposed a theoretical model of dignity that consists of the following four factors: (a) Menschenwürde or basic human dignity that all people hold equally, which provides the grounds for equal human rights and cannot be diminished, (b) dignity of merit depending on social or cultural standing in society, (c) dignity of moral stature that can be gained or lost through the morality of one’s actions, and (d) dignity of identity that is dependent on the integrity of body and mind and also self-image. In this model, the interplay of menschenwürde as a stable factor and the other three variable factors determines the respect for self and other people. Similarly, Jacobson (2007) described two distinct meanings of dignity: (a) human dignity that is an inherent, unconditional, and immeasurable value that belongs to every human being, and (b) social dignity that is contextual, measurable, and experienced through interactions in social settings.

A number of studies have explored the concept of dignity in health care settings by examining the perspective of patients and staff involved in their care. Baillie (2009) investigated the meaning of dignity and its contributing factors in an acute hospital setting by interviewing 26 patients and 13 registered nurses and their assistants. Both patients and staff indicated that dignity comprised feelings of being comfortable and in control, being valued, having appropriate or acceptable physical appearance, and having mutually respectful behaviour with people around them. Factors that were believed to influence dignity included the hospital environment (privacy, other patients, physical
environment), patient factors (attitude, age, extent of illness, relationships with staff), and staff behaviour (authoritarian vs courteous interactions, provision of privacy, friendliness). It was noted that the meaning of dignity and the influencing factors varied significantly among patients and staff, thus underscoring its complexity.

Periyakoil et al. (2009) explored patient and health professional perspectives of factors influencing loss of dignity at the end of life, and then created and empirically tested a brief screening tool called the Dignity Card-Sort Tool. First, analyses of open-ended survey responses of 69 palliative care health professionals yielded 18 items that were classified into eight key dignity themes: Respect, Acceptance, Self-Image, Quality of Care, Connectedness, Autonomy, Comfort, and Other (including toileting function and cognitive impairment). Second, 83 palliative nurses, 190 palliative community patients, and 26 palliative hospice patients ranked the 18 items in importance to erode sense of dignity at the end of life. Factor analyses resulted in six factors accounting for 63% of variance, and one key item from each factor was used in the final six-item Dignity Card-Sort Tool. The items were: 1. When others treat her/him without respect, 2. When her/his wishes are not carried out, 3. When she/he is medically mismanaged, 4. When she/he loses ability to choose, 5. When she/he feels ashamed, and 6. When she/he dies in pain. Further analyses revealed that nurses and physicians ranked items 1, 2 and 4 as the most important factors influencing perceptions of dignity while both palliative inpatients and community patients rated items 3 and 6 as most important. The authors of the card sort tool suggested that a possible reason for this discrepancy might be that nurses and physicians, unlike patients, could not as easily identify with the items and they perceived basic patient needs of quality care and pain control as “a given” thus shifting their focus to more abstract concepts of respect and ability to choose.

More recently, van Gennip, Pasman, Oosterveld-Vlug, Willems, and Onwuteaka-Philipsen (2013) outlined the development of a preliminary model of dignity as applied to a wider population of patients living with chronic illnesses including cancer, early-stage dementia, Crohn’s disease, and HIV. Thirty-four patients were interviewed in their homes about their personal understanding of dignity and whether they feel dignified or not. It was found that chronic illness can indirectly impact sense of dignity by changing one’s self-identity, the sense of self within relationships/interactions, and the sense of self within wider societal norms and expectations. The authors suggested that further longitudinal research is required in order to ascertain how the sense of dignity may change as the chronic illness continues to progress.
2.4 Chochinov’s Dignity Model

The most comprehensive model of dignity in palliative care patients was provided by Chochinov and his research team who have completed a series of qualitative and quantitative studies examining this issue. Chochinov et al. (2002a) conducted semi-structured interviews with 50 inpatients and outpatients with advanced terminal cancer focusing on how patients experienced dignity as they approached death. The qualitative analyses of these interviews resulted in the generation of an empirical Dignity Model in palliative care patients (Figure 2.1) and further direction regarding development of dignity-conserving care. In contrast to universal definitions, this model refers to dignity as an “umbrella concept” where sense of dignity is determined by the interplay of factors that conserve and threaten it in combination with patients’ unique characteristics and the circumstances of their illness. As a result, not all factors tend to be experienced or reported by patients and ones that are reported tend to vary in intensity and effect.

<table>
<thead>
<tr>
<th>ILLNESS RELATED CONCERNS</th>
<th>DIGNITY CONSERVING REPertoire</th>
<th>SOCIAL DIGNITY INVENTORY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Independence</td>
<td>Dignity Conserving Perspectives</td>
<td>Privacy Boundaries</td>
</tr>
<tr>
<td>Cognitive Acuity</td>
<td>Continuity of Self</td>
<td>Social Support</td>
</tr>
<tr>
<td>Functional Capacity</td>
<td>Role Preservation</td>
<td>Care Tenor</td>
</tr>
<tr>
<td>Symptom Distress</td>
<td>Generativity / Legacy</td>
<td>Burden to Others</td>
</tr>
<tr>
<td>Physical Distress</td>
<td>Maintenance of Pride</td>
<td></td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>Hopefulness</td>
<td></td>
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<tr>
<td>• Medical Uncertainty</td>
<td>Autonomy / Control</td>
<td></td>
</tr>
<tr>
<td>• Death Anxiety</td>
<td>Acceptance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Resilience / Fighting Spirit</td>
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Within the Illness Related Concerns, Level of Independence refers to the degree of reliance a person has on others and it includes maintenance of both mental ability and physical functioning associated with activities of daily living. Symptom Distress is comprised of both psychological distress and physical discomfort related to the progression of one’s illness. This includes distress caused by medical uncertainty,
anticipatory grief, and death anxiety as well as severe manifestations of demoralisation and depressive disorders.

In the model, Dignity Conserving Repertoire is proposed to buffer against threats to one’s sense of dignity. In this context, Continuity of Self refers to the sense of self or self-identity being relatively unchanged despite one’s advancing illness. In other words, maintaining a stable and balanced view of self that is consistent with the self-identity prior to the advanced illness has the potential to preserve one’s sense of dignity. Role Preservation refers to an ability to continue to function in usual roles or adjusted roles despite the advancing illness as a way to maintain one’s sense of self. Generativity / Legacy refers to a sense of comfort that one would leave something lasting that transcends one’s death. This includes tangible matters as well as sense of legacy through life achievements and accomplishments. Therefore, this factor in particular is consistent with Erikson’s developmental stages of generativity vs stagnation and ego-integrity vs despair (Erikson, 1963; Erikson & Erikson, 1998) where a person’s awareness of approaching death precipitates the need to maintaining productivity and evaluate one’s life narrative in order to resolve remaining psychosocial issues.

Maintenance of Pride refers to an ability to maintain self-respect and a positive self-concept despite the effects of advancing illness. This includes both self-perception of pride and the need for others to see and acknowledge this pride. Hopefulness in this context is associated with ability to see life as enduring having sustained a sense of meaning or purpose. Similarly, Autonomy/Control refers to the ability to sustain a sense of autonomy or control over life circumstances and the effects of advanced illness. This subtheme is differentiated from the Level of Independence theme in that it refers to a subjective and internally-mediated sense of self as opposed to cognitive or functional capacity. Acceptance refers to an internal process of resigning oneself to life circumstances and an advancing illness in order to maintain a sense of dignity. In contrast, Resilience/Fighting spirit is an alternative coping strategy of mental determination to overcome illness-related concerns and to improve quality of life. In addition to the above perspectives that conserve dignity, practices that preserve sense of dignity include helpful strategies such as maintaining focus on the here-and-now (Living in the Moment); maintaining usual routines, schedules, and activities while coping with the effects of advancing illness (Maintaining Normalcy); and turning towards or finding comfort in one’s religious or spiritual system of beliefs and practices (Seeking Spiritual Comfort).
Finally, Social Dignity includes five themes that refer to social circumstances and relationship dynamics that influence sense of dignity. Privacy Boundaries refers to the extent to which one’s personal boundary is encroached upon during an episode of care. Social Support can also influence sense of dignity through presence of a helpful and available network of supports including family, friends, other patients, and health care providers. Care Tenor refers to the attitude of health-care providers towards patients and the resulting interaction between them. It includes both content and style of communication and it is mediated by a patient’s personal perceptions of this communication. Burden to Others refers to distress caused by fears of current or future over-reliance on others and the impact this would have on the carers or health-care providers. On the other hand, Aftermath Concerns refers to worries or fears that one’s death would cause significant burden and challenges to others. Table 2.1 outlines the factors and subthemes of Chochinov’s Dignity Model, along with suggested interview questions and multidisciplinary therapeutic interventions for each factor/subtheme.

Chochinov et al. (2002b) subsequently collected quantitative data in order to examine the influences of various demographic and illness-related variables on sense of dignity in 213 palliative care inpatients and outpatients. One hundred and fourteen (54%) of patients indicated no loss of dignity whilst 16 patients (7%) indicated that loss of dignity was a significant problem for them. These patients also reported an associated sense of being degraded or ashamed, increased dependence including requiring help with bathing, distressing changes in appearance, sense of burdening others, sense of hopelessness, poorer quality of life, loss of the will to live, and desire for death. Proximity to death did not account for differences in dignity. None of the 20 outpatients reported significant loss of dignity. This suggests that degree of autonomy and independence maintained in a home setting, as opposed to care received in a hospital, is a mediating factor of patient dignity. Finally, younger patients were more likely to report significant loss of dignity compared with older patients (Chochinov et al., 2002b).
Table 2.1: Chochinov’s Dignity Model factors, questions and interventions.

<table>
<thead>
<tr>
<th>FACTORS/SUBTHEMES</th>
<th>DIGNITY-RELATED QUESTIONS</th>
<th>THERAPEUTIC INTERVENTIONS</th>
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<tbody>
<tr>
<td><strong>Illness-Related Concerns</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom Distress</td>
<td>“How comfortable are you?”</td>
<td>Vigilance to symptom management</td>
</tr>
<tr>
<td>Physical Distress</td>
<td>“Is there anything we can do to make you more comfortable?”</td>
<td>Frequent assessment</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>“How are you coping with what is happening to you?”</td>
<td>Application of comfort care</td>
</tr>
<tr>
<td>Medical Uncertainty</td>
<td>“Is there anything further about your illness that you would like to know?”</td>
<td>Assume a supportive stance</td>
</tr>
<tr>
<td>Death Anxiety</td>
<td>“Are there things about the later stages of your illness that you would like to discuss?”</td>
<td>Empathetic listening</td>
</tr>
<tr>
<td>Independence</td>
<td>“Has your illness made you more dependent on others?”</td>
<td>Upon request, provide accurate, understandable information and strategies to deal with possible future crises</td>
</tr>
<tr>
<td>Cognitive Acuity</td>
<td>“Are you having any difficulty with your thinking?”</td>
<td>Treat delirium</td>
</tr>
<tr>
<td>Functional Capacity</td>
<td>“How much are you able to do for yourself?”</td>
<td>When possible, avoid sedating medication(s)</td>
</tr>
<tr>
<td>Dignity-Conserving Repertoire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuity of Self</td>
<td>“Are there things about you that this disease does not affect?”</td>
<td>Acknowledge and take interest in those aspects of the patient’s life that he/she most values</td>
</tr>
<tr>
<td>Role Preservation</td>
<td>“What things did you do before you were sick that were most important to you?”</td>
<td>See the patient as worthy of honour, respect, and esteem</td>
</tr>
<tr>
<td>Maintenance of Pride</td>
<td>“What about you or your life are you most proud of?”</td>
<td></td>
</tr>
<tr>
<td>Hopefulness</td>
<td>“What is still possible?”</td>
<td>Encourage and enable the patient to participate in meaningful or purposeful activities</td>
</tr>
<tr>
<td>Autonomy/Control</td>
<td>“How in control do you feel?”</td>
<td>Involve patient in treatment and care decisions</td>
</tr>
<tr>
<td>Generativity/Legacy</td>
<td>“How do you want to be remembered?”</td>
<td>Life project (e.g., making audio/video tapes, writing letters, journaling)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>“How at peace are you with what is happening to you?”</td>
<td>Dignity psychotherapy</td>
</tr>
<tr>
<td>Resilience/Fighting Spirit</td>
<td>“What part of you is strongest right now?”</td>
<td>Support the patient in his/her outlook</td>
</tr>
<tr>
<td>Dignity-Conserving Practices</td>
<td></td>
<td>Encourage doing things that enhance his/her sense of well-being (e.g., meditation, light exercise, listening to music)</td>
</tr>
<tr>
<td>Living in the Moment</td>
<td>“Are there things that take your mind away from illness, and offer you comfort?”</td>
<td>Allow the patient to participate in normal routines, or take comfort in momentary distractions (e.g., daily outings, light exercise, listening to music)</td>
</tr>
<tr>
<td>Maintaining Normalcy</td>
<td>“Are there things you still enjoy doing on a regular basis?”</td>
<td>Make referrals to chaplain or spiritual leader</td>
</tr>
<tr>
<td>Finding Spiritual Comfort</td>
<td>“Is there a religious or spiritual community that you are, or would like to be, connected with?”</td>
<td>Enable the patient to participate in particular spiritual and/or culturally based practices</td>
</tr>
<tr>
<td><strong>Social Dignity Inventory</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privacy Boundaries</td>
<td>“What about your privacy or your body is important to you?”</td>
<td>Ask permission to examine patient</td>
</tr>
<tr>
<td>Social Support</td>
<td>“Who are the people that are most important to you?”</td>
<td>Proper draping to safeguard and respect privacy</td>
</tr>
<tr>
<td>Care Tenor</td>
<td>“Is there anything in the way you are treated that is undermining your sense of dignity?”</td>
<td>Liberal policies about visitation, rooming in Enlist involvement of a wide support network</td>
</tr>
<tr>
<td>Burden to Others</td>
<td>“Do you worry about being a burden to others?”</td>
<td>Treat the patient as worthy of honour, esteem, and respect; adopt a stance conveying this</td>
</tr>
<tr>
<td>Aftermath Concerns</td>
<td>“What are your biggest concerns for the people you will leave behind?”</td>
<td>Encourage discussion about these concerns with those they fear they are burdening</td>
</tr>
</tbody>
</table>

Subsequently, Hack et al. (2004) conducted further exploratory factor analyses with this data in order to identify factors that may underlie patients’ experiences reported in the Chochinov et al. (2002b) study. Six primary factors that accounted for 40.5% of variance were: Pain, Intimate Dependency, Hopelessness/Depression, Informal Supports, Formal Support, and Quality of Life. The researchers further explored the relationships between these factors and significant loss of dignity using regression. It was found that Quality of Life, Hopelessness/Depression, and Intimate Dependency were the strongest correlates with patients’ sense of dignity (Hack et al., 2004). This factor structure was consistent with the Dignity Model, suggesting that dignity-conserving care is multifaceted and based on each individual’s needs, wishes, and circumstances.

Chochinov et al. (2006) provided further evidence supporting the validity of the Dignity Model. Twenty-two items were derived from the Dignity Model’s themes and subthemes and rated by 211 palliative care patients with regard to how they were or could be related to their sense of dignity. With the exception of “thinking about how life might end”, all items were endorsed by more than half of patients. The issues most strongly related to sense of dignity were: “not being treated with respect or understanding” (87.1%), “feeling a burden to others” (87.1%), “feeling you do not have control over your life” (83.7%), “not feeling you made a meaningful or lasting contribution” (83.3%), and “not being able to independently manage bodily functions” (82.9%). Demographic variables including age, gender, education, and religious affiliation significantly influenced issues attributed to their sense of dignity. Younger patients were more likely to ascribe a diminished sense of dignity to an inability to perform activities of daily living, problems with bodily functions, thoughts about how life would end, and privacy and acceptance problems. Women were more likely to report changes in appearance, inability to think clearly, and meaningful spiritual life as most related to sense of dignity. Patients with higher education endorsed more overall items and those with religious affiliation were more likely to endorse difficulty with acceptance and not having a meaningful spiritual life as related to sense of dignity.

While the above-mentioned studies provided increasing evidence for the Dignity Model, there was a notable lack of assessment tools specifically measuring the sense of dignity and its influencing factors among palliative patients. In order to address this gap, Chochinov et al. (2008) designed and tested a novel 25-item assessment tool based on the Dignity Model: The Patient Dignity Inventory (PDI). In order to investigate its
psychometric properties, the PDI was administered to 253 palliative care patients, along with the Beck Depression Inventory, revised Edmonton Symptom Assessment Scale, the suffering and dignity items from the Structured Interview Assessment of Symptoms and Concerns in Palliative Care, the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being, and an additional measure of subjective well-being. Cronbach’s coefficient alpha for the PDI was 0.93 and the test-retest reliability was $r = 0.85$ (Chochinov et al., 2008).

Factor analysis of the PDI resulted in the following five factors accounting for 58% of overall variation from 21 items: Symptom Distress, Existential Distress, Dependency, Peace of Mind, and Social Support (Chochinov et al., 2008). Face validity and concurrent validity were excellent although Existential Distress did not correlate with the will to live and sense of dignity measures, again suggesting a multifaceted nature of this construct. The Peace of Mind factor, which consisted of items about making a meaningful contribution, unfinished business, and spiritual life, had the lowest internal consistency and did not correlate significantly with any of the measures except for the Inner Peace factor from the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being. The authors suggested that this finding was influenced by spirituality’s lack of definitional specificity and subjective interpretation. Based on this initial analysis, the PDI was deemed to show good reliability and validity as a measure of dignity-related distress. The PDI has subsequently been validated in multiple languages and utilised in various palliative care settings and patient populations, including non-malignant conditions (Chochinov et al., 2016).

2.5 Chapter Summary

Existential and spiritual distress, demoralisation, and perceived loss of dignity are complex, dynamic, multidimensional concepts that are essential to (a) better understanding of the sense of suffering and requests to die near end of life, (b) development of best practice multidisciplinary models of care in palliative care settings, and (c) evaluation of evidence-based psychotherapeutic interventions near end-of-life. These multidimensional concepts also continue to lack consistent frameworks that define their core features, thus undermining the ability of palliative care clinicians to adequately assess, conceptualise, and treat sources of suffering. The contribution of loss of dignity to an overall sense of suffering near end of life was established by the development of several empirical models of dignity, of which the most prominent and most utilised in palliative care settings is Chochinov’s Dignity Model (Chochinov et al.,
2002a). This empirically validated model conceptualises dignity as an “umbrella concept” for a number of biopsychosocial factors that protect and threaten it in combination with patients’ unique personal and social characteristics. Furthermore, this model has provided a foundation for ways of providing dignity-conserving interventions and informed the development of a novel psychotherapeutic intervention specifically tailored to addressing dignity-related distress in palliative care patients, called Dignity Therapy (Chochinov et al., 2004). This intervention is described in the following Chapter.
3.1 Introduction to Dignity Therapy

Quality patient-centred palliative care requires both management of symptom distress and the provision of multidisciplinary interventions that address the psychological, social, existential, and spiritual domains of distress. In comparison to evidence-based management of physical aspects of advanced illness, there is a notable lag in development and evaluation of systematic manualised psychotherapeutic interventions specifically tailored to terminally ill patients. This is particularly the case for existential and spiritual sources of distress where the paucity of such empirical evidence is even more pronounced (LeMay & Wilson, 2008).

In addressing this issue, a research team led by Harvey Chochinov utilised the Dignity Model that was examined in Chapter 2 to guide the development of a brief individual psychotherapeutic intervention called Dignity Therapy (Chochinov et al., 2002a; Chochinov et al., 2004). This intervention aims to bolster the person’s sense of dignity and alleviate associated sources of distress by engaging patients in the process of reviewing their life experiences and assisting them to create a legacy document. This document typically includes aspects of people’s lives that they see as important or meaningful, personal history that they would want others to know, words of wisdom, personal values, hopes and dreams for their loved ones, and things that need to be said or repeated to their loved ones such as words of comfort or solace (Chochinov et al., 2005). The therapist adopts an empathic, non-judgmental, and flexible approach in facilitating exploration of these themes. Although the Dignity Therapy protocol includes
suggested interview questions (Table 3.1), patients are able to construct the interview as they desire and focus on themes most important or meaningful to them or their family. The final legacy document is then given back to patients who then typically share it with their family, close friends or carers. Patients and their families are also encouraged to keep the legacy document secured along with other important documents, with the aim of increasing the likelihood of it being accessible to those who will outlive them.

Table 3.1: Examples of interview questions used in Dignity Therapy:

Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important? When did you feel most alive?

Are there particular things that you would want your family to know about you, and are there particular things you would want them to remember?

What are the most important roles you have played in your life (family roles, vocational roles, community service roles, etc)? Why were they so important to you, and what do you think you accomplished within those roles?

What are your most important achievements, and what do you feel most proud of?

Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?

What are your hopes and dreams for your loved ones?

What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?

Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?

In creating this permanent record, are there other things that you would like included?

From “A Phase II randomised controlled trial assessing the feasibility, acceptability and potential effectiveness of dignity therapy for older people in care homes: Study protocol,” by Sue Hall et al., 2009, BMC Geriatrics, 9, p. 9. CC BY-NC-ND.

3.1.1 Standard Dignity Therapy Protocol

In his book Dignity Therapy: Final Words for Final Days, Chochinov (2012) outlined the most comprehensive guide to standardising Dignity Therapy in palliative care settings. The therapeutic process typically begins with determining which patients might benefit from Dignity Therapy and being mindful of potential contraindications and exclusion criteria. Key eligibility criteria typically include presence of a life-limiting disease; interest and motivation to take part after initial education about this
therapeutic approach; and the ability for therapists, patients, and transcriptionists to speak the same language. Of note is that Dignity Therapy does not require patients to acknowledge or discuss their poor prognosis, although therapeutic effectiveness is likely to be facilitated with increased awareness and acceptance of the approaching death (Chochinov, 2012). Key exclusion criteria under normal circumstances include being too physically ill, and experiencing impaired cognitive ability, where either or both of these factors limit meaningful, reflective, and accurate responses. Use of cognitive screening measures and multidisciplinary clinical consensus may be required in more complex patient presentations. Additionally, people with a life-expectancy of less than two weeks would normally not be included in the treatment protocol as this is the approximate length of time that it takes to complete the intervention.

In the first session, the therapist typically explains the rationale and process of Dignity Therapy, introduces the suggested interview topics, identifies potential recipients of the completed legacy document, discusses patients’ wishes regarding the possible presence of key family/carers during the therapy, and answers any remaining questions. If appropriate, a copy of the suggested interview topics is also left with patients for them to consider prior to the next session.

In subsequent sessions, the Dignity Therapy interview is conducted. If patients wish, a close family member or carer can be present during interview sessions. Session content and process are described in the next section of this chapter. All interview sessions are audio recorded and transcribed verbatim within 24 to 48 hours of completing the interview, typically by an assistant or a dedicated transcriptionist. The length and total number of sessions are largely dependent on patient and family wishes and their ability to tolerate this intervention physically, cognitively, and emotionally. Dignity Therapy studies to date have suggested that approximately four clinical hours over two to three sessions were deemed sufficient to meet therapeutic goals (Fitchett et al., 2015). In his therapy guide, Chochinov (2012) suggested that even one hour of clinical time may be sufficient in allowing for meaningful therapeutic outcomes to be demonstrated. He attributed this to the complexities of working with terminally ill patients and a highly dynamic nature of their physical, psychological, and social functioning at that point in their life.

In preparation for the final session, the interview transcript is edited by the therapist in order to transform the verbatim interview transcript into a continuous document that is interspersed by the interview questions. In this crucial and sensitive
step, care is taken to minimise any changes to words used by individual patients. Instead, editorial changes include removing unnecessary words (e.g., “you know”, “uh”, “hmm”), adjusting the sentence structure and syntax, correcting timeline sequences and spellings, and finding an ending to the legacy document that the patient deems to be appropriate or meaningful. The key rationale of this process is that it allows for more efficient use of the relatively short therapeutic time where patients focus more on the content of their legacy document and less on the way it is initially structured or organised (Chochinov, 2012). As with every other facet of this intervention, the editing process needs to be completed in a timely manner given the risk of physical and cognitive deterioration in this patient population.

The final session involves meeting a patient for a joint review of the draft legacy document by either reviewing the paper copy or by reading out the document to the patient. This allows each patient and their family/carer to have a final say on its content and structure. Following the final edits, the therapist prints and binds as many copies of the legacy document as requested, and presents them to the patient who can then share them as they wish.

### 3.1.2 Therapeutic Content and Process

The content and process of Dignity Therapy are closely guided by the themes and subthemes described in the Dignity Model (Chochinov et al., 2002a; Chochinov, 2012). The essential component of this intervention is the need for therapists to convey respect, unconditional positive regard, and sincere validation for each patient. In other words, the role of the therapist is not just to facilitate and guide the relevant discussion, but also to imbue the therapeutic interaction with dignity where patients feel heard, accepted, valued, and honoured. This empathic and non-judgmental approach is consistent with the Dignity Model’s theme of care tenor, which suggests that the way that conversations with palliative care patients are conducted is just as important as the content of these conversations. The collaborative and timely process of creating a legacy document, and generating it in a way that increases the likelihood of its existence for considerable time after one’s death, may further enhance patients’ perceptions of legacy, hope, meaning, and purpose. The emphasis on the whole person, as opposed to primarily concerns related to the illness progression, serves to reinforce the themes of the Dignity Model related to the continuity of self, role preservation, and maintenance of pride and self-worth. This model’s themes of autonomy and control are enhanced by giving patients the freedom to structure their legacy document as they desire and make decisions on
whom to share it with when this process is completed. Similarly, the aftermath concerns subtheme is signified by the inclusion of questions that allow expression and discussion of grief-related issues, and providing an opportunity to record messages that offer comfort and solace to loved ones after one’s passing (Chochinov, 2012).

Dignity Therapy content and process are also consistent with Erikson’s (1963) theory of lifespan development and specifically the psychosocial stages of generativity vs stagnation (middle adulthood), and ego-integrity vs despair (older adulthood). In this framework, generativity refers to the connection with the next generation, passing skills and knowledge to others, being productive, and leaving a lasting legacy. On the opposite side of this spectrum, stagnation refers to general sense of apathy, lack of contribution to society, preoccupation with own needs and lack of care for others. Although deemed critical in middle adulthood, Erikson and Erikson (1998) argued that generativity is essential to successful ageing among older adults as well. Late adulthood was conceptualised by Erikson as an interplay between ego-integrity and despair. Ego integrity includes looking back on one's life with a sense of meaning, acceptance of past life events, fulfilment, and general absence of death anxiety. Despair refers to a sense of disappointment with one’s life trajectory, significant guilt or regret about past events, and a poor sense of accomplishment in life. As with other developmental stages, successful transition through these stages involves reaching a balance between their opposing poles (Van Hiel, Mervielde, & De Fruyt, 2006) and incorporating both poles into a dynamic and complex understanding of the world (Torges, Stewart, & Duncan, 2008). Subsequently, interventions such as Dignity Therapy can potentially assist participants with both (a) maintaining sense of generativity, including connections with future generations, passing skills and knowledge to others, maintaining sense of productivity, and sense of having left a lasting legacy, and (b) perceived ego-integrity, including looking back on one's life with a sense of meaning, acceptance, and satisfaction and with an absence of death anxiety or significant resentment, guilt, or regret. However, no study prior to the current research project had explored or evaluated these specific therapeutic outcomes with Dignity Therapy or other similar interventions. Chapter 4 of the dissertation provides further information about the aims of this Doctoral research.

Several qualitative studies have examined the content of Dignity Therapy legacy documents in order to better understand how this intervention may impact patients and their families or carers. Hack et al. (2010) randomly chose 50 legacy documents from
the initial phase I trial of Dignity Therapy and qualitatively evaluated them with latent content and constant comparative analysis techniques. Several core values were apparent, including family, pleasure, caring, sense of accomplishment, true friendship, and rich experience. Similarly, in a study of 23 legacy documents created in a hospice setting, the most commonly discussed topics in rank order were autobiographical information, love, lessons learned in life, defining roles, accomplishments, character traits, unfinished business, hopes and dreams, catalysts, overcoming challenges, and guidance for others (Montross, Winters, & Irwin, 2011).

Tait, Schryer, McDougall, and Lingard (2011) qualitatively analysed 12 legacy documents in terms of narrative types and themes. Three overarching narrative types emerged, each containing further themes and subthemes: (a) Evaluation narratives in which patients reflected on their lives prior to current illness, (b) Transition narratives with the focus on their transitioning or changing health condition, and (c) Legacy narratives which involved discussions of newfound perspective when facing death, and stories or messages for their loved ones. The authors found that these narratives were not necessarily determined by the therapeutic protocol or the suggested interview questions that therapists implemented. Instead, patients appeared empowered to explore these narrative types and themes as a way of reaching a “sense of order and meaning from the chaotic experience of dying” (p. 299).

3.2 Dignity Therapy Acceptability, Feasibility, and Effectiveness

Dignity Therapy is brief, flexible, can be completed at the bedside, and has the ability to positively influence both patients and their families or carers (Chochinov et al., 2005). In comparison to other suitable psychotherapeutic interventions for patients approaching end of life, it places less emphasis on insight, interpretation, and skill-building and instead focuses on the process of enhancing generativity, meaning, and purpose. As a result, it is particularly suitable for use with palliative care patients, as long as medical symptoms are reasonably managed and patients are able to maintain sufficient cognitive ability to actively participate (Chochinov, 2012). Although relatively novel and tailored specifically to palliative care settings, Dignity Therapy has several consistencies with aspects of other interventions. For example, empathy and connectedness are central to all supportive counselling approaches, whilst emphasising the sense of meaning, hope, and adjusting to own mortality are central to Logotherapy and other meaning-based psychotherapies. Similarly, reviewing life’s experiences and working towards resolution of past conflicts, traumas or unfinished business are key
components of a Life Review intervention and other narrative therapies. Further comparisons between Dignity Therapy and the other relevant psychotherapeutic interventions are examined in this Chapter in sections 3.3.2 Comparison of Dignity Therapy with Life Review and 3.4.5 Comparison of Dignity Therapy with Other Psychotherapeutic Interventions Utilised in Palliative Care Settings.

