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**Improving Dignity of Care in Community-Dwelling Patients with Early-Stage  
Dementia**

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***Dedicated to all who are suffering and dying in Ukraine:  
may humanity emerge from this senseless war  
invigorated and renewed by your  
dignity and integrity***

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## ABSTRACT

**Purpose.** The aims of this thesis were to study the feasibility of implementation of Dignity Therapy in older persons with early stages of dementia and their chosen caregiver by adapting the dignity therapy question protocol to both patient and caregiver, and to examine the themes emerging from the resultant dual voice generativity documents. **Methods.** Community-dwelling persons 60 years and older diagnosed with mild dementia and their chosen caregiver underwent dignity therapy separately using a modified version of the dignity therapy question protocol for the caregiver. The resultant edited transcripts were then joined to create a “dual-voice” generativity document which was then presented to the dyad. Clinical measures of dignity, mood, anxiety, caregiver burden, and hopelessness were carried out before and after the therapy for descriptive purposes and to provide clinical context to our qualitative data. The transcripts were analysed using the Interpretative Phenomenological Analysis (IPA) methodology. **Results.** All 12 participants (6 dyads) included in the study completed the study protocol. The patients had a diagnosis of Mild Cognitive Impairment (33%), Alzheimer’s Dementia (50%), and Parkinson’s Disease Dementia (17%) (mean age  $\pm$  SD =  $76 \pm 8$  years ; male = 67%; mean MoCA  $\pm$  SD =  $22 \pm 1.3$ ). All patients had at least a secondary school education (33%) and the majority had a tertiary education (67%). All patients were married and all chosen caregivers were their respective spouses. The use of the adapted dignity therapy question protocol with the caregiver allowed for the creation of a dual-voice generativity document and the procedures were well-tolerated and found to be acceptable by all 12 participants using the Dignity Therapy Protocol Feedback Questionnaire (DTPFQ); 67% reported that the dual-voice generativity document would be helpful to their families. Qualitative analysis of patterns of meaning in the data revealed four superordinate themes related to *relationships* (including *togetherness* and *self-actualization* through the other), their *roots* (including the *social context* of their family background, *transgenerational* influences, and salient interpersonal *beginnings* and shared memories), *respect* (both inherent as well as derived from personal and professional roles), and *receding health and the dawn of the ending* (including concerns related to the future and integrity concerns). There was strong convergence in patients and their caregivers in all four superordinate themes emerging from the analysis. **Conclusions.** The adaptation of dignity therapy to patient-caregiver dyads in early dementia is well-tolerated and results in a rich dual-voice generativity document revealing a strongly convergent set of themes relating to meaning. Addressing and resolving issues related to togetherness, self-actualization, decline and eventual demise in light of a person’s roots and significant roles assumed during their life may provide fertile areas for therapeutic intervention in the early stages of dementia using a dyadic approach. Future prospective studies using mixed methods are needed to assess the impact of therapeutic interventions based on Dignity in Care on mental wellbeing and caregiver burden, as well as its impact on patient care and behavioral and psychological symptoms with advancing dementia.

**Obiettivo.** Gli obiettivi di questa tesi erano di studiare la fattibilità dell'implementazione della Dignity Therapy nelle persone anziane in stadi precoci di demenza e nel loro caregiver adattando il Dementia Therapy Question Protocol sia al paziente che al caregiver, e di esaminare i temi emergenti dal risultante documento di generatività a doppia voce. **Metodo.** Le persone residenti in comunità di età pari o superiore a 60 anni con diagnosi di demenza lieve e il loro caregiver scelto sono stati sottoposti a terapia della dignità separatamente utilizzando una versione modificata del Dementia Therapy Question Protocol per il caregiver. Le trascrizioni modificate risultanti sono state quindi unite per creare un documento di generatività "a doppia voce" che è stato poi presentato alla diade. Le misure cliniche di dignità, umore, ansia, burden del caregiver e disperazione sono state eseguite prima e dopo la terapia a scopo descrittivo e per fornire un contesto clinico ai nostri dati qualificativi. I transcript sono stati analizzati utilizzando la metodologia Interpretative Phenomenological Analysis (IPA). **Risultati.** Tutti i 12 partecipanti (6 diadi) inclusi nello studio hanno completato il protocollo di studio. I pazienti avevano una diagnosi di decadimento cognitivo lieve (33%), demenza di Alzheimer (50%) e demenza di Parkinson (17%) (età media  $\pm$  SD =  $76 \pm 8$  anni; maschio = 67%; MoCA  $\pm$  SD medio =  $22 \pm 1.3$ ). Tutti i pazienti avevano almeno un'istruzione secondaria (33%) e la maggior parte aveva un'istruzione terziaria (67%). Tutti i pazienti erano sposati e tutti i caregiver scelti erano i rispettivi coniugi. L'uso del protocollo della terapia della dignità adattato con il caregiver ha permesso la creazione di un documento di generatività a doppia voce e le procedure sono state ben tollerate e sono risultate accettabili da tutti i 12 partecipanti utilizzando il Dignity Therapy Protocol Feedback Questionnaire (DTPFQ) e il 67% ha riferito che il documento di generatività a doppia voce sarebbe stato utile alle loro famiglie. L'analisi qualitativa dei modelli di significato dei dati ha rivelato quattro temi sovraordinati relativi alle *relazioni* (tra cui "unione" e autorealizzazione attraverso l'altro), *le loro radici* (incluso il contesto sociale del loro background familiare, le influenze transgenerazionali e gli inizi interpersonali salienti e i ricordi condivisi) *il rispetto* (sia intrinseco che così come derivato da ruoli personali e professionali), e salute sfuggente e l'alba della fine (comprese le preoccupazioni relative al futuro e le preoccupazioni sull'integrità). È stata dimostrata una notevole convergenza nei pazienti e nei loro caregiver in tutti e quattro i temi sovraordinati emersi dall'analisi. **Conclusioni.** L'adattamento della terapia della dignità alle diadi paziente-caregiver nella demenza precoce è ben tollerato e si traduce in un ricco documento di generatività a doppia voce che rivela un insieme fortemente convergente di temi relativi al significato. Affrontare e risolvere i problemi relativi all'unione, all'autorealizzazione, al declino e all'eventuale morte in vista delle radici di una persona e dei ruoli significativi assunti durante la sua vita può fornire aree fertili per l'intervento terapeutico nelle prime fasi della demenza utilizzando un approccio diadico. Sono necessari futuri studi prospettici che utilizzino metodi misti per valutare l'impatto degli interventi terapeutici basati su Dignity in Care sul benessere mentale e sul carico del caregiver, nonché il suo impatto sulla cura del paziente e sui sintomi comportamentali e psicologici con l'avanzare della demenza.

## **Introduction**

Dignity therapy is a brief individualized psychotherapy developed to alleviate the emotional and existential distress and enhance the quality of life in individuals at the end of life (Chochinov, 2002; Chochinov et al, 2005; Chochinov et al, 2011) While the therapy resembles other forms of therapy related to life review (Garland & Garland, 2001), dignity therapy differs in its focus on meaning and preservation of dignity through the collaborative creation of a generativity document as a lasting written legacy. It has been shown to decrease psychological distress, depression, and anxiety in patients at the end of life, as well as an improved perceived end-of-life experience in their carers (Martinez et al, 2017; Li et al, 2020; Cuevas et al, 2021). The model has been studied in elderly patients with cognitive decline with promising results (Chochinov et al, 2012; Johnston et al, 2016; Jenewein et al; 2021). However, the presentation and natural history of dementia suggests that modifications in the goals and application of the dignity therapy must be undertaken in dementia (Johnston et al, 2016). Preventing caregiver burden and burnout is key to the successful provision of community care in dementia since it is the most common reason for admission to long-term care (Chan et al, 2003). Dignity therapy offers a brief time-limited methodology that can easily be applied in different medical settings to facilitate dignity-oriented dialogue with the individual with signs and symptoms of mild cognitive difficulties and early dementia. Few studies have systematically evaluated its impact on family members of patients with terminal illness though a number of studies have included caregivers as proxies or additional support/input in the creation of the generativity document (Chochinov et al, 2012; Johnston et al, 2016), and existing evidence indicates that it both a source of comfort as well as a tool towards addressing and resolving end-of-life issues including bereavement (Martinez et al, 2017; Grijo et al, 2021). We therefore propose a feasibility study to evaluate the implementation of dignity therapy in community-dwelling early dementia patients using a dyadic approach to integrate their informal caregiver in the therapeutic process, and conduct a qualitative analysis on the resultant dual-voice generativity documents to explore the emerging themes and the extent of their convergence in patients and caregivers.

## **Study Description**

Dignity therapy is a brief psychotherapy designed to relieve psychological and existential distress in patients with terminal illness. The feasibility and acceptability of dignity therapy has been studied dementia and elderly patients residing in long-term care facilities (Chochinov et al, 2012) and patients with mild cognitive difficulties in the community (Johnston et al, 2016; Jenewein et al, 2021)

with promising results in terms of feasibility, acceptability, and early indications of an impact on mood, anxiety, and dignity (Jenewein et al, 2021). Dementia is most often a progressive illness with cognitive, functional, and neuropsychiatric difficulties that incur a very high burden on formal and informal caregivers resulting in caregiver burnout and admission to long-term care home (Cerejeira et al, 2012). In contrast to other terminal conditions, dementia has a very insidious onset and slow progression and results in significant personal and caregiver biopsychosocial burden ranging from grief reactions, existential crisis, mood and anxiety symptoms, behavioral and other neuropsychiatric symptoms, and burnout. Patients are often in denial of the full extent of their cognitive and functional changes, while caregivers are often overwhelmed by a combination of grief, care-giving burden, and fear of the future (Cheng et al, 2010; Cheng et al, 2019).

Clinical guidelines based primarily on expert consensus have recommended the use non-pharmacological approaches for the management of behavioral and psychological symptoms of dementia, including the use of psychosocial modalities to prevent behavioral disturbance (Kales et al, 2019). However, general applicability of these guidelines has been limited since patients and their caregivers often present in crisis situations to the attention of busy clinical services, leading to the more widespread use of antipsychotic medication despite their well-known severe adverse effects in dementia and early admission to long-term care. Briefer therapeutic modalities such as reminiscence therapy based on autobiographical memories to improve well-being have shown promising results (Elfrink et al, 2018; Cuevas et al, 2020), but do not address the issues of grief and meaning in the early stages of dementia, nor do they assist caregivers in advance care planning (Chochinov et al, 2004). Dignity therapy allows for the involvement of the caregiver in the therapeutic process (Johnston et al, 2016), and results in a tangible personal document that can be used by formal and informal caregivers beyond the formal therapeutic sessions. Moreover it offers a therapeutic space to explore “difficult” issues that are often left unsaid for fear of hurting the other such that the patient and caregiver lose the final opportunity to explore and share that which is truly meaningful in the person’s life and express their wishes for themselves and their loved ones for after they are gone.

We therefore propose a study to establish the feasibility of adapting dignity therapy using a dyadic approach to community-dwelling elderly patients with mild cognitive difficulties and their informal caregiver and examine the emerging themes from the resultant dual-voice generativity document.

## **A. SPECIFIC AIMS**

The aims of this study were to assess the feasibility of adapting the Dignity Therapy Question



Protocol to community-dwelling elderly individuals ( $\geq 60$  years with a Montreal Cognitive Assessment (MoCA) score of  $\geq 20$ ) and their informal caregiver/significant other as identified by the patients themselves, and to evaluate the main themes and subthemes emerging from the outcome of the Dignity Therapy Question Protocol (DTQP) using qualitative analysis of the generativity documents. As part of our feasibility study we also collected clinical data to measure mood, anxiety, demoralization, and hope in both patients and their informal caregiver at baseline, on receiving the generativity document, and two weeks after completion of dignity therapy. Given the small sample-size of this qualitative study these clinical data will be used for descriptive purposes only.

## **STUDY AIMS**

***Aim # 1:*** Determine the feasibility and acceptability of improving dignity of care on the patient and caregiver using Dignity Therapy using a dyadic approach.

***Aim # 2:*** Qualitative analysis of the transcripts from the Dignity Therapy applied to patient and caregiver to identify superordinate and subordinate themes emerging from the dual-voice generativity documents and the convergence of the superordinate themes within the dyads.

## **Sample Size**

The primary aim of this study was to determine the feasibility and acceptability of applying Dignity Therapy to the patient-caregiver dyad in community-dwelling individuals aged sixty years or older with and without mild cognitive difficulties, and to identify and determine the convergence and divergence in themes and subthemes resulting from the transcripts of the therapy sessions in both patient and caregiver. For this purpose a sample of 6-10 dual-voice transcripts is expected to be sufficient for idiographic qualitative analysis using Interpretative Phenomenological Analysis (IPA). We originally sought to recruit a sample of 20 patient-caregiver dyads to allow for the estimation of statistical parameters for sample size calculations in future quantitative prospective studies using clinical measures of mood, anxiety, demoralization, dignity, hopelessness, and caregiver burden. Unfortunately the implementation of the study coincided with the outbreak of SARS-CoV-2 in February 2020. This resulted in the closure of our psychogeriatric outpatient clinics in Malta for an extended period of time. Since these clinics were the gatekeeper for study participant recruitment, the outbreak severely restricted our ability to recruit research subjects. For this reason the total number of study

participants in this study is restricted to 12 subjects (6 patient-caregiver dyads) and all study visits and therapeutic procedures were conducted in subjects' own homes.

## **B. BACKGROUND AND SIGNIFICANCE**

In this section, we discuss the public health importance of closing the knowledge gap in what is known about the neuropsychiatric sequelae of cognitive impairment and their management within the context of the expected growth of this population. Dementia is a clinical syndrome associated with neurodegenerative illness that results in impairments in more than one cognitive domain with resultant functional impairment.

Most dementias, with possible exceptions of those caused by traumatic brain injury and cerebrovascular accidents, are progressive. The most common etiology is Alzheimer's disease, cerebrovascular disease, and dementia with lewy bodies (Ballard et al, 2011; Ballard et al, 2013). The etiology determines the rate of cognitive and functional decline, though disease progression shows significant individual variability. Notwithstanding modest improvement in cognitive symptoms with acetylcholinesterase inhibitors and memantine (Corbett et al, 2013) in some patients, most patients continue to decline over time with progressive degeneration of cerebral function. Most patients experience neuropsychiatric symptoms including anxiety, mood, and psychotic symptoms, and these symptoms are most common in the early to moderate stages of dementias. Caregiver burden and admission to long-term care is predicted by neuropsychiatric symptoms (Chan et al, 2003), such that effective management of neuropsychiatric symptoms has significant public health and economic significance since admission to long-term care and caregiving constitutes the largest fraction of cost in dementia (Hurd et al, 2014). Pharmacotherapeutic modalities to address neuropsychiatric symptoms of dementia are problematic due to a combination of lack of evidence base (e.g. antidepressants in depression), known adverse effects in the elderly (e.g. falls and sedation with benzodiazepines, older antidepressants, and carbamazepine), incontinence and cardiovascular sensitivity (e.g. acetylcholinesterase inhibitors), or evidence suggesting worsening of symptoms (e.g. sodium valproate) (Seibert et al, 2021). The best studies showing some modest positive effect has been shown for antipsychotic medications, particularly when their use is specifically for psychotic symptoms and aggression, though their use is limited by their well-known neurological side effects as well as an increased risk of cerebrovascular accidents and all-cause mortality (Kales et al, 2019).

Given the complex etiology of behavioral and psychological symptoms of dementia, a holistic approach to care is necessary to address the various biopsychosocial issues underlying behavioral and

psychological presentations. Indeed, clinical guidelines recommend minimizing drug exposure and toxicity by using non-pharmacological strategies whenever possible (Kennedy et al, 2021), though the effectiveness of these strategies is generally resource-intensive and limited in applicability. Caregiver burden and resultant psychopathology is also very high in dementia care (Dunkin et al, 1998) and is complicated by the psychosocial effects of caregiving including complex grief reactions over a protracted time-period, physical burden and fatigue, social isolation, and loss of work and personal interests. Traditional psychotherapeutic approaches including Cognitive and Interpersonal Psychotherapy fail to address the biopsychosocial complexity of these difficulties, pay little attention aspects of dementia like personhood (Kitwood & Bredin, 1992), meaning, and existential issues, and are often both time- and human resource- intensive limiting their widespread applicability in clinical settings outside of tertiary or university-based settings.

Dignity therapy was developed to address illness-related concerns and the sense of meaning and purpose derived from one's life experience and social relations in patients with advanced cancer. It has been adapted to several clinical conditions and settings including older persons in care homes (Hall et al, 2009; Hall et al 2012). Dementia presents a unique situation in that while the same illness and existential concerns clearly arise, they present in a context of slow cognitive decline, significant neuropsychiatric presentations including anxiety, depression, and behavioral difficulties, and a loss of independence and autonomy that compromises dignity and personhood. Furthermore, the natural history of dementia makes it ideal for the creation of advance care planning at a time when the affected individual is still capable of communication. However, this process is challenging for most patients and their families due to the sensitive nature of the discussion. Dignity therapy can provide an opportunity to begin an open discussion on advance directives which is not only important for the patient but also relieves the caregiver of the fear of difficult decisions in the future. Dignity therapy requires a relatively brief training period of a few days and involves the use of a guided interview to record significant autobiographical events which are then transcribed and presented to the patient for feedback and edits, and then presenting the final generativity document to the patient as a written legacy that can be shared with caregivers even when the individual is no longer capable of communication. In patients with terminal illness other than dementia it has been shown to increase the individual's sense of dignity and quality of life and has been found helpful by both formal and informal caregivers (Martinez et al, 2017). It has been adapted for individuals with motor neuron disease (Bentley et al, 2012; Bentley et al, 2014; Bentley et al, 2014), elderly patients in long-term care facilities (Hall et al, 2012; Chochinov et al, 2012), and early dementia (Chochinov et al, 2012; Johnston et al, 2016; Jenewein et al, 2021) with good self-reported benefit by patients and families. In a feasibility study in patients with early dementia, Johnston and colleagues modified Dignity Therapy to allow for additional time and prompting during the interview

in a sample of 27 participants including 7 individuals with early-stage dementia residing in the community, 7 family members, and 7 formal caregivers (Johnston et al, 2016). The affected individuals had either normal cognitive status or relatively mild cognitive difficulties with mini-mental state examination scores ranging between 21-30/30, showed no other psychiatric or significant behavioral issues, and were able to provide written informed consent. Outcome measures included the Herth Hope Index (HHI), the Patient Dignity Inventory (PDI), and the Perceived Quality of Life and Satisfaction with Quality Life Ratings. The authors concluded that the therapy was perceived to be helpful by affected individuals and caregivers, and the tools used for outcome measures including the PDI were acceptable and feasible (Johnston et al, 2016). The study was not designed to measure effectiveness and was limited by the small numbers and the relatively high MMSE scores at baseline but provided a basis for future controlled studies designed to assess effectiveness.

## **C. LITERATURE REVIEW**

### **1. The Illness**

Dementia is best defined as a clinical syndrome with progressive decline of multiple cognitive domains associated with deterioration of activities of daily living. The precursor of dementia has been referred to a “Mild Cognitive Impairment” (MCI) (Jongsiriyanyong et al, 2018) in which there is no significant decline in activities of daily living or function notwithstanding mild impairment in cognition, a state that has been redefined by the Diagnostic and Statistical Manual of Mental Disorders 5 (APA, 2013) as minor neurocognitive disorder in which the affected person has evidence of modest cognitive decline despite normal performance in complex activities. DSM-5 has similarly reclassified the term dementia as major neurocognitive disorder in which the individual shows significant decline in memory or other cognitive domain that interferes with independent living. This redefinition has allowed for the variability in presentations of cognitive decline that do not always include memory in their initial stages (e.g. Huntington’s Disease, Lewy Body Dementia, and Primary Progressive Aphasia), and recognizes the high rate of progression to progression of cognitive and functional state in those individuals presenting with significant cognitive symptoms despite preservation of function on activities of daily living. This notwithstanding, the term dementia continues to be widely used both in the literature and in policy documents, and it’s use here is synonymous with the DSM-5 term major neurocognitive disorder.

Since age is the predominant risk factor for dementia, increased life expectancy has led to a dramatic and ongoing rise in the prevalence of dementia in developed countries, such that

dementia is now considered a 'global public health priority' (Alzheimer's Disease International & World Health Organization 2012). In Europe approximately 10 million individuals suffered from dementia in 2010, with the numbers expected to double by 2050 (Prince et al, 2013). The economic implications of this unprecedented rise in dementia in such a brief period has seen policy makers trying to catch up primarily through resources directed at early detection, symptomatic management, community, and institutional care. The unfortunate casualty in this approach has been the personal burden of this disorder, particularly in its impact on personhood and caregiver distress. While most individuals with progressive dementia are suffering from a slowly progressive terminal condition, most palliative measures to date have focused on the terminal phase of cancer and more recently other medical conditions that have a relatively short prognosis of less than one year. On the other hand, most progressive dementias have a median prognosis of 8 years, so that they do not fulfill traditional hospice care criteria, even though a palliative strategy to care can still be adopted as the disease progresses (Vellani et al, 2021).

Several nonpharmacological strategies have been shown to be effective in managing personal distress and behavioral issues in dementia, though the widespread implementation of these therapeutic modalities has been limited since resources tend to be taken up by other necessary but cost-intensive measures including long-term care facilities. While pharmacological measures primarily in the form of drugs targeting central acetylcholinesterase, their impact is at best modest in the early stages of dementia. Similarly, pharmacological management of behavioral and psychological symptoms are limited by their modest effects and significant risk of morbidity and mortality. This has resulted in negative attitudes to the care of persons with dementia by professionals (Liu et al, 2013) due to a sense of helplessness. Hence a need to improve the dignity of care in dementia in different medical and social settings is increasingly felt and highlighted in dementia strategies in the European Union (Wright et al, 2018) that include dignity as one the foundational elements in the respective states' dementia strategies. While a focus on more holistic strategies with persons with dementia by improving family members (Whitlatch et al, 2006) has improved awareness of unmet needs and avoidance of 'talking over' affected individuals, an easily accessible method for dignity-oriented dialogue is missing.

## **The Person with Early Dementia**

Anosognosia, or lack of awareness of the illness, is present in most patients with early signs of dementia especially in those with a lower educational status and higher neuropsychiatric symptoms (Castrillo Sanz et al, 2015). Indeed, medical attention for cognitive decline is most commonly initiated by family members, with affected individuals respectfully tagging along whilst failing to appreciate the nature of their loved ones' concerns. Lack of awareness of the condition is a double-edged sword that presents both advantages and disadvantages to both person with dementia and his/her caregiver. While decreasing distress resulting directly from acknowledging the progressive losses, it also results in secondary distress from a host of behavioral and psychological symptoms that include a sense of insecurity resulting in anxiety, frustration from inability to accomplish tasks, misidentification and misinterpretation of environmental cues, persons, and events, and catastrophic reactions that can range from panic attacks to aggressive behavior. Caregivers are therefore often unable to process their own reactions to the diagnosis with the person affected by dementia, initiating a long process of grief (Brigg et al, 2010) that is often complicated by anxiety, depression, and burnout. Emotions including anger at unresolved past issues with the person with dementia cannot be resolved with their loved one, while society now expects them to carry this new burden of care in addition to other ongoing commitments.

Behavioral and Psychological Symptoms of Dementia (BPSD) is a term used for a heterogenous group of non-cognitive neuropsychiatric sequelae of dementia irrespective of its subtype/aetiology including psychomotor agitation, depression, anxiety, apathy, disinhibition, elation, irritability, sleep disturbance, and psychotic symptoms (Kales et al, 2019). Most persons with dementia experience BPSD, and the symptoms are present in 35-85% of patients with minor cognitive disorder (Monastero et al 2009), though they are generally less prevalent and severe in community-dwelling individuals compared to those residing in residential settings. Depression, anxiety, and apathy are the most common symptoms, and often precede diagnosis of dementia and herald a worse prognosis (Monastero et al 2009).

## **2. The Caregiver**

As Europe undergoes the dramatic demographic changes we are witnessing, the highest burden of care falls on informal caregivers in the community, the great majority of whom are family members. Caregivers of persons with dementia have been shown to be significantly more stressed than non-caregivers (Cheng et al, 2017), and show very high prevalence rates of depressive and

anxiety symptoms (34% & 44% respectively) in addition to having a higher risk of other physical disorders (Sallim et al, 2015). In a two-year longitudinal study, KJ Joling and colleagues found a very high cumulative incidence of anxiety (37%) and depressive (55%) disorders in carers who were either not diagnosable or symptom-free at baseline prior to adopting their caregiving role (Joling et al, 2015). In addition to the personal burden this places on the caregiver, the indirect cost to the person with dementia is that caregiver burden is associated admission to long-term care facility (Gaugler et al, 2011; Eska et al, 2013; Ding-Cheng et al, 2003) which may create its own set of emotional reactions in the caregiver (Gaugler et al, 2009). It is therefore not surprising that caregiver depression has been associated with increased healthcare costs (Zhu et al, 2015). Society therefore gains if it found better ways to address the psychological health of informal caregivers due to its direct and indirect effects on persons with dementia and health care costs on society.

The mediators of caregiver burden in dementia have been studied in several studies. Behavioral and psychological symptoms of dementia (BPSD) have been shown to present more challenges to the caregiver than cognitive and functional impairments, in part due to the negative effect on care provision (e.g. resisting personal care). BPSD is strongly correlated with caregiver burden and depression, with lower correlations found for functional impairment and cognitive impairment (Pinquart et al, 2004). Furthermore, BPSD early in dementia and subsequent increase in BPSD with disease progression predicts future caregiver burden (Gaugler JE et al, 2000, 2005, & 2010; Shim et al, 2016). Biological correlates of caregiver stress reported in the literature have shown that caregivers of patients with BPSD have higher cortisol levels even after controlling for sleep disorders, as well as physical and depressive symptoms (de Vugt et al, 2005; Savla et al, 2011).

The different dimensions of caregiver burden have been studied in a cross-sectional study which showed that while caregiver depression, social isolation, emotional strain, and physical strain were all associated with both patient behavioral and physical disturbances with various contribution by cognitive decline, relationship strain perceived by the caregiver was only related to behavioral symptoms, and that this strain was directly correlated with increasing behavioral neuropsychiatric symptom scores (Bass et al, 2012). Disruptive behaviors are consistently found to be more disturbing to caregivers (Fauth & Gibbons, 2014). This is consistent with findings in patients with the behavioral variant of frontotemporal dementia where disruptive behavior was shown to damage the mutual relationship between the caregiver and the person with dementia (Mioshi et al, 2013). These studies suggest that therapeutic modalities aimed at preventing or

attenuating this relationship strain in dementia may have a significant impact on subsequent caregiver burnout, as well as benefit the person with dementia at least indirectly.

### **3. Therapeutics**

#### **3.1 Pharmacological Management of Dementia**

The pharmacological management of dementia can be classified into three broad groups:

- a. Management of medical factors that may be aetiological to the cognitive decline
- b. Management of pharmacotherapeutic targets that are mechanistically associated with the dementing process
- c. Management of non-cognitive aspects of dementia

Given the broad nature of major neurocognitive disorders, not surprisingly there is no single common aetiological factor predicting or predisposing to the various conditions. Nonetheless, most patients presenting with cognitive and functional decline suffer from one of the three most common causes namely Alzheimer's Disease, Vascular Dementia, and Lewy Body Dementia. While the pathophysiology of each of these conditions is distinct, Alzheimer's and Vascular Dementia do share the common modifiable risk factors of cardiovascular disease including obesity, hypertension, diabetes, abnormal lipid profile, and a sedentary lifestyle (Deckers et al, 2015). Hence patients' pharmacological management often addresses the common outcomes of these risk factors to attenuate risk of further cardiovascular disease. Similarly, in targeting known pathophysiological aspects of dementia, cardiovascular pharmacotherapeutic approaches predominate in vascular dementia, cholinesterase inhibitors and to a lesser extent memantine in Alzheimer's disease, and dopaminergic agonists though with significant limitations in Lewy Body Dementia (Ballard 2013). Nonetheless, cardiovascular approaches and cholinesterase inhibitors can be helpful in all three conditions. Other known causes of cognitive decline include nutritional deficiencies including vitamins B1, 9, and 12 deficiency, hypothyroidism, and alcohol related dementia are treated by addressing the primary cause, though often with less-than-optimal outcomes in some cases. Finally other rarer causes of dementia including the primary progressive aphasia (including bvFTD), multiple system atrophy, Jacob-Creutzfeldt disease, and Huntington's chorea often follow a relentless and more aggressive course with limited impact of any of the above therapeutic modalities.



A wide variety of psychotropic medications including antipsychotics, antidepressants, mood stabilizers, and benzodiazepines are commonly used to manage BPSD when non-pharmacological approaches have either failed, are not available, or when the behaviors are placing the individual or others in harm's way or are very distressing to the individual (e.g. depression or psychosis) Ballard & Corbett, 2010). Their evidence-base and efficacy is variable, and depends on the target symptoms and drug used, and clinicians are advised to use them judiciously given their limitations and harmful effects (Gauthier et al, 2010; Corbett et al, 2014; Kales et al, 2019).

Antipsychotic medications, despite their bad reputation derived in part from the negative outcome of the CATIE-AD study (Schneider et al, 2003; Tariot et al, 2008) and subsequent epidemiological data on their increased risk of mortality and cerebrovascular accidents (Schneider et al, 2005; Schneider et al, 2006; Maust et al, 2015), remain an important therapeutic option with modest efficacy in specific BPSD symptoms namely aggression, psychosis, and agitation (Calsolaro et al, 2019). They are widely used off-label despite their well-known side effect profile, with the best evidence available for risperidone (Kales et al, 2019). Following Schneider's seminal study showing increased risk for mortality and cerebrovascular accidents, there followed a shift from atypical antipsychotics to haloperidol, though the latter has subsequently been shown to have a higher risk especially in the first month of treatment. It is recommended that antipsychotic use in BPSD be restricted to psychotic symptoms, aggression, and agitation when all other non-pharmacological modalities are either ineffective and in the best interest of the patient (Corbett et al, 2014). The risk of mortality continues beyond the first year (Ballard et al, 2009). To minimize risks, clinical guidelines recommend a re-evaluation after three months with a trial of discontinuation (Zuidema et al, 2015), though a high relapse rate of the same BPSD that triggered initial prescription often results in longer-term use (Ballard et al, 2009).

Antidepressant medication, specifically the SSRI citalopram (Pollock et al, 2007), may have some role to play in both BPSD in general and depressive symptoms in dementia though the effect in both is variable likely due to the variable etiology of BPSD and the difficulty in diagnosing depression in dementia. Nonetheless, their better tolerability and safety profile makes them better first-line agents to antipsychotic agents like risperidone (Pollock et al, 2007) except when psychosis or severe agitation and aggression make the latter a better first choice.

Anticonvulsant mood stabilizers have an established history in their off-label use in impulse control disorders in psychiatry, so their use in disruptive behaviors in dementia is not surprising, though the evidence is rather weak (Konovalov et al, 2008) and valproate has been shown to be both ineffective as well as associated with increased risk of falls, infections, and gastrointestinal disorders in Alzheimer's

Dementia (Lonergan and Luxenberg, 2009). Perhaps surprisingly, given their widespread use, there is no evidence-base for the use of benzodiazepines, though they are commonly used for acute agitation and anxiety in dementia.

The management of non-cognitive aspects of dementia includes a broad group of considerations of which BPSD is only one. While a thorough review of this topic is not the intended target of this thesis, these aspects of care intersect of behavioral disturbances in dementia due to unmet needs. These include attention to all causes of frailty, enhancing and preserving mobility as far as possible, prevention of falls, preserving continence using behavioral and pharmacological interventions, skin care and oral hygiene, ensuring adequate nutrition and exercise, respecting, and maintaining autonomy including appropriate use of legal mechanisms available locally to protect the individual's civil rights, and attention to the social, and spiritual needs of the individual. This complex mix of important yet specialized issues require a more holistic and interdisciplinary approach to the management of dementia (Rodriquez et al, 2020).

### **3.2 Non-Pharmacological Management of Dementia**

A number of operationalized strategies and pathways have been developed to assess and manage BPSD. All include a careful history, attention to unmet needs, review of medications, physical examination with particular attention to pain and discomfort, and laboratory tests as indicated. Non-pharmacological therapies for dementia can be classified in five categories:

- a. Therapies targeting cognitive and emotional state (reminiscence therapy and life-story work, dignity therapy, simulated presence, validation therapy)
- b. Therapies involving sensory stimulation (acupuncture, aromatherapy, light therapy, massage, music, Snoezelen multisensory stimulation, transcutaneous electrical nerve stimulation)
- c. Therapies based on behavioral modification
- d. Other therapies including exercise and pet-assisted therapy
- e. Individualized psychoeducational interventions for caregivers

Despite multiple studies investigating these non-pharmacological approaches, most studies include small samples making definitive statements on their efficacy problematic. However, most recent literature has focused on therapies based on life review work, including reminiscence therapy (Cuevas et al, 2020) and life story books (Garland & Garland, 2001). Dignity therapy bears some resemblance to life-review given its basis on a review of specific aspects of a person's life, though it was developed

specifically for persons with terminal illness and is based on a specific model (dignity model) from which an operationalized structured inventory focused specifically on meaning and dignity (Chochinov 2002). Given the specific relevance to the present proposal, these therapeutic modalities shall be described in greater detail in the following section.