Chochinov et al. (2005) provided the initial evidence of feasibility of Dignity Therapy among 100 palliative care patients in a phase I trial, one-group, pre/post-test study. A manualised intervention protocol was administered in Canada by a psychiatrist (Prof Chochinov) and a palliative nurse, and in Australia by a psychologist and two palliative care nurses. An assessment battery was administered before and after intervention covering a range of physical, psychological, and existential outcomes. At post-test, 91% of patients indicated feeling satisfied or highly satisfied with Dignity Therapy while 76% indicated improved sense of dignity. Similarly, 67% and 68% of patients indicated that it improved their sense of meaning and purpose respectively, and 81% reported that their families had found or would find this intervention helpful. Significant improvements were found for suffering and depressed mood while improvements in dignity approached statistical significance. There were no significant changes in hopelessness, desire for death, anxiety, will-to-live, and suicide wishes. Pre-test measures of quality of life, dignity, suffering, and suicidality correlated significantly with finding the intervention helpful, suggesting that patients with more initial psychosocial despair seemed to particularly benefit from this intervention. Similarly, finding the intervention helpful to self and also to family both significantly correlated with heightened sense of meaning and purpose, lessened sense of suffering, and increased will to live. Despite the challenges of measuring changes in distress in patients near end-of-life, it was concluded that Dignity Therapy was a feasible and potentially effective intervention in addressing suffering and distress in palliative patients (Chochinov et al., 2005).

Dignity Therapy also showed potential to be of significant benefit to family members of dying patients. About a year following the deaths of patients in the Chochinov et al. (2005) study, 60 family members completed feedback questionnaires about the impact of this intervention on themselves and their family member (McClement et al., 2007). A majority of family members reported that Dignity Therapy was helpful to the patient (95%) in that it heightened their sense of dignity (78%) and sense of purpose (72%) and helped them prepare for death (65%), whilst 43% reported
that it reduced the patient’s sense of suffering. Regarding this intervention’s impacts on themselves, family members reported help with bereavement (78%) and that the legacy document was an ongoing source of comfort (77%) and would be recommended to other families in a similar situation (95%; McClement et al., 2007).

Following these initial encouraging findings, Chochinov et al. (2011) conducted a phase II international multicentre RCT comparing Dignity Therapy with Standard Care and Client Centred Care (CCC) in 441 patients receiving palliative care in hospital, hospice, or at home. CCC involved supportive counselling with a primary focus on here-and-now concerns as opposed to generativity or legacy themes. There were no significant group differences on any of the primary outcome measures of sense of dignity, quality of life, anxiety, depression, or medical symptoms. However, Dignity Therapy recipients were significantly more likely to report benefiting from this intervention compared to the other groups on a post-intervention survey. More specifically, they reported improved sense of dignity, quality of life, self-identity, and helpfulness to their family, whilst spiritual well-being and low mood were also reported as improved compared to CCC and Standard Care, respectively. This discrepancy between standardised outcome measures and self-reported benefits of intervention was consistent with the prior phase I trial. The study’s authors noted that, despite adequate power, the study’s ability to demonstrate meaningful outcomes on standardised measures was likely impeded by floor effects due to participants’ low levels of baseline distress. Moreover, it seemed that the standardised outcome measures used were not very sensitive to change in palliative care patients, when compared with patients’ personalised self-reports of change. Consequently, Dignity Therapy was recommended for use with palliative care patients along with the need for further efficacy research with more varied demographics and higher levels of baseline distress (Chochinov et al., 2011).

Over the last decade, there has been a considerable growth in international research examining the feasibility and effectiveness of Dignity Therapy across several patient populations, care settings, and cultures (Bentley, O'Connor, Shaw, & Breen, 2017). Fitchett et al. (2015) conducted a systematic review of studies that utilised this intervention with palliative care patients, whilst excluding studies that examined direct impacts on family/carers. Out of 25 articles representing 15 independent studies, 12 were of quantitative nature comprising eight uncontrolled feasibility studies and four RCTs. There were also five qualitative studies and three case reports. Dignity Therapy
was found to have excellent acceptability with patients consistently reporting high levels of satisfaction and perceived benefit for themselves and their family/carers post-intervention. Findings about feasibility were mixed in that most studies reported at least some issues with recruitment and retention, particularly with inclusion of patients with higher levels of distress. These challenges were not unusual in the wider palliative care literature given the frequent descriptions of these difficulties such as problems with meeting enrolment goals and therefore with achieving adequate power (Steinheuser et al., 2006). For example, Lindqvist, Threlkeld, Street, and Tishelman (2015) conducted a feasibility study of Dignity Therapy in a specialised palliative care home service. Out of 62 patients, staff deemed 52 patients as being unsuitable for Dignity Therapy due to general frailty, deterioration, or cognitive impairment. Lindqvist et al. additionally reported that some patients who declined to participate in Dignity Therapy indicated that this intervention was superfluous to their immediate needs, that the process and content of Dignity Therapy was too difficult for them physically or emotionally, and that the interview questions were culturally not appropriate for them.

Effectiveness was also mixed in that there was a general paucity of change in primary study outcomes in RCTs, as determined by self-report measures of dignity-related distress, emotional and spiritual well-being, and quality of life (Fitchett et al., 2015). For example, the only RCT adequately powered to detect small to moderate effects (Chochinov et al., 2011) did not demonstrate any significant changes in primary outcome measures post-intervention. These findings were largely mirrored in a smaller RCT by Hall et al. (2011) with the exception that the intervention group showed higher levels of hope than the control group at both 1- and 4-week follow-up. In that study, it was suggested that dignity-related distress, quality of life, and other palliative outcomes are multi-component constructs that may not be amenable to change by provision of Dignity Therapy alone. Thus, incorporation of more specific existential, spiritual, and social aspects of patients’ experiences into study outcomes was recommended in future efficacy studies.

In order to address the problem of floor effects due to low baseline levels of distress, Juliao, Oliveira, Nunes, Vaz Carneiro, and Barbosa (2014) conducted an RCT with 80 palliative care patients whose scores of depression and anxiety were relatively high at baseline. Patients who had received Dignity Therapy had significantly lower depression and anxiety scores compared to the standard palliative care control group at days 4, 15, and 30 of follow-up. These findings suggest that Dignity Therapy may be
effective in short-term reductions of emotional distress in people with elevated anxiety and depression scores. Nevertheless, more specific psychosocial mechanisms of change following Dignity Therapy remain to be determined, as well as outcome comparisons with other psychotherapeutic interventions near end of life.

3.2.1 Family and Carer Perspectives

The potential for both immediate and long-term benefit to families, carers, and friends of palliative care patients is a unique aspect of Dignity Therapy. Following the initial promising findings (McClement et al., 2007), there have been several studies that have further examined this therapeutic outcome. Goddard, Speck, Martin, and Hall (2013) interviewed 14 family members of Dignity Therapy participants in order to explore their views and experiences. Perceived benefits included (a) acquiring new knowledge that deepened their understanding of their family member, (b) enhanced communication related to reminiscing together and clarifying stories, and (c) potential helpfulness with the bereavement process. However, some family members also expressed concerns about contents of legacy documents and that it may have placed additional strain on family dynamics and relationships.

Hall, Goddard, Speck, Martin, and Higginson (2013) interviewed nine family members of Dignity Therapy participants and also found perceived relationship benefits stemming from improved communication and knowledge of each other. However, six family members also expressed potential negative experiences relating to contents of legacy documents and possible reactions of other family, and the physical and emotional demands on patients given their advanced illness. Of note is that family members remained positive about the overall therapeutic impact and there were no instances of significant distress caused by their participation in this intervention. These mixed findings were also reflected in a study of 18 family members and carers of people with motor neurone disease who took part in Dignity Therapy (Bentley, O’Connor, Kane, & Breen, 2014). Half of the family/carers found the intervention helpful to them and almost all reported that the patient taking part in the intervention had benefited from doing so. There were no significant group changes in self-reported hopefulness, anxiety, or depression, whilst an increase in family/carer burden was noted that correlated with physical decline of patients. Clinicians providing Dignity Therapy are therefore required to have not just high levels of communication skills and training, but also to carefully consider interpersonal family dynamics and potential sources of distress for family/carers following the active intervention.
The impacts of Dignity Therapy on family members or carers were evaluated as part of the current program of research. Additionally, feedback was sought from family/carers’ perspectives regarding the therapeutic impacts on patients, based on their observation. The themes emerging from the feedback from families and carers are outlined in the second paper presented in Chapter 6 of the Doctoral Dissertation.

3.2.2 Clinician Perspectives

Further information on the utility and potential effectiveness of Dignity Therapy is provided by studies that investigated perspectives of health professionals who were either directly or indirectly involved with the intervention. Montross, Meier, De Cervantes-Monteith, Vashistha, and Irwin (2013) conducted interviews with 18 hospice staff members who had referred patients for this intervention and also asked them to complete a short rating scale. Staff included social workers, chaplains, nurses, and medical practitioners with an average of seven years of hospice experience. Dignity Therapy was consistently rated as worthwhile, helpful, highly recommended, and somewhat able to reduce pain and suffering. Key benefits identified during qualitative interviews included increasing connection with patients, allowing patient reflections and existential discussions, affirmation of beliefs and values, increasing sense of purpose, and facilitating a positive healing experience.

Impacts on clinicians who directly provided Dignity Therapy were evaluated by Tait and Hodges (2013). In this study, seven family medicine residents and five psychiatry residents were recruited during their first year of rotation in palliative care. They were provided with a Dignity Therapy learning guide and brief supervision with the principal investigator prior to providing this intervention. The authors noted that the aim was to achieve basic competency only in providing this therapy. Recipients of Dignity Therapy were 12 palliative care inpatients with a life expectancy of less than six months and no cognitive impairment. Following the provision of Dignity Therapy, each medical resident took part in a semi-structured interview. Most residents reported being more comfortable than expected during patient interviews. They reflected positively on the patient-centred therapeutic approach, the lessons learned from patients, and the impact of this on their own professional and personal lives. The residents also drew comparisons of their experience to the traditional medical interview. Most reported that conversations with dying patients and the focus on patient stories are poorly taught and modelled during medical training. Based on these findings, the authors emphasised the
need to provide medical trainees with opportunities to directly and authentically focus on patient life stories, separate from the regular medical management.

3.2.3 Dignity Therapy in Other Patient Settings

Feasibility, acceptability, and potential effectiveness of Dignity Therapy have also been investigated with people receiving care in final years of life as opposed to final months, including residents in care homes or facilities (Chochinov et al., 2012; Goddard et al., 2013; Hall, Goddard, Opio, Speck, & Higginson, 2012), people with motor neurone disease (Bentley et al., 2014), and people with early dementia (Johnston et al., 2016). The findings have generally mirrored the palliative care studies in that Dignity Therapy is highly acceptable and feasible with these patient groups with modifications such as allowing additional time to deliver the intervention and utilising alternative communication approaches when speech impairment is a concern. Similarly, therapeutic efficacy remains uncertain due to low levels of baseline distress and a general lack of change in primary outcome measures among participants in research studies. Of note is that one Japanese feasibility study (Akechi et al., 2012) reported a high refusal rate of 86% among eligible patients with advanced cancer. Primary reasons for participation refusal were concerns that it would make them think about death and reasons for offering this intervention to them while they were dying. This suggests that researchers also need to be mindful of cultural considerations and appropriate ways of communicating the aims of Dignity Therapy whilst being respectful of patients’ needs and coping mechanisms. Further research is needed to determine the extent of revisions to the therapy protocol that may be required for different cultural groups, given that Dignity Therapy has predominantly been developed and researched in English-speaking countries. Additionally, there is a need to establish cost-effectiveness of Dignity Therapy given the difficulties in determining the socially-acceptable cost to achieve its potential benefits, and the ongoing general bias against attributing economic value to improvements that results from psychosocial interventions (Hack, 2012).

3.3 Introduction to Life Review

As noted previously in Chapter 1, Life Review is a psychotherapeutic intervention that has similarities to Dignity Therapy. Life Review was initially conceptualised as an intervention in aged care by Robert Butler in his 1963 paper “The Life Review: An Interpretation of Reminiscence in the Aged”. In this landmark paper, Butler described this intervention as a:
naturally occurring, universal mental process characterised by the progressive return to consciousness of past experiences, and particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences and conflicts can be surveyed and reintegrated. Presumably this process is prompted by the realisation of approaching dissolution and death, and the inability to maintain one's sense of personal invulnerability. It is further shaped by contemporaneous experiences and its nature and outcome are affected by the lifelong unfolding of character (Butler, 1963, p. 66).

The impacts of this paper and Butler’s work in general on the field of gerontology were profound (Achenbaum, 2013). It not only provided the framework for more meaningful therapeutic interactions with the older population but also emphasised the potential of healthy, productive, and positive ageing. This was in stark contrast to the conventional wisdom and prevailing attitudes at the time that typically described older age as a period of multifaceted decline, disability, and death (Achenbaum, 2013). Butler also went further to coin the term “ageism” to describe the individual and institutionalised prejudice and discrimination towards the elderly at the time. His work with elderly patients in both individual and group Life Review led him to conclude that this process is a normal function of the later years that is essential to the psychological task of attaching meaning to life experiences (Butler, 2002). Furthermore, he posited that:

memories, reminiscence, and nostalgia all play a part in the process. Far from living in the past or exhibiting “wandering of the mind”, as was commonly thought, older people were engaged in the important psychological task of making sense of the life they had lived (Butler, 2002, p.1).

This view is consistent with Victor Frankl’s (1975) notion that “meaning must be found and cannot be given” (p. 112) and that it is “something to discover rather than to invent” (p. 113).

Over the last few decades, a variety of therapeutic Life Review interventions have been utilised in aged care settings, with diverse aims such as stimulating cognitive functioning, increasing general life satisfaction, achieving a sense of peace and acceptance, and providing early interventions for major depression (Bohlmeijer, Smit, & Cuijpers, 2003; Stinson & Kirk, 2006). The number of published papers on Life
Review and reminiscence has also increased from about three per year immediately after Butler’s 1963 seminal paper to about 15 per year in the early 2000s (Hendrix & Haight, 2002). Whilst the terms “Life Review” and “Reminiscence” have been most commonly used in the contemporary literature, there are also a number of other terms that refer to similar interventions, such as life story, life reflection, guided autobiography, and personal narrative. These interventions tend to be uniquely defined by their respective authors or used interchangeably at other times (Haber, 2006). Standardised definitions of these therapeutic interventions have not yet been achieved, though significant progress has been made in differentiating the Life Review process from Reminiscence.

General reminiscence is a descriptive activity that tends to be passive, spontaneous, light-hearted, and typically a pleasant experience for participants as they recall past events in their life (Gibson, 1994; Haber, 2006). At its simplest, reminiscence involves daydreaming, story-telling, and nostalgia, either as an individual or in a group context. This process can be further extended by guided activities such as creating memory boxes, photo albums, scrapbooks, cookbooks, and other creative processes. However, several authors have noted that mere stimulation and engagement in reminiscence does not necessarily lead to improved psychological or physical well-being (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007). For example, Wong and Watt (1991) identified six different types of reminiscence: integrative, instrumental, transmissive, narrative, escapist, and obsessive. Of these, only integrative and instrumental reminiscence were associated with successful aging. Webster (1993; 1997) developed the Reminiscence Function Scale and identified the following eight functional components of reminiscence: boredom reduction, death preparation, identity formation, conversation, maintenance of intimacy, revival of bitterness, teaching/informing, and problem solving. These functions have been found to cluster into three distinct groups, which were named self-positive reminiscence functions, self-negative reminiscence functions, and prosocial reminiscence functions (O’Rourke, Carmel, Chaudhury, Polchenko, & Bachner, 2013). Self-negative functions; which include persistent ruminations about difficult life memories and using memories to cope with understimulation, boredom, and grief; have been found to be associated with poorer psychological, emotional, and physical well-being (King, Cappeliez, Canham, & O’Rourke, 2017). The opposite associations were found across multiple studies for self-positive functions such as finding meaning in life, coming to terms with death/dying,
and problem-solving; and prosocial functions such as sharing memories for social benefit and teaching/informing others (King et al., 2017).

On the other hand, Life Review typically includes a combination of evaluative and descriptive processes, the ratio of which will depend on each participant and whether they are assisted in coming to terms with some of their more difficult memories or experiences (Keall et al., 2015). This approach expands on general reminiscence by taking this process to a deeper level in search of meaning of past events, resolution of conflicts, and completion of life tasks (Haber, 2006). In contemporary literature, Life Review has typically been utilised as a relatively structured and sometimes manualised psychotherapeutic approach that involves a guided review of the entire lifespan, or at the very least its most salient aspects. It usually involves examination and discussion of both positive and negative life experiences, with the goals of attaching meaning to these life experiences; resolving inner conflicts; and achieving a sense of peace, acceptance, and ego-integrity (Trueman & Parker, 2006; Stinson & Kirk, 2006). This process is consistent with Butler’s (2002) description of Life Review goals to be “righting of old wrongs, making up with estranged family members or friends, coming to accept one's mortality, gaining a sense of serenity, pride in accomplishment, and a feeling of having done one's best” (p.4). Other authors have noted that Life Review and Reminiscence can potentially contribute to successful aging through the following processes (a) identity-forming and self-continuity, (b) enhancement of meaning in life and coherence, (c) preservation of sense of mastery, and (d) promotion of acceptance and reconciliation (Bohlmeijer et al., 2007).

As with Dignity Therapy, Life Review’s therapeutic goals are consistent with Erikson’s (1963) psychosocial developmental stages of generativity vs stagnation and ego-integrity vs despair (Haber, 2006). More specifically, interventions such as Life Review can potentially assist participants with maintaining a connection with future generations; passing skills and knowledge to others; maintaining sense of productivity; looking back on one's life with a sense of meaning, acceptance, and satisfaction; and reducing a sense of resentment, guilt, or regret.

The explicit incorporation of Erikson’s theory of psychosocial development into Butler’s conceptualisation of Life Review formed the basis for a particular subtype of such intervention called Life Review Experiencing Form (LREF; Haight, 1992). In LREF, a therapist facilitates a discussion and guided review of each of Erikson’s psychosocial stages, typically in order starting from early childhood, with the aim of
resolving issues at each stage. The ultimate goals of this intervention are to achieve
greater sense of wisdom, inner peace, and integrity in the older population (Haight,
Michel, & Hendrix, 2000). However, no empirical Life Review study to date has
directly examined Erikson’s psychosocial stages as potential treatment outcomes in any
patient population. Instead, Life Review outcomes relating to Erikson’s psychosocial
stages have been implied by measuring associated dependent variables. For example,
Haight et al. (2000) examined the extended outcomes of Life Review in 52 nursing
home residents who lived for at least three years after commencement of this study.
Ego-integrity as a treatment outcome was inferred through measures of life satisfaction,
psychological well-being, and self-esteem. Similarly, sense of despair as a treatment
outcome was inferred through measures of depression, hopelessness, and suicidal
ideation. Subsequent studies have provided further evidence that sense of ego-integrity
was negatively associated with depression and positively associated with psychological
well-being (Rylands & Rickwood, 2001; James & Zarrett, 2005). However, it is
difficult to draw conclusions from correlational research regarding the specific impact
of Life Review interventions on Erikson’s developmental stages (Morgan, 2000), in the
absence of direct measurement of the relevant constructs in intervention studies. One of
the aims of the Doctoral research was to develop a brief measure of Erikson’s concepts
of generativity and ego-integrity that could be utilised as an indicator of Life Review
outcomes in palliative care settings. Subsequent chapters of this Doctoral dissertation
provide further information regarding the specific research goals, methodology, and
context.

3.3.1 Life Review and Reminiscence Therapy Outcomes

Bohlmeijer et al. (2007) conducted a meta-analysis of effects of Life Review and
Reminiscence interventions on life satisfaction and psychological well-being in older
adults residing in the community or nursing/residential homes. Fifteen controlled
outcome studies met the inclusion criteria, of which seven utilised Life Review and the
others utilised Reminiscence as the intervention. Life Review was more likely to be
provided on an individual basis (four studies) whilst Reminiscence interventions were
predominately group based (six studies). Most studies randomly allocated participants
to active treatment or a control group including no-treatment, placebo interventions, or
care as usual. The overall effect size of 0.54 was indicative of a moderate influence of
these interventions on life satisfaction and psychological well-being. However, Life
Review was found to have a significantly larger effect on psychological well-being than
Reminiscence (effect size of 1.04 vs 0.40, respectively). The authors attributed this to the relatively more involving content and process of Life Review sessions that focus on evaluation and synthesis of the past, reconciliation of any feelings of sadness and regret, and achievement of self-acceptance. On the other hand, the authors suggested that simple Reminiscence may be more likely to involve self-negative functions or maladaptive ruminations about the past, as operationalised by O’Rourke et al. (2013). Individual and group interventions were equally effective. There were no other moderating intervention characteristics found, although there were insufficient data for calculation of long-term treatment effects. The authors suggested further replication studies of the effects of Life Review and Reminiscence interventions, stronger international collaboration efforts, and development of more formalised therapeutic frameworks or guidelines.

The potential impacts of Life Review interventions on depressive symptoms in the elderly have also been well-documented. Bohlmeijer et al. (2003) conducted a meta-analysis of the effects of Life Review and Reminiscence on depressive symptoms in elderly patients. Twenty studies met the inclusion criteria though only four studies were classified as “high-quality” by their use of random assignment to groups, relatively low drop-out rates, use of a well-defined protocol, and use of follow-up outcome measures. The effect sizes of both the overall group of studies and the high-quality studies were indicative of clinically and statistically significant effects of Life Review and Reminiscence therapy on depressive symptoms in the general aged population. There were no significant outcome differences between the two therapies. The authors recommended that further large RCTs with sufficient statistical power and additional patient populations were required in order to reach a better understanding of the therapeutic effectiveness and outcomes of these interventions.

The utilisation of Life Review interventions with palliative care patients has only in recent years been evaluated and reported in the literature (Wang, Chow, & Chan, 2017). Keall et al. (2015) conducted a systematic review of studies that quantitatively evaluated a broad range of therapeutic Life Review interventions in palliative care settings. Fourteen studies met the inclusion criteria, describing 10 distinct interventions including Life Review Intervention, One-Week Short-Term Life Review, Forgiveness Therapy, Legacy Activities, and Outlook. Dignity Therapy and meaning-centred psychotherapies were also included in the systematic review. Interventions ranged from one to eight 15- to 160-minute sessions, and were provided by a range of health
professionals including psychologists, social workers, and nurses. Participants survived between 28 and 110 days post completion. The results of the systematic review suggested that briefer interventions had lower attrition rates and were more likely to show significant improvements on outcome measures compared to relatively longer interventions. None of the interventions met the criteria for a well-established treatment, as per Chambless and Hollon (1998) criteria for defining empirically supported therapies. Instead, all included interventions with exception of Outlook and Legacy Activities were deemed to be probably efficacious. More specifically, a probably efficacious treatment is one that meets most of the well-established criteria but has not been validated independently outside of the primary research team and has not demonstrated sustained superiority over time.

Keall et al. (2015) stated that it was difficult to draw more detailed conclusions or recommend any one particular therapeutic approach over others. They attributed this to diversity of interventions and outcome measures, relatively small sample sizes, high attrition rates, and low or inconsistent screening of baseline distress. However, it was noted that Life Review interventions show considerable potential in demonstrating clinically meaningful patient outcomes, such as improving psychosocial, existential, and spiritual well-being. Keall et al. concluded that further demonstration of clinical efficacy in high-quality controlled studies is needed for these interventions to be more readily accepted into standard clinical practice in palliative care settings.

### 3.3.2 Comparison of Dignity Therapy with Life Review

Detailed comparison of Dignity Therapy with Life Review interventions is challenging, given the latter’s relative lack of standardisation in terms of therapeutic methodology, session content, and process (Haber, 2006). This lack of standardisation is further evidenced by the view of some researchers that Dignity Therapy is a variation of therapeutic Life Review (e.g. Keall, Clayton, & Butow, 2014; Keall et al., 2015). This is contrary to Chochinov’s conceptualisation of Dignity Therapy, which suggests that it is theoretically and logistically distinct from Life Review and other psychotherapeutic treatments (Chochinov et al., 2004).

Both approaches indeed share a number of key similarities. For example, both emphasise the need for therapists to validate patients’ life experiences by conveying to them a genuine unconditional positive regard and respect (Chochinov, 2012; Haber, 2006). Both also have the potential to foster a sense of dignity by eliciting the human story rather than just the illness story, and by helping patients attach meaning to
important events in their life (Tait et al., 2011). The therapeutic aims of both Dignity Therapy and Life Review are consistent with Erikson’s (1963) developmental stages of generativity vs stagnation, and ego-integrity vs despair. More specifically, these interventions may assist palliative care patients in successfully transitioning through these stages by balancing their opposing poles and incorporating this process into a dynamic understanding of the world (van Hiel, Mervielde, & Fruyt, 2006; Torges, Stewart, & Duncan, 2008).

Both interventions are also relatively brief and flexible, though Life Review interventions tend to vary significantly in the number and length of therapy sessions (Keall et al., 2015). Whilst both approaches invite patients to share the most important or most memorable aspects of their life, they also tend to differ in terms of the ratio between in-session evaluative and descriptive processes. Traditional Life Review, and particularly approaches such as the LREF, place relatively more importance on the evaluative process such as assisting patients in coming to terms with their more difficult memories or experiences throughout their lifespan (Keall et al., 2015). On the other hand, Dignity Therapy is a relatively more descriptive process that places less emphasis on insight, interpretation, and skill-building. Instead, emphasis is placed on enhancing generativity, meaning, and purpose through the creation of a legacy document. The legacy document provides a specific means to positively influence the families or carers of patients, including during and after the bereavement process. Additionally, the two interventions are guided by a differing set of theoretical underpinnings. Life Review interventions have their theoretical basis in Robert Butler’s (1963) conceptualisation of this therapy and his wider contribution to our understanding of productive and positive ageing and the care of the elderly. Dignity Therapy is closely guided by the themes and subthemes described in the empirical mode of dignity in palliative care patients (Chochinov et al., 2002a; Chochinov, 2012). It is therefore considered to be suitable for use with terminally ill patients, providing their physical and cognitive functioning do not preclude their active participation (Chochinov, 2012).

Of note is that some Life Review interventions have incorporated an additional component of creating a life story book, DVD, or other tangible records of people’s lives as part of intervention. For example, Ando, Morita, Okamoto, and Ninosaka (2008) developed the Short-Term Life Review for use with palliative care patients. The aim of this two-session intervention is to guide patients in structured life review and create a visual album for patients to keep. This album typically contains key words from
answers to each interview question, along with photos or drawings from books or magazines associated with these key words. Morgan (2000) further expanded the LREF approach by taking notes during sessions and compiling this information into a “Life Story Book” that was provided to each patient. Similar to Dignity Therapy, patients were also given an opportunity to review and edit the content of their Life Story Book, as required. Morgan suggested that this extension of the LREF provided a sense of continuity between sessions, and an opportunity for patients to actively engage in and enjoy the process. Positive social interactions with staff and family were also noted. Morgan noted that “most of the information recorded in the life story books was factual in nature as opposed to records of specific incidents that occurred during the life-span” (p. 95). Specific session content analysis was not provided by the author. This suggests that Life Story Books in this study were primarily a tool to aid recollection of predominately factual and positive memories after treatment completion. This is in contrast to a Dignity Therapy legacy document, which incorporates autobiographical information with other themes such as personal values, words of wisdom, and special messages for loved ones.

3.4 Other Psychotherapeutic Interventions Evaluated in Palliative Care Settings

There has traditionally been little empirical research done on psychotherapeutic interventions for palliative care patients (Chochinov et al., 2004). Furthermore, there are only a few brief psychotherapeutic interventions designed specifically to address various psychosocial, existential, and spiritual concerns in this patient population (Hall et al., 2013). Over the past two decades, several other psychotherapeutic approaches have been utilised with palliative care patients in addition to Dignity Therapy and Life Review interventions (Rosenfeld et al., 2017). To place the interventions used within this Doctoral project in context, these other psychotherapies used in palliative care are briefly outlined below, followed by their comparisons to Dignity Therapy.

3.4.1 Supportive Counselling and Supportive-Expressive Group Therapy

Supportive counselling aims to strengthen existing coping mechanisms, enhance adaptation by encouraging emotional expression, improve self-esteem and self-efficacy, and consequently decrease adverse psychological and emotional reactions (Manne et al., 2007). It involves maintaining a therapeutic relationship based on empathy and emotional validation and the therapist is typically non-directive and non-interpretive. There is some evidence that individual supportive counselling can be beneficial for cancer patients receiving active treatments (e.g. Manne et al., 2007; Owen, Klapow,
Hicken, & Tucker, 2001). However, there is limited research on its efficacy among advanced cancer patients or palliative patients.

Supportive-Expressive Group Therapy (SEGT) is a long-term, manualised, unstructured group intervention that provides an opportunity for patients to share their emotional experiences in a supportive environment, improve social relationships, decrease isolation and stigma, and examine existential concerns (Classen et al., 2001; 2008). Participants are also encouraged to “detoxify death” through a range of experiential exercises, meditation, and self-reflection (LeMay & Wilson, 2008). To date, there have been several RCTs examining the efficacy of long-term SEGT in women with advanced breast cancer (Classen et al., 2001; Goodwin et al., 2001; Kissane et al., 2007). There is evidence that long-term SEGT can result in improvements in depressive symptoms, traumatic stress symptoms, social functioning, perceived quality of life, and perceived pain in this patient population. Positive initial results have also been reported with a briefer 12-week version of SEGT in women with newly diagnosed breast cancer (Spiegel et al., 1999). However, a later study of women with primary breast cancer found no evidence of reduction in distress as a result of SEGT (Classen et al., 2008). Further research is required before conclusions can be drawn about its efficacy in palliative care settings (LeMay & Wilson, 2008).

3.4.2 Cognitive-Behavioural Therapy

Cognitive-behavioural therapy (CBT) is a structured, systematic, and goal-oriented psychotherapy that aims to help patients overcome difficulties by identifying and modifying unhelpful thinking patterns, behaviours, and emotional responses. In recent years, themes of values, meaning, mindfulness, and acceptance have also been integrated in the “third wave” of behavioural therapy (Hayes, Follette, & Linehan, 2004).

Studies that have evaluated CBT with cancer patients have typically found positive outcomes for depression, anxiety, fatigue, or general distress (Savard et al., 2006). However, a limited number of studies have evaluated CBT in palliative patients or patients with advanced cancer. Savard et al. conducted an RCT of cognitive therapy for depression in women with advanced breast cancer. Forty-five women were assigned to either eight sessions of individual cognitive therapy or a waitlist-control group followed by eight sessions of cognitive therapy. Patients receiving cognitive therapy had significantly lowered depression scores compared to untreated patients. The cognitive therapy in both groups resulted in additional reductions of anxiety, fatigue,
and insomnia and the effects were well sustained at 3-month and 6-month follow-ups. No significant changes were found in immune functioning.