#### **4.3.1 Meaning-Centered Psychotherapy**

Meaning-centred psychotherapy refers to therapeutic approaches whose goal is to enhance the meaning of life thereby increasing spiritual well-being and quality of life. This psychotherapeutic approach derives from the work of Viktor Frankl's existential theory (Frankl 1992) which proposes that human beings are primarily driven by a desire to find meaning in their everyday life and especially in times of suffering and distress (Barnes, 2000). In this model, attention to meaning in the context of terminal care reduces suffering and improves well-being. Meaning-Centered Psychotherapy is related to life-story therapies in that it posits that meaning is related to the creation of legacy through a review of their past, present, and future, in addition to attitudes towards adversity and engagement with life. It has been applied and tested in both individual and group brief therapy (up to eight sessions) (Breitbart 2002) in advanced cancer and seeks to facilitate a personal legacy project that may involve addressing relationship issues that were meaningful, travel to a place that always captured their imagination, or creation of a life story in the form of a video, book, or other format. Sessions are semi-structured and manualized, and conducted in such a manner that in each session the therapist creates a specific exercise based on a meaning-related question or project such as listing past meaningful experiences, exploring identity before and after cancer diagnosis, significant memories, relationships, roles and contributions in life, confronting death anxiety, enhancing autonomy through exploration of ongoing responsibilities, and exploring attitudes towards life. Meaning-Centered Psychotherapy was first studied within a group format in a randomized controlled study comparing it to supportive therapy over 8 weeks (Breitbart et al, 2010). While the study did find a higher improvement in spiritual wellbeing and a decrease in depressive symptoms in the active group, the high attrition limited generalizability and questioned its feasibility both in its group format and duration for patients with terminal cancer. The study was followed by a randomized controlled study of seven weekly individual sessions of Meaning-Centered Therapy in Individual Format compared to a control group receiving therapeutic massage. This large study (n=120) included subjects suffering from terminal solid tumours (Breitbart et al, 2012). Both groups showed a similar good retention rate (66 vs 61%), but the active group showed a significantly higher post-treatment spiritual well-being and quality of life as well as significant decrease physical symptom distress. In contrast to the group-based therapy results, this study showed no impact of meaning-centred individual therapy on anxiety, depression, or hopelessness. Despite limitations

imposed by higher attrition rates in the group-based therapy, the *apparent* superiority (no head-to-head trials done) suggests that the group-based process can positively enhance outcomes in meaning-based therapies, a finding that may have implications to our present proposed study.

#### **4.3.2 Life Review, Life Story Books, and Reminiscence Therapy**

Reminiscence is a form of therapeutic life review that was developed by Robert Butler, a geriatric psychiatrist, who became interested in the value of life review in late life when reading Eric Erikson's theory of growth and development (Cuevas et al, 2020). Life review is a process in which an individual is encouraged to review and evaluate his or her life experiences chronologically which may result in the production of tangible 'life story book' (Elfrink et al, 2018) which may take various forms including a written document, scrapbook, album, or memory box (Woods et al 2005). Before their adaptation to older persons and dementia, life story books were originally developed for work with children though they are now widely used in dementia care (Elfrink et al, 2018). They are often recommended to prevent or tackle various behavioral and psychological manifestations of dementia as a tangible reminder of the individual's identity and personhood. Life review as applied to dementia, therefore, can be thought of as a highly structured form of reminiscence in which the person with dementia is the creator and editor of the outcome of the process (Garland and Garland 2001). Indeed, several studies of life review in dementia have shown it to improve wellbeing, mood, anxiety, and self-esteem, with best results obtained when it is combined with the creation of a life story book (Elfrink et al, 2018). However, this form of life review requires the involvement of significant professional human resource to engage the person with dementia in the life review process. Indeed, adaptations of life review is most frequently applied in dementia practice without the involvement of the person with dementia: carers or family members are encouraged to create a "life-story book" in the form of albums, memory box, videos or other formats and present it to the person with dementia without necessarily involving the patient in its' creation (see for example "life story template" at [www.dementiauk.org](http://www.dementiauk.org)).

#### **4.3.3 Dignity Therapy**

As we approach the end of life, the importance of achieving good physical care including pain management is at least as important as achieving a sense of spiritual peace and strengthening important relationships in one's life (Singer et al, 1999). The importance of meaning in one's life can be seen clinically in terminally ill patients with what has been termed "demoralization syndrome" presenting as hopelessness, loss of meaning, and a desire to die (Kissane et al, 2001). A number of psychotherapeutic approaches have been used to address psychosocial and spiritual concerns in

terminal care including supportive therapy which seeks to bolster the individual's existent coping skills and social support network, psychodynamic therapy that uses the therapeutic relationship to address unconscious conflicts, interpersonal therapy that includes psychoeducation, grief, role transition, and interpersonal disputes which are all highly relevant to end of life care, cognitive behavioral therapy that seeks to modify cognitive distortions contributing to depression and demoralization, existential supportive/expressive therapy in a group setting, logotherapy which emphasizes the individual's autonomy over their outlook in life by focusing on activities that bring the most meaning and purpose to one's life, grief therapy work using a variety of therapeutic interventions, life narrative that seeks to place the current suffering within the context of the trajectory of the individual's life, and life review (see review by Chochinov et al, 2004). In palliative settings most of these therapeutic approaches other than supportive therapy are too time- and resource- intensive making them difficult to implement especially within the context of time-limitations of a terminal illness.

Dignity therapy was developed to address these limitations while focusing on enhancing dignity and meaning at end of life. This led to the development of the dignity model to provide what Harvey Chochinov termed a "therapeutic map" for caregivers leading to "dignity-conserving care" to address physical, psychological, social, and spiritual issues at end of life (Chochinov, 2004).

In a qualitative study of 50 individuals receiving terminal care, the same group identified three categories of patients' subjective concerns: *Illness-related concerns*, *dignity conserving repertoire*, and *social dignity inventory* (Chochinov et al, 2002). Each of these three categories included themes and subthemes that served as the basis for a dignity model. Dignity therapy as a therapeutic modality is primarily guided by specific subthemes of the model including generativity, continuity of self, maintaining pride and hope, preservation of one's role, addressing the issue of being a burden on others, and existential concerns of what happens after one has died. In so doing a dying person is provided the opportunity to explore aspects of life that are perceived as most meaningful, identify aspects of their personal history for which they wish to be remembered for, take the opportunity to express things that the individual feels need to be said before they die, and create a written document focused on these themes as a written legacy to their identified loved one/s called the generativity document.

The therapist guides the patient using a list of nine standard protocol questions to guide the conversation in addressing these issues, audio records the session, transcribes it verbatim, edits it using established guidelines, and then reads it out aloud to the patient allowing for editing input before producing a final document that is given to the patient (appendix A). This process takes place at the

patient's bedside within three sessions and is completed within two weeks addressing some of the logistic and time limitations of other therapeutic modalities (Chochinov 2012). While fundamentally borrowing from other therapeutic modalities including supportive therapy in its empathetic and non-judgemental approach, meaning centred therapy and existential approaches in its focus on meaning and existential concerns, and uses techniques from life review and autobiographical techniques of creating a life-story book, it's empirical basis on a theoretical model derived from patients' subjective concerns about dignity at end of life and its emphasis on *enhancing the process of meaning* and *spiritual well-being* without placing excessive weight on interpretation, insight, or working through of the issues, set it apart from the preceding therapies at end of life.

Martinez et al (2017) conducted a systematic literature review on the effectiveness of Dignity Therapy and identified five randomized controlled clinical trials for dignity therapy that have supported its beneficial clinical effect especially in mood and anxiety symptoms, while non-randomized studies have suggested significant improvements in existential and psychosocial distress. Overall all studies have shown a positive perception of the therapy by both formal and informal caregivers and professionals of the beneficial effect of the therapy. Li et al (2020) conducted the first meta-analysis including ten randomized controlled studies (both English and Chinese language) that included cancer patients using dignity therapy compared to standard care and showed that the therapy offers a promising approach to depression, anxiety, and dignity-related distress though conclusions were limited due to small samples and low quality of the studies.

Cuevas et al (2021) conducted a systematic literature review of dignity therapy limited to end of life care and identified 451 articles, of which 28 met their inclusion criteria for dignity therapy in end-of-life care, palliative care, hospice care, and terminal care across all age-groups. They included 16 quantitative, 9 qualitative, and 3 mixed-method studies primarily conducted in the USA, Australia, Canada, Japan, and Taiwan. The quantitative studies primarily used a pretest and post-test intervention design, while the qualitative studies were either case-based or grounded theory designs. Dignity therapy was noted to be highly acceptable to both patients and family caregivers, and no feasibility issues were observed. The Patient Dignity Inventory, Herth Hope Index, Zarit Burden Interview, Herth Hope Index, and the Hospital Anxiety and Depression Scale were the main outcome measures included in the studies. Family members reported that the therapy would be a source of comfort in bereavement and improved scores on depression, anxiety, and hope. Qualitative data identified core values of family, autonomy, sense of self or identity, spirituality, hope, acceptance, and sense of purpose.

One small randomized controlled trial (RCT) was carried out in a sample of 60 older residents in a nursing home in the UK showing no major cognitive impairment (Hall et al, 2012). The results from the control group who received standard psychological and spiritual care did not differ significantly from the intervention group who received dignity therapy in addition to the standard care, though both groups showed significant improvement on meaning as measured by the dignity inventory and both therapeutic approaches were perceived to be helpful by the family. This study was limited by the low level of baseline perceived distress related to dignity as well as high levels of hopefulness in both groups, echoing results from Chochinov's large RCT that included 441 subjects receiving palliative care comparing DT with two control groups receiving client centered therapy and standard palliative care (Chochinov 2011). All groups showed low levels of baseline distress as assessed by the Hospital Anxiety and Depression Scale (HADS), and while the DT group (but not the control groups) showed a reduction in depression scores, the result was not significant.

Two RCT's were carried out in subjects with high levels of baseline emotional distress. Rudilla et al (2016) recently compared the effect of DT with counselling in a pilot study that included small sample of 70 subjects in a palliative care home. They reported a significant decrease in anxiety but not depression following DT, but the manner in which the therapy was conducted in the two groups was not explained in the study. The other study compared DT with standard palliative care (SPC) in subjects with life-threatening diseases (Juliao et al, 2017) and found a significant decrease in both depression and anxiety using the Hospital Anxiety & Depression Scale, HADS (Bocerean & Dupret, 2014) at 4, 15, and 30 days from baseline in the DT group only, with an opposite trend in the control group. The authors also note a higher mean survival time for the DT group compared to the control group. This is consistent with Chochinov's earlier non-randomized study of 100 subjects with terminal cancer receiving DT were subjects who benefited most from DT were more likely to have reported greater psychosocial distress at baseline (Chochinov et al, 2005) as well as that from a more recent RCT in patients with early dementia (Jenewein et al, 2021). Taken together these studies suggest that the impact of DT on psychosocial distress may only be meaningful if applied to individuals with a high level of baseline distress since floor effects likely minimize the impact of those who already have low or normal levels of distress and hopelessness.

Sue Hall and colleagues (Hall et al, 2009) conducted a qualitative study of 18 residents living in nursing homes using a descriptive approach. Their results were analyzed both deductively using the dignity model and inductively from the participants' views. They noted that common to the themes derived from the dignity model, participants focused on illness-related concerns, social aspects of their illness experience, and dignity conserving repertoire, but not subthemes related to death. Furthermore,

participants identified two new themes related to symptoms arising from old age rather than illness, and distress resulted from multiple losses (including their home, family, friends, roles, function, and independence) rather than thoughts of impending death.

#### 4.3.4 Dignity Therapy in Dementia

Dignity therapy was originally created to decrease psychosocial distress and enhance dignity and spiritual wellbeing in persons in an advanced state of a terminal illness. Existential issues, loss of dignity, and resultant psychosocial distress is common to other life situations including that of normal ageing that is associated with a gradual loss of physical and sometimes cognitive function, with a gradual increased reliance on other aspects of daily function that were once independent and autonomous in nature. While growing old should not be equated with a terminal illness and death as revealed by Hall et al (2009), the gradual transition from mid-life to late-life brings with it a normative psychological transition associated with an implicit life review and negotiation of losses and missed opportunities (Holland et al, 2009).

The dignity model therefore lends itself well to assisting elderly individuals through clarification of their life's values and meaning as the inevitable end of life approaches (Hack et al, 2010) since a review of one's life experience is universal in older persons. This process involves not only a reminiscence of one's life but includes the re-examination and integration of past experiences and conflicts to achieve what Eric Erikson called a state of "integrity" referring to the integration of all aspects of one's past experience in the identity of the psychologically healthy older adult (Holland et al, 2009). To some extent this resembles the process of life review in which both positive and negative life experiences are integrated in one's narrative. Indeed, reminiscence and life review have been shown to result in a moderate impact on life satisfaction and emotional being and depressive symptoms in older adults (Korte et al et al, 2009; Pot et al, 2010; Korte et al 2012; Weterhof et al, 2014).

Chochinov et al studied DT in 23 care home residents aged 56-94 years with mini-mental state examination (MMSE) scores > 21/30 and informal family caregivers closely involved with the residents who were also asked to provide feedback on the DT that their loved ones had received (Chochinov et al, 2012). The family members were also directly involved in the DT process for those more cognitively impaired subjects, and in those instances of more severe cognitive difficulties hampering active participation in the DT (n = 11) the family members participated directly in the DT even without any input from the subject who may or may not have been present for the DT and creation of the generativity document. The outcome was assessed using a post-intervention questionnaire for both



residents, family members, and health care providers. Most of the participants found the therapy helpful or thought that it was useful for their loved one. Interestingly health care providers not only perceived the therapy as helpful, but also reported that it changed the manner in which they perceived the resident as a result of new insights on the individual that resulted from the DT.

Bridget Johnston and colleagues assessed the feasibility of DT in early-stage dementia in a small mixed-methods study of seven persons with early stage dementia aged 71-82 living in the community (Johnston et al 2016 & 2017). They noted that the methods and outcome measures used were appropriate, though they required more time to complete the therapy and edit the generativity document compared to DT in other palliative care settings. The interviews were conducted with both patient and family member present, and the latter often helped to prompt and confirm events. They identified the main themes emerging from a multisource qualitative analysis including patient interviews, focus group, and family members: *a life in context*, *a key to connect*, and *personal legacy* (Johnston et al, 2016). In the analysis of the generativity documents the emerging themes were those of the individuals' values, essence and affirmation of the self, forgiveness and resolution, and existentialism/meaning of life (Johnston B et al, 2017).

The identification of these themes in a personalized account in the generativity document may provide a basis to connect with the individual even at a later stage of the illness, and a basis for behavioral manifestations that emerge in dementia – that is, unmasking the “person” behind the behavior may improve communication and help the caregiver better understand and respond appropriately and effectively.

In terms of quantitative outcome measures (Patient Dignity Inventory (PDI), Herth Hope Index (HHI), and Quality of Life rating), most subjects were able to complete these measures, though they needed additional help and guidance with understanding and completing them. The PDI, which is the longest of the scales and includes the fundamental questions of the dignity model, was completed by all participants with consistency noted in most participants (4/7), and at least a good level of understanding and appropriate completion in all participants (Johnston et al, 2016).

#### **4.3.5 Improving the Dignity of Care in Dementia**

As discussed above, the adaptation of DT to conditions and situations beyond those with advanced cancer is feasible and acceptable to patients and relatives of older adults in care homes, motor neurone disease, and early-stage dementia. Similarly its mode of application can be adapted successfully.

Testoni and colleagues used an adapted mode of implementation of Dignity Therapy using photographs to trigger conversation and memories on meaningful life values (Testoni et al, 2020). Nonetheless, the need for trained therapists remains a stumbling block in the widespread implementation and study of therapeutic modalities in practice. A variation of dignity therapy called Dignity Talk (Guo et al, 2018) has been developed in an attempt to produce a series of questions for the patient and family member to which they respond to together without a therapist. The questions which are based on the patient dignity inventory offer an opportunity to broach difficult questions thereby enhancing communication and decreasing isolation at end of life. While intuitively useful, it's application in dementia is limited by (a) lack of a generativity document that can be referred to once patient's condition advances; (b) in dementia the focus is less on the patient distress and more on the caregiver's as part of grief (Brandstatter et al, 2014), a need to gradually change roles, and then grief for loss of own role and that of the loved one – hence while the distress is happening within the dyad, it is often felt disproportionately by the caregiver.

We propose that Dignity Therapy need not be adapted to dementia, but rather the mode of its administration adapted to ensure participation of key persons in the person's life. Through separate administration of the PDI to both patient and identified caregiver, the subsequent creation by the therapist of a 'double-voice' joint generativity document reflecting the perspectives of each of the dyad to the same question posed by the PDI allows for the creation of a unique living document of a relationship which may with time appear to be gradually lost with loss of cognitive function but remains preserved in the shared document. The document therefore can be used to periodically reminisce on the meaning of the 'cared for' and allow for an ongoing grief process of the caregiver across the various stages of the condition.

Families often deal with early dementia through either shock, denial, or rationalization in order that they may make difficult decisions. Other primitive defense mechanisms are often also at play, including splitting and projection with family and formal caregivers or professionals. Integrating the caregiver in Dignity Therapy may allow for a healthy expression of meaning and congruent emotion, which in turn may facilitate healthy grief, decrease caregiver distress, and better care for the patient with dementia. We therefore adapted the Dignity Therapy Question Protocol to include the caregiver in the present study (Appendix B).

## **D. RESEARCH DESIGN AND METHODS**

### (a) Context of the study within SARS-CoV-2 epidemic

The study was conducted in 2020-2021 coinciding with the outbreak of SARS-CoV-2 which severely restricted the original recruitment goal of 20 patient-caregiver dyads to allow for a mixed-methods analytic strategy. Nonetheless, the protocol was modified to allow for the conduct of the study in the subjects' own home given that all ambulatory clinics were closed and clinical sessions in most countries including Malta adapted to this reality through the use of telepsychiatry. The design and results presented in this thesis therefore focus on the qualitative data since the sample size was considered inadequate for a quantitative approach but adequate for an idiographic approach using Interpretative Phenomenological Analysis (IPA). The quantitative data are presented for descriptive purposes only, and to help contextualize the qualitative data derived from the dual-voice generativity document.

### (b) Training and supervision in Dignity Therapy

The therapy sessions were conducted by the investigator and two postgraduate students enrolled in a Master's Degree programme in Geriatrics and Gerontology at the University of Malta who form part of the researcher's team (a specialist in geriatric psychiatry and a senior resident in geriatric psychiatry). The team received formal training in Dignity Therapy by Prof L Grassi and Prof M.G. Nanni at the University of Ferrara, Italy. The training programme took place in 2019-2020 and consisted of didactic classes on the theoretical aspects of Dignity Therapy, practical demonstration of Dignity Therapy, and the editing process of the transcripts to create the generativity document. This was followed by online sessions during which transcripts were presented and reviewed to ensure fidelity to the study protocol. A pilot study was then conducted on a dyad to ensure feasibility of the adapted DTPQ to the caregiver and that a valid dual-voice generativity document could be created. This pilot also served for reflection on the study design and resulted minor modifications in the study visits highlighted below.

### (c) Personal contextual reflections on the process of the analysis of idiographic qualitative data

Concurrent with the Dignity Therapy training and conduct of this thesis, the investigator also initiated and is presently enrolled in the intermediate stage of formal training in Cognitive Analytic Therapy (CAT) (Hallam 2021) supervised by Jessie Emilion, Cognitive Analytic Psychology Lead at the Munro Centre in London, UK. The context of my interest in CAT informed my own formative approach

to the Interpretative Phenomenological Approach (IPA) methodology. Consistent with all qualitative and quantitative approaches, IPA asks of the investigator to consciously strive to minimize bias in one's reading and extraction of patterns of meaning in the subjects' accounts, also known as epoché or bracketing in phenomenological literature. It invites the investigator to engage in the resultant patterns of meaning emerging from the transcripts and allow for the use of psychological language in their interpretation and identification of superordinate and subordinate themes. As a geriatric psychiatrist trained in the London, the USA, and Canada in both quantitative research and psychotherapeutic techniques including psychodynamic, interpersonal, and cognitive behavioral therapies, this approach to phenomenological research struck me both in its scientific discipline as well as the use of psychological language in interpreting patterns of meaning that were derived by the same investigator - a process that seeks to refrain from allowing personal biases and assumptions to intrude on the data analysis so as to allow the subjects' own inherent meaning to emerge uncontaminated by one's own personal and psychological machinations. It is at this meta-level that I found my ongoing CAT training most useful: like most therapeutic approaches CAT seeks the preservation of the observing ego in the process of both data gathering, reformulation and therapeutic sessions. However it also demands of the therapist engage in a therapeutic role that is not hierarchical, that is, one that seeks as a goal that the therapist accompany the client with an attitude of co-therapists: CAT therapists like to say that there is one therapist in the beginning but two therapists at the end of the therapy. The third element of CAT that is of relevance to my IPA approach to this study is its focus on reciprocity, or 'reciprocal roles' in the CAT language. This highly intuitive and useful concept refers to the origin and persistence of our psychological attitudes and resultant behavior starting from our very early interactions with "the other" which is based on the objects relations theory. CAT however sees this object internalization as relational - that is a process that involves being at once the recipient and the perpetrator of the psychological process being introjected. Thus a loving mother's care is introjected as "loved by and loving to" and is then enacted early in life in play (eg caring for a doll) and later in adult relationships. CAT seeks to identify these reciprocal roles and the resultant cognitive processes and patterns of behaviors used to deal with their outcome, then identifying 'exits' from problematic cognitive processes and behaviors identified in the early 'reformulation' stage (Ryle & Fawkes, 2007). CAT's focus on reciprocal roles in the formulation of the therapeutic goals become very relevant when approaching a dyadic approach to Dignity Therapy as opposed to the traditional application to a (lone) client since in creating a "dual-voice" one immediately encounters reciprocal role relations (RRR), a pattern of interaction originating in early life relationships and maintained in adult life. It is these reciprocal role relations that made the largest impact on my own interpretative phenomenological analytic approach in the final stages of integrating patterns of meaning as shall be seen in the discussion.

#### (d) Inclusion Criteria

Community-dwelling elderly individuals  $\geq 60$  years old (henceforth referred to as 'patients' and identified by 'P' in the results section to distinguish them from the 'caregiver' or 'C' referring to the patient's chosen person having a caregiver role). Participants were recruited using convenience sampling from outpatient clinics at Karin Grech Rehabilitation Hospital (KGRH), a dedicated rehabilitation facility for the elderly incorporating a multidisciplinary team approach including geriatric medicine, geriatric psychiatry, psychotherapy, physical and occupational therapy, social support and other allied care professionals as needed. Community-dwelling patients fluent in both of the national languages (Maltese and English) with a clinical diagnosis of mild cognitive impairment (MCI) or early stage dementia (ESD) with a Montreal Cognitive Assessment (MoCA) score of  $\geq 20/30$  and their identified informal (i.e. not-paid) caregiver were eligible for recruitment in the study. Caregivers were included in the study provided they gave their informed consent, were selected independently by the patient, and had no known cognitive impairment with a MoCA score  $\geq 25/30$  confirmed at baseline study visit (T0).

#### (e) Use of the Montreal Cognitive Assessment (MoCA) instrument

The Montreal Cognitive Assessment (MoCA) is a brief neuropsychological battery adapted for bed-side use testing short-term memory, visuospatial skills, orientation, language, and executive function including attention, working-memory, and concentration. It was designed to address the limitations of the widely used Mini Mental State Examination (MMSE) which is less sensitive to earlier stages of cognitive decline (Arevalo-Rodriguez 2015; Nasreddine 2005). The MoCA is very sensitive to detecting mild cognitive impairment in persons with an MMSE score of  $\geq 25$  points, and is freely available and translated in multiple languages including Maltese. Notwithstanding its high sensitivity, the MoCA suffers from a lower specificity for the diagnosis of dementia (Smith, Gildeh and Holmes 2007), though for our purposes the diagnostic specificity was considered less important in terms of the specific aims of the study.

#### (f) Ethical Considerations

The study protocol and informed consent documents were approved by the Faculty Research Ethics Committee (FREC) of the Faculty of Social Wellbeing of the University of Malta and the Institutional Research Committee of Karin Grech Rehabilitation Hospital (KGRH) since recruitment was conducted through the clinical facilities at KGRH. Study information was disseminated to clinicians at

KGRH who identified potentially eligible patients and invited the patient-caregiver dyads to contact the researcher who then met with the dyad to complete the informed consent process and assess for eligibility as per inclusion criteria. Participants were free to withdraw from the study at any stage of the study protocol without adverse impact to their clinical care provision and all anonymized study documentation and digital audio recordings stored securely. The study was conducted in accordance with General Data Protection Regulation (GDPR).

A real danger in reporting ideographic data is the potential for revealing identifiable confidential information when reporting the qualitative results, particularly when providing data quotes to substantiate the emergent themes. To address this issue in this thesis I have taken the following additional precautions. While the demographic and clinical data are reported (for descriptive purposes only), the quotes in the results section supporting the emerging themes are not linked back to these data. The reason is to prevent potentially identifiable information being revealed by linking demographics with quotations from the life stories contained in the generativity documents. All participants are given fictitious names in the results section and certain detail in the quotations that could identify the participant was removed or changed such that it did not impact the meaning of the quote. Similarly I have not added examples of full generativity documents to this thesis since even if de-identified/anonymized, the highly personal nature of the content of these documents would be easily identified by relatives or acquaintances of the study participants particularly in a small island community. Rather I chose to quote de-identified sections of the transcripts in the results and discussion section to support and better illustrate the emerging themes. I have also been careful to preserve the confidentiality of the participants by not providing the given title of documents that stood out from the rest since anyone with who the participant chose to share the document with would easily identify the authors of the respective generativity documents. I do acknowledge that these omissions (made for the sake of preserving confidentiality) limit the readers' appreciation of the depth and structure of these dual-voice generativity documents. However, in the final analysis the participants are the ultimate owners of their generativity documents and the precautions taken are particularly important in a relatively small community residing on the island of Malta.

#### (g) Study Visits

Both patient and caregiver were enrolled in the study after completing the informed consent process in Maltese or English (T0). The Montreal Cognitive Assessment Scale (MoCA) were administered to all patients and designated caregivers signing the informed consent document to determine whether the inclusion criterion of MoCA score of  $\geq 20/30$  for patients and  $\geq 25/30$  for

caregivers were met (T0). The Dignity Therapy Question Protocol (Appendix A) (Chochinov et al, 2005) was utilized to facilitate the dignity therapy session with the patient, and all procedures were carried out as described by Chochoniv et al (2005). The protocol was also adapted for use with the caregiver with minor modification to add the caregiver's voice to the resultant dual-voice generativity document (Appendix B). Subject visits were scheduled as per Table 1. We considered having a single conjoint session with both caregiver and patient. The principle advantage of this methodology would have been resource-related: a single therapist would carry out the session with both. However, we opted to have separate sessions for patient and caregiver for the following reasons. It has been evident in our clinical work that caregivers tend to 'dominate' sessions and are inclined to 'speak for' their loved one. Conversely, dementia patients almost universally turn to look at their caregiver whenever they are asked questions in their presence which may have biased the generativity document towards the caregiver responses. Rather our goal was to create a genuine dual-voice generativity document incorporating the patient's and caregiver's perspectives of the most meaningful aspects of the patient's life and in which both voices were independent of each other. For this reason the sessions with the patient and caregiver were conducted by two separate therapists to ensure that neither therapeutic process contaminated the other, and sessions were audio recorded for the purpose of transcription. Each separate session took on average 60 minutes – while patients tended to have a relative paucity of information to offer and needed more prompting and redirection due to their cognitive difficulties, caregivers made up for this by tending to be more voluminous in their responses.

Two separate transcripts were thus created during the first Dignity Therapy Session (T1) and these were edited by the therapist to eliminate colloquialisms and non-starters and the edited transcripts were presented to the patient and caregiver separately at the next session (T2) scheduled within a week of the first dignity therapy session. Consistent with the non-judgmental therapeutic approach of the Dignity Therapy methodology, no attempt was made to influence, interpret, or question the response provided by either the patient or the designated caregiver in the creation of the generativity documents. We made no attempt to correct/edit discrepancies/disagreements between patient and caregiver in the editing process, though for the purpose of coherence we allowed minor editing of cognitive distortions relating to time-periods and repetitions related to dementia in the patient without changing the content or meaning of what was said. During T2 the patient and caregiver were given the opportunity to read or listen to their transcript read out to them, and to edit or add to any part of the text. Due to the nature of early-stage dementia as well as the multiple medical comorbidities in older individuals including limited visual acuity, the transcribed document was read back verbatim slowly to the patient, though patients also had the option to read through the document if their condition allowed. The two edited transcripts were then merged to form a dual-voice generativity document. In

the case of any discordance between patient and designated caregiver, both perspectives were retained in the combined generativity document which was presented to the dyad (together) within one week of the second session (T3). Our pilot study suggested that at T3 the dyad felt the need for minor edits to the final dual-voice document, so study participants were given the opportunity to make final edits to their voice as they thought fit at T3. A hard copy of the final generativity document was presented to the dyad in a final session (T4) scheduled within two weeks of T3. The post-intervention clinical assessments were conducted at T0 and T4.



Table 1. Schedule of Study Visits

Visit # (T#)	Week	Reason For Visit	Study interventions
0	0	Informed Consent Inclusion Criteria Baseline Clinical Measures	Informed Consent Process MoCA Patient Dignity Inventory (PDI) Hospital Anxiety and Depression Scale (HADS) Demoralization Scale-II (DS-II) Herth Hope Index (HHI) Zarit Burden Interview (ZBI-12)
1	1	DT	Dignity Therapy Question Protocol (DTQP)
2	2	Editing of generativity document	Presentation of transcript of DTQP and editing of transcript
3	3	Presentation of joint generativity document	Presentation of edited joint generativity document to patient-caregiver dyad.
4	5	Clinical Outcome Measures	Patient Dignity Inventory (PDI). Dignity Therapy Patient Feedback Questionnaire (DTPFQ) Hospital Anxiety and Depression Scale (HADS) Demoralization Scale-II (DS-II) Herth Hope Index (HHI) Zarit Burden Interview (ZBI-12)

(h) Data Analysis

Given the idiographic nature of the data resulting from the semistructured interview employed in this study (DTQP), the Interpretative Phenomenologic Analytic methodology was used in our qualitative analysis. Each generativity document was analysed individually before any attempts at generalization with careful consideration to ensure awareness of personal biases and prevent them from contaminating the interpretation of the subject's data. This was enabled by the writing of brief personal reactions to the data following an initial read of all the documents prior to any attempt at extracting meaning from the transcripts. The data was then re-read line-by-line making notes about the the salient aspects of the data including thoughts, observations, and reflections on the meaning of the text. In the second stage of the analysis these initial notes were used to extract patterns of meaning in the text

using psychological language where appropriate while consciously making every effort to avoid imposing personal beliefs and biases on the emerging patterns of meaning. The preceding steps were conducted for each generativity document independently. In the next step the emergent themes from each transcript were identified and the investigator sought to structure these patterns into clusters and hierarchies of meaning resulting in the main superordinate and subordinate themes that were recorded in a table. The patterns of meaning resulting from patient and carers in the individual generativity documents were then inspected for convergence or divergence of superordinate themes for each dyad.

## **E. RESULTS**

### **(a) Study Participants**

Eleven patient-caregiver dyads were identified by the gatekeepers and referred to the investigators for participation in the study. Of these, three dyads decided not to participate on learning more about the study and one dyad signed informed consent but did not meet inclusion criteria for participation (caregiver with MoCA < 25). Of the remaining seven dyads who fulfilled inclusion criteria, one dyad was withdrawn from the study at T0 before starting dignity therapy due to significant psychiatric comorbidity in the caregiver that required clinical attention.

The patients had a diagnosis of Mild Cognitive Impairment (MCI) (33%), Dementia of the Alzheimer's Type (DAT) (50%), and Parkinson's Disease Dementia (PDD) (17%) (mean age  $\pm$  SD = 76  $\pm$  8 years ; male = 67%; mean MoCA  $\pm$  SD = 22  $\pm$  1.3). All patients had at least a secondary school education (33%) and the majority had a tertiary education (67%). Caregivers had a spousal relationship with the patients (female = 67%) and had an overall lower level of education overall (33% tertiary, 50% secondary, 17% primary) and a mean MoCA score of 28.5 ( $\pm$  1). The patients' and caregivers' demographics and clinical scores before and after dignity therapy are listed in Table 2.