Moorey et al. (2009) conducted an RCT of CBT for anxiety and depression in palliative patients in which clinical nurse specialists (CNS) were taught to deliver basic cognitive behavioural techniques. CNS’s were randomly allocated to receive training in CBT ($n = 8$) or continue their usual practice ($n = 7$), and tests of competence in CBT were carried out. Eighty home-care patients entered the trial after 328 patients (54%) were identified as having clinically significant anxiety or depression on the Hospital Anxiety and Depression Scale. Assessments were carried out at baseline, 6, 10, and 16 weeks. Patients receiving CBT had lower anxiety scores over time while there was no significant treatment effect found for depression. The authors noted significant attrition due to physical morbidity and mortality with 58% of patients taking part at week 6, and 43% taking part at week 16. Other concurrent physical and psychosocial variables were also noted in both patient groups that may have confounded the outcome data, though this was comparable across the groups. The authors concluded that further research is required on the effect of training non-mental health clinicians in provision of CBT and in understanding components of this therapy that may be most effective in palliative care settings.

### 3.4.3 Existential Psychotherapies

Existential psychotherapies are a group of interventions that aim to explicitly address questions about one’s existence, under the assumption that overcoming existential distress may lead to a decrease or prevention of psychopathology or further suffering (Vos, Craig, & Cooper, 2015). Logotherapy is one such type of existential psychotherapy. This intervention was initially developed by Victor Frankl with the aims of reducing distress and suffering by finding meaning in one’s existence (Frankl, 1985). The primary tenets of Logotherapy are that life has meaning under all circumstances and that people have the ability to reach this meaning. To Frankl, meaning emerges by actively contributing to the world through self-expression or creativity, by experiencing aspects of the world that one considers to be important, and through attitudes adopted towards aspects of the world that cannot be changed including suffering.

Kang et al. (2009) evaluated the effects of a Logotherapy education program in adolescents with terminal cancer. Seventeen adolescents aged 11 to 18 participated in the program for five days in one week, while 12 adolescents received nursing care as usual. The groups were non-equivalent and non-synchronised. The patients in the
treatment group reported significant changes in suffering and meaning of life, while no significant change was found in spiritual well-being. Despite these encouraging results, individual Logotherapy was not originally designed for palliative patients or patients with advanced cancer (Chochinov et al., 2004) and there are currently no published RCTs in this patient population.

In response to the need to specifically address existential and spiritual concerns among patients with advanced disease, William Breitbart and colleagues developed Meaning-Centred Group Psychotherapy (MCGP; Breitbart, 2002; Greenstein & Breitbart, 2000). MCGP is a manualised eight-week intervention grounded in the work of influential existential psychotherapy figures including Viktor Frankl and Irvin Yalom (Breitbart, 2016). It aims to help patients enhance and sustain their sense of meaning, peace and purpose in life, even with the awareness of approaching death. This is achieved through a mix of didactic teaching, facilitation of group discussion, and engagement in experiential exercises centred around themes related to meaning and advanced cancer (Breitbart, 2016).

Breitbart et al. (2010) conducted a pilot RCT with advanced cancer patients who were allocated to either MCGP group \( n = 49 \) or an eight-week Supportive Psychotherapy Group (SPG, \( n = 41 \)). Fifty-five patients completed the eight-week intervention (MCGP = 35; SPG = 20), while 38 completed the two-month follow-up assessment (MCGP = 25; SPG = 13). Attrition was primarily due to patient death or physical deterioration. Compared to SPG, patients taking part in MCGP showed significant improvements on measures of spiritual well-being, sense of meaning and peace, and faith. Significant improvements were also reported in anxiety and desire for death at the two-month follow-up. The authors concluded that MCGP is a potentially beneficial intervention for emotional and spiritual suffering near end of life, though further research with larger samples is required in order to replicate these initial findings.

Breitbart et al. (2015) subsequently conducted a larger RCT where advanced cancer patients were allocated to either MCGP \( n = 132 \) or SPG \( n = 121 \). An initial attrition rate of 32% was reported due to scheduling conflicts, deteriorating health, and loss of interest. Of 172 patients that began treatment, 127 completed the eight-week intervention programs and 102 patients completed the two-month follow-up assessment. Compared to SPG, patients receiving MCGP showed significantly greater improvements on the measures of spiritual well-being and quality of life, and
significantly greater reductions on the measures of depression, hopelessness, desire for death, and physical symptom distress. Furthermore, desire for death and sense of hopelessness were only improved by the MCGP, suggesting that higher levels of distress and despair respond better to an existential intervention compared to more traditional supportive therapy. The authors concluded that this study provides compelling evidence that MCGP is an efficacious psychotherapeutic intervention in palliative care settings.

3.4.4 Systematic Reviews of Psychotherapeutic Interventions for Depression in Palliative Care Settings

Ly, Chidgey, Addington-Hall, and Hotopf (2002) conducted a systematic review of RCTs on the treatment of depression in palliative care patients with less than 6 months life expectancy. There were no RCTs that specifically assessed psychotherapy, whilst there were three RCTs that assessed pharmacological treatments.

Akechi et al. (2008) also conducted systematic reviews of RCTs in which they investigated the effects of psychotherapy for treating depression among advanced cancer patients. Compared to the Ly et al. study, the patient population was broader in that the main inclusion criterion was the diagnosis of incurable cancer and there was no criterion for life-expectancy. Out of the six studies included, four used supportive psychotherapy, one used cognitive behavioural therapy (CBT), and one used problem-solving therapy. The authors found that psychotherapy had a significant effect on the treatment of depression in advanced cancer patients. The findings for anxiety and general distress were similar, although the findings for anxiety did not reach statistical significance. However, there was little available research on the effectiveness of psychotherapy for patients diagnosed with clinical depression including major depressive disorder. Akechi et al. concluded that more well-designed clinical trials are required to address this issue.

Li et al. (2017) conducted a first meta-analysis of RCTs of psychological, pharmacological, and collaborative care interventions for depression in cancer patients. Collaborative care interventions were defined as multicomponent strategies tailored to the severity of depression and “characterised by active collaboration between psychiatry specialist and primary care providers, assisted by a care manager who provides psychological interventions and monitors treatment compliance and outcomes” (p. 583-584). Both psychological and pharmacological interventions were equally effective in the short-term (up to 12 weeks post-treatment) but treatment effects were not sustained
at long-term. Collaborative care resulted in significantly reduced depression scores compared with usual care, and this effect was sustained up to 12 months post-treatment. Although this meta-analysis did not focus specifically on palliative care patients or settings, the authors suggested that collaborative care approaches may provide key advantages in terms of demonstrating outcomes compared to treatments provided in isolation.

3.4.5 Comparison of Dignity Therapy with Other Psychotherapeutic Interventions Utilised in Palliative Care Settings

There are a number of clinical considerations to take into account when comparing Dignity Therapy with other psychotherapeutic interventions in palliative care settings. The importance of the therapeutic relationship and understanding of the wider context of patients’ experiences cannot be overstated (LeMay & Wilson, 2008). There is evidence that some patients with advanced cancer value the quality of the therapeutic relationship more than the opportunity to learn coping skills and strategies to manage their distress (MacCormack et al., 2001). Flexibility with regards to session schedules, frequency, content, and duration is also relevant in this patient population, given the likely impacts of progressive disease. Benefits of individual versus group interventions also need to be considered. Group interventions such as the MCGP may offer a number of advantages compared to individual interventions, including the shared validation and normalisation of experiences, fostering hope, reducing sense of isolation, and promoting social connectedness and support (LeMay & Wilson, 2008). On the other hand, individual interventions may be more likely to benefit people who are too unwell to leave their home or hospital bed, or those who prefer to maintain privacy in a confidential therapeutic space.

Dignity Therapy shares a number of elements with the psychotherapeutic approaches mentioned above. Its emphasis on empathy, respect, and connectedness is common to all psychotherapies, and is a central component of supportive psychotherapy. Its focus on themes of meaning, hope, and mortality is shared with existential psychotherapies, and the exploration of life stories is consistent with narrative therapy interventions (Chochinov et al., 2004). In contrast to other psychotherapies, Dignity Therapy was developed for specific use with dying patients and their families. It is grounded in an empirical model that is based on palliative care patients’ perceptions of the role of dignity in their lives (Chochinov, 2012). In contrast to CBT and MCGP, it places less emphasis on insight, interpretation, provision of
didactic information, and skill-building. Dignity Therapy’s acceptability and feasibility in palliative care settings are accentuated by being relatively brief, flexible, and by directly involving key family members/carers in its process (Chochinov, 2012). Dignity Therapy also has a unique potential to be of benefit to family members or carers prior to, during and after the bereavement process (Hall et al., 2013). However, it remains to be seen whether these relatively unique psychotherapeutic aspects will translate into meaningful clinical outcomes for palliative care patients and their families (Fitchett et al., 2015).

3.5 **Limitations of Previous Dignity Therapy Research**

Over the last decade, there has been a considerable growth in international research examining the acceptability, feasibility and effectiveness of Dignity Therapy. Prior studies have consistently demonstrated its excellent acceptability among palliative care patients (Fitchett et al., 2015). Dignity Therapy tends to be associated with high levels of satisfaction and subjective benefit by patients for themselves and their families, as well as by family members for themselves and the patients. However, feasibility of this intervention remains mixed given the recruitment and retention issues, and its overall effectiveness in controlled studies remains uncertain (LeMay & Wilson, 2008; Fitchett et al., 2015). This is in part due to the limitations of Dignity Therapy research to date, including difficulties in choosing appropriate measures of outcomes and efficacy, uncertain therapeutic impacts of the legacy creation component of this intervention, other methodological concerns such as underpowered studies, and floor effects associated with low levels of distress.

3.5.1 **Recruitment and Retention Issues**

Recruitment and retention issues are not unusual in studies evaluating intervention outcomes in palliative care patients, and there are frequent descriptions of difficulties such as problems with meeting enrolment goals and achieving adequate power for statistical analyses in this patient population (Steinheuser et al., 2006). Dignity Therapy studies to date have consistently reported issues with recruitment and retention, particularly in relation to patients with higher levels of distress (Fitchett et al., 2015). Hall et al. (2011) noted that the tendency to include non-distressed palliative care patients in controlled Dignity Therapy studies may increase the likelihood of achieving adequate statistical power at the expense of leaving little room for improvement on standard outcome measures. In addition to physical and cognitive deterioration, there is evidence that recruitment may also be impeded by patients’ expectations that Dignity
Therapy would be too emotionally challenging, superfluous to their needs, or culturally inappropriate (Lindqvist et al., 2015). Further research is required to determine the feasibility of administering Dignity Therapy by a variety of multidisciplinary clinicians, and across a greater range of patient populations, settings, and cultures (Fitchett et al., 2015).

3.5.2 Difficulties in Measuring Therapeutic Outcomes

The primary outcomes of Dignity Therapy in RCTs have been largely determined by self-report measures of dignity-related distress (e.g., PDI), emotional and spiritual well-being, perceived quality of life, and other measures such as clinician-rated palliative care outcomes (Fitchett et al., 2015). However, these therapeutic outcomes are multi-component constructs that may not be amenable to change by provision of Dignity Therapy alone (Hall et al., 2011). This may be particularly the case for self-reported measures of physical symptoms and quality of life, whose items typically lack responsiveness to change in palliative care settings (Albers et al., 2010). Additionally, the symptomatic relief of distress is only one potential benefit or purpose of psychotherapeutic interventions in palliative care patients. Other potentially measurable benefits of Dignity Therapy may include prevention of distress, and promotion of subjective well-being, sense of purpose, and meaning in life (Chochinov et al., 2011).

This suggests that incorporation of more specific psychological, social, and existential aspects of palliative patients’ experiences is required in future studies in order to better understand the therapeutic outcomes of Dignity Therapy.

Measurement of therapeutic outcomes is likely further impeded by challenges with achieving adequate statistical power and overcoming floor or ceiling effects in the measures of pre-intervention distress (Fitchett et al., 2015). For example, the only Dignity Therapy RCT adequately powered to detect small to moderate effects (Chochinov et al., 2011) also reported significant floor effects of measures of distress due to inclusion of participants with relatively low levels of physical, social, and emotional distress.

3.5.3 Uncertain Effectiveness of Creating a Legacy Document and Lack of Direct Comparisons to Other Life Review Interventions

Studies of legacy document themes have demonstrated that Dignity Therapy can facilitate a sensitive and personalised exploration of broad range of themes and processes that people nearing end of life consider important and meaningful to them (Hack et al., 2010; Tait et al., 2011). However, it is not currently known how the
specific act of creating a legacy document may influence the themes and subthemes explored during Dignity Therapy sessions. For example, legacy documents are typically created with the goal or expectation that they will be shared with family members/carers, and eventually archived for future generations. Could the awareness of this key aspect of Dignity Therapy contribute to patients exploring narratives and themes that otherwise would not have been explored if the session content remained entirely private and confidential? Are there important themes and narratives that are less likely to be explored or addressed to a lesser extent during Dignity Therapy sessions because of its focus on creating a lasting legacy document, even with the opportunity to later edit the interview transcript? No study to date has directly compared therapeutic outcomes of Dignity Therapy with similar psychotherapeutic interventions such as Life Review that omit the creation of a life story or legacy document. Therefore, the contributions of the unique act of creating a legacy document to the session content and therapeutic outcomes of Dignity Therapy remains uncertain.

3.6 Chapter Summary

In comparison to evidence-based medical management of various impacts of advancing disease, there remains a notable lag in the development and evaluation of systematic manualised psychotherapeutic interventions specifically tailored to the needs and concerns of palliative care patients. The paucity of empirical evidence of psychotherapeutic interventions for existential concerns near end of life is particularly striking (LeMay & Wilson, 2008).

As part of addressing this issue, Harvey Chochinov and his team developed Dignity Therapy based on their earlier empirical work on the sense of dignity in dying patients. This intervention aims to address aspects of psychosocial and existential distress by facilitating a guided review of one’s life story and assisting people in creating a lasting legacy document. The contents of this document are determined by each patient, though it typically includes aspects of life deemed to be most important or poignant, personal values, hopes and dreams for loved ones, and special messages to others including words of comfort or solace. This relatively novel and manualised intervention is particularly well-suited to palliative care settings in that it is brief, flexible, task-oriented, and conducted on an individual basis but also with input from family/carers as appropriate.

Life Review interventions are similarly flexible, brief, and suitable for use in palliative care settings. Although there is a limited standardisation and manualisation of
Life Review interventions, this process typically involves a graduated review of the lifespan in order for patients to address or process key life experiences, explore life’s meaning and purpose, and achieve sense of acceptance (Stinson & Kirk, 2006; Trueman & Parker, 2006). There is increasing empirical evidence for acceptability and feasibility of both Dignity Therapy and Life Review interventions in palliative care settings, though their efficacy remains uncertain due to limited empirical evidence and difficulties in overcoming methodological issues such as recruitment and retention issues and difficulties measuring therapeutic outcomes (Fitchett et al., 2015; Keall et al., 2015).

Dignity Therapy also shares a number of elements with other psychotherapeutic interventions such as CBT, SEGT, and MCGP. More specifically, it emphasises the quality of the therapeutic relationship, and focuses on the themes of meaning, hope, and mortality. On the other hand, it places relatively less emphasis on insight, interpretation, psychoeducation, and skill-building, and can directly involve family/carers in the therapeutic process if appropriate. However, it remains to be seen to what extent these unique psychotherapeutic aspects will translate into meaningful clinical outcomes for people approaching end of life and their families or carers (Fitchett et al., 2015). More well-designed clinical trials are required to clarify the utility and effectiveness of Dignity Therapy and other psychotherapeutic interventions in palliative care settings (LeMay & Wilson, 2008; Okuyama et al., 2017). The following chapter provides an overview of the clinical research conducted in this project, which was designed to further improve the understanding of Dignity Therapy outcomes.
CHAPTER 4: OVERVIEW OF STUDIES CONDUCTED AS PART OF THE DOCTORAL THESIS

Chapter Four summarises the empirical basis for the three studies that were conducted as part of this Doctoral research and how they fit together as a larger body of research. The rationale, aims, and methodology of each study are presented. The local context of the research is also outlined.

4.1 Basis of Research

The literature reviews presented in the initial three Chapters of the Dissertation have served as a basis for development of the studies conducted as part of the Doctoral Thesis. More specifically, Chapter 1 presented the multidisciplinary nature of palliative care, and outlined research priorities and needs that psychologists are well placed to contribute to. This includes the need to further progress psychotherapeutic research and improve understanding of its outcomes in this patient population. Chapter 2 reviewed the literature on the concepts of suffering, existential and spiritual distress, demoralisation, and dignity near end of life. These complex dynamic concepts are essential to conceptualisation of suffering near end of life, development of best practice models of care, and evaluation of evidence-based psychotherapeutic interventions for palliative care patients. The contribution of the Dignity Model (Chochinov et al., 2002a) to improved clinical practice and patient care in palliative care settings was also outlined. This model has provided a theoretical foundation for development of various dignity-conserving interventions including Dignity Therapy (Chochinov et al., 2004). Chapter 3 reviewed the literature on the clinical utilisation of Dignity Therapy in palliative care settings, in light of the general lag in the development and evaluation of systematic manualised psychotherapeutic interventions in palliative care settings. Comparisons to other relevant psychotherapeutic modalities including Life Review were presented. It was noted that Dignity Therapy was specifically developed for use with the palliative patient population in that it is relatively brief; task-oriented; flexible in its focus on themes of meaning, hope, and mortality; and directly involves family/carers as appropriate. These attributes likely contribute to Dignity Therapy’s outstanding acceptability among palliative care patients and their families or carers (Fitchett et al., 2015).
However, a number of significant limitations have also been identified in prior Dignity Therapy research including recruitment and retention issues, difficulties in demonstrating treatment outcomes, and a general lack of controlled studies comparing Dignity Therapy with Life Review or similar interventions. The empirical component of the thesis is comprised of three separate though related studies that were guided by the above-mentioned issues and limitations in the literature to date. Their shared goal was to examine and better understand the therapeutic outcome measurement, efficacy, and processes of Dignity Therapy and Life Review interventions for palliative care patients. The rationale, aim and methodology of each study are presented in the following section.

4.2 Study 1 - Development of a Brief Measure of Generativity and Ego-Integrity for Use in Palliative Care Settings

4.2.1 Rationale

In Erikson’s (1963) psychosocial theory of lifespan development, middle adulthood is conceptualised as an active and dynamic interplay between generativity and stagnation, whilst late adulthood involves a similar interplay between ego-integrity and despair. In this context, generativity refers to a person’s connection with the next generation, passing skills and knowledge to others, being productive, and leaving a lasting legacy. In essence, generativity involves a desire to invest one’s substance into forms of life and work that will outlive oneself (Kotre, 1984). Generativity can therefore be expressed not just in parenting, care-taking, or family life, but also on a larger community scale through activities such as teaching, mentoring, volunteering, and contributing to other causes that one perceives as important or meaningful (McAdams & Logan, 2004). As such, motivation to engage in generative behaviours can also occur at other stages of life though generative desires are typically more likely to be fulfilled in middle adulthood (Hauser, 2013; Stewart & Vandewater, 1998).

McAdams, Hart, and Maruna (1998) further expanded on Erikson’s and Kotre’s conceptualisations of generativity by encompassing the following seven specific domains: inner desire for symbolic immortality, cultural demands or societal norms, generative concern for future generations, belief in the goodness or worthwhileness of humanity, commitment to generative goals, generative actions, and narration of generativity that becomes a part of one’s life story and self-identity. This model
therefore suggests that generative concerns and behaviours take on a deeply personal meaning in one’s life as they are incorporated into one’s self-defining life story.

On the other hand, Erikson referred to stagnation as absence of such generative desire, a sense of apathy, and preoccupation with own needs to the detriment of care for others and contribution to the wider society. In other words, instead of considering what can be given or contributed to others, people instead are too preoccupied about what they can get from others (Hamachek, 1990). Sense of stagnation could also result from a perception that generative behaviours are no longer possible and the resulting disappointment that one no longer has any positive or meaningful impact on others (McAdams & Logan, 2004). This can be particularly evident in the context of major life changes such as retirement, acute medical issues, or other losses. However, care needs to be taken in attributing economic or cultural influences to the sense of stagnation. For example, self-preoccupation can be a function of survival as opposed to stagnation: “The individual who does not know when he will next eat a good meal may not have the psychosocial luxury to worry about the next generation” (McAdams & Logan, 2004, p. 17). Of note is that generativity can still be readily witnessed in situations of extreme poverty or crisis such as people mobilising their relatively few resources in order to help others in even greater need (Melo, 2008).

In comparison to generativity, ego-integrity refers to a complex and holistic self-understanding that is characterised by looking back on life with a sense of meaning, acceptance of past life events, sense of fulfilment and a general absence of death anxiety (Erikson, 1963; Erikson & Erikson, 1998). Erikson deemed this process to be most prominent in older age where people are relatively more likely to contemplate and reflect on the events of the past. However, for some people this process is characterised by despair, or sense of disappointment with one’s life trajectory, significant guilt or regret about past events, and an accompanying sense of sadness or bitterness. As with Erikson’s other developmental stages, effective transition through ego-integrity vs despair processes involves reaching a sense of balance between the opposing poles and incorporating them into a dynamic and complex understanding of the world (Torges et al., 2008; Van Hiel et al., 2006). This process takes place within each person’s psychosocial and cultural context, and is therefore shaped by each person’s unique life experiences (Chang et al., 2008). The majority of studies to date have conceptualised ego-integrity and despair as a one-dimensional structure with two opposing poles. Westerhof, Bohlmeijer, and McAdams (2015) suggested these concepts could also be
conceptualised as two different though related dimensions. More specifically, these authors suggested that adults are able to simultaneously experience both ego-integrity and despair, and recommended further research in understanding how these concepts may be related to other constructs such as mental health and personality traits (Westerhof et al., 2015).

There is increasing empirical evidence for the validity of both the generativity vs stagnation and ego-integrity vs despair stages of psychosocial development (Bradley, 1997; Bradley & Marcia, 1998; James & Zarrett, 2006; Hearn et al., 2012). Data from longitudinal studies has provided evidence that resolution of regrets corresponds with higher levels of ego-integrity, and that higher levels of generativity in midlife can predict higher levels of ego-integrity a decade later (Torges et al., 2008). Increased sense of generativity has been associated with satisfaction with life, mental health, self-esteem, and a sense of coherence in life, and was negatively associated with reported depression (McAdams & Azarow, 1996; Melo, 2008). Similarly, sense of ego-integrity was negatively associated with depression and positively associated with psychological well-being (James & Zarrett, 2005; Rylands & Rickwood, 2001). There is also evidence that generativity and ego-integrity tend to be relatively independent of contextual factors such as gender, marital status, and parental status (Melo, 2008; Westerhof et al., 2015).

However, little is known about the role of generativity and ego-integrity in the context of advanced disease, and their roles as possible contributors or alleviators of the sense of suffering (Black & Rubenstein, 2009; de Mederios, 2009). Jacobsen et al. (2006) related demoralisation near end of life to Erikson’s (1963) concept of despair, in that both can involve sense of regret over the life that was lived, along with loss of meaning, sense of hopelessness, and fear of mortality. Jacobsen et al. found the symptoms of demoralisation to be distinct from symptoms of major depression, though suggested that further research is required whether demoralisation is the sense of despair as operationalised by Erikson: “it is still too early to conclude for certain whether the emergent factor is end-of-life despair or whether the symptoms of demoralization define a depressive state in the context of advanced cancer” (p. 14).

Further studies are also required to determine whether ego-integrity and despair can be impacted by reminiscence or life review processes (Westerhof et al., 2015). For example, no empirical study of Life Review interventions to date has directly examined Erikson’s psychosocial stages as potential treatment outcomes in any patient population.
Instead, psychotherapeutic impacts on generativity and ego-integrity have been inferred by measuring associated dependent variables (Haight et al., 2000). It is difficult to draw conclusions from correlational research regarding the potential impact of psychotherapeutic interventions on Erikson’s developmental stages (Morgan, 2000).

The lack of suitable measures of generativity and ego-integrity in palliative care settings has been a key barrier to evaluating the potential importance of these concepts as psychotherapeutic outcomes. Measurement of generativity and ego-integrity has typically involved analyses of self-report questionnaires, behavioural checklists, and qualitative analyses of biographical information. However, such measures may not be suitable for use with older people due to their intended aims, inappropriate wording of items, and length of time required for completion of assessment (Schoklitsch & Baumann, 2011). Other measures that have been trialled in palliative care settings such as the PDI (Chochinov et al., 2008) directly include, at best, single items of generativity and ego-integrity. To date, no psychotherapeutic outcome measure has been designed specifically to assess these concepts in the palliative patient population.

4.2.2 Aim

The aim of the first study was to develop a brief self-report measure of Erikson’s concepts of generativity and ego-integrity that would be suitable for use in palliative care settings. The utility of this specific measure is twofold. First, it would allow for further exploration and better understanding of the relevance of generativity and ego-integrity in patients approaching end of life. This would be facilitated by the more direct and appropriate measurement of these concepts as opposed to reliance on related concepts such as life satisfaction and psychological well-being used in previous studies (e.g., Haight et al., 2000). Second, this measure could be used as an indicator of psychotherapeutic outcomes that extends beyond the standard measures of physical, psychosocial, and spiritual well-being. This is essential, given that the previous measurement of these other constructs has been relatively insensitive in detecting effects of Dignity Therapy and Life Review, and that the therapeutic content, process, and goals of these interventions are consistent with Erikson’s concepts of generativity and ego-integrity.

4.2.3 Methodology

In order to achieve the aim of Study 1, a new brief measure of generativity and ego-integrity was developed based on the following two existing and validated measures: the Loyola Generativity Scale (McAdams & de St. Aubin, 1992), and Ryff
and Heincke’s (1983) Ego-Integrity Questionnaire. A total of eleven items was selected from these measures based on their theoretical representativeness and appropriateness for use with palliative care patients. Minor adjustments to wording of original items were made in order to further improve the face validity and suitability for palliative care settings. The subsequent measure was then administered to a purposive sample of 143 adults that was recruited through a research participation website. A principal components analysis was conducted in order to explore the latent structure of the items, and check whether the factor solution corresponded to the generativity and ego-integrity items selected from their respective original scales.

4.3  **Study 2 - Dignity Therapy and Life Review for Palliative Care Patients: A Randomised Controlled Trial**

4.3.1 **Rationale**

As outlined in Chapter 3 of the dissertation, systematic reviews to date have found that Dignity Therapy has consistently high acceptability and satisfaction rates among patients and their families/carers, variable feasibility due to issues with recruitment and retention, and generally uncertain effectiveness due to the limited effects on primary outcome measures (Fitchett et al., 2015). Primary limitations of empirical studies of Dignity Therapy to date include difficulties in choosing appropriate measures of outcomes and efficacy, uncertain therapeutic impacts of the unique legacy-creation component of this intervention, and other methodological concerns such as underpowered studies and floor effects associated with low levels of distress at pre-test. Similarly, there is sufficient evidence that Life Review interventions are acceptable and feasible in palliative care settings though their efficacy remains uncertain due to limited empirical evidence and methodological issues such as attrition rates and floor/ceiling effects of outcome measures (Keall et al., 2015). Additionally, it remains uncertain whether Dignity Therapy and Life Review can lead to more specific therapeutic outcomes such as those associated with Erikson’s (1963) psychosocial developmental stages of generativity vs stagnation and ego-integrity vs despair. This is despite the inclusion of generativity as a component of the Dignity Model (Chochinov et al., 2002a) and Chochinov’s (2012) reference to legacy documents as “generativity documents”. Additional well-designed clinical trials of Dignity Therapy and similar interventions are required in order to clarify their utility and effectiveness in palliative care settings (LeMay & Wilson, 2008; Okuyama et al., 2017).
4.3.2 Aim

The aim of the second study was to examine and better understand the efficacy of Dignity Therapy for palliative care patients by comparing this intervention with Life Review and a Waitlist Control Group in an RCT.

4.3.3 Methodology

The RCT utilised a number of novel methodologies in order to achieve its aims. First, Dignity Therapy and Life Review sessions were structured in a way that the primary difference between these interventions was the creation of a legacy document. Life Review sessions were guided by the Dignity Therapy questions and themes presented in Table 3.1, with the exception that any references to creating legacy documents were omitted. This approach allowed for the length of therapeutic input to be controlled for across the interventions. Both interventions were also conducted by the same therapist, with the aim of minimising potential therapist bias or influences that could occur when psychotherapies are provided by separate clinicians. Additionally, random group allocation was implemented. As is common in psychotherapeutic research, it was not possible for the interventions to be masked to either the therapist or participants. The methodological isolation of the specific act of creating a legacy document and evaluation of its therapeutic impacts is unprecedented in the literature. Whilst the Life Review protocol was guided by Dignity Therapy interview questions, this intervention still fell within the general scope of standard therapeutic life review interventions previously described in the literature (Haber, 2006; Tait et al., 2011). Life Review interventions are typically not standardised or manualised, and instead are relatively flexible with regard to the therapeutic content and process (Keall et al., 2015). Both Dignity Therapy and Life Review interventions were expected to facilitate the validation of patients’ life experiences through demonstration of genuine unconditional positive regard and respect. Their shared focus on the entire life story as opposed to the illness or deterioration was expected to assist patients in attaching meaning to key life events and further bolster their sense of dignity (Chochinov, 2012; Tait et al., 2011). Nevertheless, it was also expected that the ratio between in-session evaluative and descriptive processes would differ across the two interventions. Traditional Life Review approaches tend to place relatively more importance on the evaluative process such as assisting patients in coming to terms with more difficult or distressing memories and life experiences (Keall et al., 2015). In comparison, Dignity Therapy can be a relatively more descriptive process that places less emphasis on insight and interpretation, and
instead emphasises enhancement of generativity, meaning, and purpose through the creation of a legacy document.

Second, the RCT included a Waitlist Control Group where participants were provided with standard Dignity Therapy after a waiting period of 10 days. This facilitated a more effective evaluation of the therapeutic outcomes of Dignity Therapy and Life Review interventions. Furthermore, it enabled the exploration of within-group changes on outcome measures by comparing three distinct time points: pre-test, second pre-test after the waiting period, and post-test after Dignity Therapy. The relatively short waiting period of 10 days was deemed appropriate for the palliative care setting in reaching a balance between not waiting long enough for meaningful control group comparisons and waiting for too long with the resulting inflated benefits of intervention groups due to control group patient deterioration and attrition.

The use of waitlist control groups is standard practice in trials of psychotherapeutic regimes and this method is preferred over untreated control groups given that it is unethical to withhold interventions from patients that are seeking them (Elliot & Brown, 2002). The benefits of use of waitlist control groups need to be weighed up against several potential ethical and practical concerns (Devilly & McFarlane, 2009). These include the possibility of denying people access to their legal or humanitarian rights by not immediately providing gold-standard evidence-based treatments, risk of increasing the attrition rate, possibility that significant group differences may arise from the waiting being detrimental as opposed to treatment being beneficial, and difficulties in comparing long-term group outcomes given that waitlist control groups receive standard treatment after a set waiting period. However, these concerns do not apply to all trials and for this proposed study, the benefits of including a Waitlist Control Group outweighed its disadvantages. Dignity Therapy was a novel intervention whose efficacy was even less certain at the time of designing and implementing this study. It was deemed unlikely that participants would suffer serious or irreversible harm by not receiving Dignity Therapy at all (Life Review Group) or receiving this intervention after a short waiting period (Waitlist Control Group). Also, the relatively short waiting period of 10 days minimised the risk of increased attrition rate impacting treatment outcomes that may occur with longer waiting periods. The possible issue of not being able to measure long-term outcomes was deemed not applicable in this study in context of the patient population.
Third, the Brief Measure of Generativity and Ego-Integrity that was developed and evaluated in the first study was used as a key outcome measure in the RCT. This allowed for more direct measurement of the potential importance of these concepts in determining therapeutic impacts of Dignity Therapy and Life Review interventions. Exploration of possible within-group changes in the questionnaire scores for Waitlist Control Group participants was expected to further contribute to the understanding of how these concepts may change over time. In addition to the brief self-report measure of generativity and ego-integrity, participants were asked an open-ended question about engagement in generative behaviours.

Consistent with prior Dignity Therapy efficacy studies (e.g., Chochinov et al., 2011), therapeutic outcomes were also assessed in terms of perceived quality of life (Functional Assessment of Cancer Therapy-General; FACT-G; Cella et al., 1993), and perceived sense of dignity (PDI; Chochinov et al., 2008). Participants’ and their family/carer’s beliefs about the various impacts of interventions were also assessed with the Treatment Evaluation Form (15 items) and a Family Evaluation Form (15 items).

The RCT was conducted by the candidate who has been employed since 2009 as a full-time clinical psychologist at the Gold Coast Hospital (GCH) Cancer Service, and subsequently the Gold Coast University Hospital (GCUH) Cancer and Blood Disorders Service. This clinical role remained unchanged throughout the timeframe of the Doctoral Candidature. As a result, this arrangement was particularly facilitative of a collaborative approach to research methodology between Griffith University and the GCUH clinical setting.

The potential clinician-researcher dual role was identified early in the research planning stage. This was managed by the use of strict inclusion and exclusion participation criteria where cancer or palliative care patients that were previously seen by the candidate in a clinical capacity were excluded from participating in the RCT. The patients that met this exclusion criteria were still provided the standard Dignity Therapy intervention outside of the research protocol, given the preliminary evidence of its acceptability, feasibility, and effectiveness at the time (Chochinov et al., 2005; McClement et al., 2007). Additionally, all session interviews were transcribed by a paid professional transcriber (research assistant), or occasionally by the primary author when the research assistant was unavailable. This was consistent with the standard Dignity Therapy protocol (Chochinov, 2012). In order to reduce potential response bias, participant questionnaires were not administered by the candidate, and instead were
administered by postgraduate psychology interns, other members of the multidisciplinary treating team, or they were self-administered when requested.

Additional risk mitigation strategies were implemented in the RCT. There was no evidence from previous research that completion of any of the questionnaires utilised in the RCT was associated with elevated emotional distress. A management plan was implemented in order to manage emotional distress at any point during study participation and prevent further harm. This included discontinuing the study participation, reviewing participant needs at the time, and offering and arranging follow-up with other clinicians or external agencies as appropriate. A list of these contact numbers and other supports was prepared to be made available to participants or their families/carers. The RCT was prospectively registered on the Australia New Zealand Clinical Trials Registry (Registration number: ACTRN12618000057280).

4.3.4 Local Context of Research

The RCT was conducted with inpatients and outpatients at the following three sites: (a) the GCH Cancer Services, (b) the GCUH Cancer and Blood Disorders Service, and (c) the Robina Hospital Supportive and Palliative Care Service. Additionally, a third of participants were visited at their home.

The GCH was a major health facility in Southport, Queensland, with an average annual admission of over 60,000 patients (Gold Coast Health, 2013). This hospital was decommissioned in September 2013 and all hospital patients were transferred to the GCUH that opened at the same time. The GCUH is currently one of Queensland’s largest health, teaching, and research facilities (Gold Coast Health, 2018a). It is located adjacent to the Griffith University Gold Coast campus. This facility includes extensive inpatient and ambulatory cancer care, provided by multidisciplinary medical, nursing, and allied health teams. Primary medical treatment modalities for cancer patients include surgical interventions, chemotherapy, radiation therapy, and autologous stem-cell transplantation. The GCUH also has a dedicated medical and nursing team that provides consultative palliative care.

Robina Hospital is also a large public teaching hospital that is part of the wider health hub that also includes community health services (Gold Coast Health, 2018b). It provides extensive multidisciplinary palliative care services in a purpose-built inpatient ward and a specialist outpatient clinic. Additionally, the specialist palliative care community service team provides a consultative service in patients’ homes, and provides support to General Practitioners and other clinicians.
4.4 Study 3 - Dignity Therapy and Life Review for Palliative Care Patients: A Qualitative Study

4.4.1 Rationale

The process of creating a legacy document as part of Dignity Therapy is facilitative of a sensitive and personalised exploration of broad range of themes that people nearing end of life consider important and meaningful to them (Tait et al., 2011). For example, Hack et al. (2010) found that Dignity Therapy allowed patients to focus on “overarching truths, feelings and insights” and that this discussion was particularly facilitative of exploration of one’s core values (p. 721). However, little is known about how the process of creating a legacy document influences the themes and subthemes that participants choose to explore during therapy sessions. Hack et al. suggested that themes expressed during Dignity Therapy tend to be heartfelt, honest, and genuine. It is also possible that one’s awareness of the creation of a legacy document could lead to exploration of narratives and themes that otherwise would not have been explored if the session content remained entirely confidential. Similarly, it is not known whether there are important themes and narratives that would be more or less likely to be explored during similar psychotherapeutic interventions that omit the creation of a life story or legacy document, such as Life Review. Further exploration of these processes is required in order to better understand the therapeutic benefits and drawbacks of these interventions and specifically the key aspect of Dignity Therapy – the creation of a lasting permanent legacy document.

4.4.2 Aim

The primary aim of the third study was to utilise qualitative methods in order to explore and better understand thematic similarities and differences between Dignity Therapy and Life Review sessions conducted in the RCT. It was expected that the use of qualitative methods to compare interventions would further contribute to the evaluation of the treatment outcomes reported in the RCT (Lewin, Glenton, & Oxman, 2009).

4.4.3 Methodology

Dignity Therapy legacy documents and Life Review session transcripts were compared across the following a priori themes: (a) sense of generativity and ego-integrity based on Erik Erikson’s (1963) psychosocial theory, (b) the empirical model of dignity (Chochinov et al., 2002a), and (c) personal or core values that were previously
identified to be prevalent in Dignity Therapy legacy documents (Hack et al., 2010). In order to achieve its aims, this study utilised the framework method of thematic data analysis. This approach aims to identify commonalities and differences in qualitative data, explore the relationships between different parts of this data, and seek descriptive or explanatory conclusions about the data by identifying the underlying themes (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The specific systematic steps to data analysis included familiarisation with the data, coding of both a priori themes (deductive) and open themes (inductive), development and application of a working analytical framework, and finally charting this data into the framework matrix in order to interpret the data. The key strength of this approach is that it is comprehensive yet flexible in conducting comparison analyses that are both deductive and inductive (Gale et al., 2013). As such, it is particularly suitable for analysis of interview data where themes are generated by making comparisons within and between cases.

4.5 Chapter Summary

In order to more effectively meet the complex psychosocial and existential needs of palliative care patients, there is a need to establish an evidence base for systematically developed psychotherapeutic interventions that are specifically tailored to this patient population. This project has utilised several novel methodologies in order to achieve its aims of better understanding the utility and effectiveness of Dignity Therapy and Life Review interventions. A new brief self-report measure of generativity and ego-integrity was developed for specific use in palliative care settings, and used in the subsequent RCT as an outcome measure. The RCT was designed to better understand the impacts of creating a legacy document by controlling for interview questions, session length, and use of the same therapist in the Life Review protocol. A Waitlist Control Group allowed for specific exploration of not just between-groups differences on outcome measures but also within-group changes by comparing pre-test with the second pre-test after the waiting period, and post-test after Dignity Therapy. The interpretation of the RCT outcomes was further supplemented by the framework method of thematic data analysis that was utilised in the final study. The following three Chapters are comprised of the three papers published in their respective peer-reviewed journals.
Chapter Five consists of a published paper titled: “Development of a Measure of Generativity and Ego-Integrity for Use in Palliative Care Settings”. A statement of contribution to co-authored published paper is also included. This paper was published in the peer-reviewed journal, Palliative and Supportive Care. It outlines the development of a brief self-report measure of Erikson’s concepts of generativity and ego-integrity that is suitable for use with palliative care patients. Initial psychometric properties were reported, along with impressions of its suitability and utility in this patient population. Recommendations for future research are also outlined.
STUDY 1
STATEMENT OF CONTRIBUTION TO CO-AUTHORED PUBLISHED PAPER

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:


My contribution to the paper involved:

- Review and interpretation of existing literature
- Scale development and study design
- Facilitated participant recruitment
- Conducted data analysis and interpretation of results
- Writing of the paper
- Identifying implications for future research

We agree to the inclusion of this paper in this doctoral research submitted for examination. The journal in which this paper has been published is peer-reviewed. Permission has been provided by the publisher, Cambridge University Press, to reproduce this paper as part of this doctoral thesis.

(Signed)……………………………………………(Date): 11/09/2018

Dean Vuksanovic

(Countersigned)……………………………………………(Date): 11/09/2018

Principal Supervisor: Dr Heather Green
Development of a brief measure of generativity and ego-integrity for use in palliative care settings

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School of Applied Psychology, Griffith University, Gold Coast Campus, Southport, Queensland, Australia
(RECEIVED October 1, 2014; ACCEPTED December 21, 2014)

ABSTRACT

Objective: Our aim was to develop and test a brief measure of generativity and ego-integrity that is suitable for use in palliative care settings.

Method: Two measures of generativity and ego-integrity were modified and combined to create a new 11-item questionnaire, which was then administered to 143 adults. A principal-component analysis with oblique rotation was performed in order to identify underlying components that can best account for variation in the 11 questionnaire items.

Results: The two-component solution was consistent with the items that, on conceptual grounds, were intended to comprise the two constructs assessed by the questionnaire.

Significance of Results: Results suggest that the selected 11 items were good representatives of the larger scales from which they were selected, and they are expected to provide a useful means of measuring these concepts near the end of life.

KEYWORDS: Generativity, Ego-integrity, Palliative care, End of life

INTRODUCTION

Understanding the psychological and social aspects of the final stages of human development is essential to providing optimal care to palliative care patients. In Erik Erikson's (1963) psychosocial theory of lifespan development, middle adulthood was conceptualized as an active and dynamic interplay between generativity and stagnation. Generativity includes provision of care and guidance to future generations, maintaining productivity through work or other activities, and a sense of leaving a lasting legacy. On the other hand, stagnation refers to apathy, lack of contribution to society, preoccupation with one's own needs, and an absence of care for others. Although critical in middle adulthood, Erikson and Erikson (1997) acknowledged that generativity is essential to successful aging among older adults as well.

In comparison, late adulthood was conceptualized by Erikson as an interplay between ego-integrity and despair. Ego-integrity includes looking back on one's life with a sense of meaning, acceptance of past life events, a sense of growing wise with age, and an absence of death anxiety. Despair refers to a sense of disappointment with life's trajectory, guilt or regret about past events, and a poor sense of accomplishment in life. Successful transition through these stages involves reaching a balance between their opposing poles (van Hiel et al., 2006) and incorporating both poles into a dynamic and complex understanding of the world (Torgerson et al., 2008).

Erikson’s theory has served as a basis for investigations on psychosocial development throughout the lifespan. There is evidence for the validity of both the generativity and ego-integrity stages (Bradley, 1997; Bradley & Marcia, 1998; James & Zarrett, 2005; Hearn et al., 2012). McAdams and de St. Aubin (1992) developed and tested a comprehensive model of generativity that encompasses inner cognitions, desires, generative behaviors, and cultural demands. An increased sense of generativity was associated with
self-report indices of life satisfaction, happiness, self-esteem, goal stability, and a sense of coherence in life, and was negatively associated with depression (McAdams & Azarow, 1996). Similarly, achieving a sense of ego-integrity was negatively associated with depression and positively associated with psychological well-being (Rylands & Rickwood, 2001; James & Zarrett, 2005). Consistent with Erikson’s model, there is empirical evidence of a positive association between generativity and ego-integrity, including data from longitudinal studies (Torges et al., 2008).

Measurement of generativity and ego-integrity has typically involved analyses of self-report questionnaires, behavioral checklists, and autobiographical recollections. However, the intended aims, wording of items, and length of administration of such measures are not readily suitable for use with older people (Schoklitsch & Baumann, 2011) or with palliative care patients, whose health is typically deteriorating. Measures with excellent face validity for use with palliative care patients (e.g., the Patient Dignity Inventory; Chochinov et al., 2008) include, at best, single-item measures of generativity and ego-integrity. No measure has been designed specifically to assess these concepts in the palliative patient population, and this is a significant barrier against an understanding of their importance at, or near, the end of life. In order to address this issue, the aim of our present study was to develop and evaluate a measure of generativity and ego-integrity that would be suitable for use in palliative care settings.

SCALE DEVELOPMENT

The new brief measure of generativity and ego-integrity was based on two existing and validated measures of these concepts that were derived from Erikson’s psychosocial theory of lifespan development: the Loyola Generativity Scale (McAdams & de St. Aubin, 1992) and Ryff and Heintze’s (1983) Ego-Integrity Questionnaire. Both measures have good internal consistency, test–retest reliability, and convergent and discriminant validity. Some 20 items from the Loyola Generativity Scale were grouped into their 5 theoretical components (McAdams & de St. Aubin, 1992), after which 6 items were selected based on their representativeness of each theoretical component and suitability for administration to palliative care patients. Similarly, five items were selected from Ryff and Heintze’s Ego-Integrity Questionnaire based on their representativeness of the theoretical concept of ego-integrity and suitability for administration to palliative care patients.

Minor adjustments to the wording of original items were made to five original items from the Loyola Generativity Scale and three from Ryff and Heintze’s Ego-Integrity Questionnaire in order to further improve item face validity. The selected 11 items were combined into one measure, and a 5-point Likert-type scale (strongly disagree, disagree, neutral, agree, strongly agree) was utilized. The final measure was named the Brief Measure of Generativity and Ego-Integrity (see Table 1).

### METHOD

Participants were 143 adults living in New Zealand who were recruited via a research-oriented website (www.researchstudies.co.nz) after the research had been approved by a human research ethics committee. All participants completed the new questionnaire and a demographics questionnaire online. No financial or other compensation was provided. The sample size is adequate for factor-analytic studies of 11-item questionnaires (Tabachnick & Fidell, 2001). The mean age of the sample was 44.9 years ($SD = 13.9$, range = $20–82$). The majority of the sample were women (78.3%). The median number of children was two, ranging between none and seven, with 72.7% of participants having at least one child. The most frequent marital status was married (46.9%), followed by never married (21.7%), de facto (14%), separated or divorced (13.3%), and widowed (4.2%). The majority of the sample completed one or more years of tertiary education (77.5%), while the rest either completed high school (15.5%) or did not complete high school (7%). The majority were currently working and/or studying (80.1%), and the remaining participants were retired (11.3%) or semi-retired (8.5%).

<table>
<thead>
<tr>
<th>Table 1. Items comprising the brief measure of generativity and ego-integrity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I pass along the knowledge that I have gained through my experiences.</td>
</tr>
<tr>
<td>2. I think that I will be remembered for a long time after I die.</td>
</tr>
<tr>
<td>3. I am not making a meaningful and lasting contribution to other people.</td>
</tr>
<tr>
<td>4. I am committed to many different kinds of people, groups, and activities.</td>
</tr>
<tr>
<td>5. I have done nothing that will survive after I die.</td>
</tr>
<tr>
<td>6. Other people would say that I am very productive.</td>
</tr>
<tr>
<td>7. I feel contented with what I have accomplished in my life.</td>
</tr>
<tr>
<td>8. I still feel angry about some of my life experiences.</td>
</tr>
<tr>
<td>9. My life has been fulfilling, and I am not frightened by the thought of death.</td>
</tr>
<tr>
<td>10. When I consider the ups and downs of my past life, they somehow fit together in a meaningful way.</td>
</tr>
<tr>
<td>11. I have had disappointments in life that I will never be able to accept.</td>
</tr>
</tbody>
</table>

Downloaded from https://www.cambridge.org/core; Griffith University, on 26 Jun 2017 at 11:15:37, subject to the Cambridge Core terms of use, available at https://www.cambridge.org/core/terms. https://doi.org/10.1017/S0848462517000206
Table 2. Pattern matrix for the two-factor solution (total sample)

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1 (Generativity)</th>
<th>Factor 2 (Ego-Integrity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I pass along the knowledge that I have gained through my experiences</td>
<td>0.44</td>
<td>0.13</td>
</tr>
<tr>
<td>I think that I will be remembered for a long time after I die</td>
<td>0.75</td>
<td>-0.04</td>
</tr>
<tr>
<td>I am not making a meaningful and lasting contribution to other people</td>
<td>0.72</td>
<td>-0.078</td>
</tr>
<tr>
<td>I am committed to many different kinds of people, groups, and activities</td>
<td>0.76</td>
<td>-0.15</td>
</tr>
<tr>
<td>I have done nothing that will survive after I die</td>
<td>0.75</td>
<td>0.07</td>
</tr>
<tr>
<td>Other people would say that I am very productive</td>
<td>0.62</td>
<td>0.07</td>
</tr>
<tr>
<td>I feel contented with what I have accomplished in my life</td>
<td>0.62</td>
<td>0.31</td>
</tr>
<tr>
<td>I still feel angry about some of my life experiences</td>
<td>0.07</td>
<td>0.75</td>
</tr>
<tr>
<td>My life has been fulfilling, and I am not frightened by the thought of death</td>
<td>0.21</td>
<td>0.58</td>
</tr>
<tr>
<td>When I consider the ups and downs of my past life, they somehow fit together in a meaningful way</td>
<td>0.29</td>
<td>0.55</td>
</tr>
<tr>
<td>I have had disappointments in life that I will never be able to accept</td>
<td>-0.28</td>
<td>0.91</td>
</tr>
</tbody>
</table>

RESULTS

The data were screened and the factorability of 11 questionnaire items was examined. A principal-component analysis was employed to identify the latent structure of the items to check if the generativity items loaded together on one latent variable and if the ego-integrity items loaded together on a second latent variable. Oblique (oblimin) rotation was performed due to the theoretical and empirical relationships between generativity and ego-integrity. Two empirical indices regarding the data's correlation matrix revealed that it was suitable for factor analysis: Bartlett's test of sphericity was significant ($\chi^2(55) = 423.37, p < 0.001$), and Kaiser's measure of sampling adequacy was 0.82. Parallel analysis was conducted in order to accurately determine the number of components to retain (O'Connor, 2000). Two factors exceeded the parallel test cutoff (3.94 > 1.61, 1.63 > 1.43, respectively) and explained a total of 50.57% of the variance. The two-factor solution showed that the six generativity items from the Loyola Generativity Scale had the highest loadings on the first factor (see Table 2). Four of five ego-integrity items from the Ryff and Heintze's (1983) Ego-Integrity Questionnaire had the highest loadings on the second factor, while the remaining item, "I feel contented with what I have accomplished in my life," had the highest loading on the first factor.

Given that the ego-integrity items are more relevant and applicable to middle and late adulthood, it was unclear whether the same latent structure obtained for the whole sample would be present in older participants. Therefore, factor analysis was repeated with the 80 participants who were at least 40 years of age. The assumptions of sampling adequacy (Kaiser-Meyer-Olkin measure = 0.80) and sphericity (Bartlett's test, $\chi^2(55) = 324.27, p < 0.001$) were met. Principal-component analysis with oblique (oblimin) rotation was repeated with all 11 items. Similar to the previous analysis, the two factors exceeded the parallel test cutoff (4.53 > 1.83, 1.73 > 1.58, respectively) and explained a total of 56.90% of the variance. The two-factor solution showed that the six generativity items had the highest loadings on the first factor and the five ego-integrity items had the highest loadings on the second (see Table 3).

Finally, Cronbach's $\alpha$ was computed for the generativity and ego-integrity subscales in order to determine their internal consistency. The values of $\alpha$ for both subscales (0.78 and 0.73, respectively) suggested acceptable internal consistency, particularly as the total number of items in each scale was relatively low. The $\alpha$ coefficients further improved (0.83 and 0.61, respectively) to demonstrate good internal consistency when only data from participants 40 years and above were included. No improvements in internal consistency were found with deletion of any items in either of the two analyses.

DISCUSSION

The aim of our study was to develop and evaluate a brief self-report measure of Erikson's concepts of generativity and ego-integrity for use with participants who have a limited life expectancy. The results showed that the 11 selected items were good representations of the larger scales from which they were selected in that they were able to consistently and efficiently measure aspects of generativity and ego-integrity. This was particularly the case when middle-aged and older adults were included in the analysis, in line with the theoretical and empirical models of these two concepts. The resulting 11-item questionnaire addresses a number of difficulties in reliably measuring a sense of generativity and ego-integrity in palliative care settings. First, the wording of items...
Table 3. Pattern matrix for the two-factor solution (participants 40 years old and above)

<table>
<thead>
<tr>
<th></th>
<th>Factor 1 (Generativity)</th>
<th>Factor 2 (Ego-Integrity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I pass along the knowledge that I have gained through my experiences.</td>
<td>0.60</td>
<td>0.02</td>
</tr>
<tr>
<td>I think that I will be remembered for a long time after I die.</td>
<td>0.74</td>
<td>0.06</td>
</tr>
<tr>
<td>I am not making a meaningful and lasting contribution to other people.</td>
<td>0.67</td>
<td>0.03</td>
</tr>
<tr>
<td>I am committed to many different kinds of people, groups, and activities.</td>
<td>0.78</td>
<td>-0.13</td>
</tr>
<tr>
<td>I have done nothing that will survive after I die.</td>
<td>0.84</td>
<td>-0.00</td>
</tr>
<tr>
<td>Other people would say that I am very productive.</td>
<td>0.06</td>
<td>0.09</td>
</tr>
<tr>
<td>I feel contented with what I have accomplished in my life.</td>
<td>0.36</td>
<td>0.47</td>
</tr>
<tr>
<td>I still feel angry about some of my life experiences.</td>
<td>0.13</td>
<td>0.74</td>
</tr>
<tr>
<td>My life has been fulfilling, and I am not frightened by the thought of death.</td>
<td>0.08</td>
<td>0.74</td>
</tr>
<tr>
<td>When I consider the ups and downs of my past life, they somehow fit together in a meaningful way.</td>
<td>0.10</td>
<td>0.68</td>
</tr>
<tr>
<td>I have had disappointments in life that I will never be able to accept.</td>
<td>-0.96</td>
<td>0.94</td>
</tr>
</tbody>
</table>

and the relatively brief administration time would allow for more efficient assessment than previous measures among participants who may be medically unwell, have reduced energy levels, or shorter attention spans. Second, the use of a standardized measurement of generativity and ego-integrity allows for direct theoretical and empirical comparisons of these two concepts while eliminating challenges associated with comparison of measures that may significantly differ from each other. This is particularly important given that Erikson's psychosocial stages are both sequential and interrelated (Erikson, 1982). Finally, the inherent flexibility of this measure allows for further modification and testing, as required.

The development of this brief self-report measure takes us closer to being able to assess and understand the importance of a sense of generativity and ego-integrity in palliative care settings. However, further evaluations of this measure are required in order to determine its utility at or near the end of life, including (a) further testing with participants with limited life-expectancy, (b) further validation of the subscales by examining their associations with other relevant measures, and (c) inclusion of items controlling for the possible effect of social desirability. As such, this measure is likely to further evolve with subsequent research and testing. Of note is that a comprehensive multimodal approach to assessment of Erikson's psychosocial stages in palliative care settings would also need to include measurement of population-specific behavioral indicators and narrative accounts (McAdams & de St. Aubin, 1992) as well as consideration of various time perspectives (e.g., past, present, future) and inclusion of family perspectives (Schonlith & Baumann, 2011). Therefore, further development and testing of other assessment tools and methodologies is needed in order to comprehensively assess Erikson's psychosocial stages among palliative care patients. Overall, the newly developed Brief Measure of Generativity and Ego-Integrity possesses good initial psychometric properties and contributes to our ability to assess these concepts among people who have a limited life expectancy.

REFERENCES


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Brief measure of generativity and ego-integrity


Chapter Six consists of a published paper titled “Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial”. A statement of contribution to co-authored published paper is also included. This paper was published in a peer-reviewed palliative care journal, *Journal of Pain and Symptom Management*. The aim of the RCT was to examine and better understand the utility and efficacy of Dignity Therapy for palliative care patients by comparing this intervention with Life Review and a Waitlist Control Group. Several novel methodological aspects were outlined, including (a) utilisation of the Brief Measure of Generativity and Ego-Integrity from the first study, (b) controlling for interview questions, session length, and therapist influences during Life Review, and (c) provision and evaluation of Dignity Therapy after a set waiting period in the Waitlist Control Group. Clinical and research implications of the results were presented, and recommendations for future research were made.
STUDY 2
STATEMENT OF CONTRIBUTION TO CO-AUTHORED PUBLISHED PAPER

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:


My contribution to the paper involved:

- Review and interpretation of existing literature
- Development of study design and methodology
- Facilitated participant recruitment
- Conducted psychotherapeutic interventions
- Conducted data analysis and interpretation of results
- Writing of the paper
- Identifying implications for future research

We agree to the inclusion of this paper in this doctoral research submitted for examination. The journal in which this paper has been published is peer-reviewed. Permission has been provided by the publisher, Elsevier, to reproduce this paper as part of this doctoral thesis.

(Signed)……………………………………..(Date): 11/09/2018
Dean Vuksanovic

(Countersigned)……………………………………..(Date): 11/09/2018
Principal Supervisor: Dr Heather Green
Original Article

Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial

Dean Vukanovic, MClinPsych, Heather J. Green, PhD, Murray Dyck, PhD, and Shirley A. Morrisey, PhD
Menzies Health Institute Queensland and School of Applied Psychology, Griffith University, Gold Coast Campus, Southport, Queensland, Australia

Abstract

Context. Dignity therapy (DT) is a psychotherapeutic intervention with increasing evidence of acceptability and utility in palliative care settings.

Objectives. The aim of this study was to evaluate the legacy creation component of DT by comparing this intervention with life review (LR) and waitlist control (WC) groups.

Methods. Seventy adults with advanced terminal disease were randomly allocated to DT, LR, or WC followed by DT, of which 56 completed the study protocol. LR followed an identical protocol to DT except that no legacy document was created in LR. Primary outcome measures were the Brief Generativity and Ego-Integrity Questionnaire, Patient Dignity Inventory, Functional Assessment of Cancer Therapy-General, version 4, and treatment evaluation questionnaires.

Results. Unlike LR and WC groups, DT recipients demonstrated significantly increased generativity and ego-integrity scores at study completion. There were no significant changes for dignity-related distress or physical, social, emotional, and functional well-being among the three groups. There were also no significant changes in primary outcomes after the provision of DT after the waiting period in the WC group. High acceptability and satisfaction with interventions were noted for recipients of both DT and LR and family/carers of DT participants.

Conclusion. This study provides initial evidence that the specific process of legacy creation is able to positively affect sense of generativity, meaning, and acceptance near end of life. High acceptability and satisfaction rates for both DT and LR and positive impacts on families/carers of DT participants provide additional support for clinical utility of these interventions. Further evaluation of specific mechanisms of change post-intervention is required given DT’s uncertain efficacy on other primary outcomes. J Pain Symptom Manage 2017;53:162–170 © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
Dignity therapy, life review, randomized controlled trial, RCT, palliative

Introduction

Palliative care patients are at increased risk of experiencing psychological, social, and spiritual distress associated with the impacts of their advancing disease.1–5 Provision of psychosocial care is an integral part of contemporary palliative care whose aim is to meet complex multifaceted needs of terminally ill patients and their families/carers. However, there is evidence that palliative care clinicians are insufficiently prepared to assess and treat psychosocial distress, and there is no established consensus on what constitutes quality existential and spiritual care.1–4 Although the evidence base is growing for systematically developed, manualized psychotherapeutic interventions aimed at addressing existential and spiritual suffering near end of life, it remains to be seen whether any one intervention is superior to others.5

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One psychotherapeutic intervention with an increasing evidence of its utility and acceptability in palliative care settings is dignity therapy (DT). The broad aim of this intervention was to bolster psychosocial, emotional, and existential well-being through the process of life review (LR) and creating a lasting legacy document that typically contains important or meaningful memories, values, words of wisdom, and special messages to loved ones. DT is specifically tailored to palliative patients by 1) being grounded in an empirical model of dignity that was specifically developed with this patient population, 2) placing less emphasis on insight and skill building, and instead enhancing meaning, purpose, and sense of dignity, and 3) being relatively brief and flexible. A recent systematic review\(^6\) found that DT has exceptionally high acceptability and satisfaction rates, variable feasibility due to recruitment and retention issues, and uncertain effectiveness because of a general absence of effects on primary outcome measures immediately after intervention. Demonstrating therapeutic outcomes was further complicated by participants’ relatively low initial distress levels and resulting ceiling or floor effects of outcome measures. The authors concluded that further clinical feasibility studies are required along using outcome measures that place less emphasis on physical symptoms/functions and more emphasis on specific existential, spiritual, and social aspects of patients’ experiences at variable time intervals.

LR is a brief psychotherapy suitable for use in palliative care settings. Typically, a graduated review of the lifespan is conducted with goals of addressing or processing the person’s life experiences, finding meaning in life, and achieving ego-integrity.\(^7,8\) A recent systematic review\(^7\) has found that LR interventions are viable and “probably efficacious” in palliative care although it was noted that issues with patient attrition rates, floor/ceiling effects of outcome measures, and generally limited empirical evidence are key barriers to wider adoption of these interventions into clinical practice.