### **(b) Feasibility & Participant Satisfaction**

All six dyads starting dignity therapy completed all study visits and procedures with no difficulties noted in the completion of clinical instruments or engagement with the therapeutic process. Results from the DTPFQ showed that Dignity Therapy was well tolerated and found to be acceptable by all participants with no adverse events documented. Participants reported that it was useful and satisfactory, and that it enhanced meaning in their lives, while 67% reported that it would be helpful to their family though it was perceived to have minimal impact on how they were perceived by healthcare professionals, which is perhaps not surprising given that the sessions were conducted in a domiciliary

setting. Had the study been conducted in a more typical clinical setting (medical outpatient clinic or hospital setting), making the generativity documents available to the patient's direct healthcare workers with the patient's consent would be expected to enhance the appreciation of the 'person' behind the 'patient', though this question in the DTPFQ was not adapted to our domiciliary setting.

Table 2. Demographic and Clinical Characteristics of the Patients (P) and Caregivers (C). Clinical scores are reported for patients and caregivers, giving the baseline (top) and post-intervention (scores) for the respective clinical instruments. <sup>1</sup> MoCA, Montreal Cognitive Assessment Scale (Arevalo-Rodriguez 2015); <sup>2</sup> PDI, Patient Dignity Inventory (Chochinov et al, 20012); <sup>3</sup> HADS for Anxiety & Depression, Hospital Anxiety & Depression Scale, clinically relevant scores for each subscale > 7 (Bjelland et al, 2002); <sup>4</sup> DS-II, Demoralization Scale – M&P, Meaning & Purpose and D&C, Distress & Coping Ability (Robinson et al, 2016<sup>a,b</sup>); <sup>5</sup> HHI, Herth Hope Index (Herth 1992); <sup>6</sup> ZBI-12, Zarit Burden Interview (Bedard et al, 2001).

Dyad	Age	Gender	MoCA <sup>1</sup>	Education	Clinical Diagnosis	PDI <sup>2</sup>	HADS-Anxiety <sup>3</sup>	HADS-Dep <sup>3</sup>	DS-II M&P <sup>4</sup>	DS-II D&C <sup>4</sup>	HHI <sup>5</sup>	ZBI-12 <sup>6</sup>
P1	87	M	20	Tertiary	PDD	73	1	6	7	9	34	
C1	87	F	27	Secondary		52	2	7	5	4	29	
						40	9	6	2	9	40	27
						38	8	5	2	3	39	18
P2	86	M	21	Secondary	MCI	35	6	1	4	5	37	
C2	82	F	28	Primary		37	9	3	3	3	40	
						27	3	1	1	2	44	5
						31	5	2	1	4	35	5
P3	71	F	23	Secondary	DAT	33	7	6	3	5	41	
C3	72	M	28	Primary		33	9	6	3	6	38	
						29	5	3	1	6	44	5
						27	5	1	0	3	45	7
P4	67	F	23	Secondary	DAT	27	3	1	1	2	47	
C4	66	M	29	Tertiary		27	3	0	0	1	43	
						28	4	1	0	2	41	6
						26	1	0	0	1	37	6
P5	73	M	22	Secondary	DAT	41	12	7	3	8	30	
C5	65	F	29	Tertiary		35	8	4	2	5	33	
						29	4	2	0	2	40	7
						28	2	1	0	4	39	5
P6	74	M	23	Tertiary	MCI	33	7	1	3	8	36	
C6	73	F	30	Secondary		28	1	0	1	4	38	
						30	1	5	1	2	33	0
						27	0	1	1	1	33	2

### (c) Results of Qualitative Analysis

The dignity therapy question protocol (Appendix A) is a semi-structured interview consisting of a series of eleven questions on areas relating to values and meaning. As such it is a very personal account highlighting personal memories and accomplishments held with pride, personal and professional roles, and life lessons that they wish to pass on. It's focus on details of individual life events and personal experience lends itself to an interpretative phenomenological analytic approach which was the methodology used on this thesis for the qualitative analysis of the dual-voice generativity documents. The aim of this analysis was to identify superordinate and subordinate themes emerging from these transcripts and whether the inclusion of the dual voice (which was "joined" by the therapist but reported independently by the patients and their caregiver in separate DT sessions) reveals any convergence or divergence in the emergent themes. It is important to emphasise that the caregivers' sessions were independent of the patients' sessions, using a modified dignity therapy question protocol that sought their perspectives on the most important and meaningful aspects of the patients' life as well as those areas in their own life that was influenced by the patient (Appendix B). Thus for example, whereas the patient was asked "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?", the caregiver was independently asked "tell me a little about meaningful moments that you shared with (your loved one), particularly the parts that you either remember most or are the most important?". Similarly while the patient was asked "what are your most important accomplishments, and what do you feel most proud of?", their caregiver was asked "tell me about how (your loved one) influenced your life?" and "what are the most important accomplishments that you reached in your life thanks to your loved one?". Thus rather than act as a "proxy" to help the patient respond to the DTPQ prompts as done in previous studies (Chochinov, 2012), the caregiver provided an independent voice to the generativity document: we did not ask them what they 'thought' was most meaningful or most important accomplishment for their loved one, but rather sought objective memories of important and meaningful shared moments with their loved one, and how their loved one impacted their own life. The caregivers' contribution to the 'dual-voice' generativity document allowed for a rich relational approach not only to the actual structure of the document but also to the emerging themes which will be discussed later.

From the analysis of the dual-voice documents four superordinate themes emerged: the value of *relationships*, the individuals' *roots*, *respect* both inherent and those derived from personal or professional roles (Hawryluck 2004), and issues related to *receding life and the dawn of the end* (Table 3). Close examination of individual dual-voice documents revealed strong convergence in patients

and their caregivers with regards to all four superordinate themes, that is both patient and their caregiver within each dyad provided data for each of the four emergent superordinate themes.

In the next sections these superordinate and subordinate themes will be presented in detail, with quotes from the transcripts supporting the patterns of meaning underlying the emergent themes. It should be noted that notwithstanding the idiographic nature of each account, the dyads recruited in this study all had a spousal relationship. Furthermore they all shared many years of life experience such that they had the opportunity to know the other very well. This may in part explain both the richness of the accounts and emergent themes as well as the strong thematic convergence.

Table 3. Themes emerging from the Qualitative Analysis

Superordinate Themes	Subordinate Themes
<p><b>1. Relationships</b></p>	<p><b>(a) Togetherness</b></p> <ul style="list-style-type: none"> <li>- 'Being and doing together'</li> <li>- 'Being known'</li> </ul> <p><b>(b) Self-actualization through the other</b></p> <ul style="list-style-type: none"> <li>- <i>Space to grow</i></li> <li>- <i>Making</i> the other 'whole'</li> <li>- <i>Keeping</i> the other 'whole'</li> <li>- <i>'Being seen'</i></li> </ul>
<p><b>2. Roots</b></p>	<p><b>(a) Social context</b>  <b>(b) Transgenerational influence</b>  <b>(c) Interpersonal</b></p> <ul style="list-style-type: none"> <li>- beginnings</li> <li>- life shared</li> </ul>
<p><b>3. Respect</b></p>	<p><b>(a) Respect derived from Roles</b>  <b>(b) Inherent Respect</b></p>
<p><b>4. Receding Health and the Dawn of the Ending</b></p>	<p><b>(a) Concerns related to the Future</b></p> <ul style="list-style-type: none"> <li>- Uncertainty &amp; Hope</li> <li>- Inevitable decline &amp; death</li> <li>- Legacy</li> </ul> <p><b>(b) Integrity</b></p> <ul style="list-style-type: none"> <li>- Dealing with Role Transitions</li> <li>- Sense of 'fullness in life lived'</li> <li>- Regrets</li> </ul>

## 1. RELATIONSHIPS

The central value of relationships emerged in every dual-voice generativity document. While the relationship of the dyad (spousal) may suggest that this is expected, even when the narrative indicated significant tensions and regrets related to their relationship, the inherent value placed on relating or the wish to relate with the other persisted throughout the transcript. Furthermore, this theme consisted of three subordinate themes that explained the source of meaning of relationships. These consisted of the value placed on (i) *'being and doing together'* and *'being known to another'* which I termed *'togetherness'*, and (ii) *'self actualization through the other'*. These subordinate themes were variably mediated by attributes of *agreableness* (gratitude, validating, empowering, humour, humility, altruism, generosity, empathy, affection), *conscienciousness* (respect, honesty, tenacity, industriousness, reliability, loyalty, trustworthiness), *authenticity*, *mindfulness*, and *spirituality*. David (C) illustrates the value of these attributes as he reflects on his hope that they will find a way to get through Barbara's (P) cognitive decline by saying "a worm manages to survive in a pebble", echoing Barbara's (P) own initial reflections of their modest beginnings when she said that despite having very little it was more than sufficient for them. The underlying meaning of these statements is that his love and affection for Barbara (P) transcends the reality of her decline and eventual demise, and that with humility, tenacity, respect, loyalty, hard work, and a faith in the transcendent they are hopeful in their ability to deal with their current adversity together as they have always done.

People live their lives in relation to others, and in so doing assume roles that take on a very personal meaning. In this thesis two origins of meaningful roles were identified in the dual-voice generativity documents, family roles and professional roles. Meaningful family roles were present in all dyads supporting the significance of common goals in relationships, though the most commonly cited as expected were spousal and parental roles, with grandparental and avuncular roles mentioned less frequently. The (spousal) roles provided a context for togetherness ('being and doing' together, for example as parents) and self-actualization (making the other whole, for example by validating and facilitating the other's role as a parent). While professional roles provided an opportunity for togetherness by allowing space for the other to grow and in so doing also making them whole through their self-actualization as a professional, for some they also distracted from the more meaningful aspects of their lives which later led to regrets as was poignantly pointed out by John (P) when he said "I lost alot. I was the loser!".



## 1.1 Togetherness

The value placed on relationship, especially their spousal relationship, was both a recurring and highly convergent theme in all generativity documents. All dyads went into significant detail of how they first met many decades ago, and how their relationship became a space where they grew by 'being and doing' together while sharing a set of common objectives, and 'being known to another' (intimacy). These in turn necessitated a significant investment of time and effort, as well as an attitude of reciprocity.

For John (P), an accomplished professional, "the most important roles (he) had were always with (his) wife", while Mary (C) echoes this 'being and doing together' in her tender description of their relationship: "...we went to dances with a group of friends, that is how I got to know him; and we *kept* dancing together from then on..". Despite John's busy professional life, he and Mary shared a strong sense of devotion to their children's interest which was their common goal throughout their married life. For Sandra (C) this togetherness also had transgenerational roots: "we came from similar families, I was only 18 and he 22 when we married" that matured into a serene sense of 'being together' with Paul (P) such that now they sit together for hours in their family room "he watching news or reading and I do my own things as I do not like news or sports, but he is not offended by this". Barbara (P) reports that "they enjoy each other's company" despite having very different personalities, and attributes this to their being very frank/direct with one another such that "if something bothers me about David (C) I just tell him, and he likewise". For David (C) his wife Barbara (P) means everything and echoes her sentiment by saying "and she was always by my side" and that in her he "found a partner in every aspect of his life (ie personal and professional)" so much so that when she went through serious illness in the past he "felt as though he himself was going to die – she being part of (him)". What is remarkable about this highly convergent pattern of togetherness is that taken as a whole their stories are not without setbacks and adversities. Though Stephen (C) describes a "very normal life" with Edna (P), they had taken a long break in their courtship and subsequently experienced other significant family stressors. He credits their 'being and doing things together' for their relationship: "we always lived together, and when we went out, we went out together". This despite both Edna (P) and Stephen (C) having had busy professional careers, with Stephen spending long days at work. This sense of togetherness extends to their relationship with their adult children and their partners such that the children are very respectful, travel together as a family, and enjoy intimate meals full of laughter. George (P) described his wife Louise (C) as "the best mother!", raising their children assuming a common goal achieved through hard work and a result of a life they "built together". Indeed Louise (C) mirrors his pride and validates his role as a father by saying that she "always did and will forever think of him as their childrens' father".

Stephen (C) shares his learnt wisdom by stating that failed relationships are often the result of neglecting this togetherness by “focusing on the future and forgetting about the present, working hard to invest in material wealth and neglecting their relationship”. He goes on to compare life to a citrus fruit and the need to “squeeze out the richness from it”, a process that requires both effort and tenacity. George (P) reminds us that tenacity is the secret to the dynamic process of the growth of a relationship, while Louise (C) echoes this in a very simple but tender account of how the couple grew gradually closer to the other over many years of painful striggles. She notes that during this time she understood the meaning of certain behaviors that had bothered her for many years which were rooted in transgenerational meaning. Edna (P) stresses the importance of reciprocity in meaningful bonds “..if you love people, people will love you – that’s what family is – we were brought up like that – you can’t break up with your family; that is nice being a family when one thinks about the other”.

In her classic book ‘The Seven Levels of Intimacy: The Art of Loving and the Joy of Being Loved’, Deborah Bigelow (2005) describes how the ability to let one’s guard down (in our ‘nakedness’) allows the other to be authentic, leading to a deeper reciprocity in sharing one’s legitimate needs be they physical, emotional, intellectual, or spiritual. Indeed ‘being known to another’ emerged in the dual-voice generativity documents as a sine-qua-non of a meaningful relationship.

Barbara (P) illustrates this most simply by saying “What else can I say to David (C), we know each other inside out! I think I told him everything, and don’t worry he did too..!” When Edna (P) is asked whether there were any other things she wanted her loved one to know about her, she retorted: “The children? No! They know it all. I am an open book”. Indeed she extends a certain level of intimacy to her loyal clients of many years who Stephen (C) reminds us have “grown old with her”, and she feels “known” by them and that she “knows them” too.

The saliance of togetherness is sadly perhaps best felt in its very absence. Joseph (P) wishes to talk to Patricia (C) about his decline and approaching death but feels she does not want to talk about it. Interestingly on her part Patricia (C) laments his not listening or being “quite there”. One significant element about Joseph’s dual-voice generativity document was that the title given to the document by the therapist (long before the document was analyzed qualitatively) was rather impersonal compared to the titles given to all the other documents suggesting they were reacting to the ‘doing with’ but not engaged with the ‘being with’ of their togetherness. Similarly the lack of convergence in certain very significant aspects of their shared life-events points to a certain paucity in shared/expressed meaning despite convergence of thematic saliance (that is, something can be very meaningful to both but not necessarily expressed or shared).

## **1.2 Self-actualization through the other**

In seeking meaning in their life story, relationships can serve as either a sterile atmosphere where the seeds of potential cannot sprout, a vast and lonely environment that leaves too much open space such that each walks alone in separate directions, or a fertile space where each fertilizes the other's growth and potential. The idiographic accounts in the six dyads all converged on the importance of self-actualization through their most significant relationship (in our dyads, the spouse), though one dyad also exemplified the yearning for each other's presence or validation.

### **1.2.1 Allowing Space for Growth**

John (P) credited his wife for "always encouraging me to do all things" and for "being behind me without overdoing it if I can put it this way", while Barbara (P) appreciated that her married life provided her a space wherein nobody interfered with her decisions, something that was very meaning given her roots. This space for growth was also afforded to the children by Stephen (C) and Edna (P) who did not make much fuss about their children's normative developmental issues even if they gave them grief (e.g. in adolescence), thereby also giving them space to grow and individuate. Louise (C) may not necessarily have felt an immediate attraction to George (P), however she "felt comfortable with (him)" as he gave her the freedom to be herself and make her own choices. This does not imply 'not caring for the other' as she tells us that "before I go out he always kisses me and tells me to take care and drive carefully.. and recently he even told me he loved me – I felt that, it really struck me". Patricia (C) on the other hand found a lot of space to do her own things as her husband was frequently immersed in his career. While this allowed for self-actualization, it did not contribute to it through togetherness but rather occurred despite the relative paucity thereof.

### **1.2.2. Making the Other Whole**

John (P) credits Mary (C) for "being at the forefront" of social activities complementing his own rather quiet nature thereby "bringing life to my work" making their "roles complementary". On her part Mary (C) was the person who allowed for spontaneity while appreciating his thoughtful nature: "he was always my staff.. while I often made decisions on the spur of the moment he was always more thoughtful". Paul (P) confesses he is incapable of anything related to practical daily life outside his job and credits Sandra (C) for taking care of everything, while she identifies her own educational limitations and how she relies on him for anything related to written material. Similarly David (C) acknowledges his

lack of education and credits Barbara (P) for encouraging him to use his strengths, “without pushing him aside” – David (C) considers this latter aspect of Barbara (P), that is her encouraging without upstaging or denigrating him as “one of her most beautiful attributes”. Barbara (P) on her part credits him for learning to stand up for herself. Edna (P) enabled Stephen (C) to grow his business by building her own professional practice at home so that she could be available to the children at all times (their common goal), and Louise (C) overcame her inferiority and scepticism about intimate relationships through her married life to a “gentleman”. There is a tenderness in this description especially as her self-actualization through her loved one is followed by a profound statement of togetherness “he was always there and so was I”. George (P) considers his most important role in life: “I want them (his children) to remember the good times we had together including the time they accompanied me to sea – the children mean everything to me! I am so proud of them and love them so much”. When asked about what his most important role in life he reiterated “as a father. I did my best to raise them well. We used to take them to church, to prayer meetings – they came with us too. We went once a week. I always loved them...”. Louise (C) notes that for a long time he was not interested in these religious activities but that she patiently waited for him and her tenacity meant that George’s (P) life narrative evolved to support his most important role as a father. In so doing Louise (C) made his life ‘whole’ by making it possible for George (P) to fulfill his most important role in life, and becoming the means to his legacy through his children.