The aims of this study were to compare DT with LR and a waitlist control (WC) group on a range of outcome measures. The LR intervention in this study was delivered in an identical manner to DT except that no legacy document was generated, thus allowing for an unprecedented evaluation of this unique aspect of DT. The WC group also received DT after a set waiting period, allowing for controlled within-group comparisons. It was hypothesized that DT would be superior to the other groups on a measure of generativity and that DT and LR would be superior to a WC group before active treatment on the measures of ego-integrity, dignity, and perceived quality of life. Participant and family/carer satisfaction with interventions were explored.

**Methods**

**Design**

A randomized controlled trial was used to enroll a sample of 70 participants to DT, LR, or a WC group. Participants were randomized after the completion of self-report measures at pre-test. Subsequent assessments were completed when interventions finished or after a 10-day waiting period for the WC group (post-test). This waiting period approximated the average DT/LR intervention time and reduced the risk of increased attrition rate and subsequent inflated benefits of intervention groups because of patient deterioration. WC participants then completed assessments after DT (post-test 2). This study was approved by university and hospital research ethics committees, and all participants provided written informed consent.

**Participants**

Inclusion criteria were 1) at least 18 years old, 2) diagnosed with advanced disease with a life expectancy of less than 12 months based on clinical consensus, 3) receiving specialist multidisciplinary palliative care either in a hospital or home setting, 4) able to communicate in English and provide consent, and 5) able to commit to up to four contacts over ~10 days during active interventions. Exclusion criteria were illness severity that precluded protocol completion; significant cognitive impairment based on clinical consensus, and, if applicable, cognitive assessment or previous intervention from the primary investigator in his clinical psychologist role.

**Measures**

The Brief Measure of Generativity and Ego-Integrity\(^10\) (Appendix 1) is an 11-item measure of Erikson’s concepts of generativity and ego-integrity with good internal consistency that was developed for use in palliative care settings. Generativity refers to care and concern for future generations, maintaining productivity and a sense of leaving a lasting legacy. Ego-integrity refers to looking back on life with a sense of meaning, acceptance of past events, sense of growing wise with age, and general absence of death anxiety. Factor analysis of the current sample demonstrated the same two-factor structure as the scale development sample, except that one item proposed for the generativity scale did not load on either factor and was removed from subsequent analyses (Item 5). Responses from 1 = strongly disagree to 5 = strongly agree are averaged across subscales, with reverse scoring when necessary, so that higher subscale means indicate higher levels of generativity and ego-integrity.

The Patient Dignity Inventory (PDI) is a reliable and valid 25-item measure of dignity-related distress.
that is based on the empirical model of dignity.\textsuperscript{11} The PDI has a total scale ranging from 25 to 125 where higher scores indicate greater distress.

Perceived quality of life was measured by the Functional Assessment of Cancer Therapy-General, version 4 (FACT-G\textsuperscript{15}). The FACT-G contains 27 items divided into four primary quality of life domains: physical well-being, social/family well-being, emotional well-being, and functional well-being. Higher scores indicate better perceived well-being. The FACT-G has established psychometric properties with good reliability and validity and it is appropriate for use with patients with cancer and other chronic illness conditions.\textsuperscript{13,14}

A Treatment Evaluation Form (15 items) measured participants’ beliefs about the impacts of DT or LR on their well-being and that of their family/carers. A Family Evaluation Form (15 items) measured family/carer perceptions of impacts of DT on themselves and the participant. Both measures were modeled on participant feedback questionnaires used in previous DT studies.\textsuperscript{15}

Four clinician-rated measures of well-being were administered at baseline and post-test based on clinical consensus of participants’ medical treating team: 1) Palliative Care Phase Instrument, 2) Australia-Modified Karnofsky Performance Scale, 3) Resource Utilization Groups—Activities of Daily Living, and 4) Problem Severity Score (PSS). These measures are part of an Australian palliative care outcomes and benchmarking system\textsuperscript{16} that were used as standard practice by the medical setting in which this study was conducted.

**Procedure**

Seventy participants were recruited from March 2012 to December 2015, of which 56 completed the study protocol. Eligible patients were informed about the study by a member of their treating team and chose whether to consent to contact from the first author. The first session involved the provision of informed consent and baseline assessment conducted by a clinician or student not affiliated with this study. Alternatively, if study participation occurred in a home setting, participants self-completed the questionnaires or mailed them in. Participants were then randomly assigned to DT, LR, or WC groups by block randomization with a fixed block size of 6. Allocation concealment used sequentially numbered sealed envelopes for consecutive eligible participants. Figure 1 shows the participant flow for this study.

**Intervention Groups**

DT was provided by the first author, a clinical psychologist experienced in working with advanced

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Fig. 1. CONSORT diagram.
cancer patients. The therapist attended two 3-day DT training workshops conducted by Harvey Chochinov whose research team developed DT and used therapy resources that were either provided as part of training or published elsewhere. Protocol adherence and a random sample of completed session transcripts were reviewed by an external supervisor experienced in providing DT supervision. Participants were given the DT question framework and asked to consider what they may wish to talk about. The second meeting was scheduled as soon as it could be arranged. The standard framework of questions provided a flexible guide for the interview in which disclosure of thoughts, feelings, and memories was facilitated. Both DT and LR sessions were audiorecorded and transcribed verbatim by a research assistant or occasionally the first author within 48 hours. The DT transcript then underwent an editing process and was reviewed with participants in a follow-up session. The finalized version of their legacy document was returned to participants, to be passed along to a recipient of their choice.

LR was also provided by the first author. The LR protocol, recording and transcription, were identical to DT with the exception that the legacy document was not generated or provided to participants. Questions used in DT that specifically mentioned a legacy document were excluded from the LR protocol. Participants in the WC group were provided with standard DT after the completion of their 10-day waiting period. There were no significant differences between the three groups in the length of therapy sessions in minutes ($M_{DT} = 58.05$ [SD = 30.71], $M_{LR} = 54.29$ [SD = 10.33], $M_{WC} = 61.39$ [SD = 25]), or the word count of audio transcripts ($M_{DT} = 4089$ [SD = 2256], $M_{LR} = 4731$ [SD = 2525], $M_{WC} = 3866$ [SD = 1018]).

**Statistical Analyses**

Participants who completed the study protocol were included in statistical analyses (SPSS, version 21). A series of 3 x 2 ANOVAs were conducted for the primary outcome measures using Group (DT vs. LR vs. WC) and Trial (pre-test vs. post-test) as independent variables. One-way repeated-measures ANOVAs were performed to further assess changes in the primary outcome measures for the WC participants across the three time periods. Relevant assumptions were met; minor departures from homogeneity of variances were not considered problematic. In significant interaction effects, simple effects were examined when a normal distribution was reasonably approximated. All comparisons were done on a 2-tailed basis. With an alpha set at 0.05, a desired power set at 0.80, and a large effect size using Cohen's value for such an effect size of 0.8, the estimated recruitment target was 26 participants per arm (GPow, version 3.1).

**Results**

Table 1 shows that the demographic characteristics and clinician ratings were generally well balanced at baseline. Thirty-one of the 56 participants were women. The mean age was 57.7 years (range = 25–83) and 33 participants (58.9%) were married or in defacto relationships. The median number of children in each group was two with four participants (7.1%) having no children. Thirty-seven participants (66.1%) were seen as outpatients or at home, and the rest were seen at inpatient wards. Thirty-one participants (55.4%) were religiously affiliated and 53 (94.6%) did not work or were retired. Thirty-nine participants (69.6%) completed high school, 15 (28.8%) completed at least some tertiary education, whereas three did not complete high school. Table 1 demonstrates that a range of malignancies were present, with only two participants having nonmalignant conditions. No differences were found in median survival times after study completion between the three groups (87 days [range = 8–455] in the DT group; 88 days [range = 10–412] in the LR group, and 73 days [range = 23–495] in the WC group).

There were no significant differences between the three groups or between baseline and post-test scores in each group on the Palliative Care Phase Instrument, Australia-Modified Karnofsky Performance Scale, and Resource Utilization Groups—Activities of Daily Living measures. On the PSS at pre-test, WC participants had significantly lower scores than DT participants (but not LR participants) on the following subscales: pain, t(36) = 2.12, $P = 0.04$; other, t(36) = 3.04, $P = 0.004$; and psychological/spiritual, t(36) = 2.67, $P = 0.01$. There were no other significant differences on the PSS. More WC participants reported being involved in or completing other legacy activities (55.6%) compared with DT (35%) and LR (22.2%) participants. Such activities included collating photographs and other personal items, writing letters or cards for family members, and arranging special gifts. No participants previously took part in DT, LR, or similar interventions.

**Impacts of Interventions on Generativity and Ego-Integrity Scores**

There was a significant group x trial interaction for generativity, $F(2, 53) = 8.73, P = 0.001$, partial $\eta^2 = 0.25$. Simple effects analysis showed that participants in the DT group had significantly higher generativity factor scores at completion of the study (95% CI 2.67, 3.41) compared with baseline (95% CI 3.32, 4.15,
Table 1
Demographic Characteristics and Clinician Ratings of Participants at Baseline*

<table>
<thead>
<tr>
<th></th>
<th>Dignity Therapy (n = 20)</th>
<th>Life Review (n = 18)</th>
<th>Waitlist Control (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>55.95 (14.45)</td>
<td>62.33 (16.16)</td>
<td>54.94 (15.80)</td>
</tr>
<tr>
<td>Gender (Female)</td>
<td>11 (55%)</td>
<td>9 (50%)</td>
<td>11 (61%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>13 (65%)</td>
<td>7 (38.9%)</td>
<td>10 (55.6%)</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>3 (15%)</td>
<td>7 (38.9%)</td>
<td>6 (33.3%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2 (10%)</td>
<td>3 (16.7%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>1 (5%)</td>
<td>1 (5.6%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Never married</td>
<td>2 (10%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No. of children</td>
<td>2 (0-4)</td>
<td>2 (0-4)</td>
<td>2 (0-5)</td>
</tr>
<tr>
<td>Care setting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient palliative care</td>
<td>8 (40%)</td>
<td>7 (39.9%)</td>
<td>4 (22.2%)</td>
</tr>
<tr>
<td>Outpatient or home</td>
<td>12 (60%)</td>
<td>11 (61.1%)</td>
<td>14 (77.8%)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>4 (20%)</td>
<td>5 (27.8%)</td>
<td>4 (22.2%)</td>
</tr>
<tr>
<td>Anglican</td>
<td>3 (15%)</td>
<td>3 (16.7%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Other (Christian)</td>
<td>1 (5%)</td>
<td>2 (11.2%)</td>
<td>4 (22.2%)</td>
</tr>
<tr>
<td>Other (non-Christian)</td>
<td>1 (5%)</td>
<td>0</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>No religion</td>
<td>11 (55%)</td>
<td>8 (44.4%)</td>
<td>6 (33.3%)</td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>2 (10%)</td>
<td>4 (22.2%)</td>
<td>5 (27.8%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>13 (65%)</td>
<td>7 (38.9%)</td>
<td>10 (55.6%)</td>
</tr>
<tr>
<td>Other family/friends</td>
<td>5 (25%)</td>
<td>7 (38.9%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Working arrangement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working and/or studying</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Semi-working/semi-retired</td>
<td>1 (5%)</td>
<td>1 (5.6%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Not working/retired</td>
<td>10 (95%)</td>
<td>17 (94.4%)</td>
<td>17 (94.4%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>1 (5%)</td>
<td>0</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Completed high school</td>
<td>16 (80%)</td>
<td>14 (77.8%)</td>
<td>9 (50%)</td>
</tr>
<tr>
<td>One or more years of tertiary education</td>
<td>3 (15%)</td>
<td>4 (22.2%)</td>
<td>8 (44.4%)</td>
</tr>
<tr>
<td>Primary cancer site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>5 (25%)</td>
<td>3 (16.7%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Breast</td>
<td>4 (20%)</td>
<td>2 (11.2%)</td>
<td>8 (44.4%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>4 (20%)</td>
<td>6 (35.3%)</td>
<td>5 (27.8%)</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>1 (5%)</td>
<td>5 (27.8%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Haematological</td>
<td>1 (5%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Brain</td>
<td>2 (10%)</td>
<td>0</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Other solid tumors</td>
<td>2 (10%)</td>
<td>1 (5.6%)</td>
<td>0</td>
</tr>
<tr>
<td>Nonmalignant</td>
<td>1 (5%)</td>
<td>1 (5.6%)</td>
<td>0</td>
</tr>
<tr>
<td>PQI (pre-test)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable</td>
<td>16 (80%)</td>
<td>13 (72.2%)</td>
<td>15 (83.3%)</td>
</tr>
<tr>
<td>Unstable</td>
<td>4 (20%)</td>
<td>5 (27.8%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Terminal</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>AKPS (pre-test)†</td>
<td>51 (11.19)</td>
<td>53.33 (12.38)</td>
<td>57.78 (9.43)</td>
</tr>
<tr>
<td>RUG-ADL (pre-test)‡</td>
<td>7.70 (3.85)</td>
<td>7.33 (3.94)</td>
<td>6.90 (1.51)</td>
</tr>
<tr>
<td>Problem Severity Score (pre-test)‡</td>
<td>2.70 (0.66)</td>
<td>2.56 (0.86)</td>
<td>2.22 (0.73)</td>
</tr>
<tr>
<td>Pain</td>
<td>2.70 (0.66)</td>
<td>2.56 (0.86)</td>
<td>2.22 (0.73)</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>2.90 (0.31)</td>
<td>2.67 (0.84)</td>
<td>2.22 (0.94)</td>
</tr>
<tr>
<td>Psychological and spiritual</td>
<td>2.35 (0.59)</td>
<td>2.00 (0.84)</td>
<td>1.78 (0.73)</td>
</tr>
<tr>
<td>Family/carer</td>
<td>2.15 (0.93)</td>
<td>2.44 (0.71)</td>
<td>2.00 (0.77)</td>
</tr>
<tr>
<td>Other legacy activities</td>
<td>7 (35%)</td>
<td>4 (22.2%)</td>
<td>10 (55.6%)</td>
</tr>
<tr>
<td>Yes</td>
<td>13 (65%)</td>
<td>14 (77.8%)</td>
<td>8 (44.4%)</td>
</tr>
</tbody>
</table>

*Data are mean (SD), number (%) or median (range).
†Score range 0 = dead to 100 = normal performance status.
‡Score range 4 = independent functioning to 18 = requires two or more assistants for bed mobility, toileting, transfers and eating.
§P < 0.001. No significant changes in generativity were found for LR and WC participants. There was also a significant group × trial interaction for ego-integrity, F (2, 53) = 3.20, P = 0.049, partial η² = 0.11. Participants in the DT group had significantly higher ego-integrity scores at study completion (95% CI 3.17, 3.77) compared with baseline (95% CI 3.48, 4.22), P = 0.01. No significant changes in ego-integrity scores were found for LR and WC participants. Figure 2 shows the group differences in generativity and ego-integrity estimated marginal means. An analysis of generativity and ego-integrity scores for the WC
participants across three time periods (pre-test vs. post-test vs. post-test 2) found no significant changes in these measures.

Impact of Intervention Groups on PDI and FACT-G Scores

Table 2 lists the sources of distress measured by the PDI across testing times for each intervention group. There were no significant differences found between the three study groups on the individual PDI items or the total PDI scores. Within the WC group, there were no significant changes in the total PDI scores across the three assessment points.

There were no main effects of group on the FACT-G subscale scores with the exception of the Functional Well-Being subscale where the WC group scored significantly higher compared with the other two groups, F(2, 53) = 5.06, P = 0.01; MDT = 10.18, MWC = 12.11, MWC = 15.94. Within the WC group, there were no significant changes in the FACT-G subscale scores across the three trial periods.

Treatment Evaluation

Treatment evaluation scores were combined for DT and WC participants given that they received identical interventions and the scores did not significantly differ between these two groups. DT was rated as significantly more helpful than LR in being helpful to the participant’s family now or in the future (87.1% vs. 33.3%, respectively, t(44) = 3.34, P = 0.002) and in the way that their family saw or appreciated them (77.4% vs. 33.3%, t(44) = 2.64, P = 0.01).

Both DT and LR were deemed to be helpful (83.9% vs. 86.7%, respectively), as helpful as other aspects of health care (74.2% vs. 73.3%), would be recommended to others (90.3% vs. 86.7%), made participants feel more valued or worthwhile (74.2% vs. 66.7%), improved sense of dignity (58.1% vs. 60%), made participants feel that life was more meaningful (74.2% vs. 73.3%), and resulted in a heightened sense of purpose (54.8% vs. 60%). Participants rated DT higher than LR on helping them prepare for the future (64.5% vs. 33.3%) and helping with unfinished business (64.5% vs. 40%) although these differences were not statistically significant. There were lesser group differences in quality of life (32.3% vs. 6.7%, respectively), spiritual well-being (48.4% vs. 20%), sadness or depression (32.3% vs. 26.7%), and suffering (32.3% vs. 26.7%).

Fifteen family members or carers completed the Family Evaluation Form, of which 93.3% reported DT to be helpful, 66.7% that it changed the way they saw or appreciated their family member, and all family/carers stated they would recommend DT to others. With respect to the recipients of DT, their family/carers also reported that DT was helpful to them (100%), as helpful as other aspects of health care (88%), that it helped with unfinished business (60%), reduced sadness or depression (60%), made the person feel more worthwhile or valued (93.3%), improved sense of dignity (80%), made them feel that life was more meaningful (86.7%), heightened sense of purpose (86.7%), and helped them prepare for the future (73.3%). There were lesser improvements in family/carer ratings of participants’ quality of life (46.7%), spiritual well-being (53.3%), and suffering (33.3%).

Discussion

This is the first study to 1) compare Dignity Therapy to Life Review in a way that the legacy creation component of DT could be specifically evaluated, 2) use concepts of generativity and ego-integrity as primary outcome measures, and 3) use a Waitlist Control group that received DT after a set waiting period to measure longitudinal changes in treatment outcomes. Four important findings can be deduced from the data.

First, DT participants demonstrated significantly greater improvements in their sense of generativity and ego-integrity than LR and WC groups, which
supported the primary hypothesis. This suggests that the specific process of developing a legacy document that transcends own death has the potential to improve perceived productivity, guidance, and contribution to future generations and assist people in looking back on life with a sense of meaning and acceptance. Given Erikson’s conceptualization of these concepts as active and dynamic dichotomies (generativity vs. stagnation; ego-integrity vs. despair), DT also has the potential to reduce aspects of stagnation including apathy, poor contribution to others, and preoccupation with own needs and reduce aspects of despair such as guilt or regret about past events and a poor sense of accomplishment. There is evidence that increased sense of generativity and ego-integrity are positively associated with psychological and emotional well-being and negatively associated with depression. These mechanisms, therefore, need to be considered in explaining previous findings that DT is able to reduce anxiety and depressive features in more severely distressed participants, particularly in the short term. Of note is that the provision of DT in the WC group after the waiting period did not result in significant improvements on any outcomes. This group differed in some aspects to the DT group that randomization was unable to control, such as better functional well-being and better clinician ratings of pain, psychological/spiritual distress, and other symptoms. The WC group was also more likely than the others to have engaged in other memory or legacy activities before participation in this study, and it is possible that these activities may have had an indirect effect on the primary outcomes.

Second, the hypothesis that LR would also improve sense of ego-integrity was not supported by the data. This suggests that quantifiable ego-integrity enhancement is dependent on more than a time-limited LR approach used in this study. An LR protocol with an
expanded scope and length may have resulted in enhanced treatment outcomes. It is also possible that LR resulted in participants discussing and evaluating aspects of their life that they otherwise may not have in DT sessions. Qualitative analyses of DT and LR interviews are needed to explore differences in session content between the two groups (to be reported separately).

Third, there were no differences between the three groups on dignity-related distress and perceived quality of life outcomes including physical, social, emotional, and functional well-being. This finding is generally consistent with previous DT studies, and likely reflects the complex multifaceted nature of adjusting to the impacts of an advancing disease, limitations of self-report measures in being able to capture psychosocial outcomes near end-of-life, further compounded by floor effects, and the need for DT studies to have sufficient power to detect small to moderate effects in treatment outcomes.

Fourth, both DT and LR interventions had high acceptability and satisfaction. Combined with the high satisfaction of family/carers of DT participants, this finding provides further evidence of the immediate and long-term benefits that generating a legacy document can have on individuals and their families/carers.

**Limitations**

One limitation of this study was the inadequate power to detect small effects given the modest sample size in each group and only mild-to-moderate levels of distress at baseline. The possibility of delayed treatment effects could not be excluded. Spiritual well-being, helpfulness, and clinical depression/anxiety items were incorporated into the outcome measures, but use of specific validated measures of these domains may have been warranted. Finally, participant expectancies may not have been equivalent across the three groups given the non-concealed intervention allocation, as is common in psychotherapeutic interventions.

**Implications for Future Research**

Identification, recruitment, and retention issues are common among DT studies to date but not unexpected in the wider palliative care context. Future studies need to consider the multimodal measurements of generativity and ego-integrity that involve behavioral indicators, changes, family perspectives, and qualitative examinations of therapy transcripts, the potential impacts of pre-existing legacy activities on treatment outcomes, post-treatment utilization of legacy documents, such as through social media, inclusion of participants with higher levels of psychosocial distress, involvement of clinicians from multidisciplinary backgrounds and across diverse settings, and examination of LR family/carer outcomes post-intervention.

**Conclusion**

This study provides initial evidence that the specific process of legacy creation is able to positively impact sense of generativity and ego-integrity near end of life. No detectable changes in the sense of dignity or perceived quality of life after DT and LR underscores the need for further adequately powered research to delineate specific mechanisms of change following these interventions instead of reliance on broad outcome measures. The clinical utility of DT in particular is supported by the high acceptability and satisfaction rates among participants and their families/carers.

**Disclosures and Acknowledgments**

The authors wish to thank all those who participated in this study. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The authors declare no conflicts of interest.

**References**


Appendix I

*Items Comprising the Brief Measure of Generativity and Ego-Integrity*

1. I pass along the knowledge that I have gained through my experiences.
2. I think that I will be remembered for a long time after I die.
3. I am not making a meaningful and lasting contribution to other people.
4. I am committed to many different kinds of people, groups, and activities.
5. I have done nothing that will survive after I die.
6. Other people would say that I am very productive.
7. I feel contented with what I have accomplished in my life.
8. I still feel angry about some of my life experiences.
9. My life has been fulfilling, and I am not frightened by the thought of death.
10. When I consider the ups and downs of my past life, they somehow fit together in a meaningful way.
11. I have had disappointments in life that I will never be able to accept.
Chapter Seven consists of a published paper titled: “Dignity Therapy and Life Review for Palliative Care Patients: A Qualitative Study”. A statement of contribution to co-authored published paper is also included. This paper was published in a peer-reviewed palliative care journal, *Journal of Pain and Symptom Management*. Its primary aim was to qualitatively analyse and better understand thematic similarities and differences between Dignity Therapy and Life Review sessions conducted in the second study. Legacy document and Life Review session transcripts were compared across three a priori themes: (a) sense of generativity and ego-integrity (Erikson, 1963), (b) the empirical model of dignity (Chochinov et al., 2002a), and (c) core values (Hack et al., 2010). Clinical and research implications of the results were presented, and recommendations for future research were made.
STUDY 3
STATEMENT OF CONTRIBUTION TO CO-AUTHORED PUBLISHED PAPER

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:


My contribution to the paper involved:

- Review and interpretation of existing literature
- Development of study design and methodology
- Facilitated participant recruitment
- Conducted psychotherapeutic interventions
- Conducted data analysis and interpretation of results
- Writing of the paper
- Identifying implications for future research

We agree to the inclusion of this paper in this doctoral research submitted for examination. The journal in which this paper has been published is peer-reviewed. Permission has been provided by the publisher, Elsevier, to reproduce this paper as part of this doctoral thesis.

(Signed)……………………………………..(Date): 11/09/2018

Dean Vuksanovic

(Countersigned)……………………………………..(Date): 11/09/2018

Principal Supervisor: Dr Heather Green
Original Article

Dignity Therapy and Life Review for Palliative Care Patients: A Qualitative Study

Dean Vuksanovic, M Clin Psych, Heather Green, PhD, Shirley Morrissey, PhD, and Sharelle Smith, M Clin Psych
Menzies Health Institute Queensland and School of Applied Psychology (D.V., H.G., S.M.), Griffith University, Gold Coast Campus, Southport, Queensland; and Gold Coast University Hospital (D.V., S.S.), Southport, Queensland, Australia

Abstract

Context. Dignity therapy (DT) is a psychotherapeutic intervention whose aim was to bolster the sense of purpose, meaning, and sense of dignity in patients with terminal disease.

Objectives. The aim of this study was to explore, compare, and better understand the content of standard DT, waitlist DT (WDT), and Life Review (LR) that used the DT interview protocol but omitted the creation of legacy documents.

Methods. Efficacy of these interventions was previously documented in a sample of 56 participants. In this study, DT and WDT legacy documents and LR session transcripts were qualitatively analyzed using the Framework approach, both deductively and inductively.

Results. All participants expressed a diverse set of beliefs, values, memories, and important relationships with the majority also indicating at least some sense of meaning and acceptance despite disappointments, regrets, and the impacts of illness. Sense of legacy, fighting spirit, and hope were particularly prevalent in legacy documents (DT and WDT groups), whereas relationship regrets, self-blame, unfinished business, and aftermath concerns were more likely to be expressed during the LR process. Themes of spirituality, illness impacts, and unfinished business were relatively less common in WDT participants.

Conclusion. This study provides further insight into what palliative care patients consider to be most important and meaningful to them when taking part in DT and LR. Creating legacy documents is likely to result in session content that is different in several key areas compared with LR, even when controlling for interview questions, therapist influences, and session length. Consideration of the above is essential in optimizing psychotherapeutic outcomes near end of life. J Pain Symptom Manage 2017;54:530–537. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
Dignity therapy, life Review, qualitative, palliative

Introduction

Key tasks in palliative care include identifying and managing physical, psychosocial, existential, and spiritual contributors to distress. Preservation of dignity is essential, given that perceived loss of dignity near end of life is associated with high levels of distress, loss of the will to live, and increased desire to die.1,2 Emerging models of patient dignity3,4 emphasize the need for dignity-conserving interventions to be multidisciplinary, multidimensional, and involve individuals’ wider social context.

Dignity therapy (DT) is one psychotherapeutic intervention with increasing evidence of utility and acceptability in palliative care settings. The aims of this intervention are to increase sense of meaning, purpose, and dignity near end of life through the process of creating a lasting legacy document. Life Review (LR) is another brief psychotherapeutic intervention that shares DT’s goals of improving sense of meaning, purpose, and acceptance through a graduated review of the lifespan and its most salient narratives. Empirical evidence suggests that DT has high acceptability and

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satisfaction, variable feasibility, and uncertain and inconsistent effectiveness on primary outcome measures. Similarly, LRs are considered viable and acceptable in palliative care settings, but there is variable empirical evidence on their clinical efficacy.

Our randomized controlled trial (RCT) compared DT with LR and a waitlist-control group that received DT after a waiting period (WDT) on several outcome measures. LR used an almost identical treatment protocol to DT except that a legacy document was not created, thus allowing for evaluation of this key component of DT. Sense of generativity and ego-integrity significantly improved at study completion for DT recipients only, whereas dignity-related distress and perceived quality of life remained unchanged in all three groups after interventions. Both DT and LR were rated highly in acceptability and satisfaction among participants. These mixed findings were generally consistent with prior studies evaluating DT, thus emphasizing the need to use multimodal outcome indicators extending beyond quantitative measures.

Therefore, the aim of this study was to use qualitative research methods to further explore and better understand the similarities and differences between DT, WDT, and LR sessions conducted in the RCT. Groups were compared across the following broad predetermined themes: 1) sense of generativity and ego-integrity based on Erik Erikson’s psychosocial theory, 2) empirical model of dignity and 3) core values. The first two themes aligned with the quantitative measures that were used in our original study. The core values theme was included based on a previous qualitative analysis of 50 DT transcripts that found an overwhelming prevalence of core values such as family, pleasure, caring, achievement, and friendship. A key benefit of qualitative methods is that they can be used alongside RCTs in evaluating outcomes of complex interventions that are difficult to determine by using quantitative methods alone.

Methods
Study Design
This qualitative study was conducted after completion of an RCT that compared DT, WDT, and LR groups on multiple outcome measures. Further details of randomization, inclusion/exclusion criteria, recruitment, interventions, and outcome measures are available in our original study.

Participants
Seventy adults with advanced cancer or non-malignant disease were recruited between March 2012 and December 2015, of which 56 completed the study protocol. Participants were randomly assigned to DT, WDT, or LR (20, 18, and 18, respectively). All participants had a life expectancy of 12 months or less and all were receiving palliative care either in a hospital or home setting.

Intervention Groups
Interventions were provided by the first author, an experienced clinical psychologist who had previously completed DT training workshops. The LR therapy protocol was identical to DT except that no legacy document was generated or used. Participants in WDT were provided with standard DT after completing a 10-day waiting period. Adherence to therapy protocol was regularly monitored. All therapy sessions were audio recorded and transcribed verbatim by a research assistant, with DT transcripts undergoing further editing and review processes with participants as per protocol. There were no significant differences among the three groups in the length of therapy sessions or the word count of interview transcripts.

Qualitative Analysis
The framework method for analysis of qualitative data was used. This thematic approach is comprehensive, flexible, and well suited for applied qualitative studies that aim to summarize data to answer preidentified research questions. It is particularly suitable for this study given that the comparison analysis was both deductive (a priori themes selected based on previous literature) and inductive (themes further refined from the data through coding). Consequently, analysis was also more descriptive than interpretative, and it was conducted systematically and rigorously (Table 1).

The coding process in Step 4 was consistent with Campbell et al. in that the primary author coded DT legacy documents and LR transcripts first, then provided the secondary author with copies of transcripts that highlighted coded text but withheld coding themes. This allowed for evaluation of intercoder reliability and agreement by addressing issues that preclude the use of the usual intercoder reliability coefficients (e.g., Cohen’s kappa), including 1) discriminant capability of the coding framework given the large number and complexity of coding themes and 2) high likelihood of not selecting matching sections of text during coding. Intercoder correlation was 83%, whereas intercoder agreement after review and attempted resolution of coding disagreements was 96%.

Ethical Approval
This study was approved by Griffith University and Gold Coast Hospital and Health Service Human Research Ethics Committees (PSY/08/12/HREC and HREC/11/QGC/83, respectively) and met the required regulatory standards for research with human participants.
Table 1

Details of Qualitative Analyses

1. D. V. and S. S. read the completed legacy documents (DT and WDT groups) and transcripts of LR sessions to familiarize themselves with the data.
2. D. V. and S. S. developed a preliminary coding framework based on predetermined themes (generativity and ego-integrity concepts, theoretical model of dignity, and core values). This was subsequently reviewed by H. G. and S. M. and agreed on.
3. D. V. and S. S. independently coded six randomly selected legacy documents/LR transcripts (two of each intervention group).
4. D. V. and S. S. compared and discussed the preliminary coding, developed the working coding framework and a coding manual which included definitions of themes and example quotes from participants (see Appendix).
5. D. V. and S. S. coded nine randomly selected legacy documents/LR transcripts (three of each intervention group), compared and discussed findings, resolved any disagreements, and agreed on the final coding framework.
6. D. V. coded all 56 legacy documents/LR transcripts using the final framework matrix. Values were coded in parallel to the other themes given their inherent overlap.

DT = dignity therapy; WDT = waitlist DT; LR = Life Review.

Results

Participant Characteristics

Table 2 shows that the demographic characteristics were generally well balanced across groups. No difference was found in median survival times after study completion between the three groups (DT = 87 days [range = 8–455]; LR = 88 days [range = 10–412]; WDT = 73 days [range = 23–495]). No participants previously took part in DT, LR, or similar interventions, although half of WDT participants reported being involved in other legacy activities such as writing letters, cards, or arranging special gifts compared to a third and a fifth of DT and LR participants, respectively.

Table 2

Demographic Characteristics and Clinician Ratings of Participants at Baseline

<table>
<thead>
<tr>
<th></th>
<th>Dignity Therapy (n = 20)</th>
<th>Life Review (n = 18)</th>
<th>Waitlist Dignity Therapy (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>55.95 (14.45)</td>
<td>62.33 (16.16)</td>
<td>54.94 (13.80)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (45%)</td>
<td>9 (50%)</td>
<td>7 (38.9%)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (55%)</td>
<td>9 (50%)</td>
<td>11 (61.1%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>15 (65%)</td>
<td>7 (38.9%)</td>
<td>10 (56.6%)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>5 (15%)</td>
<td>7 (38.9%)</td>
<td>6 (33.3%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (5%)</td>
<td>3 (16.7%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>De facto</td>
<td>1 (5%)</td>
<td>1 (5.6%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Never married</td>
<td>2 (10%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>2 (10%)</td>
<td>4 (22.2%)</td>
<td>5 (27.8%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>15 (65%)</td>
<td>7 (38.9%)</td>
<td>10 (56.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (25%)</td>
<td>7 (38.9%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>No. of children</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Care setting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient palliative care</td>
<td>8 (40%)</td>
<td>7 (38.9%)</td>
<td>4 (22.2%)</td>
</tr>
<tr>
<td>Outpatient or home</td>
<td>12 (60%)</td>
<td>11 (61.1%)</td>
<td>14 (77.8%)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>8 (40%)</td>
<td>10 (55.6%)</td>
<td>11 (61.1%)</td>
</tr>
<tr>
<td>Other (non-Christian)</td>
<td>1 (5%)</td>
<td>0</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>No religion</td>
<td>11 (55%)</td>
<td>8 (44.4%)</td>
<td>6 (33.3%)</td>
</tr>
<tr>
<td>Palliative care phase instrument</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable</td>
<td>16 (80%)</td>
<td>13 (72.2%)</td>
<td>15 (83.3%)</td>
</tr>
<tr>
<td>Unstable</td>
<td>4 (20%)</td>
<td>5 (27.8%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Terminal</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Australia-Modified Karnofsky</td>
<td>51 (11.19)</td>
<td>53.53 (12.38)</td>
<td>57.78 (9.43)</td>
</tr>
<tr>
<td>Performance Scale(^a)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RUG-ADL(^b)</td>
<td>7.70 (3.85)</td>
<td>7.33 (3.94)</td>
<td>6.00 (1.91)</td>
</tr>
<tr>
<td>Problem Severity Score(^c)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>2.70 (0.66)</td>
<td>2.56 (0.86)</td>
<td>2.22 (0.73)</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>2.90 (0.31)</td>
<td>2.67 (0.84)</td>
<td>2.22 (0.94)</td>
</tr>
<tr>
<td>Psychological and spiritual</td>
<td>2.35 (0.59)</td>
<td>2.00 (0.84)</td>
<td>1.78 (0.75)</td>
</tr>
<tr>
<td>Family/Carer</td>
<td>2.15 (0.95)</td>
<td>2.44 (0.71)</td>
<td>2.00 (0.77)</td>
</tr>
</tbody>
</table>

\(^a\) Data are mean (SD), number (%) or median (range).
\(^b\) Score range 0 = dead to 100 = normal performance status.
\(^c\) Score range: 4 = independent functioning to 18 = requires two or more assistants for bed mobility, toileting, transfers, and eating.
\(^d\) 1 = absent, 2 = mild, 3 = moderate, 4 = severe.


**Themes**

Table 3 shows the 15 identified themes and their frequency comparisons between the three intervention groups.

**Themes Prevalent in All Groups**

Participants typically commenced the therapeutic process by sharing “General Autobiographical Information” perceived as important or memorable, such as their developmental history, social/family context, and historical events at the time. These recollections were often detailed and extended into expressions of “Delights and Joys” with an accompanying brighter affect. Intertwined in all participants’ interviews were expressions of “Care and Guidance for Others,” including empathy, care for others, and willingness to guide or contribute to future generations. This included historical recollections: “I wanted an education, I wanted to do something and help people, that was my ambition. I ended up being good at that, we both care about other people,” and current beliefs and behaviors “If someone helps me, I will then try to help them back if I can. We are trying to teach the girls that they have to be honest with each other and look after each other.” Similarly, all participants acknowledged “Important Roles and Relationships” that had featured in their lives with no apparent thematic differences between the groups. For example, one DT participant spoke about her role as a mother to her children: “I loved being a mother and I’d always say, I was like a Helicopter Mum.” Other participants spoke about important relationships: “My granddaughter, she is everything to me, without her I have nothing” (LR), and: “I made a lot of very good friendships that lasted for over 40 years. I met my beautiful wife there as well” (WDT). Not all relationships were described as positive or supportive but were still coded under this theme when participants considered them important in their wider life narrative: “She was harsh with discipline, too harsh, and she used to call all the shots but I would still respect her, she was my mother” (LR).

Similarly, most participants in all groups indicated that they reached a sense of “Meaning and Acceptance” about at least some of their previous life challenges or stressors. This often involved benefit finding: “This might sound a bit terrible but in a way getting cancer about 10 years ago was life changing but it’s been for the good, not just the bad. So actually in the last 10 years, I have probably become a better person” (DT), or developing insight and self-awareness: “There are a lot of things that have hurt me in my life, a lot. I don’t hold any malice or anger and I can see why I would not want to. I can understand the reason for it. I have always come out with a gain, even if it was years later” (WDT). Acceptance of own mortality was encapsulated in statements such as: “I’ve traveled a fair bit, I’m content with my life. I know it’s early to pass away but kids pass away early, it’s part of life” (DT); “That’s my feeling, satisfaction. I could leave earth now and I will not be afraid. I’m not afraid of passing on, so now, my job is done” (LR); and “I guess that’s what the whole life cycle is about. Having children, generations moving on. I am happy to go when my time comes” (WDT). Occasionally, participants linked their sense of meaning and acceptance directly to the intervention they were receiving: “So when I realized that, I could then not worry about it any longer. Wow! I tell you what, when I talk to you, it reminds me of the good times and also the bad things that happened but it’s helping me put these memories in their boxes. Things make a bit more sense now” (LR).

Many participants also expressed “Disappointments and Regrets” about past events or experiences. In DT and WDT, contexts varied such as past decisions

**Table 3**

<table>
<thead>
<tr>
<th>Themes Consistent Between Groups</th>
<th>Dignity Therapy (n = 20)</th>
<th>Life Review (n = 18)</th>
<th>Welfare Dignity Therapy (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General autobiographical information</td>
<td>20 (100%)</td>
<td>18 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>Values</td>
<td>20 (100%)</td>
<td>18 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>Care and guidance for others</td>
<td>20 (100%)</td>
<td>18 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>Important roles and relationships</td>
<td>20 (100%)</td>
<td>18 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>Meaning and acceptance</td>
<td>20 (100%)</td>
<td>17 (94.4%)</td>
<td>17 (94.4%)</td>
</tr>
<tr>
<td>Delights and Joys</td>
<td>19 (95%)</td>
<td>18 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>Disappointments or regrets</td>
<td>19 (95%)</td>
<td>18 (100%)</td>
<td>16 (88.9%)</td>
</tr>
<tr>
<td>Other productive behaviors</td>
<td>12 (60%)</td>
<td>11 (61.1%)</td>
<td>11 (61.1%)</td>
</tr>
<tr>
<td>Themes inconsistent between groups</td>
<td>Sense of legacy</td>
<td>19 (95%)</td>
<td>7 (38.9%)</td>
</tr>
<tr>
<td>Fighting spirit and resilience</td>
<td>17 (85%)</td>
<td>12 (66.7%)</td>
<td>16 (88.9%)</td>
</tr>
<tr>
<td>Hopefulness</td>
<td>15 (75%)</td>
<td>11 (61.1%)</td>
<td>17 (94.4%)</td>
</tr>
<tr>
<td>Impact of illness</td>
<td>12 (60%)</td>
<td>12 (66.7%)</td>
<td>9 (50%)</td>
</tr>
<tr>
<td>Spirituality</td>
<td>11 (55%)</td>
<td>11 (61.1%)</td>
<td>7 (38.9%)</td>
</tr>
<tr>
<td>Unfinished business</td>
<td>5 (25%)</td>
<td>14 (77.8%)</td>
<td>7 (38.9%)</td>
</tr>
<tr>
<td>Aftermath concerns</td>
<td>5 (25%)</td>
<td>9 (50%)</td>
<td>8 (44.4%)</td>
</tr>
</tbody>
</table>
resulting in unfavorable outcomes, unresolved grief, perceptions of negative societal changes, world events, and environmental losses. For example, one DT participant spoke of several regrets that she struggled to adjust to: “They wouldn’t let me get out of the Army, it was traumatic ... There are nights that I don’t sleep because of decisions that I’ve made in my past and things that have happened to me in my past,” while one man was disappointed about wider world events: “The Government on behalf of the people is shackled with ever increasing debt that is not repayable ... I am convinced that the scheming banksters and corrupted political types are cooking up a new war.” This theme was more homogeneous in LR in that most participants reflected on interpersonal regrets and perceived failings in life with a higher likelihood of attaching self-blame regarding these events. This was evident in statements like: “My whole life has been a one play act. I’ve failed in my duty as a dad, if I’d been a proper father maybe it would have been different,” and “You go through a grieving process about the things that could have been. It was horrendous but I deserved it because I stayed in that marriage 10 years too long and what I did to my husband was extremely unfair.”

“Other Productive Behaviors” indicative of current or recent functional well-being were described by about half the participants: “And even here in this hospital, I sit down and I have a great conversation with anyone ... they ask me what I think and I tell them” (LR). At other times, compiling keepsakes or writing letters was important to participants: “what I am going to do is I will write her a letter, I’ll write it and then put it aside” (WDT), and maintaining some sense of normality: “I’m trying to stay focused on what I can do, get out in the sun, get moving and enjoy things around me” (DT).

All participants also expressed their personal “Values” or enduring core principles and beliefs that help define one’s sense of self and guide behaviors. Participants expressed a wide range of values with no apparent thematic differences between groups. The predominant values were “family,” “friendships,” and “caring for others,” as one WDT participant stated: “Family is important to me, it’s about the connection and relationships you have to other people. If you don’t have family, you don’t have much, everything doesn’t mean much. It’s just the principle.” Values involving independence and overcoming adversity were also prevalent: “It’s important not to be too hard on ourselves if we make a mistake or if we fall. We need to somehow try to turn it around to a positive, not dwell on it too much. Adapting is key, that’s what I learned” (DT). “Honesty/integrity,” “hard work,” and “respect” were expressed by a third of all participants, while relatively less common were values involving “equality/tolerance,” “simplicity,” “purpose,” “spirituality,” “health,” “conformity/discipline,” “curiosity/education,” and “travel/adventure.” Some participants carefully described a specific value that shaped their lives. For example, one man in his 60s spoke passionately about simplicity being key to humanity’s survival: “We can’t take back the time but if the human race wants to survive they’ll have to give up this ‘me, me, me’ attitude wanting more and more! Stick to simplicity and enjoy life. I think we are getting very very spoiled. You come to this earth with nothing and we can live a much simpler life without all this luxury.”

Themes More Frequent in DT and WDT

Compared with the LR group, almost all DT participants and most WDT participants described a “Sense of Legacy” or perception that they were able to leave something lasting that transcends their death. This was often expressed as occurring in the family context: “It’s good because they’re following in my footsteps and they have learned the right values. I’m very proud to know that my children are able to do that and that they will have these values long after I am gone” (DT), or in the therapy context: “That’s why I was happy to create this legacy document because if I’m not there when my son is a young man, I hope these words will guide him and that there will be people helping him to know what is good and what is bad, to help him to have a wonderful life.” At other times, sense of legacy developed from contribution to local community, society or maintaining cultural identity: “I’m Maori and we do have a big history of tribal links in New Zealand. For the grandchildren, they now know where they are from, who’s who in the family, and to know that they have support there” (LR).

Similarly, DT and WDT participants were more likely than LR participants to express “Hopefulness and Fighting Spirit and Resilience,” including both historical or current determination to overcome challenges and adversity: “I’m very determined ... you have to stand up for what you believe in, whatever it might be. I expect to be here, I am a positive person with positive attitude but it could be my last Christmas” (DT). One LR participant described experiencing significant family stressors in the past and stated: “It’s things like that which make me very upset and I have to stop and think, no I can’t fight the world and I don’t have to fight the world. It’s memories like that, that I am living with and I’m trying to accept them and put them aside.” Another DT participant spoke fondly of his young family and expressed the following words with awareness that they would likely be read in the future: “With all my children, I hope, I know they’re going to grow up to be brilliant and caring people. I just wish that I can be there for them but
I hope they’re going to learn from their mistakes and that they will find someone to love as much as I love their mum.”

**Themes More Frequent in LR**

On the other hand, LR participants were more likely to express concerns about “Unfinished Business,” which typically involved conflictual interpersonal relationships: “That messed things up there and I haven’t had anything to do with it since then, I’ve just been avoiding it. I don’t know. Maybe I’ll get back to it eventually but there is a good chance I won’t be able to do things that still need to be done,” or historical events that had an ongoing impact: “I’m trying to fight some of those bad things that happened to me a child, now that I’m getting sick. Those bad things are coming back in vision if I close my eyes.” In comparison, DT and WDT participants typically expressed their sense of unfinished business in the context of anticipatory grief: “I just don’t know what to say … it’s basically me saying good-bye and I am not ready for that. I’d like to think that I will be seeing these kids grow up but I know I won’t be able to.”

“Aftermath Concerns” refers to concerns about significant burden or challenges to others after one’s death. Although there were no apparent thematic differences between groups, this theme was most prevalent in LR and WDT participants with concerns typically involving uncertainty about financial and emotional impacts on surviving family members: “I don’t know how my husband is going to cope. The boys are not interested in the farm so I don’t know what will happen there, that’s one thing that worries me. And how will he survive with all of the modern technology” (LR).

**Other Themes With Prevalence Discrepancies**

“Spirituality and Impacts of Illness” were somewhat less likely to be acknowledged by WDT participants compared with the other groups. Spirituality refers to philosophical, theological, or other important personal beliefs from which participants drew comfort and solace. For one DT participant, spirituality was closely linked with their religious beliefs: “Knowing there is a higher power, knowing that I am not alone and that I can turn to the Bible when I need to. God is in control and he is in me so I’m not scared.”

On the other hand, one LR participant found comfort in thoughts and visions of connecting with loved ones after death: “There is something out there but I don’t know what yet. I’m always here for them, whether I’m here on this life or somewhere else, I’ll always be at that water edge. They’ve only got to go to the water’s edge anywhere and that’s where they’ll find me.”

Illness impacts typically involved physical symptoms or losses: “I don’t have much of an appetite and can’t go trotting off and eating beautiful seafood like I’d loved to”; cognitive changes: “it’s just so hard for me to remember things at the moment,” and psychosocial impacts: “I feel like I’ve had enough. It’s too hard now, I cannot go on anymore. I’ve reached the end of it.” There were no other apparent thematic differences between the groups.

**Discussion**

The aim of this study was to qualitatively examine the content of legacy documents created as part of DT and WDT interventions and compare them to LR session transcripts where LR was provided in such a way that the key difference between these interventions was the legacy creation component. Consistent with prior qualitative DT studies, the findings suggest that people nearing end of life will reflect on, consider, and affirm a diverse set of life experiences, special memories, sentiments, beliefs, and relationships when given an opportunity to undertake either DT or LR. Each participant story was underpinned by a set of core values that were essential in understanding one’s sense of identity and purpose. These values also appeared to facilitate people’s search for meaning, particularly when faced with adversity or misfortune. Given that all participants were also acutely aware of their limited life expectancy, this was consistent with Victor Frankl’s idea that people are compelled to contemplate their existence and attach meaning to bleak situations, suffering, or dying. Approaching end of life is therefore characterized not only by change, grief, and loss but also by opportunity for considerable personal and interpersonal growth for both patients and those around them. This growth can be further fostered by an empathic, nonjudgmental, and flexible nature of dignity-conserving care, whose principles are outlined in the empirical model of dignity.

A key finding of this study is that the content of participant interviews varied to an extent depending on whether a legacy document was being created, even when controlling for factors such as interview questions, therapist influences, and session length. Compared to LR transcripts, legacy documents in DT and WDT groups were more likely to include and at greater detail themes involving resilience, hope, and affirmation of legacy that transcended the dying process. This is perhaps not surprising given that the DT process is by its nature productive, cooperative, meaningful, and facilitative of Erikson’s concepts of generativity and ego-integrity near end of life. For example, it was common for legacy documents to include direct messages to loved ones with awareness that these messages would one day be received and appreciated. LR also consistently
involved themes of meaning, acceptance, disappointments, and regrets. However, it was relatively more common for LR participants to discuss interpersonal disappointments, self-blame in relation to regrets, and express specific concerns about unfinished business and the aftermath of their expected death such as fear of burdening others. These discussions were likely facilitated by the confidential nature of LR that minimized the influence of fear of upsetting family/carers, particularly in light of random allocation to interventions and group comparability.

Legacy documents created after a set waiting period were thematically similar and consistent with ones created in standard DT, with exception of somewhat less prevalent expressions of spirituality and impact of illness, and more prevalent aftermath concerns. This is largely consistent with our original study findings and reinforces the likelihood that group randomization was not able to control all relevant variables such as physical and functional well-being and prior engagement in legacy activities.

**Limitations and Future Directions**

One limitation of this study was that LR was relatively time limited and emphasized integration of important life stories, memories, values, and other related themes with awareness of limited life expectancy, as opposed to active resolution of past conflicts, traumas, or unfinished business. Future studies may consider extending the psychotherapeutic scope of LR to focus on the latter and include participants with higher levels of psychosocial distress, which could result in different quantitative and qualitative outcomes. In addition, LR session transcripts were compared with DT’s edited legacy documents. Although the DT editing process typically involved minor editorial changes, there were a few instances where participants decided to remove portions of text they deemed unsuitable for their families. Consistent with study aims, only completed legacy documents were analyzed, although future studies may wish to also explore DT unedited interview transcripts. Finally, further research is required on the possibility of delayed therapeutic impacts for suitable participants.

**Conclusion**

Relatively brief and targeted interventions such as DT and LR provide a unique opportunity for palliative care patients to reflect on and affirm aspects of their life that are most important to them, with the ultimate aim of realizing one’s psychological, emotional, and interpersonal potential near end of life. The legacy creation component of DT was particularly facilitative of exploration of resilience, hope, and enduring sense of legacy but possibly to the detriment of deeper exploration of themes such as interpersonal regrets, unfinished business, and concerns about the aftermath. Therefore, careful tailoring of these interventions to the needs, wishes, and abilities of dying patients is essential in optimizing therapeutic goals and outcomes.

**Disclosures and Acknowledgments**

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**References**


### Appendix

**Description of Coding Themes and Example Quotes From Participants**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autobiographical information</td>
<td>General autobiographical recollections and reminiscence</td>
<td>I was born in Brisbane in 1938. A dear friend of my mother’s had a private school nearby and that’s the school I went to. The modern way of doing things is to borrow money to buy a big lounge suite and dining room. With us, if we can’t afford it, then we don’t have it. That was always the way we lived. I did what I could for the grandchildren too, and now I feel very close to them. I always tell them to come and ask for help if they need it. The comradery and relationships that I developed during that period are ongoing, right up until now. You do the best that you can do, and you can only do what you know. There is time for everything and I think my time is up now to move on. If I go tomorrow, I’m contended. Some beautiful gorgeous memories from that time. I have been back since and the feeling is still there … feeling of security and happiness. We won’t talk about the other half, it wasn’t a good marriage, there is still resentment there. I am 52, what have I accomplished? Sod all. That’s probably the only regretful part of my life.</td>
</tr>
<tr>
<td>Values</td>
<td>Enduring core principles and beliefs that help define one’s sense of self and guide behaviors</td>
<td></td>
</tr>
<tr>
<td>Care and guidance for others</td>
<td>Expressions of empathy, care, and willingness to guide or contribute to others including future generations</td>
<td></td>
</tr>
<tr>
<td>Important roles and relationships</td>
<td>Significant roles and relationships in life, past and present</td>
<td></td>
</tr>
<tr>
<td>Meaning and acceptance</td>
<td>Sense of meaning in life, satisfaction, and acceptance of past events</td>
<td></td>
</tr>
<tr>
<td>Delights and joys</td>
<td>Special memories or matters in life that people enjoy, cherish, or take pleasure in</td>
<td></td>
</tr>
<tr>
<td>Disappointments or regrets</td>
<td>Expressions of disappointment, regret, unhappiness, or sorrow for past actions or events</td>
<td></td>
</tr>
<tr>
<td>Other productive behaviors</td>
<td>Behaviors suggestive of productivity and functional well-being</td>
<td>I’ll be traveling again soon in two weeks. Just today I sent two cards off to England and a parcel to my daughter in America. How old and haggard I’ve become, how sick I’ve become. I’m really proud of my children, they’ve all turned out really, really well. I’ll live in their memory and that’s the only place you can. I’m very determined. I expect to be here, I am a positive person with positive attitude but it could be my last Christmas. When I go, I want life to go on for them, especially the kids. I just hope they are happy, healthy, and have a long and successful life. Spiritualitry, even being clairvoyant, yes it is massive, it’s been a very big part of my life. I did want to see my kids grow up, but unless there is a miracle, this won’t happen. I just wish I had more time with them. That worries me, if she was more financially secure I would be more at ease with dying.</td>
</tr>
<tr>
<td>Impact of illness</td>
<td>Physical, psychosocial, or spiritual impacts of illness</td>
<td></td>
</tr>
<tr>
<td>Sense of legacy</td>
<td>Sense of comfort that one would leave something lasting that transcends one’s death</td>
<td></td>
</tr>
<tr>
<td>Fighting spirit and resilience</td>
<td>Determination to overcome challenges, barriers, or adversity</td>
<td></td>
</tr>
<tr>
<td>Hopefulness</td>
<td>Expressions of hope for the future, including for self, others, and the world</td>
<td></td>
</tr>
<tr>
<td>Spirituality</td>
<td>Philosophical, theological, or other personal beliefs indicative of spiritual well-being</td>
<td></td>
</tr>
<tr>
<td>Unfinished business</td>
<td>Issues or stressors that have not yet been addressed and resolved before dying</td>
<td></td>
</tr>
<tr>
<td>Aftermath concerns</td>
<td>Worries or fears of significant burden and challenges to others after one’s death</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 8: GENERAL DISCUSSION

Chapter Eight concludes this thesis with a discussion of the key research findings. Clinical and research implications of each of the three studies are outlined, in context of their strengths and limitations. Recommendations are also made for future research evaluating Dignity Therapy and Life Review interventions as well as for clinicians utilising these interventions in palliative care settings. The final closing words complete the Chapter and the thesis.

If it all stops
Would you say you loved?
If it all stops
Was it good enough?
If it all stops
Could you say you tried?
If it all stops
Was it justified?
If it all stops
Was it all a waste?
If it all stops
Were you out of place?
If it all stops
Did you play your part?
If it all stops
Were you who you are? (Roganovic, 2018)

8.1 Introduction

Quality multidisciplinary palliative care aims to meet complex biopsychosocial needs of patients and their families/carers, and as such it relies on cooperation and coordination of a variety of health professionals. In addition to the management of various medical issues, goals of care may also include addressing psychological, social, existential, and spiritual domains of distress (Chochinov et al., 2004; Chochinov et al., 2009; Steinheuser et al., 2000). Therefore, it is essential to establish an evidence base for systematic manualised psychotherapeutic interventions aimed at addressing various psychosocial and existential sources of distress near end of life (LeMay & Wilson, 2008). The broad aims of this project were to conduct empirical research that examined the outcome measurement, efficacy, and processes of Dignity Therapy and Life Review interventions for palliative care patients.
8.2 Development of a Brief Measure of Generativity and Ego-Integrity for Use in Palliative Care Settings – Key Findings

The aim of Study 1 was to develop a brief self-report measure of Erikson’s (1963) concepts of generativity and ego-integrity that would be suitable for use with patients receiving palliative care. The findings indicate that the 11 generativity and ego-integrity items that comprise the Brief Measure of Generativity and Ego-Integrity are good representatives of the larger respective measures they were selected from. The factor analysis resulted in a two-factor solution that was consistent with theoretical and empirical models of these concepts. The internal consistency of the two subscales was adequate for the total sample, and improved further when only data from participants above 40 years of age were included in the analysis. This suggests that the generativity and ego-integrity items included in this measure are suitable for use with middle-aged and older adults, i.e., the main age groups of recipients of palliative care. Study 2 provided further direct evidence for the utility of this measure in palliative care settings. Repeat factor analysis for the RCT data showed that the same two-factor structure was retained in the palliative care sample, with the exception of one of the items that was removed from subsequent analyses in the study.

The resulting Brief Measure of Generativity and Ego-Integrity attempts to address several issues associated with assessing these constructs in palliative care settings. The adjusted wording of original items and the relatively brief administration time are likely conducive to more efficient use among participants approaching end of life than general measures not specifically developed for this population. For these patients, changes in physical, psychological, and cognitive functioning may preclude the use of lengthier and more complex assessment measures of concepts such as generativity and ego-integrity. Predominant use of other assessment tools such as behavioural checklists may be similarly poorly suited to this population given the prevalence of functional losses and patients’ perception of diminished quality of life (Hack et al., 2004; Lloyd-Williams et al., 2004). Such limitations are a known barrier to understanding the relevance of these concepts in older adults (Schoklitsch & Baumann, 2011). This measure also allows for more direct measurement of generativity and ego-integrity as opposed to measuring theoretically related constructs such as life satisfaction and psychological well-being, and inferring their impact on sense of generativity and ego-integrity (e.g. Haight et al., 2000). As a result, this measure could continue to be utilised as an indicator of psychotherapeutic outcomes for palliative care patients. Additionally, the
availability of generativity and ego-integrity subscales in one standardised measure allows for simpler and more reliable comparisons of these two concepts. This is achieved by controlling for issues that can arise when measures of these constructs differ to each other in scope of assessment, administration, and psychometric properties. The need to better understand the relationship between generativity and ego-integrity is underscored by evidence that generativity in midlife can predict ego-integrity later in life (Torges et al., 2008). This is important given that generativity and ego-integrity have been positively associated with a number of indicators of psychological well-being, and negatively associated with depressive symptoms (McAdams & Azarow, 1996; Melo, 2008; James & Zarrett, 2005; Rylands & Rickwood, 2001).

There are several limitations associated with the development of this measure. Its relatively brief nature may present a challenge in capturing some of the conceptual nuances associated with its subscales. Its focus is also on participants’ perceptions of their generativity, stagnation, ego-integrity and despair, and at the specific time of administering this measure. In order to reach a more comprehensive understanding of the possible roles of these concepts for each palliative care patient, additional assessment modalities need to be considered such as clinical interview data, population-specific behavioural indicators of these concepts, evaluation of life narratives such as life stories or reminiscence, assessment of longitudinal changes, and inclusion of family perspectives (McAdams & de St Aubin, 1992; Schoklitsch & Baumann, 2011). Its utility still needs to be demonstrated with other palliative care patient subpopulations (e.g., Motor Neurone Disease), younger patients, people from more diverse cultural backgrounds, and with an Australian sample given that the measure was developed with New Zealand participants. Further validation studies would benefit from use of guidelines for systematic reviews of patient-reported outcomes such as the COSMIN (Prinsen et al., 2018). Overall, the newly developed Brief Measure of Generativity and Ego-Integrity demonstrates good initial psychometric properties, and contributes to our ability to assess these concepts among palliative care patients.

8.3 Dignity Therapy and Life Review for Palliative Care Patients – Key RCT Findings

The primary aim of Study 2 was to reach a better understanding of the utility and efficacy of Dignity Therapy in palliative care settings by comparing this intervention with Life Review and a Waitlist Control Group in a RCT. In order to achieve this aim, the following methodological features were implemented in the study design: (a)
Dignity Therapy and Life Review were conducted in a way that the legacy creation component of Dignity Therapy was able to be specifically evaluated, (b) the Brief Generativity and Ego-Integrity Questionnaire was utilised as a treatment outcome measure, and (c) the Waitlist Control Group received Dignity Therapy after a population-tailored waiting period in order to measure longitudinal changes in treatment outcomes. The following key findings can be deduced from the analysis of the RCT data.

Patients who received standard Dignity Therapy had significantly higher generativity and ego-integrity scores at completion of the study compared to baseline (Appendix B). There were no significant changes in these scores in the Life Review Group and the Waitlist Control Group. This suggests that Dignity Therapy and specifically its productive process of creating a tangible legacy document is able to positively impact both the generativity vs stagnation and the ego-integrity vs despair stages of psychosocial development (Erikson, 1963). With regard to generativity, the results suggest that the collaborative creation of a legacy document can improve sense of productivity through facilitated guidance and contribution to future generations. This, in turn, may reduce indicators of stagnation such as sense of apathy about other people or the society at large, perceived inability to contribute to future generations, and disappointment about no longer having any positive or meaningful impact on others (Hamachek, 1990; McAdams & Logan, 2004). Similarly, the results suggest that this intervention can bolster one’s sense of ego-integrity or looking back on life with a sense of meaning, acceptance, and fulfilment. In turn, it can also reduce the indicators of despair such as death anxiety, disappointment with one’s life trajectory, and significant guilt or regret about past events (Erikson & Erikson, 1998).