### **1.2.3 Keeping the Other Whole**

While differences in coping/personality styles present us with opportunities to make the other whole through complementarity, adverse life events including illness and psychosocial stressors often create gaps or cracks in our ability to cope, denting our dignity and interrupt our life’s journey as we knew it. It is this sense of ‘conservation of dignity by the other’ to make the person whole again that emerged in the dual-voice documents. On dealing with Paul’s (P) many humiliations in his professional career, Sandra (C) tenderly relates how she stood by him and maintained his sense of respect, while at a later time when he experienced memory loss and other medical problems she discreetly took over the management of his prescriptions and prepared his pillbox without necessarily making it obvious to him so as “not to offend him”. In so doing she maintains a sense of continuity for him (“the rest he takes care of himself”) by filling in the gaps in his cognitive abilities, keeping him whole. She does the same socially when he forgets peoples’ names, gently reminding him the names of who they meet so as not to embarrass him and allow him to maintain his routine. There is a sense of ‘knowing’ and ‘being known’ in the interaction as she continues “nobody will take care of him the way I do; he does not reply as he knows its true (giggles affectionately); I know that I am the one to suffer, but at least he does not have

to suffer". Similarly Edna (P) whose cognitive decline is very clearly impacting her ability to maintain her previous independent activities of daily living tells us that "all is OK" since they both know where they stand and that they can resolve conflicts by talking about them. Stephen (C) on his part is proud in how she maintains herself – while acknowledging Edna's (P) obvious decline, he admires and validates the part of herself that remains. He proudly reports that she "helps herself" by doing simple things like listening to music while on his part he wakes up very early in the morning to prepare lunch so that when he comes back from work (which now is curtailed to lunchtime) they can have lunch together and maintain her own sense of continuity and "normal life". The fortitude with which she defends herself psychologically is mirrored by his sensitivity to the emerging gaps in her personhood – he does not seek to break through her psychological defensive structure but rather supports it and keeps her whole. In this wholeness he finds that "love remains", and that she "adores him and makes him feel special" – a reciprocity of 'giving and being given' that cements their sense of togetherness while conserving each other's dignity.

#### **1.2.4 Being Seen**

Validation is a fundamental aspect of healthy human relationship and a key component in effective communication in dementia. Indeed 'validation therapy' is an effective strategy to address behavioral problems stemming from a patient's interpretation and response to a memory, thought or situation (Feil 2013). In order to validate a person's perspective one must be willing to step into their shoes and see their reality through their own eyes, then reflect this appreciation of their reality empathatically.

'Being seen', acknowledged, or validated emerged as an important subordinate theme in meaningful relationships. Mary (C) felt that John (P) "always seemed to be proud of me and had a very good opinion of me... I liked the fact that he appreciated me.... He likes everything, is easy going, and accepts what I say". Mary's self-actualization through 'being seen' needs to be appreciated in light of her always having followed and stood besides her husband in the pursuit of his demanding professional career while caring for their children. It would have been natural for her to feel as though she played 'second fiddle' to his career, yet John (P) validated her and always made her feel appreciated and important. This echoes David's (C) reflection on how Barbara (P) validated him without upstaging him, and John's (P) own reflection on how Mary (C) was "always behind him without overdoing it..". David (C) praises Barbara (P) for validating him ("she praises me") and helped him believe in himself and overcome his sense of inferiority by showing him and validating his strengths which he then used in his business ventures. Louise (C) is thankful for George's (P) noticing and complimenting her on her dress,

such that she regularly seeks his feedback since “it must take something that he really dislikes for him to criticize me”. This level of intimacy is reflected back when she continues “and naturally I do not let him be shabby in what he wears!”. For Joseph (P) being seen was very significant to his profession, particularly by those who had the know-how to appreciate his work, possibly making up for his childhood when he felt unseen. Yet, while Patricia (C) went to great lengths to closely follow his work and ‘see him’, this validation did not appear to have the same impact possibly given his need for validation derived in a professional context once again highlighting a discordance in assigning meaning in their life (that is, the source of the meaning was different).

## **2. ROOTS**

Across the dual-voice generativity documents the meaning of one’s origins and rootedness was prominent. Indeed Joseph’s (C) opening sentence was “I have a story!”, a story steeped in tradition and only understood within a transgenerational context that undoubtedly coloured the formation of his own interpersonal relationships. The three subordinate themes underlying the meaning of rootedness were the wider social context in which the individual grew up, transgenerational factors including tradition that influenced their attitudes and behaviors, and the foundations of significant interpersonal relationships (which I term “beginnings” including courtship, marriage, and birth of offspring) and the subsequent sharing of life experience and memories.

### **2.1 Social Context**

The socioeconomic context of the subjects’ background was highlighted in all generativity documents, some more explicitly while others less so through the mention of comfortable homes, parents of high social standing, or recreational activities associated with better means. For some the issue of financial means was mentioned in passing and the term “sacrifice’ often reserved for decisions made for the sake of others, while for others financial means clearly impacted the opportunities for education, development of professional, and personal interests. What was eminently clear however was that financial background had no impact on the emerging patterns of meaning or themes derived from the generativity document.

It seems that, in the final analysis, one’s roots in terms of socioeconomics provided colour (for example higher socioeconomic roots resulted in greater likelihood for travel abroad, landing professional jobs and having children with a tertiary education, and less likelihood for socioeconomic life adversities) but influenced neither content nor the hierarchical structure of the emergent themes. Nor

did the socioeconomic backgrounds seem to impact the convergence or otherwise of the themes or their underlying meaning. Thus for example Edna (P) and Stephen (C) who had a comfortable socioeconomic background placed similar value on relationships with a strong sense of togetherness, self-actualization and rootedness as Barbara (P) and David (C) who had a more modest socioeconomic background and level of education. Conversely despite similar levels of education, John (P) and Mary (C) showed widely divergent patterns of relatedness compared with Joseph (P) and Patricia (C) particularly in togetherness, self-actualization, and space for growth. The strong convergence in all four superordinate themes between members of all dyads despite wide differences in levels of education and socioeconomic backgrounds suggest that core aspects of source of meaning with advancing age and decline in health may be universal attributes. As Barbara (P) put it “when we got married we were penniless and could hardly afford a wedding.. we scraped through our savings to buy furniture for a tiny apartment, but for us it was plenty”.

## **2.2 Transgenerational influence**

In her opening statement, Barbara (P) expresses the deep significance of the passing on of tradition by her parents and extended family, and her own passing on of these same traditions to her children: “we used to start decorating early for holidays, and adults used to set aside some money every week for a big family gathering (the following year)... I did the same with my own children”. She then continues to describe the important value of family outings by the sea. The importance of the sea for islanders is again highlighted by George (P) “I used to go swimming.. I loved it.. I found it relaxing” and he then goes on to tell us how he has tried and still hopes to pass this on to his children. We have already seen how Louise (C) learnt to appreciate George’s (P) behavior through her better understanding of the value he placed on certain activities which he inherited from his own family traditions.

John (P) speaks of his rootedness to the island as he describes his feelings about having had to move abroad for professional reasons: “I would not stay (away) too long as it meant staying away from the island for a long time – we always looked forward to coming back to Malta”. Rootedness is also derived from one’s family of origin which was highlighted by all dyads. Edna (P) expressed a sense of admiration for her parents which must have imprinted on her the image of loving parents she sought to pass on to her own children, and her description of her father as “big and strong” likely the source of her own determination and independent spirit. George (P) describes in some detail the legacy received from his own parents: “when I was young it was a beautiful time; I loved my parents; my mother taught me the importance of faith; my father had a boat and I often accompanied him ferrying tourists in the

harbour where he also worked; he was hard-working, he had two jobs – he taught me the value of being industrious”. Now he spends time with his brother at least once a week thereby reconnecting with his past.

The most poignant example of transgenerational influence was given by Joseph (P) whose mother made a religious vow to visit a well known shrine every year after his own brush with death as an infant. This is a story he naturally has no recollection of but which he ‘inherited’ from his mother and now continues to honour every year himself.

### **2.3 Significant Interpersonal Relationships**

Perhaps the most obvious reminder of one’s own rootedness is the connection with the immediate family present in all the dyads included in this study. They all describe how they met, their courtship, and then marriage, and all describe this aspect of their story in some detail highlighting the value placed on their initial encounter with their spouse. Subsequently this ‘beginning’ is celebrated in anniversaries, and new beginnings in the form of the birth of their children and their subsequent marriages or hope thereof. What was striking in the data was the tenderness and detail with which these beginnings were described, and the high degree of convergence in all dyads of this aspect of their rootedness. Sandra (C2) recounts their first kiss and the reaction of a person who happened to see them, and Barbara (P) recalls details of her initial encounter with David (C) including where she was sitting and what she was doing when he approached her, while David (C) recounts the same details from his perspective. All participants consider it significant to recount where they each came from (that is, which town or village) likely a reflection of a bygone post-WW2 era where transportation was less accessible and distances seemed further than they really are on the island. Patricia (6) describes details of their first encounter, providing a glimpse into her affectionate nature. Similarly wedding anniversaries and the birth of children are celebrated and form very meaningful memories that contribute to the creation of their shared roots.

### **3.0 RESPECT**

The value of being respected or being worthy of respect was present in all generativity documents and highly congruent in the dual-voice transcripts. Just like relationships, respect can only exist within a reciprocal context (respect – respected): hence being respected automatically assumes a reciprocal role. This reciprocity emerged in the documents as either respect that emanated from personal or professional roles (for example, being respected as a parent or for their professional



accomplishments or talents) as well as respect that is inherent and not dependent or emanating from any role.

Much like legacy through personal roles, inherent respect is perhaps somewhat harder to describe than respect emanating through professional roles. It is not difficult to appreciate Patricia's respect and admiration for her husband's artistic skills when she says "he used to make me feel his art - he was very talented", or Mary's (C) admiration for her husband's success "he was very successful, so I also enjoyed seeing all the success and the respect he gets, I am very proud". It may perhaps be a little harder to appreciate the meaning of being a "gentleman". Louise (C) proudly describes her husband "the fact remains that he was a principled man, he makes me proud to be married to him". George's (P) respect here comes from an inherent quality which Louise (C) attributes to his being a man of principle, a quality he must have attained through his behavior across his many roles in life. As she tries to go deeper into what makes him respectable however, Louise can only conclude that he is simply "a gentleman": ".. deep down George has many good qualities. He was always a gentleman". Moreover, this inherent attribute of respect made her whole: "I had a sense of inferiority (related to marriage), so the fact that I met a *respectable* man like him...changed my mind". Sandra (C) describes Paul (P) as "always righteous – like an Englishman – always righteous and at work he was loved, always respected, whenever they see him now they stop to talk to him..". Such moral attributes, while again revealed through one's roles, are intrinsic and are not necessarily derived from any particular role or status in life. In George's (P) case no amount of professional humiliation he suffered could dent this source of respect. These transcendent values that make one 'deserving of respect' are also demonstrated in respect for parents beyond their parental role per se as shown by statements made to Barbara (P) by her daughter when she told her daughter "I wish I could give you more (financial support) but I can't"; her daughter replies: "mother you gave us so much, so much, so much.. you gave us so much, more than you could". Notice also Edna's (P) response when her father presented her with a gift in appreciation for caring for him in old age: "I started crying and asked him - why daddy? – I appreciated but I didn't want the gifts – I didn't do it for gifts". Hence Edna's (P) respect for her father, while arguably emanating from his parental role, transcends any concrete source and becomes inherent or simply being 'worthy of respect'.

#### **4.0 Receding Health and the Dawn of the Ending**

As much as there are beginnings, any story must have an ending. Indeed Joseph (P) who opened his generativity document with "I have a story", towards the ends shares his wish to discuss concerns about his inevitable death and decline acknowledging that he needs help even to "take out

the garbage these days”. Given the clinical context through which the dyads were recruited for this study, it is not surprising that the carers (if not all patients due to their cognitive difficulties) were well aware at some level of the clinical concerns relating to cognitive decline. The superordinate theme emerging from the data was that of receding health and the dawn of the ending, and the underlying source of meaning of this theme emerge from (a) concerns related to the future (uncertainty & hope, inevitable decline, and legacy to be left after they are gone), and (b) integrity concerns related to role transitions especially retirement, regrets, and sense of fullness in their life (psychological integrity).

#### **4.1 Concerns related to the Future**

Sandra (C) is concerned about Paul’s (P) forgetfulness, while Paul (P) is concerned about his declining health and how this will affect his loved ones. He is “unsure about how long he has to live” so he tries to “avoid spending too much money “as when I die what will happen to Sandra?”. John (P) is equally concerned about Mary (P) saying “I hope that when I leave – and I hope to leave before her – that they (children) will continue to look after her”. On her part Sandra (C) hopes Paul (P) will pass away before her as “he is incapable of caring for himself.. he is very fussy with regards to food”. David (P) is also worried about his wife’s decline as he says that he “wishes that they live the little time left in peace and serenity”. Joseph (P) started making plans for the future when he started noticing his cognitive decline by telling Patricia (C) about their financial affairs so that she can take over whenever necessary. He clearly is acutely aware of his receding health when he tells her “don’t you know I don’t have much long to live”? Patricia (C), while well aware of his decline, still hopes that he gets better demonstrating the value of both denial and hope in dealing with loss. Stephen (C) mourns the dreams they had for their future including travel to far-away countries, though he too ultimately only wishes for her “a serene life, that she is serene is very important for me and that she is comfortable and wherever I can help her I will, that is my wish (for the future)”. This process of grief with its tension between mourning loss and gradual acceptance and hope in both patients and carers is present in most generativity documents. Thus despite the obvious decline Mary (C) still hopes that John regains his health, while Barbara (P) looks forward to travelling and Edna (P) to going back to work. Louise (C) offers a sober reflection hoping he will be able to deal with his situation with more positivity (hope) so that they can enjoy the remaining time they have together, and in so doing be closer to one another. Thus Louise (C) resolves her grief by living the moment and “squeezing the juice” out of life while continuing to grow what is most important to her – their relationship.

Despite this struggle, all patients within the dyads wished to leave an imprint on the world after they are gone, in part through their profession but mostly through advice, hopes, and values transmitted to their children.

For John (P) his parental role is part of his legacy for which he wants to be remembered “I want them to remember me as a father who took their interest at heart, who always supported them, and tried to give them the best advice”. He is also proud of his professional accomplishments especially his legacy through mentorship: “I feel proud of those who worked with me and after me, I think they are grateful for the support I gave them... it is nice to see their progress and seeing them mentor other people so that my work lives on”.

John (P) wishes for his children that “in their professional careers they will always be true to themselves and supportive of good people”, echoing his own impact through mentorship of junior colleagues. Edna (P) continues on this line by asking her children to “be who you are, thats all” just like she herself was authentic in all she did. This transmission of values is an important theme for Edna (P) as she wishes for them to be “healthy and positive” but that they also “learn that it is not just you – there are other people you can help”. For Edna (P) when one is authentic (which she calls “positivity”) they are then free to be of service to others. It is this almost child-like freedom that is her legacy to her children “as I told you, positivity, that is important, because when a person is positive he can rule the world and he can help other people – he can do anything!”. John (P) also wishes to pass on the value of intergenerational respect to his children when he cautions them to “always hear and listen to others – always be available to your children when they want to discuss whatever it is”. George (P) wishes that his children remember the good time they had together and consider taking on his hobby as his legacy. Like John (P), Joseph (P) is proud of his professional accomplishments most important of which is his legacy in the form of succesful students who achieved fame for themselves.

#### **4.2 Integrity concerns**

Another source of meaning underlying the dawn of the end of life concerns psychological integrity including resolving role transitions in later life like retirement, regrets, and achieving a sense of fullness in life. Naturally all participants were at different stages of this dynamic process.