The relevance of these therapeutic impacts is further emphasised by the known negative associations of generativity and ego-integrity with depressive symptoms, and their positive associations with psychosocial well-being and satisfaction with life (James & Zarrett, 2005; McAdams & Azarow, 1996; Melo, 2008; Rylands & Rickwood, 2001). These psychological mechanisms therefore need to be considered in explaining previous research findings that Dignity Therapy is able to reduce anxiety and depressive symptoms in more distressed palliative care patients (e.g., Juialao et al., 2014). Further research might be designed to explore the possibility that generativity and ego-integrity could also be mediating associations between Dignity Therapy and significant changes in anxiety and depressive features. This exploration of specific
mediators and mechanisms of change has been a key challenge in contemporary psychotherapeutic research (Kazdin, 2007).

Whilst the above-mentioned findings contribute to a better understanding of the effects of Dignity Therapy, caution is required in generalising the results to the wider palliative care population. This is due to the finding of no significant changes in generativity and ego-integrity scores in the Waitlist Control Group, whose members also received Dignity Therapy after a set waiting time of about 10 days. More specifically, there were no significant changes in these scores between pre-test, and both the completion of the waiting period and the completion of Dignity Therapy. Further analyses of results indicated that this participant group departed from the pool of participants that received standard Dignity Therapy in a number of variables that random group allocation was not able to control for.

First, 56% of Waitlist Control Group participants engaged in other memory/legacy activities prior to this study compared to Dignity Therapy (35%) and Life Review (22%) participants. The study demographics questionnaire (Appendix C) captured the data on engagement in these activities, which included collecting special items to give to others such as photographs, personal letters or videos, sharing of important personal stories with others, or recording these stories or recollections in a written, audio or video format. Engagement in these activities may have contributed to the relatively higher pre-test generativity scores in the Waitlist Control Group compared to the other two groups, and the subsequent absence of statistically significant changes in generativity and ego-integrity scores following the provision of Dignity Therapy in this group. Further research is required to better understand the potential psychosocial impacts of these activities as well as their possible impacts on treatment outcomes.

Second, the Waitlist Control Group had significantly higher scores on the functional well-being subscale of the FACT-G than the other groups, and significantly lower ratings of pain, psychological/spiritual distress, and other symptoms compared to the Dignity Therapy Group, based on the clinical consensus of the treating medical teams. This group also had the highest attrition rate from pre-test to completion of the study (25%), though attrition was comparable to the other groups when the waiting period and the treatment phase are considered separately. These group differences may have therefore contributed to the absence of measurable outcomes in the Waitlist Control Group, particularly given the lower baseline levels of distress. Several prior
RCTs of Dignity Therapy have identified such issues as likely contributors to the general paucity of change in primary study outcomes (Fitchett et al., 2015).

No significant pre-test post-test changes were found in generativity and ego-integrity scores for the Life Review intervention, despite the utilisation of the Dignity Therapy interview protocol by the same therapist at comparable session lengths in terms of both session length and transcript word count. This suggests that the participation in a relatively brief therapeutic life review process, as operationalised in this study, might not be sufficient to significantly improve one’s sense of generativity and ego-integrity. However, these findings might not be generalised to all life review approaches, given that this type of psychotherapy has not been standardised and instead tends to be uniquely defined by their respective authors or therapists (Haber, 2006). It was noted that no participant requested or was assessed as requiring immediate additional psychotherapeutic input following the completion of Life Review. However, it is possible that an expanded Life Review therapeutic protocol beyond the one utilised in this study could have resulted in enhanced treatment outcomes. This point is explored further in Section 8.5 of this Chapter – *Implications and Recommendations for Future Research*. The variations in therapeutic outcomes between Dignity Therapy and Life Review were further investigated by conducting qualitative analyses of completed legacy documents and session transcripts in the third study. The findings are presented in the next section of this Chapter.

Furthermore, there were no significant pre-test post-test changes in all three groups on the following treatment outcomes: (a) dignity-related distress as measured by the Patient Dignity Inventory (PDI), and (b) physical, social, emotional, and functional well-being as measured by the FACT-G (Appendix B). The findings are consistent with other studies that were not able to demonstrate significant changes in distress and perceived quality of life following Dignity Therapy (Bentley et al., 2014; Chochinov et al., 2011; Hall et al., 2011). The paucity of measurable outcomes in this study are likely contributed to by relatively low baseline levels of both dignity-related distress and perceived quality of life. In absence of significant concerns on the measures at pre-test, it is increasingly difficult to demonstrate therapeutic efficacy of psychotherapeutic interventions in cancer patients (Schneider et al., 2010). This impact was likely further compounded by the relatively modest sample sizes in this study and the resulting inadequate statistical power to detect small effects. Additionally, self-reported quality of life measures used in palliative care settings such as the FACT-G may not be adequately
sensitive and responsive to change in this patient population (Albers et al., 2010; Chochinov et al., 2011). The use of more specific measures of psychosocial, existential, or spiritual well-being may be warranted in future studies, along with outcomes such as illness or prognosis acceptance, and changes in goals of care (Fitchett et al., 2015).

In light of the above-mentioned challenges in measuring and demonstrating therapeutic outcomes, feedback was sought from participants and consenting family/carers of Dignity Therapy recipients about the effects of therapy (Appendix D). Treatment evaluation scores were combined for Dignity Therapy and Waitlist Control Groups given that they received identical interventions and the feedback did not significantly differ between these two groups. The majority of Dignity Therapy and Life Review participants stated that these interventions were helpful, that they made them feel more valued or worthwhile, and improved their sense of dignity, meaning, and purpose in life. The similar proportions of Dignity Therapy and Life Review recipients reporting such benefits, for many of the treatment evaluation items (as shown in Chapter 6 on page 91), suggested that both interventions were viewed as credible and beneficial, and that there was a not a discernible difference in patient expectancies as might be anticipated if patients were influenced by researcher bias. There were some evaluation items that were rated more highly for Dignity Therapy than Life Review that were logically related to the inclusion of the legacy document component. The majority of Dignity Therapy recipients stated that this intervention helped them prepare for the future and deal with unfinished business. Additionally, Dignity Therapy was deemed relatively more helpful than Life Review for their family now or in the future, and in the way that their family saw or appreciated them. These findings suggest that the perceived benefits of Dignity Therapy extend beyond the standardised treatment outcome measures used in the study. This was also the case to an extent for Life Review in that there were no significant changes found for this intervention on the standardised measures.

Participants’ feedback regarding the improvements in sense of meaning, purpose in life, preparedness for the future, unfinished business, and helpfulness to family/carers also provide further support for the inclusion of generativity and ego-integrity variables as treatment outcomes in future Dignity Therapy studies. Whilst there were lesser group differences in the perceived improvements in quality of life, spiritual well-being, depression and suffering, about a third of Dignity Therapy recipients still reported significant benefits on these variables post-intervention. Consequently, further research
may wish to further explore the defining features of palliative care patients who report such benefits, given the otherwise minimal group differences on these variables. Future inclusion of items that control for possible response biases in the treatment evaluation forms is also recommended, despite these assessments being either self-administered or administered by clinicians/students that were not members of the research team.

Fifteen family members of Dignity Therapy recipients also provided their feedback on the impacts of this treatment. Family members of Life Review recipients were not included in the study design as they were not involved in the provision of therapy and no legacy document was created as part of this process. A majority of family members found Dignity Therapy to be helpful to both themselves and the therapy recipients, across all measured variables with the exceptions of relatively lesser improvements in ratings of participants’ quality of life and suffering. There were no reports of negative experiences as a result of this therapy. Two family members of two separate participants suggested that the content of legacy documents could have been further expanded to include other aspects of the person’s life. These findings are largely consistent with previous studies of positive impacts of Dignity Therapy on family/carers (Bentley et al., 2014; Hall et al., 2013; McClement et al., 2007). The findings also provide additional support for Dignity Therapy’s acceptability, given that the vast majority of patients and their family members stated that they would recommend this intervention to other people. Further studies may wish to also explore long-term impacts of legacy documents on family members, such as potential benefits with the bereavement process. Research recommendations are further outlined in section 8.5 Implications and Recommendations for Future Research section of this chapter.

In summary, this RCT provides initial evidence that Dignity Therapy is able to positively impact the sense of generativity and ego-integrity in palliative care patients. More specifically, the process of creating a tangible legacy document appeared to help bolster a sense of productivity/contribution to others, along with sense of meaning, purpose, and acceptance. Further support for this finding was provided by the overwhelmingly positive subjective impacts of therapy, as rated by both Dignity Therapy recipients and their families. On the other hand, this study did not demonstrate any meaningful changes in dignity-related distress, and physical, social, emotional or functional well-being, following this intervention. This is consistent with previous research, and reinforces the need for targeted measurement of relevant therapy outcomes, achieving adequate statistical power and recruitment of patients with higher
baseline levels of distress (Fitchett et al., 2015). Life Review was similarly well-received by patients, though there were no changes in pre-test to post-test scores on any of the outcome measures. The paucity of measurable treatment outcomes in the Waitlist Control Group may have been impacted by this group’s more frequent engagement in memory/legacy activities prior to the study and relatively better symptom management and functional well-being. Qualitative research methods were utilised in the third study in order to better understand the variations in therapeutic outcomes between Dignity Therapy and Life Review.

8.4 Dignity Therapy and Life Review for Palliative Care Patients – Key Findings from the Qualitative Study

The aim of Study 3 was to use qualitative methods to compare Dignity Therapy legacy documents with Life Review session transcripts in order to better understand the treatment outcomes reported in the RCT. Consistent with the RCT aims and prior qualitative research, these interventions were compared across three a priori themes: sense of generativity and ego-integrity, the empirical Dignity Model, and core values (Chochinov et al., 2002a; Erikson, 1963; Hack et al., 2010). The framework method of thematic data analysis was utilised due to its key strengths of being comprehensive yet flexible in conducting comparison analyses that are both deductive and inductive (Gale et al., 2013). The themes identified through the data analysis (Chapter 7, Table 3) were all related to the a priori themes except for the following themes identified through inductive analyses: Autobiographical Information, and Delights and Joys.

The findings indicate that patients approaching end of life will reflect on and affirm a wide range of life experiences, core values, and special memories regardless of whether they are given an opportunity to take part in Dignity Therapy or Life Review. For example, all participants spoke about their most important or meaningful memories, deeply-held personal beliefs, significant past and current roles and relationships, and their sense of generativity such as ways that they managed to either care for or contributed to others in some way. The core values varied greatly among participants, though all were reflected on and acknowledged as an enduring set of principles that served to guide one’s behaviours or important decisions in life. Almost all participants not only spoke about simple joys or pleasures in life, but also disappointments or regrets with some of their past experiences. This appeared to facilitate poignant self-reflection on ways of attaching meaning to their difficult, disappointing, or tragic life experiences as well as ways they were able to work towards reaching a level of acceptance regarding
these experiences. This process was therefore consistent with Erikson’s concept of ego-integrity vs despair, in that participants appeared to balance between these two opposing poles before incorporating them into a more dynamic and complex interpretation of their past life experiences (Torges et al., 2008; Van Hiel et al., 2006). Furthermore, as part of this process, more than half of all participants spoke about the ways they were able to maintain generative or productive behaviours and at least some functional ability despite the biopsychosocial and spiritual impacts of their progressive illness.

The consistent tendency to explore meaning in adversity, trauma, or suffering during both Dignity Therapy and Life Review interventions is consistent with Victor Frankl’s (1975) notion that “meaning must be found and cannot be given” (p. 112) and it is “something to discover rather than to invent” (p. 113). To Frankl, meaning emerges by actively contributing to the world, experiencing aspects of the world that one considers to be important, and through attitudes adopted towards aspects of life that cannot necessarily be changed including suffering. It appeared that a gentle, respectful, and guided exploration of the themes of meaning, purpose, and acceptance in this study was facilitative of the meaning-making process. The end stages of life are therefore characterised not just by themes of change, grief, and loss, but also by opportunity for further personal and interpersonal growth by patients and their families, friends, or carers.

Compared to Life Review sessions, legacy documents created as part of standard Dignity Therapy were more likely to include, and at greater detail, themes of leaving a lasting legacy that will transcend their death, fighting spirit or resilience in overcoming adversity, and hope for the future. On the other hand, the Life Review process appeared to be more facilitative of exploring concerns about unfinished business such as conflictual relationships and unresolved traumatic experiences, fear of burdening others as death approaches, and concerns about the aftermath. Additionally, it was noted that themes of disappointments or regrets in Life Review sessions were relatively more homogenous in that they tended to involve descriptions of poor decisions in life, perceived failings, and self-blame in relation to these events. Discussions about various biopsychosocial impacts of advancing illness were also most prevalent in Life Review sessions though group differences were relatively less distinct with this theme. Dignity Therapy provided in the Waitlist Control Group was largely consistent with standard Dignity Therapy, with the exceptions of relatively less prevalent discussion of impacts of illness and spirituality, and more prevalent aftermath concerns. Of note is that the
frequency of other themes related to sense of generativity and ego-integrity such as productivity, care/guidance for others, meaning, and acceptance was largely equivalent across groups.

These findings indicate that the choice of providing Dignity Therapy or Life Review can influence the session content even when controlling for interview questions, session length, and therapist influences. This is consistent with Hack et al.’s (2010) assertion that the Dignity Therapy protocol is not intended to be a therapeutic Life Review. The findings also support the assertion that Life Review is facilitative of an evaluative therapeutic process such as assisting patients in processing or coming to terms with some of their more difficult memories or life experiences (Keall et al., 2015). In comparison, Dignity Therapy is relatively more facilitative of a descriptive process given its focus on enhancing generativity, meaning, and purpose through the creation of a legacy document (Chochinov et al., 2004).

One key difference between the two therapies is that full session confidentiality was afforded during Life Review sessions given the absence of legacy document recordings or active family involvement. As outlined above, this appeared to be particularly facilitative of several key themes, though possibly to the detriment of exploration of other themes that were more prevalent in legacy documents. Of note is that there were no indications during any of the therapy sessions that patient responses to questions were insincere, overly guarded, or purposefully answered in certain ways. Rather, responses to interview questions appeared genuine and were likely guided by the patients’ perceptions of the differences in aims and goals of Dignity Therapy and Life Review. For example, it was not possible to blind treatments, and all participants were aware of the differences between the two interventions as outlined in the study Information Sheet. This was further reinforced by the necessity for random allocation to groups and adherence to research protocols. Additionally, in about a third of all Dignity Therapy sessions, patients’ family members were present and had at least some contribution to the session content.

Whilst there were no significant thematic differences between Dignity Therapy sessions with and without the presence of family members, participants were still acutely aware that their words would form legacy documents for others to eventually read. It is likely that this awareness was an additional contributor to differences in session content between the two therapies. Future Dignity Therapy studies that incorporate more than one treatment modality in their study design may wish to directly
assess patients’ perceptions of how each therapy may have influenced the session themes they eventually explored. Further research is also needed on determining whether Life Review that is expanded beyond the scope utilised in this study would result in improved treatment outcomes and whether the content and process of this expanded intervention would additionally differ to Dignity Therapy.

In summary, both Dignity Therapy and the Life Review protocol implemented in this study were facilitative of palliative care patients’ reflection and affirmation of variety of important and meaningful aspects of their lives. Patients’ personal stories were imbued with meaning, purpose, and at least some level of acceptance of their changes/losses or adversity in general. It was however noted that legacy documents were particularly facilitative of exploration of themes involving hope, resilience, and legacy. Themes involving interpersonal regrets, unfinished business, and aftermath concerns were less prevalent compared to Life Review sessions, despite controlling for interview questions, session length, and therapist influences. Therefore, individual needs, vulnerabilities, preferences, and family circumstances need to be carefully considered in the provision and evaluation of interventions such as Dignity Therapy and Life Review.

8.5 Implications and Recommendations for Future Research

Over the past decade or so, there has been considerable growth in international research examining the acceptability, feasibility, and effectiveness of Dignity Therapy across multiple patient populations, settings, and cultures. Recent literature reviews (e.g., Bentley et al., 2017; Fitchett et al., 2015) have found that patients consistently report high satisfaction and benefits for themselves and family members as a direct outcome of taking part in Dignity Therapy. This is despite well-documented feasibility issues associated with conducting and evaluating psychotherapeutic interventions with terminally ill patients, such as recruitment and retention challenges. Perhaps most strikingly, the ability of Dignity Therapy to alleviate psychological or emotional distress in palliative care patients remains uncertain. The aim of the empirical studies conducted as part of this research was to contribute to our understanding of the utility and efficacy of Dignity Therapy and Life Review in palliative care settings. This understanding may be further expanded through the following recommendations for future research.

As is common with existing Dignity Therapy literature, the RCT was conducted with older participants who exhibited relatively low levels of baseline biopsychosocial distress. Whilst this is a positive indicator that not all palliative patients are emotionally
distressed, the utility of this intervention is yet to be established in more distressed patients. One study did show promising initial evidence that patients with higher levels of depression and anxiety can benefit from taking part in this intervention (Juliao et al., 2014). There is a similar gap in the literature in other patient sub-populations such as younger patients approaching end of life (Rodriguez, Smith, & McDermit, 2018). Relatively little is also known about the possibility of delayed impacts of Dignity Therapy on both participants and their families. Therapeutic outcomes tend to be measured within days of providing final legacy documents to patients, as was the case in the RCT in this project. It is however possible that for some patients, such as those with relatively longer life expectancies at baseline, therapeutic impacts may become more prominent in later stages of their progressive disease. Similarly, further research is required to better understand long-term impacts of legacy documents and their utilisation by those who were selected to receive them. Studies to date suggest that, whilst these personalised documents could play an important role in the bereavement process of surviving family members, they could also in some circumstances be perceived as unhelpful or even harmful to family dynamics (Hall et al., 2013). An additional possibility is that some patients may take part in Dignity Therapy without intent to provide their legacy document to any other person. It is unclear how the therapeutic content, process, and treatment outcomes would differ in these situations.

Future studies may also wish to utilise more specific measures of psychosocial, existential, or spiritual well-being, and other clinical outcomes such as prevention of further distress, changes in illness perceptions, acceptance of limited life expectancy, and changes in goals of care (Chochinov et al., 2011; Fitchett et al., 2015). This is particularly the case given that measurement of Dignity Therapy outcomes can be impeded by underpowered studies, floor or ceiling effects of outcome measures, and questionable sensitivity and responsiveness to change of quality of life questionnaires (Albers et al., 2010; Chochinov et al., 2011; Fitchett et al., 2015). Better understanding is also required of the feasibility of this intervention being provided by multidisciplinary clinicians with different clinical and training backgrounds, across more diverse settings (Fitchett et al., 2015). Future clinical trials would benefit from incorporating published guidelines for conducting psychotherapeutic trials into the study design and reporting of outcomes. CONSORT is one such guideline, whose statement has recently been updated to cover considerations unique to trials of non-pharmacological treatments (Boutron et al., 2017).
Following on from the RCT findings, measurement of generativity and ego-integrity could be expanded to include population-specific behavioural changes associated with these variables, and also more specific individual and family perspectives with regard to the relevance or importance of these outcomes. Further research is also required on the possibility that factors such as generativity, ego-integrity, and spirituality could be mediating the relationship between Dignity Therapy and other outcomes such as anxiety, depressive symptoms, and requests to die. For example, there is some evidence that recipients of Dignity Therapy who identify as religious and spiritual may experience an increased sense of hopefulness post-treatment compared to those who identify as non-religious or non-spiritual (Bentley et al., 2014). Similarly, it is possible that prior or parallel engagement in activities involving reminiscence and recording of life events may be inadvertently impacting the treatment outcomes.

It also remains unknown to what extent factors such as historical adversity, unresolved trauma, dysfunctional family dynamics, or other emotional and social vulnerabilities may facilitate or hinder the psychotherapeutic processes involved in these interventions. For example, one pilot RCT found that depressive symptoms increased following Dignity Therapy and that a counselling intervention was relatively more effective in improving resilience and anxiety symptoms (Rudilla, Galiana, Oliver, & Barreto, 2015). Similarly, researchers need to be mindful of cultural considerations and appropriate ways of communicating therapeutic goals whilst being respectful of patients’ needs and coping mechanisms. Further research is needed to determine the extent of required revisions to the Dignity Therapy protocol for different cultural groups and appropriateness of this protocol in different contexts, given that this intervention has predominantly been developed and researched in English-speaking countries.

Finally, the Life Review protocol utilised in the RCT was unique in some respects in that its themes were guided by the Dignity Therapy interview protocol. Flexible population-specific adaptations of Life Review interventions are not unusual given their relative lack of standardisation in terms therapeutic methodology, session content and process (Haber, 2006). Nevertheless, future studies may wish to explore the possibility that an expanded Life Review therapeutic protocol could result in enhanced treatment outcomes.
8.6 Recommendations for Clinicians

In previous research, Dignity Therapy has been provided by clinicians from wide-ranging clinical backgrounds, training, and experience, including psychologists, psychiatrists, medical students, research nurses, social workers, and other researchers. In clinical settings this intervention may also be provided in some capacity by pastoral care workers, volunteers, or students, and at times informally and at minimal financial cost to the service. However, some uncertainties remain as to who should administer Dignity Therapy in clinical settings, and what type of training and certifications might be warranted (Bentley et al., 2017). Bentley (2014) emphasised the importance of the therapist being a member of a multidisciplinary palliative care team where relevant information, education, and screening would be discussed as part of comprehensive care. The RCT and qualitative research findings also emphasise the need for careful consideration of the psychological, emotional, and spiritual needs of palliative care patients in determining the appropriateness and potential effectiveness of both Dignity Therapy and Life Review.

There is a need to establish cost-effectiveness of Dignity Therapy given the difficulties in determining socially-acceptable costs to achieve its potential benefits, and the general bias against attributing economic value to improvements that results from psychosocial interventions (Hack, 2012). Estimated costs of providing Dignity Therapy can vary depending on the required clinical time and transcription and other costs. Transcription costs are expected to be relatively modest with one study estimating a mean of $56 USD per legacy document averaging 8 single spaced pages (Montross et al., 2011). The potential impacts of introducing Dignity Therapy on existing clinical workloads, patient ratios, flow of communication, and team dynamics are not currently known (Bentley et al., 2017).

Nevertheless, studies of perspectives of health professionals who were either directly or indirectly involved with Dignity Therapy are encouraging. For example, Montross et al. (2013) found that staff who referred patients to this intervention rated it as worthwhile, helpful, highly recommended, and somewhat able to reduce pain and suffering. Tait and Hodges (2013) reported that medical residents who were guided in providing Dignity Therapy reflected positively on the patient-centred therapeutic approach, lessons learned from the experience, and impacts on their own professional and personal lives. The authors emphasised the need to provide medical trainees with opportunities to directly and authentically focus on patient life stories.
8.7 Closing Words

People approaching end of life can present with a complex array of physical, psychological, social, existential, and spiritual needs. However, each member of the multidisciplinary palliative care team may have a role to play in helping meet these needs. This line of work can be confronting and challenging, yet also deeply meaningful and rewarding, given the privilege of working with people in their last days or weeks of life. Relatively brief psychotherapeutic interventions such as Dignity Therapy are additional tools that may enhance a patient’s sense of meaning, purpose, and acceptance as death approaches, as well as offer some comfort to the surviving family members. It is worth noting that these interventions are not universally beneficial, and certainly some patients and their family members will not want or need this type of therapeutic input. For the patients whose needs and preferences are well-matched to the goals of Dignity Therapy and Life Review, these interventions may be as worthwhile as any other aspect of their health care. After all, “although dying is inevitable, dying poorly ought not to be” (Chochinov, 2012; p. 187).
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APPENDIX A: Brief Generativity and Ego Integrity Questionnaire
**Brief Generativity and Ego-Integrity Questionnaire**

Please rate your agreement with each of the statements below by circling your response.

Use the following scale to make your choice:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I pass along the knowledge that I have gained through my experiences</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I think that I will be remembered for a long time after I die</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I am not making a meaningful and lasting contribution to other people</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I am committed to many different kinds of people, groups, and activities</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I have done nothing that will survive after I die</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>Other people would say that I am very productive</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I feel contented with what I have accomplished in my life</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I still feel angry about some of my life experiences</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>My life has been fulfilling, and I am not frightened by the thought of death</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>When I consider the ups and downs of my past life, they somehow fit together in a meaningful way</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I have had disappointments in life that I will never be able to accept</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>
APPENDIX B: Means and Standard Deviations of the Brief Generativity and Ego-Integrity Questionnaire and the FACT-G at Each Testing Time
Scores on the Brief Generativity and Ego Integrity Measure at each testing timea

<table>
<thead>
<tr>
<th>Factor</th>
<th>Dignity Therapy (n = 20)</th>
<th>Life Review (n = 18)</th>
<th>Waitlist Control (n = 18)</th>
<th>Post-test 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test</td>
<td>Post-test</td>
<td>Pre-test</td>
<td>Post-test</td>
</tr>
<tr>
<td>Generativity</td>
<td>3.04(0.76)</td>
<td>3.83(0.43)</td>
<td>3.32(1.01)</td>
<td>3.33(0.96)</td>
</tr>
<tr>
<td>Ego-Integrity</td>
<td>3.56(0.74)</td>
<td>3.85(0.84)</td>
<td>3.38(0.71)</td>
<td>3.34(0.96)</td>
</tr>
</tbody>
</table>

aData are mean (SD). A score of 1 is Strongly disagree, 2 Disagree, 3 Neutral, 4 Agree, and 5 Strongly agree.

Perceived quality of life measured by the FACT-G at each testing timea

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Dignity Therapy (n = 20)</th>
<th>Life Review (n = 18)</th>
<th>Waitlist Control (n = 18)</th>
<th>Post-test 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test</td>
<td>Post-test</td>
<td>Pre-test</td>
<td>Post-test</td>
</tr>
<tr>
<td>Physical</td>
<td>12.30(6.36)</td>
<td>14.20(4.87)</td>
<td>15.39(6.85)</td>
<td>14.78(7.38)</td>
</tr>
<tr>
<td>Well-Being</td>
<td>13.60(7.20)</td>
<td>15.20(4.90)</td>
<td>14.67(8.09)</td>
<td>16.50(7.37)</td>
</tr>
<tr>
<td>Social/Family</td>
<td>20.88(5.04)</td>
<td>21.41(4.64)</td>
<td>18.86(6.03)</td>
<td>16.85(8.17)</td>
</tr>
<tr>
<td>Well-Being</td>
<td>10.40(4.64)</td>
<td>9.95(5.93)</td>
<td>12.56(6.54)</td>
<td>11.67(6.08)</td>
</tr>
<tr>
<td>Emotional</td>
<td>57.18(14.39)</td>
<td>60.62(12.63)</td>
<td>61.47(22.28)</td>
<td>59.80(22.64)</td>
</tr>
</tbody>
</table>

aData are mean (SD). A score of 0 indicates that the issue applied Not at all in the past seven days, 1 A little bit, 2 Somewhat, 3 Quite a bit, and 4 Very much.
APPENDIX C: Participant Demographic Questionnaire
Dignity Therapy / Life Review Participant Demographic Data (page 1)

**Patient Status:** Inpatient / Outpatient / Home-Visit

**Gender:** Male / Female

**Date of Birth:**

**Number of Children:**

**Diagnosis:**

**Life Expectancy** (clinical consensus):

**Marital Status:**
- (a) Married
- (b) Defacto
- (c) Never Married
- (d) Separated or Divorced
- (e) Widowed
- (f) Other:____

**Living Arrangement:**
- (a) Spouse / Partner
- (b) Alone
- (c) Family / Friends
- (d) Other:____

**Working Arrangement:**
- (a) Working full-time
- (b) Semi-working / Semi-retired
- (c) Not working / Retired
- (d) Other:____

**Level of Education:**
- (a) Did not complete high school
- (b) Completed high school
- (c) One or more years of tertiary education
- (d) Other:____

**Religious Affiliation:**
- (a) Catholic
- (b) Anglican
- (c) Protestant
- (d) Orthodox Christian
- (e) Jewish
- (f) Muslim
- (g) No religious affiliation
- (h) Other:____
Please describe if any memory or remembrance projects that you may have started or already completed such as memory boxes, collection of special items to give to others such as photographs, personal letters or videos, having conversations about your personal stories or recollections, or recording in some way these stories or recollections:

Over the last two months, can you please tell me if you have done any activities or behaviours that involved helping others, contributing to the community, passing skills and knowledge to others or doing something that you or other people thought was important to do:

**Palliative Care Phase Instrument score** (clinical consensus):

1. Stable
2. Unstable
3. Deteriorating
4. Terminal
5. Bereaved

**Karnofsky Performance Scale score (0 – 100)** (clinical consensus):

**Resource Utilization Groups – Activities of Daily Living score** (combined; clinical consensus):

**Palliative Care Problem Severity score** (clinical consensus):

<table>
<thead>
<tr>
<th>Pain</th>
<th>Other Symptoms</th>
<th>Psychological / Spiritual</th>
<th>Family / Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Absent</td>
<td>1. Absent</td>
<td>1. Absent</td>
<td>1. Absent</td>
</tr>
</tbody>
</table>

Length of survival following participation in this study (to be completed at later time):
APPENDIX D: Dignity Therapy Evaluation Forms
# Dignity Therapy Evaluation Form – Patient Version

Please indicate your agreement with the following statements:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Taking part in Dignity Therapy:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>was helpful to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>was as helpful as other aspects of my health care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has helped me with sense of unfinished business</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has improved my quality of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has improved my spiritual wellbeing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has reduced my sense of sadness and depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has made me feel more worthwhile or valued</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has improved my sense of dignity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has made me feel that life was more meaningful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has given me a heightened sense of purpose</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has helped me prepare for future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has lessened my sense of suffering</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has or will be helpful to my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has or could change the way my family sees me or appreciates me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I would recommend this intervention to others

Thank you very much for your participation!
Dignity Therapy Evaluation Form – Family/Carer Version (page 1)

Please indicate your agreement with the following statements:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>___________’s participation in Dignity Therapy:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>was helpful to them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>was helpful to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>was as helpful as other aspects of their health care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has helped them with sense of unfinished business</td>
<td></td>
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</tr>
<tr>
<td>has improved their quality of life</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>has improved their spiritual wellbeing</td>
<td></td>
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</tr>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>has made them feel more worthwhile or valued</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>has given them a heightened sense of purpose</td>
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<td>has helped them prepare for future</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>has or could change the way I saw them or appreciated them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would recommend this intervention to others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Dignity Therapy Evaluation Form – Family/Carer Version (page 2)

Please indicate the following:

1. Were there any difficulties or negatives in creating a legacy document? If so, please describe.

2. Do you have any recommendations on how to improve this intervention? If so, please describe.

3. Do you have any other comments?

Thank you very much for your participation!
APPENDIX E: Human Research Ethics Committee Approvals
Dear Mr Vuksanovic

I write further to your application for ethical clearance for your project "Evaluation of Measure of Generativity and Ego Integrity in Older Adults" (GU Ref No: PSY/F3/10/HREC). This project has been considered by Human expedited review 1.

The Deputy chair resolved to grant this project provisional ethical clearance, subject to your response to the following matters:

A privacy statement is not required for anonymous surveys. However, since the researcher is collecting contact information and administering the surveys at nursing homes and retirement villages, then a privacy statement must be retained in the information sheet for those participants.

Clarification of the recruitment mechanism for participants other than from nursing homes and retirement villages. Also, please provide a copy of the advertisement/initial contact text as per section 5.0 of the Griffith University Research Ethics Manual (http://www.griffith.edu.au/or/ethics/humans/).

Although there are no known or anticipated risks from participating in this study, there is the potential that this research could cause psychological or emotional stress. The information material should include a list of contacts for professional counselling services.

Provision of a draft splash page, including Griffith University branding, for the online survey.

Amendment of the information sheet to include contact details for the other members of the research team. The single telephone number noted belongs to someone outside of the research team.

Amendment of the information sheet explaining that the research forms a component of the student’s academic program and specifying the program.

It is noted at E3 of the Expedited Ethical Review Checklist that participants must be 40 years or over. This, and the reason, should be mentioned in the information sheet and advertising text.

The information sheet/splash page should include the mechanism by which the participant can obtain a copy of the results and maintain anonymity of the survey responses.

The information sheet/splash page should indicate that the return of a completed questionnaire will be accepted as an expression of consent.

Please outline how the research design will maintain the anonymity of survey responses from nursing home and retirement village participants.

Replacement of the 2nd last paragraph on the Information Sheet with the following:
If you have any concerns or complaints about the ethical conduct of the research project you should contact the Senior Manager, Research Ethics and Integrity on 3735 5585 or research-ethics@griffith.edu.au.

Amendment of the Privacy Link (updated September 2010) to read as For further information consult the University’s Privacy Plan http://www.griffith.edu.au/privacy-plan or telephone (07) 3735 5585.

The contact person signing section F1 of the Expedited Ethical Review Checklist.

The contact person signing section F1 of the Expedited Ethical Review Checklist.

An appropriate authorising officer, who is not a member of the research team, completing and signing sF2 of the Expedited Ethical Review Checklist.

This decision was made on 18-Jan-11. Your response to these matters will be considered by Office for Research.

The ethical clearance for this protocol runs from 18-Jan-11 to 01-Jun-11.

Please forward your response to Karen Moorehead, Office for Research as per the details below.

Please refer to the attached sheet for the standard conditions of ethical clearance at Griffith University, as well as responses to questions commonly posed by researchers.

It would be appreciated if you could give your urgent attention to the issues raised by the Committee so that we can finalise the ethical clearance for your protocol promptly.

Regards

Karen Moorehead

Office for Research
N54 2.39 Nathan Campus
Griffith University
ph: 07 5552 9058
e-mail: k.moorehead@griffith.edu.au
web:
Dear Mr Vuksanovic

I write further to your application for a variation to your approved protocol "Evaluation of Measure of Generativity and Ego Integrity in Older Adults" (GU Ref No: PSY/F3/10/HREC). This request has been considered by the Office for Research.

The OR resolved to approve the requested variation:

Requested an extension of the ethical clearance from 01/06/2011 to 01/08/2011.

This decision is subject to ratification at the next meeting of the HREC. However, you are authorised to immediately commence the revised project on this basis. I will only contact you again about this matter if the HREC raises any additional questions or comments about this variation.

Regards

Gary Allen

Office for Research
N54 2.39 Nathan Campus
Griffith University
ph: fax: 07 5552 9058
email: g.allen@griffith.edu.au
web:
Dear Mr Vuksanovic

I write further to your application for ethical clearance for your project Prior Review: Dignity Therapy and Life Review for Inpatients and Outpatients with Advanced Cancer" (GU Ref No: PSY/08/12/HREC). This project has been considered by Human expedited review 1.

The Deputy chair resolved to grant this project conditional ethical clearance, subject to you resolving the following matters:

As per the expectations articulated in the National Statement on Ethical Conduct in Human Research (2007) and Booklet 8 of the Griffith University Research Ethics Manual, because of the prior review by another HREC, this research has been subject to a special administrative review.

Please provide an assurance that the Manager, Research Ethics will be promptly notified if any concerns or complaints are received by GCDH about the ethical conduct of this research.

The primary supervisor signing the s17 declaration (available from the forms page of the Griffith University Human Research Ethics web site or upon request from the Office for Research).

Please arrange for an appropriate authorising officer, who is not a member of the research team, to complete and sign the s18 declaration (available from the forms page of the Griffith University Human Research Ethics web site or upon request from the Office for Research).

This decision was made on 24-Jan-12. Your response to these matters will be considered by Office for Research.

The ethical clearance for this protocol runs from 24-Jan-12 to 31-Dec-14. Please forward your response to Dr Gary Allen, Manager, Research Ethics, Office for Research, as per the details below.

Please refer to the attached sheet for the standard conditions of ethical clearance at Griffith University, as well as responses to questions commonly posed by researchers.

It would be appreciated if you could give your urgent attention to the issues raised by the Committee so that we can finalise the ethical clearance for your protocol promptly.

Regards
Dr Gary Allen
Manager, Research Ethics
Office for Research
G39 room 3.55 Gold Coast Campus
Griffith University
ph: 3735 5585
fax: 07 5552 9058 email: g.allen@griffith.edu.au
Office of the Human Research Ethics Committee  
07 October 2011

Mr Dean Vuksanovic  
17/4 Shenwood Close  
Mudgeeraba, QLD 4213

Dear Mr Vuksanovic

**HREC Reference number:** HREC/11/QGC/83  
**Project title:** Dignity Therapy and Life Review for Palliative and Advanced Cancer patients

Thank you for submitting the above project for ethical and scientific review. This project was again considered by the Gold Coast Health Service District Human Research Ethics Committee (HREC) held on 28 September 2011.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Human Research Ethics Committee has granted approval of this research project. The documents reviewed and approved include:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter: Cover letter to Gold Coast Hospital HREC</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Investigator CV: Dean Vuksanovic CV</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Investigator CV: Prof Murray Dyck CV (primary supervisor)</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Investigator CV: Dr Heather Green CV (primary supervisor)</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Patient Information Sheet/Consent Form: Consent Form for recipients of Dignity Therapy or Life Review</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Patient Information Sheet/Consent Form: Information Sheet for recipients of Dignity Therapy or Life Review</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Patient Information Sheet/Consent Form: Information Sheet for families/carers of recipients of Dignity Therapy</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Patient Information Sheet/Consent Form: Consent Form for family members or carers of recipients of Dignity Therapy</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Dignity Therapy/Life Review Demographic Data Questionnaire</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Generativity &amp; Ego Integrity Questionnaire</td>
<td>1</td>
<td>27 June 2011</td>
</tr>
</tbody>
</table>
Questionnaire: Patient Dignity Inventory (Chochinov et al., 2008).  
Questionnaire: Functional Assessment of Cancer Therapy - General  
Questionnaire: Dignity Therapy Evaluation by recipients of this intervention  
Questionnaire: Life Review Evaluation by recipients of this intervention  
Questionnaire: Dignity Therapy Family/Carer Evaluation - Time 1 (immediately after completion of Dignity Therapy)  
Questionnaire: Dignity Therapy Family/Carer Evaluation - Time 2 (9-12 months post-bereavement)  
Expression of Support - Dr Rohan Vora (Director of Supportive and Palliative Care, GCHSD)  
Expression of Support - Dr Jeremy Wellwood (Director of Cancer Services, GCHSD)  
Application  
Response to Request for Further Information  
Telephone Protocol  
Patient Information Sheet/Consent Form

<table>
<thead>
<tr>
<th>Description</th>
<th>Approval Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire: Patient Dignity Inventory (Chochinov et al., 2008).</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Functional Assessment of Cancer Therapy - General</td>
<td>FACT-G</td>
</tr>
<tr>
<td>Questionnaire: Dignity Therapy Evaluation by recipients of this intervention</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Life Review Evaluation by recipients of this intervention</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Dignity Therapy Family/Carer Evaluation - Time 1 (immediately after completion of Dignity Therapy)</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Questionnaire: Dignity Therapy Family/Carer Evaluation - Time 2 (9-12 months post-bereavement)</td>
<td>27 June 2011</td>
</tr>
<tr>
<td>Expression of Support - Dr Rohan Vora (Director of Supportive and Palliative Care, GCHSD)</td>
<td>26 June 2011</td>
</tr>
<tr>
<td>Expression of Support - Dr Jeremy Wellwood (Director of Cancer Services, GCHSD)</td>
<td>29 June 2011</td>
</tr>
<tr>
<td>Application</td>
<td></td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td>01 September 2011</td>
</tr>
<tr>
<td>Telephone Protocol</td>
<td>1.0</td>
</tr>
<tr>
<td>Patient Information Sheet/Consent Form</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Please note the following conditions of approval:

1. Special Conditions:
   a. Please submit a further methodology and examples of previous research;
   b. Note that initial face to face contact must be made with potential participants;
   c. Participants must be allowed to take the information away with them for consideration before consenting to participate;
   d. Provide information on whether there is now any reason to contact the participants on the telephone and to amend the NEAF accordingly;
   e. Submit an amended NEAF to the HREC Coordinator with the required amendments.

2. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
   a. Unforeseen events that might affect continued ethical acceptability of the project.
      Serious Adverse Events must be notified to the Committee as soon as possible. In addition, the Investigator must provide a summary of the adverse events, in the specified format, including a comment as to suspected causality and whether changes are required to the Patient Information and Consent Form. In the case of Serious Adverse Events occurring at the local site, a full report is required from the Principal Investigator, including duration of treatment and outcome of event.

3. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC coordinator as per standard HREC SOP. Further advice on submitting amendments is available from

4. Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office/r (by-passing the HREC).

5. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly the HREC for review and, once HREC approval has been granted, then submitted to the RGO.

6. Amendments which do not affect either the ethical acceptability or site acceptability of the project (e.g. typographical errors) should be submitted in hard copy to the HREC coordinator. These should include a cover letter from the principal investigator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.

7. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

8. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.

9. The District administration and the Human Research Ethics Committee may inquire into the conduct of any research or purported research, whether approved or not and regardless of the source of funding, being conducted on hospital premises or claiming any association with the Hospital; or which the Committee has approved if conducted outside Gold Coast Health Service District.

HREC approval is valid for three years from the date of this letter.

Should you have any queries about the HREC’s consideration of your project please contact Dr Brian Bell on Brian_Bell@health.qld.gov.au. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the District CEO or Delegate of that site has been obtained.

A copy of this approval must be submitted to the District Research Governance Officer/Delegated Personnel with a completed Site Specific Assessment (SSA) Form for authorisation from the CEO or Delegate to conduct this research at the Gold Coast Health Service District.

Once authorisation to conduct the research has been granted, please complete the Commencement Form and return to the office of the Human Research Ethics Committee.

The HREC wishes you every success in your research.

Yours faithfully

Dr Brian Bell
CHAIR
HUMAN RESEARCH ETHICS COMMITTEE
GOLD COAST HEALTH SERVICE DISTRICT
Office of the Human Research Ethics Committee

08 May 2012

Mr Dean Vuksanovic
17/4 Sherwood Close
Mudgeeraba, QLD
4213

Dear Mr Vuksanovic

**HREC Reference number:** HREC/11/QGC/83

**Project title:** Dignity Therapy and Life Review for Palliative and Advanced Cancer patients

**Amendment number:** HREC/11/QGC/83/AM02

**Amendment Date:** 27 March 2012

The above amendment was reviewed at the meeting of the Gold Coast Health Service District HREC held on 02 May 2012.

I am pleased to advise that the amended documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notification of amendment - Variation to methodology to include home-visits to outpatients</td>
<td></td>
<td>27 March 2012</td>
</tr>
</tbody>
</table>

The Gold Coast Health Service District HREC is constituted and operates in accordance with the National Health and Medical Research Council’s “National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the “CPMP/ICH Note for Guidance on Good Clinical Practice”.

It should be noted that all requirements of the original approval still apply.

Yours faithfully,

Dr Brian Bell
Chair
Gold Coast Health Service District
Human Research Ethics Committee
19 May 2015

Emeritus Professor Drew Nesdale
Chair of the GCHHS Human Research Ethics Committee
Gold Coast University Hospital
Level 2, E Block (PED Building)
1 Hospital Blvd
Southport Qld 4215

HREC reference Number: HREC/11/QGC/83
Project title: Dignity Therapy and Life Review for Palliative and Advanced Cancer Patients

Dear Chair of the HREC,

I am writing to seek an extension to the approved completion date of this study. This research officially commenced on 15 February 2012 and unfortunately I was not aware of the GCHHS HREC requirement to complete data collection within 3 years of initial approval. This project has continued approval by the Griffith University HREC, my supervisors are Prof Murray Dyck and Dr Heather Green. Although participant recruitment has been consistent since commencement of the study, there have been ongoing difficulties in achieving the required number of participants due to patient population (advanced cancer, medical comorbidities) and also methodological requirements such as not including participants whom I have previously seen in my position as a cancer psychologist. To date, 54 participants have taken part in this study so it is expected that this study will be completed by early next year. Therefore, I would like to request for the completion time of this study to be extended by 12 months up until 15 February 2016.

Thank you for your consideration of this request, I look forward to hearing from you soon.

Yours Sincerely

Dean Vuksanovic
Clinical Psychologist
Cancer and Blood Disorders
Gold Coast Hospital and Health Service
APPENDIX F: Information Sheets and Consent Forms
INFORMATION SHEET
Evaluation of a Measure of Generativity and Ego-Integrity

Research Team: Dean Vuksanovic, BPsych(Hons), M ClinPsych, PhD Candidate (07 5687 3134)
Murray Dyck, PhD (07 5552 8251)
Heather Green, PhD (07 5552 9086)
School of Psychology, Griffith University, Gold Coast Campus
Email: Dean_Vuksanovic@health.qld.gov.au

Introduction
You are invited to take part in this research project. This research project aims to evaluate a questionnaire that measures a person’s “Generativity” and “Ego-Integrity”. Generativity refers to a person’s connection with the next generation, for passing skills and knowledge to others, for being productive, and for leaving a lasting legacy. Ego-Integrity refers to looking back on one's life with a sense of meaning, acceptance of past life events, and the absence of death anxiety.

This Information Sheet tells you about the research project and it explains the procedures involved. Please read the information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding to take part, you may wish to talk with a relative, friend or healthcare worker. Participation is voluntary and if you do not wish to take part, you do not have to. You can also withdraw from this study at any time without giving a reason or receiving a penalty. Please keep a copy of this Information Sheet.

Purpose of this research project
Main purpose of this research project is to determine the quality and usefulness of a brief questionnaire that measures Generativity and Ego-Integrity. This questionnaire was created specifically for this research project and it needs to be thoroughly evaluated before it can be used in future research projects.

Participation process
If you agree to participate, you will complete a brief anonymous questionnaire. In total, this study will take about 10 minutes of your time. Return of a completed questionnaire will be accepted as an expression of consent to take part in this study.

Participation is voluntary and confidential
Your participation in this study is completely voluntary. Your decision to participate or not participate in this research will have no effect on the treatment and support that you currently receive. You can withdraw from this research project at any time without penalty and without having to give a reason. The data you provide will remain confidential and you are NOT required to record your name or any other identifying information on any of the materials used. The data collected from this research will be reported in general terms only and you will NOT be identifiable from the data.
Benefits and risks of this research project
Although it is unlikely that you will directly benefit from the current study, your help may have important implications for research on measuring Generativity and Ego-Integrity. This questionnaire was designed specifically for this study and if its evaluation is positive, it will then play an important role in other research projects.

The anticipated risks to participants as a result of taking part in this study are minimal. You will be given the opportunity to discuss any concerns with the primary researcher both before and after your participation. In case you wish to seek professional assistance or counselling about current anxiety, depression, stress or other problems, suitable referral options are as follows:

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<th>Lifeline</th>
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<td>School of Psychology</td>
<td>Bundall Ph: (07) 5570 8590  Ph: (07) 5579 6000</td>
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<td>Griffith University Gold Coast</td>
<td>Helensvale Ph: (07) 5580 7800</td>
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<td>Ph: (07) 5552 8556</td>
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Alternatively, you may wish to contact the Australian Psychological Society for other suitable referral options. Their telephone number is 1800 333 497. Their website is www.psychology.org.au

Feedback about this research
Feedback pertaining to this study, including an anonymous overall summary of the outcomes of this study, will be sent to each participant location upon completion of this study. You may keep this Information Sheet. If you have any concerns or questions about this study or if you wish to directly obtain a copy of the summary of outcomes, you can contact us on the contact details listed above. This study is being conducted as part of Dean Vuksanovic’s Doctor or Philosophy (PhD) program at Griffith University, Gold Coast.

Ethical conduct of this research
This research project has been approved by the Human Research Ethics Committees of Uniting Care Queensland and Griffith University. This research is to be conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. If you have any concerns or complaints about the ethical conduct of the research project, you should contact the Chair of the Uniting Care Queensland Human Research Ethics Committee on (07) 3377 3377, or Senior Manager, Research Ethics and Integrity, Griffith University, on (07) 3735 5585 or research-ethics@griffith.edu.au.

Privacy statement
The information collected is confidential and will not be disclosed to any third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan http://www.griffith.edu.au/privacy-plan
INFORMATION SHEET

Dignity Therapy and Life Review for Inpatients and Outpatients with Advanced Cancer

Student Researcher: Dean Vuksanovic, BPsych(Hons), M ClinPsych, PhD Candidate (07 5687 3134)
Dean_Vuksanovic@health.qld.gov.au

Research Supervisors: Murray Dyck, PhD (07 5552 8251)
Heather Green, PhD (07 5552 9086)

Introduction
You are invited to take part in this research project. This study aims to evaluate the effectiveness of a new intervention called Dignity Therapy and also an intervention called Life Review for patients with advanced cancer. This Information Sheet tells you about the research project and it explains the procedures involved. Please read the information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding to take part, you may wish to talk with a relative, friend or healthcare worker. Participation is voluntary and if you do not wish to take part, you do not have to. You can also withdraw from this study at any time without giving a reason or receiving a penalty. Please keep a copy of this Information Sheet.

Purpose of this research
Primary purpose of this study is to evaluate the effectiveness of an intervention called Dignity Therapy for inpatients and outpatients with advanced cancer. Dignity Therapy aims to strengthen a person’s sense of worth, meaning and purpose by allowing people to create a lasting legacy document for their loved ones. A legacy document can include information about the person’s life that they see as important or meaningful, personal history that they would want others to know about, words of wisdom, life lessons, personal values, hopes and dreams for their loved ones and things that need to be said or repeated to their loved ones. People who are close to the person receiving Dignity Therapy can also take part in this process. A legacy document is created when an audio recording of this discussion is transcribed and given back to participants to make any necessary changes. Additions to the legacy document can also be made at this time. A final legacy document is given back to the person in paper form and a digital copy is included on an archival CD. Although initial evaluations of Dignity Therapy in Western Australia, Canada and the United Kingdom have yielded positive results for both participants and their families, further research is required before conclusions can be made about effectiveness of Dignity Therapy.

Secondary goal of this study is to evaluate a similar intervention called Life Review. This intervention also involves discussion about past life experiences, important achievements, personal values and hopes and dreams for loved ones. However, Life Review is different to Dignity Therapy in that it does not involve creation of a legacy document. This discussion also needs to be recorded in order to make sure that the two interventions were delivered in an identical way. Direct comparison of these two interventions has never been conducted before. This will allow for specific conclusions to be made about their effectiveness in helping patients with advanced illnesses and their families. If you agree to participate, you will take part in one of these two interventions.
Participation process
If you agree to participate, you will be asked to sign a Consent Form and then complete three questionnaires measuring your physical, psychological and social well-being. It will take you about 20 minutes to complete these questionnaires. If you have memory problems or similar concerns, it may be necessary to assess this first in order to see if you are eligible to participate. You will then be randomly allocated to one of the following three groups:

1. Dignity Therapy, where you would take part in this intervention followed by completion of the same three questionnaires and a satisfaction survey,

2. Waitlist Control Group, where after completing the questionnaires, you would first wait for about 10 days, complete the three questionnaires again, and then take part in Dignity Therapy and complete the questionnaires for the final time as well as a satisfaction survey,

3. Life Review, where you would take part in this intervention followed by completion of the three questionnaires and a satisfaction survey.

For people receiving Dignity Therapy, adults who are given a copy of the legacy document (usually a close family member or carer) will be asked if they would like to complete an evaluation form that measures the effects of Dignity Therapy. They will be provided with a separate Information Sheet and Consent Form if they would like to participate.

Participation is voluntary and confidential
Your participation in this study is completely voluntary. Not participating will not affect the care and treatment provided to you. You can also take part in Dignity Therapy without participating in the research project. You can withdraw from the study at any time without needing to give a reason. If you decide to withdraw, please notify a member of the research team and advise them whether they can keep the questionnaire data that may have already been collected.

The data you provide will be kept confidential and you are NOT required to record your name or any other identifying information on any of the materials used. Numerical codes only will be used for identifying data. The Consent Form that you will be asked to sign will be stored separately to questionnaire measures. The data collected from this research will be reported in general terms only and no participant will be identifiable from the data. Electronic data will be password protected and kept on secure computers on Queensland Health grounds. Hard copies of data will be stored in locked storage on Queensland Health grounds and destroyed after a period of fifteen years. The data collected from the completion of questionnaires will be used primarily to evaluate the effectiveness of Dignity Therapy. However, the data may also be used in subsequent research projects that expand on the current study. In this case, all data will still remain confidential with numerical codes used in order to identify data.

Benefits of this research
Based on prior research, it is likely that participation in this study will have a direct benefit for you and your family members or carer. Effects of participation will be measured by questionnaires and feedback will be provided to you and/or your family or carer upon completion of this research project. Your participation will also help to improve our understanding of the effectiveness of interventions that involve a life-review component for patients with advanced illnesses. Participation in this study may also have important implications for service delivery and research in this area.
Risks associated with this research
Anticipated risks to participants as a result of taking part in this study are minimal. Some participants may become emotional when talking about their life. Families or carers of participants may experience similar emotions. Please notify the researcher or other staff about any concerns that you may have at any time before, during or after your participation. If you or someone close to you wishes to seek professional assistance or counselling about current anxiety, depression, stress or other problems, please inform the researcher or any member of your treating team. Suitable referral options and follow-up will be provided to you.

Feedback about this research
Feedback pertaining to this study will be provided to each participant in the form of an anonymous overall summary of the outcomes of this study. This feedback will not contain any identifying information from any person. If it is not possible to provide you with this feedback due to illness or death, feedback will be made available to close family members or carers. Please advise the researcher if you do not wish for this to occur. This research is being conducted by Dean Vuksanovic as part of his PhD studies. His contact details are provided on the first page of this Information Sheet.

Ethical conduct of this research
This research project has been approved by the Human Research Ethics Committee of Griffith University and the Gold Coast Health Service District Human Research Ethics Committee. This research is to be conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. If you have any concerns or complaints about the ethical conduct of the research project, you should contact either the Senior Manager, Research Ethics and Integrity on (07) 3735 5585 or research-ethics@griffith.edu.au, or Manager, Research Ethics, Gold Coast Health Service District on (07) 5519 8010.

Privacy Statement: The conduct of this research involves the collection, access and / or use of your identified personal information. The information collected is confidential and will not be disclosed to any third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan http://www.griffith.edu.au/privacy-plan or telephone (07) 3735 5585.
CONSENT FORM
Dignity Therapy and Life Review for Inpatients and Outpatients with Advanced Cancer

Student Researcher: Dean Vuksanovic, BPsys(Hons), MClinPsych, PhD Candidate (07 5687 3134)
Dean_Vuksanovic@health.qld.gov.au

Research Supervisors: Murray Dyck, PhD (07 5552 8251)
Heather Green, PhD (07 5552 9086)

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will involve being randomly assigned to taking part in either Dignity Therapy, Life Review or Waitlist Control Group (Delayed Dignity Therapy);
- I understand that my involvement in this research will include completion of a set of questionnaires measuring my physical, psychological and social well-being. These questionnaires will be completed both before and after taking part in either Dignity Therapy or Life Review;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be direct and indirect benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without comment or penalty;
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) or Manager, Research Ethics, Gold Coast Health Service District on 5519 8010 if I have any concerns about the ethical conduct of the project; and
- I agree to participate in the project.

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Researcher Name
Signature
Date
In this research project, you have been invited to participate because your family member or the person you care for has agreed to take part in a study that investigates the effects of creating a legacy document, also known as Dignity Therapy. They have agreed for you to be invited to take part in this research. This study aims to assess your perspectives on the effects of Dignity Therapy.

This Information Sheet tells you about the research project and it explains the procedures involved. Please read the information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding to take part, you may wish to talk with a relative, friend or healthcare worker. Participation is voluntary and if you do not wish to take part, you do not have to. You can also withdraw from this study at any time without giving a reason or receiving a penalty. Please keep a copy of this Information Sheet.

Purpose of this research
Primary purpose of this study is evaluate family and/or carer perspectives on the effects of creating a legacy document that your loved one had done as part of receiving Dignity Therapy.

A legacy document that your loved one has created is likely to include information about their life that they see as important or meaningful, personal history that they would want others to know about, words of wisdom and life lessons, personal values, hopes and dreams for their loved ones, words of advice and things that need to be said or repeated to their loved ones. A legacy document is created when an audio recording of this discussion is transcribed and given back to participants to make any necessary changes. Additions to the legacy document can also be made at this time. A final legacy document is given back to the person in paper form and a digital copy is included on an archival CD.

Participation process
If you agree to participate, you will be asked to sign a Consent Form and then complete a questionnaire that investigates effects of Dignity Therapy for both yourself and the person who took part in this intervention. It will take you about five minutes to complete this questionnaire.

Participation is voluntary and confidential
The data you provide will be kept confidential and you are NOT required to record your name or any other identifying information on any of the materials used. Numerical codes only will be used for
identifying data. The Consent Form that you will be asked to sign will be stored separately to questionnaire measures. The data collected from this research will be reported in general terms only and no participant will be identifiable from the data. Electronic data will be password protected and kept on secure computers on Queensland Health grounds. Hard copies of data will be stored in locked storage on Queensland Health grounds and destroyed after a period of fifteen years. The data collected from the completion of questionnaires will be used primarily to evaluate the effectiveness of Dignity Therapy. However, the data may also be used in subsequent research projects that expand on the current study. In this case, all data will still remain confidential with numerical codes used in order to identify data.

Benefits of this research
It is likely that participation in this study will have no direct benefit for you. However, your participation will help to improve our understanding of the effectiveness of Dignity Therapy. Participation in this study may also have important implications for service delivery and research in this area. Feedback will be provided to you and/or your family upon completion of this research.

Risks associated with this research
Anticipated risks to participants as a result of taking part in this study are minimal. You may become emotional or distressed when talking about your loved one. Please notify the researcher or other staff about any concerns that you may have at any time before, during or after your participation. If you or someone close to you wishes to seek professional assistance or counselling about current anxiety, depression, stress or other problems, suitable referral options and follow-up will be provided to you.

Feedback about this research
Feedback pertaining to this study will be provided to each participant in the form of an anonymous overall summary of the outcomes of this study. This feedback will not contain any identifying information from any person. This research is being conducted by Dean Vuksanovic as part of his PhD studies. His contact details are provided on the first page of this Information Sheet.

Ethical conduct of this research
This research project has been approved by the Human Research Ethics Committee of Griffith University and the Gold Coast Health Service District Human Research Ethics Committee. This research is to be conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. If you have any concerns or complaints about the ethical conduct of the research project, you should contact either the Senior Manager, Research Ethics and Integrity on (07) 3735 5585 or research-ethics@griffith.edu.au, or Manager, Research Ethics, Gold Coast Health Service District on (07) 5519 8010.

Privacy Statement: The conduct of this research involves the collection, access and / or use of your identified personal information. The information collected is confidential and will not be disclosed to any third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan http://www.griffith.edu.au/privacy-plan or telephone (07) 3735 5585.
CONSENT FORM
Family and Carer Perspectives on Dignity Therapy

Student Researcher: Dean Vuksanovic, BPsych(Hons), MClinPsych, PhD Candidate (07 5687 3134)
Dean_Vuksanovic@health.qld.gov.au
Research Supervisors: Murray Dyck, PhD (07 5552 8251)
Heather Green, PhD (07 5552 9086)

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will involve completion of a questionnaire that evaluates effects of Dignity Therapy on family members of participants who take part in this intervention. This questionnaire will be completed soon after Dignity Therapy is completed;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that it is unlikely that there will be direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without comment or penalty;
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) or Manager, Research Ethics, Gold Coast Health Service District on 5519 8010 if I have any concerns about the ethical conduct of the project; and
- I agree to participate in the project.

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A STUDY ON LIFE REVIEW AND CREATING A LEGACY DOCUMENT
Information for cancer patients and their families or carers

Understanding the best ways to support people with advanced cancer is an important area for research. Griffith University researchers, in association with the Gold Coast Hospital Cancer Services and Supportive and Palliative Care, are running a research project where patients with advanced cancer are given the opportunity to take part in one of two interventions.

In Life Review, people are encouraged to talk about their life experiences, important achievements, personal values or things that are important in life, hopes and dreams for loved ones, and other aspects of life that are important or meaningful. In addition to this, some patients will also be assisted in creating a lasting Legacy Document for their loved ones that is created when the above conversations are recorded, transcribed, and edited with the person. This is called Dignity Therapy.

People who wish to take part will be allocated to either Life Review or Dignity Therapy, and they will receive these interventions at no cost to them. Participants will be asked to complete several questionnaires before and after these interventions in order to see how effective they are. If they wish, families or carers of participants can also evaluate how effective these interventions are for participants. Taking part in this research is completely voluntary and there are no consequences or loss of benefits if you choose not to take part.

Please inform one of the staff members if you wish to access the Information Sheet for this study, if you have any further questions or if you would like to take part in this study. You can also directly contact the Primary Researcher – Dean Vuksanovic, who works as a psychologist in Cancer Services and Supportive and Palliative Care on 07 5687 3134.

Thank you.