John (P) mourns the loss of his professional role: “you see what happens is as you grow older, you find your interests in activities you used to enjoy become less of interest to you”. However he also

expresses his regrets for not being as involved with his children's lives due to his busy professional life saying "I was the loser... I was foolish in this respect.. it is something I have missed myself, a part of life that I missed – I didn't spend much time (with them)". He offers advice on how to deal with retirement, poignantly using the good example of his own adult children, in so doing praising them for their wisdom: "once you reduce your professional work, you also reduce your ability to participate in new activities and this may leave you a bit depressed; the worst thing that can happen to a person is to have time which he can use but does not; its important to plan your retirement by having activities (outside of work)". Joseph (P) wishes his children would learn from his own mistakes suggesting his regret for not being as appreciative as he could have been: "..as I talk I realize that I do not show enough how much I appreciate (my wife)". Finally he resolves his achievements and regrets in a parting sentence, suggesting his achieving a sense of fullness in life: "when I look back at my life, I feel that overall my life was complete; that is, if I were to live my life again, there is little that I would want to change". Barbara (P) sums this up by simply saying "what else could I wish for?".

## F. DISCUSSION

We sought to study the feasibility and implementation of adapting Dignity Therapy, a brief psychotherapy that has been shown to be effective in alleviating existential distress in patients journeying through the end of their life due to terminal medical conditions, in older patients diagnosed with early stage dementia and their chosen informal caregivers. The study was very well tolerated and found to be acceptable by all participants. All study visits and procedures were completed by all dyads with no adverse outcomes reported.

Four superordinate themes (*relationships, roots, respect, and receding health*) and their respective subordinate themes (*togetherness and self-actualization, the social context and transgenerational influences* as well as *memories of salient shared interpersonal relationships, inherent and role-derived respect, and future concerns* & issues relating to psychological *integrity*) emerged from an interpretative phenomenological analysis of the dual-voice generativity documents

The emergent themes from this study highlight (a) the fundamental role of a relational perspective to the understanding of patterns of meaning, and (b) the significance of these relational patterns in older persons diagnosed with early dementia. Our data demonstrate how the meaning of an individual's life story is derived from a strong relational perspective, that in turn can be understood in light of their personal, interpersonal, and sociocultural roots, as well as and the respect assumed during their life. Furthermore, this relational perspective that started in early life persists and becomes more significant with the dawn of cognitive and physical decline. Indeed, the concerns raised related to the future and issues of psychological integrity emerging from the generativity documents were all relational.

This section will discuss these two main findings emerging from this qualitative analysis of a dual-voice generativity document, and compare the emergent themes to those previously observed in the dignity therapy literature that included older persons with early dementia using single-voice generativity documents. Finally the significance of these results using a novel approach to dignity therapy using a dyadic approach to the implementation and study of dignity-based therapy in older persons with dementia will be discussed.

Joseph (P) was clear enough in his opening statement when he said "I have a story". He was perhaps telling a story that is more universal in it's meaning than the idiographic details may suggest.

His story was told at a critical stage of it's maturity when he realized that he was declining and that he was now increasingly dependent on others even "to take out the garbage". The rootedness in one's story is perhaps never as poignant as it is in dementia wherein autobiographical memories are initially preserved while more recent memory bears the brunt of the neurodegenerative process. Way before his memories were being consolidated into long-term memories, Joseph almost lost his life as an infant and was "miraculously" saved. His mother's love and her own rootedness in tradition resulting in meaning being attributed to his survival that was then passed on to young Joseph who maintained an annual pilgrimage to honour his mother's religious vow. The source of meaning of this process cannot simply be attributed to religiosity or tradition alone, but to an attitude of gratitude to the transcendent that Joseph inherited. While he felt part of a large family, he describes being left aside by his older siblings and had to negotiate his way into their recreational activities. This may have strengthened his need to receive validation for his artistic talents such that he spent his career focused on perfecting his skills and lending his critical artistic eye to his peers and students. In his adult relationship with his wife he found space to engage in this goal of being seen and validated, while receiving constant validation from her through her faithful presence at his artistic productions. In the course of this life journey he never 'lost the plot' so to speak, and achieved the professional success through respect derived from his artistic and mentoring activities thereby leaving a mark on the world and ensuring that his own work continued through those around him. The relational pattern of 'seeing and being seen' playing out in his life not surprisingly was also played out in his closest relationships. In the dual voice document we hear his wife making every effort to 'see' him and ensure he is 'seen' by being present and giving him feedback. On her part, she waited patiently for his reciprocation, though for most of his career he was consumed in seeking this validation professionally. As he declined and became dependant on her for daily activities he started acknowledging that he may not have appreciated ('seen') her as much as he should, and regretted this. His newfound dependency now allows him an opportunity to reciprocate and grow closer as a result of his decline. Indeed he seeks an intimate expression of his acknowledgement of his decline and eventual demise, and ensures that she takes over their financial affairs while he is still well enough. Thus, when he expresses his sense of a *full* life and that he would change *nothing* in his story had he to relive his life, one realizes that indeed his life was fulfilled not only through his artistic talents and effort, but also through the validation, growing togetherness, and self actualization that was afforded by his most meaningful relationships. Patricia (P) accompanied him in his professional life, gave him space when needed earlier in his career fulfilling his need to 'be seen', and with his decline offered him an opportunity to explore and express his need for 'being known' (intimacy) while conserving his dignity (keeping him whole). She also 'made him whole' through their common goal (family), a value he was rooted in through his family of origin. He is now afforded a certain

certainly in the future through his wife's support and presence (which he never doubted) despite his decline.

George's journey towards his own psychological integrity is also achieved through relational roles with significant others. George's legacy are his children, the most important aspect of his life. His story exemplifies how meaning was acquired transgenerationally starting from his father's bequeathing his love for anything related to the sea, to his own ultimate wish for his own adult children to inherit this same interest. His humble background resulted in his having to suffer hard work and even humiliation in his jobs, though his hard work earned him his wife's respect for being a "gentleman". His own pattern of meaning was fundamentally owed to Louise's love, respect, and tenacity in their marriage that transcended the suffering she experienced as a result of a sense of isolation during parts of her marriage to George. Through her appreciation of the value of the sea that George inherited from his family of origin, she was able to understand certain behaviors that could otherwise be misinterpreted as neglectful. Similarly, while he initially refused to share in her spiritual interests, the importance in faith that he reports he had inherited from his parents was allowed to emerge through her giving him space for his initial reluctance to engage in religious activities. This process allowed for the formation of memories of being together as a family during such religious activities, which are his stated legacy to his children and thus make him whole. Louise offers him security in his decline through her constancy and loyalty, and their time together now provides him with a renewed opportunity for intimacy which may not have always been possible in their earlier years.

The relational themes described in Joseph's "story" are widely interwoven in the fabric of his dual-voice generativity document. Mary was the one who brought "life" to his professional career, as though his life's canvas without her would have been technically good but otherwise dull and colourless. Though reserved in his professional circles, he was intimately "known" by her, and "the important roles he had in his life were always done with (his) wife". This 'being and doing together' and 'being known' was intricately woven in his life story. She gave him space to grow his professional life, and made him whole by caring for their children, and later keeping him whole by preserving his dignity through his decline. She describes his own family of origin and his rootedness as a key context to understanding him, and she has now taken on stewardship of this aspect of his personhood, a proud repository of memories of shared beginnings and meaningful life events. She mirrors his worthiness of respect even at a time when he is only a shadow of his former self, and while maintaining hope she is a strong and steadfast presence alleviating his fear and uncertainty for his future. His professional and personal legacy is also relational: the mentorship he developed with younger generations (giving and receiving) perpetuates itself through their own mentorship of others so that his "work lives on", and his

children's values and professional careers reflect his own. While he regrets not having spent enough time with his children as they grew up and not having invested enough effort in his retirement, his pride in his own children actually accomplishing what he did not in this regard is a means of psychological resolution of his grief towards his sense of psychological integrity.

Paul's relationship with his wife and children provided meaning throughout his life despite the repeated professional humiliations and multiple medical problems he experienced. Sandra stood by him, both keeping him and making him whole. Even with his recent significant cognitive decline she ensured that he 'is seen' and makes up for his gaps in memory by 'curating' his meaningful lost memories when they meet ex-colleagues, thereby conserving his dignity. Similarly she cherishes and shares their shared beginnings and meaningful life stories, and validates not only the respect he received through his role as a husband, father, and professional, but also the inherent respect for his sense of righteousness. Paul is intimately known to her, so much so that nobody could ever address his needs like she does without knowing the intricate details of his fussiness relating to food, nor how to handle his sensitivity over his declining ability to complete certain activities of daily living like preparing his own prescription medications. They both treasure memories of vacations together and his legacy to his children is the knowledge of his love for them.

The fundamental value of the relational foundation of both Paul's and John's pattern of meaning, despite very different socioeconomic and educational backgrounds, and personal and professional narratives, was perhaps best reflected in the therapists' description of their generativity documents. When the dual-voice generativity documents were completed and ready to be presented to the dyad, it was felt that they each deserved a personalized 'title' reflecting the therapists' overall gestalt of the combined generativity documents into a dual-voice document. Both Paul's and John's dual-voice documents were titled 'My Life Shared with (My Wife)', likely an intuitive response to the strong relational pattern of meaning that emerged in both documents. Indeed all documents were titled with a similar relational significance including "Our Lives", "We Always Managed", and "Our Lives Together", and "My Spouse and I". These titles, while not included in the qualitative analysis since they were not the subjects' voice, highlight the relatedness that emerged in a generativity document based on a semistructured interview that for the patient never specifically inquired about the spouse per se (Appendix A). Furthermore both interviews were carried out independently by separate therapists yet the emerging relational theme were convergent suggesting that this relational pattern is not being driven by a biased contribution by the carer.



Barbara and Edna's stories differ somewhat from Johns's and Paul's stories in that both suggest a degree of lack of awareness (anosognosia) for their decline (Castrollo et al, 2016), and both have shown some degree of resistance to adapting their goals in light of their decline. Once again these two dyads have very contrasting socioeconomic and educational backgrounds, though their relational patterns of meaning is very similar and interwoven in their narrative and emerging themes.

Barbara and David's backgrounds are both modest. Barbara brings with her a transgenerational baggage that significantly impacts her relational patterns. Her family of origin provided her both with traditions that become part of her own legacy to her children, as well as a need for a space to make her own decisions and self-actualize. David validated her strengths and gave her space to establish her career and become the assertive and "direct" person she now is. Through 'being and doing' together she established a common set of goals that became her legacy (her children), and allowing David to 'know' her gave her the opportunity to let down her guard and express the affectionate part of herself albeit often disguised through a witty sense of humour. On her part she allowed David to 'be seen' without upstaging him, so that he could develop his own business, while he 'saw her' and validated her through his admiration of her talents, and his own humility in accepting her advice and support. David 'saw her' as she sat having a drink while waiting for her sister when they were younger, and validated her through his efforts to be with her. He considers her a "part of him", and validates her role as spouse, mother, and provider for their family. Their generativity document is peppered with humorous anecdotes about petty arguments and how they resolve them through open and direct dialogue demonstrating their deep sense of intimacy. While expressing a sense of anxiety for the future, David ensures the preservation of her dignity by allowing a sense of continuity in their lives despite her significant cognitive difficulties and lack of awareness thereof.

Edna and Stephen's backgrounds are more comfortable and both as well-educated. Edna's life is characterized by a sense of child-like serenity in everything she does. She does not appreciate the nature or extent of her cognitive and functional decline and as far as she is concerned her life goes on normally. There are moments of awareness when she mourns her job describing her reaction when she was told she was unable to work any longer. Stephen on his part makes her whole by curtailing his professional work, preparing and being present for meals with her, and ensuring that their life maintain the same rhythm of normality that she is accustomed to. She is 'known' very intimately to him, such that he is able to support her remaining abilities/interests while validating her appreciation for beauty and kindness. He is keenly aware and concerned about her decline, but like Sandra takes on the role of curator of her personhood, buttressing her psychological defense mechanisms where necessary and filling in any functional gaps without exposing her to humiliation. He appreciates and promotes her role

as mother, spouse, and professional and welcomes the reciprocation of his love and her admiration towards him thereby keeping her whole through reciprocity. Notwithstanding her decline and functional role transitions, he softens the impact of these blows on her ego thus helping her reach her psychological integrity. Her words of legacy to her children suggest that this is indeed achieved in that she tells them that it is in her authenticity that she found the freedom to be available to others, and bequests this to her loved ones.

Two previous studies have explored the emerging themes from single-voice generativity documents derived from older persons with cognitive decline. The first report emerged from a feasibility study including 12 cognitively intact residents and 11 cognitively impaired residents in long term homes (Chochinov 2012). Cognitively intact residents aged 65 years or older and who had an MMSE of at least 21 were included in the study. The cognitive measures of the cognitively impaired group was not given. Nonetheless, this group was significantly impaired such that a proxy was identified for each cognitively impaired participant (adult family members) who participated instead of the actual patient. The cognitively impaired index participant may or may not have been present during the actual dignity therapy sessions, and those that were participated to the degree allowed by their degree of cognitive impairment. Thus the study group may be thought of consisting of a group of mixed cognitively intact as well as mild cognitive impaired, and a group of fairly cognitively impaired subjects. Qualitative analysis was conducted by two research nurses who analyzed the content of all transcripts. Each nurse also independently reviewed two transcripts each of cognitively intact participants to identify emerging themes. The same process was applied to proxy transcripts of cognitively impaired subjects. Commonalities in themes were thus identified and used as a template for thematic analysis of the remaining transcripts. Data was then reduced and themes categorized, and checked against the data by the investigators. The implementation of dignity therapy with the intact group was unremarkable with detailed documents resulting from the encounters. On the other hand the cognitively impaired participants required substantial prompting and filling in from the proxy. All participants including those cognitively impaired found the process meaningful nonetheless. As would be expected proxies were unable to provide details of autobiographical data from the participant's early years. The emerging themes common to both groups were *imparted life lessons* (which included wisdom learnt from life experience and which they wished to impart to the next generation), *importance of relationships*, *source of pride or accomplishment*, and *delights and joys* (referring to matters in life that participants relished or recalled with pleasure). Themes of *death and loss* and *formative experiences and disappointments or regrets* were largely restricted to cognitively intact participants, while proxies (of impaired participants) focused more on *impact of illness*, *personal characteristics*, and *important roles*. Despite the study's heterogeneity it is striking that, taken together, these themes are all reflected in the emergent themes

from our own study using a dual voice approach in patients with early dementia and their spousal caregivers. Our study employed an interpretative phenomenological analysis approach that seeks to explore patterns of meaning and allows for the use of psychological concepts in the interpretation and clustering of emerging themes. In both studies the importance of relationships emerged, though our idiographic approach allowed the emergence of the underlying (or mediating) subordinate themes of togetherness and self-actualization. The theme of personal characteristics also emerged in our study but was considered subsidiary to self-actualization through the individual's *agreeableness* (gratitude, validating, empowering, humour, humility, altruism, generosity, empathy, affection), *conscientiousness* (respect, honesty, tenacity, industriousness, reliability, loyalty, trustworthiness), *authenticity*, *mindfulness*, and *spirituality*. *Source of pride and accomplishment* and *important roles* emerged in all our generativity documents and was included in the superordinate theme of *respect* derived from personal or professional roles, while our superordinate theme of *receding health and the dawn of the ending* incorporated *death and loss*, *disappointments and regrets*, and *impact of illness*, and formative experience emerged in our theme of *rootedness*.

In a mixed methods feasibility study, Johnston et al (2016) that included seven community-dwelling patients with early stage dementia with MMSE of 21 or over, seven family members of the participants with dementia, seven stakeholder participants, six focus group members, the investigators conducted a multi-source thematic analysis using a Framework Analysis approach (Ritchie & Spencer 1994) of transcripts from dignity therapy documents, post-dignity therapy interviews, focus group discussions, and stakeholder interviews. Of note, this study bore similarities with our study in that patients were community-dwelling, suffered from early stage dementia, and therapy sessions conducted in the patients' own homes. The emergent overarching themes from this analysis were *a life in context*, *a key to connect*, and *personal legacy*. All three themes are also reflected in our superordinate themes of *roots* and *receding health*. *A life in context* refers to how the process of dignity therapy helped place the participant's life in the context of their roots and their family, consistent with our *rootedness* theme and its subordinate themes of *social context*, *transgenerational influence*, and *memories of significant interpersonal beginnings and life events*. *A key to connect* refers to the ability of the dignity therapy process to provide a tool to connect with the individual in the course of further cognitive decline and assist with better understanding and personalized management of emergent behavioral issues, also consistent with our theme of *rootedness*. Finally *personal legacy* refers to the opportunity that dignity therapy provides to explore a patient's story sensitively, conservation of a person's legacy and story, as well as things they wish to say to their loved ones. This theme was included in our themes of *roots* and *receding health*. Given the different design and nature of qualitative analysis, our interpretative phenomenological analysis resulted in a somewhat richer thematic

understanding probably due to the idiographic nature of the study. Nonetheless, the convergence of themes from this multisource framework analysis with our IPA outcomes supports the content validity of our results.

Johnston and colleagues used the generativity documents from the same study (Johnston et al, 2016) to conduct an detailed qualitative analysis of the the transcripts derived from the patients with cognitive difficulties (Johnston et al, 2017). The authors conducted in-depth thematic analysis using a framework analysis approach (Ritchie & Spencer, 1994) resulting in a detailed content-based analysis. Seven single-voice generativity documents we analyzed from patients with dementia of mixed aetiology resulting in four main themes: *origins of values*, *essence of affirmation*, *forgiveness and resolution*, and *existentialism/meaning of life*. The *origins of values* themes mirrors our *rootedness* theme and described as upbringing and early life impacting on decisions, core values and the setting of future life course. *Essence and affirmation of self* related to accomplishments and achievements determining self-actualization, affirming and preserving a sense of self – echoing the themes of *self-actualization* ('being seen') and *respect* assumed through professional roles in our study. *Forgiveness and resolution* related to interpersonal bonds, especially family bonds, resolutions of disconnection and tensions, and reciprocity – echoing the interpersonal *roots*, *receding health* (integrity) issues, and the overarching theme of reciprocal roles emerging from our study. Finally *existentialism/meaning of life* once again echo concerns for the future and achieving psychological integrity emerging from our study.

In summary, the results of two previous qualitative analyses from data obtained in older patients with early stage dementia resulted in themes that were convergent with ours, and all themes reported in these studies were captured in our thematic clustering, validating the content of the data emerging from the dual-voice generativity document using the dyadic approach used in our study. Our interpretative phenomenological analytic approach, as opposed to a strict content-based analysis, resulted in very convergent content as well an opportunity to explore the meaning of the emergent themes in psychological terms. A overarching 'story' emerges of how an individual approaching later years and decline deals with existential concerns relating to the future through strength derived in rootedness in past interpersonal experiences be they lived or transmitted through previous generations thereby deriving a sense of being deserving of respect. As one seeks to resolve regrets and loss, the self actualized through the other, by being and doing with the other, is made and kept whole by the other facilitating psychological integrity and the ability to bequeath a legacy – as Barbara would have said: "what else would one wish for?".

Our study results are consistent with earlier studies confirming the feasibility and acceptability of Dignity Therapy in early stage dementia (Chochinov 2012; Johnston 2015; Jenewein 2021). It is the first study to explore the implementation of a dyadic approach to dignity therapy that results in a dual-voice generativity document. Our results confirm the feasibility and acceptability of this dyadic approach, and our idiographic qualitative data resulted in themes convergent with those in published data from single-voice generativity documents. A recent pilot randomized wait-list controlled study in 54 community dwelling patients with early stage dementia (Jenewein 2021) did not find significant group by time interactions for Hospital Anxiety and Depression Scale (HADS) and the Patient Dignity Inventory (PDI) even though there was a significant decrease in HADS scores in both groups at the three-month follow up. Family members who were not necessarily the patient's caregiver were allowed to participate and contribute to the dignity therapy sessions. The study was conducted over a period of two years, and had an highly acceptable drop-out rate of 11 %, the majority related to wait-list condition confirming the feasibility and acceptability of dignity therapy in early stage dementia. In addition to being inadequately powered, the authors argue that there was a floor effect at baseline (that is, at baseline the HADS score were very low and limited room for improvement with therapy). They recommend that future studies should consider restricting inclusion to subjects with high degree of psychological distress. Visual inspection of our own clinical data provided only for descriptive purposes support this analysis and recommendation. While the scope of our own study was not to examine clinical efficacy, our original exploratory goals of generating pilot data for sample size calculations of future randomized controlled studies were thwarted by the outbreak of SARS-Cov2.

The pilot data from the Swiss study is therefore welcome and confirms our own preliminary impression that studies seeking therapeutic effects of Dignity Therapy must consider the likelihood of a floor effect. Most patients with early dementia suffer from at least some degree of anosognosia and generally not associated with significant caregiver burden at this stage. To address this reality future randomized controlled studies using Dignity Therapy may wish to consider taking a different approach to the methodology and primary outcome measures of the studies. In the first instance, more general designs using Dignity Therapy applied to representative samples of patients with early dementia would do well to seek to restrict inclusion criteria to patients and/or caregivers with a high degree of psychological and existential distress at baseline. Alternatively, and in the author's opinion more interesting and likely to yield clinically useful and meaningful results, would be to use Dignity Therapy as the first step in the therapeutic strategy. Arguably the the expectation that a rather broad/non-specific application of Dignity Therapy to address a predetermined clinical outcome (e.g. low mood, anxiety, caregiver burden) is perhaps a case of expecting too much of a good thing. On the other hand we have shown that Dignity Therapy and the subsequent interpretative phenomenological analysis of

the emerging dual-voice generativity documents yields four robust themes that are based on relational patterns. It may perhaps be more fruitful to identify the specific theme or sub-themes that are associated with the patient's or caregiver's distress, and address these themes using another therapeutic modality specific to the theme. Thus akin to pragmatic pharmacotherapeutic RCT's, such trials may consider incorporating Family Systems Therapy approaches including Murray Bowen's Intergenerational Approach (Bowen, M et al, 2013) and Salvador Minuchin's Structural Approach (Minuchin, S et al, 2021) to address issues relating to self-actualization and togetherness. Similarly brief therapeutic approaches combining cognitive and psychodynamic therapy such as Anthony Ryle's Cognitive Analytic Therapy (CAT) (Ryle A & Fawkes L, 2007) may be used to address distress derived from dysfunctional transgenerational relational patterns, Mark Miller's adaptation of Interpersonal psychotherapy (IPT) to the elderly for distress derived from role transitions and loss (Carriera K et al, 2008), and Victor Frankl's logotherapy to existential distress relating to the dawn of life's end (Frankl VE, 1992). Alternatively, smaller but well-designed studies may seek to include participants with distress emanating from these specific areas. In an era of personalized medicine, psychotherapy is perhaps ideally suited for personalization of therapeutic strategies rather than embark in large and expensive non-specific RCT's which are often designed as a 'one-size fits all' approach.

Our study is subject to a number of limitations. The small sample recruited in our study precluded the use of a mixed methods approach thereby dampening our original goals (Ounalli 2020). Quantitative analysis of the clinical measures would have allowed for the examination of the impact of dignity therapy on patient distress and caregiver burnout, as well as a deeper understanding of the role of relationships, roots, respect, and issues concerning receding health on the outcome of the therapy. Towards this end, we are in the process of expanding this dataset in collaboration with our international colleagues and look forward to adequately powered double-blind studies exploring the effect of dignity therapy in early dementia using a dyadic approach. The relative homogeneity of our sample of dyads in terms of their spousal relation is both a strength and limitation. Our data did not include persons in different states of life and types of relationships such that it can be argued that the results of these ideographic data are not generalizable beyond spousal relationships or indeed the dyads themselves. However the goal of an idiographic understanding of each generativity document was never to extract a universal or generalizable truth but to extract patterns of meaning unique to that particular dyad. The value of the emergent themes and subthemes therefore is in its inherent value within the dyad. On the other hand the robust convergence across dyads and the consistency of our findings in light of previous qualitative studies of samples of the same population of patients with early dementia suggests that the results have tapped into aspects of meaning that are not unique to the six individual dyads participating in this study. Furthermore, these results demonstrate rather robustly the patterns of meaning that

emerged in six dyads using a brief psychotherapeutic intervention: while the goal of any intervention is ultimately alleviation of distress, understanding the psychological mechanics, so to speak, of the process of healing is of fundamental value both to the clinician using the tool as well as the investigator seeking to further its implementation. Notwithstanding these limitations, our qualitative data have not only confirmed themes emerging from previous studies of Dignity Therapy but provide a deeper understanding of the underlying source of the patterns of meaning of these emergent superordinate themes. While our study was not adequately powered to evaluate for significant differences in quantitative clinical measures, Janewein et al's recent RCT has shown that Dignity Therapy is a promising therapeutic modality to address mood and anxiety in early dementia (Janewein J et al, 2022). We propose that the emerging themes and subthemes in the present study be considered as a basis for future prospective intervention studies designed to decrease distress in both patients and caregivers of patients experiencing behavioral and psychological symptoms of dementia.

## **G. CONCLUSIONS**

Our qualitative data suggest that as persons approach the early stage of dementia their source of meaning is expressed in four superordinate themes incorporating relationships, roots, respect, and receding health. These four "R's" emerge from patterns of meaning that are all based on relational patterns emanating from togetherness, self-actualization, social context, transgenerational influence, significant shared interpersonal experiences, respect, concern for the future, and achieving psychological integrity. As relational beings, cognitive decline presents major obstacles to communication and maintenance of expression to these patterns of meaning. While loss and role transitions are part of the process of maturity, their management and resolution relies heavily on the maintenance of a person's dignity and personhood through the other (Kitwood & Bredin, 1992). Modern medical practice leans heavily on pharmacological and social approaches for the management of behavioral and psychological symptoms of dementia, while largely paying lip-service to psychological interventions. This has resulted in a variety of cognitive, behavioral and social measures to address the behavioral and functional devastation of neurocognitive disorders which are indeed welcome and necessary, but insufficient to address the unmet needs of these patients. Our subordinate themes serve to shed some light on these unmet needs. Arguably, the dyads who graciously accepted to participate in this research study represented a self-selected group that has been fortunate to have 'an other' accompany them at the dawn of their ending as witnessed by their low levels of psychological distress observed. Perhaps it is the nature of the recruitment process in such studies that we unwittingly bias the enrollment to subjects who have the luxury of a caring other responding to a call for study participants, and thus are more likely have these fundamental meaningful needs met by an other. Nonetheless, it

behooves us to enter into a detailed inquiry of the normative so that we may better appreciate the building blocks of psychological health. Our idiographic data illustrate how as patients with early dementia entered the dawn of their decline, they were anchored in their relational roots from which they derived their self respect, and through these same relational processes found a way to resolve their concerns related to the future and reached various levels of psychological integrity. Exploring whether these same themes persist or otherwise in dyads with more conflicted relationships is an area worthy of independent study. While our dyads were not overtly conflicted, more subtle and less subtle conflicts were indeed noted in our analyses as described above. Our approach to such areas of disagreement/conflict was to present it faithfully in the generativity document. The themes and subthemes emerging from these more 'conflicted' dyads did not differ from the seemingly less 'conflicted' dyads, so that the author predicts that the themes of relationships, roots, respect, and receding health would persist in more conflicted dyads. I also predict that while the subthemes will be similarly robust, that their relative salience will differ significantly in conflicted dyads and thus allow for their forming the basis of a personalized therapeutic approach.

We propose therefore, that the dignity model applied in a dyadic approach offers a unique opportunity to identify the source of an individual's pattern of meanings which can be the focus for therapeutic intervention. While it is natural for a clinician to engage in the 'prescription' of a therapy for an ailment, we often fail to perceive the need for personalization of our therapeutic interventions. Indeed, pharmacological intervention is heading towards 'personalized medicine'. Dignity Therapy using a dyadic approach allows for a personal perspective to universal psychological growth thus providing a window of opportunity to use this personalized information for therapeutic purpose either as a focus of therapeutic intervention or as an outcome measure. In so doing intervention studies would address the personal source of an individual distress rather than engage in a 'carpet-bombing approach' that assumes that all human dysfunctional psychological and behavioral symptoms of dementia result from a specific pathophysiology that can be targeted specifically with a broad non-specific intervention. This personalized and pragmatic approach to the behavioral and psychological symptoms of dementia derived from a deeper phenomenological understanding of the relational underpinning of meaning thus has the potential to contribute to a more dignified approach to care.



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## APPENDIX A

### Dignity Therapy Question Protocol (Patient)

1. 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?

**Ghidli ftit dwar hajtek; partikolarment daww il-partijiet li jew tiftakar l-aktar, jew li huwa l-aktar important? Meta hassejtek verament qed tghix?**

2. Are there specific things that you would want them to remember?

**Hemm xi affarijiet partikolari li tixtieq il-familja tiegħek tkun taf dwar, u hemm xi affarijiet li tridhom jiftakru?**

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

**Liema huma l-aktar irwoli importanti li kellek f'hajtek (familjari, vokazzjonali, servizzi fil-komunita', eċċ)? Ghaliex kienu importanti ghalik, u x'tahseb li ksibt f'dawn l-irwoli? Bhal perezempju qed nghidu ahna, fuq il-familja, fuq ix-xogħol, kif tkellimna tiġa', fil-komunita'. Ghaliex kienu importanti ghalik, u x'tahseb li ksibt b'dawn l-irwoli?**

4. What are your most important accomplishments, and what do you feel most proud of?

**X'inhuma l-aktar kisbiet importanti tiegħek, u biex thossok l-aktar kburi?**

5. What are your hopes and dreams for your loved ones?

**X'holm jew xewqat għandek għal maħbubin tiegħek?**

6. What have you learned about life that you would want to pass along to others?

**Tghallim xi haġa dwar il-hajja li tixtieq tghaddi lil haddiehor?**

7. What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?

**X'pariri tixtieq tghaddi lil [ibnek, bintek, martek, raġel tiegħek, ohrajn?**

8. 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?

**Hemm xi affarijiet li thoss li għandek trid tghid lil maħbubin tiegħek, jew xi affarijiet li tixtieq tiehu l-hin biex terġa' tghidilhom?**

9. Are their words or phrases even instructions you would like to offer your family, in order to provide help prepare them for the future?

**Hemm xi kliem jew istruzzjonijiet li tixtieq tagħti 'l familtek, sabiex tghinhom jippreparaw għal futur?**

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

**Hemm xi affarijiet ohra li tixtieq jiġu miżjuda fid-dokument finali?**



## APPENDIX B

### Dementia Therapy Question Protocol (Caregiver)

1. Tell me a little about meaningful moments that you shared with \_\_\_\_\_, particularly the parts that you either remember most or are the most important?

**Tista' tghidli ftit dwar żmien jew mument li qsamt ma' \_\_\_\_\_, li jfissru hafna ghalik?**

2. Could you identify a particular moment or episode when you felt particularly good or valued thanks to \_\_\_\_\_?

**Tista' taħseb f'xi żmien jew mument fejn int hassejtek ferħan/a hafna jew tassew apprezzat/a minn \_\_\_\_\_?**

3. Are there specific aspects or memories that you will always remember him or her by?

**Hemm xi aspetti jew memorji ta' \_\_\_\_\_ li dejjem ser jibqgħu f'qalbek?**

4. Tell me about how \_\_\_\_\_ influenced your life?

**Għidli ftit dwar is-sehem li \_\_\_\_\_ kellu f'ħajtek? X' effett kellu/a fuq ħajtek?**

5. What are the most important accomplishments that you reached in your life thanks to \_\_\_\_\_?

**Meta taħseb dwar dak li ksibt int f'ħajtek, liema kienu dawk li l-aktar ġew influenzati minn \_\_\_\_\_?**

6. What do you feel most proud of about \_\_\_\_\_?

**X'jagħmlek kburi/ja minn \_\_\_\_\_?**

7. Are there things that you feel need to be said to \_\_\_\_\_, or things that you would want to say again?

**Hemm xi affarijiet li għadek tixtieq tgħid jew tħoss li trid tgħid lil \_\_\_\_\_, kemm jekk għidhom qabel u kemm jekk le, jew tixtieq li terġa' tgħidhom?**

8. What do you wish for most for \_\_\_\_\_?

**X'tixtieq l-aktar għal \_\_\_\_\_?**

9. What have you learnt about life thanks to \_\_\_\_\_?

**X'tgħallimt f'ħajtek permezz ta' \_\_\_\_\_?**

10. What kind of advice or words of guidance that \_\_\_\_\_ shared with you that helped you across your own life pathway?

**Kien hemm xi parir jew kelma tajba li qallek/qaltlek \_\_\_\_\_ li għinitek b'mod speċjali f'ħajtek?**

11. Are there any specific life lessons, advice or words of guidance that you received from \_\_\_\_\_ that you always cherish?

**Kien hemm xi parir jew kelma tajba li qallek/qaltlek \_\_\_\_\_ li dejjem se żżomm f'qalbek?**

12. In creating this permanent record, are there other meaningful things about \_\_\_\_\_ that you would like include?

**Hemm xi kummenti jew ħsibijiet importanti oħra dwar \_\_\_\_\_ li tixtieq li jitniżżlu f'dan id-dokument?**