

**THE IMPACT OF DIGNITY THERAPY ON DEPRESSION AND ANXIETY
IN THE PATIENT-CAREGIVER DYAD, IN THE CONTEXT OF MILD
COGNITIVE IMPAIRMENT AND EARLY-STAGE DEMENTIA**

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ABSTRACT

The phenomenon of ageing has made mental health in older adults a public health priority on an international level. One of the most salient conditions requiring addressing in this demographic is dementia, its behavioural and psychological symptoms and the consequent burden (and psychological sequelae) on their caregivers. Non-pharmacological interventions have been identified as a pivotal component of meaning-centred approach in this patient population. Dignity Therapy (DT), whilst originally devised for use in palliative care populations, has been noted to have potential in neurocognitive disorders (which are non-cancer terminal conditions). This study aimed to assess the feasibility and acceptability of DT in dementia, looking at anxiety and depression as outcomes of interest. This study was the first of its kind to adapt DT into a dyadic approach, making the caregiver a direct participant of the intervention, thus emphasising the complex and interdependent nature that exists between a person with dementia (PWD) and their caregiver. The study employed a single-group pretest-posttest design. 12 participants (6 dyads) were recruited through the Day Hospital at Karin Grech Hospital. The Hospital Anxiety and Depression Scale (HADS) was used to measure the outcomes of interest at baseline (T0) and 2 weeks post-intervention (T4). The Dignity Therapy Patient Feedback Questionnaire (DTPFQ) was carried out to assess feasibility. In PWD, DT was associated with non-significant reductions in depression (Pre $M=3.67$, $SD=2.94$; Post $M=3.33$, $SD=2.94$; $t(5)=0.47$, $p=0.33$) and anxiety (Pre $M=6.00$, $SD=3.80$; Post $M=5.33$, $SD=3.724$; $t(5)=0.46$, $p=0.33$). In caregivers, DT was associated with near-significant reductions in depression (Pre $M=3.00$, $SD=2.10$; Post $M=1.67$, $SD=1.75$; $t(5)=2.00$, $p=0.051$) and non-significant reductions in anxiety (Pre $M=4.33$, $SD=2.66$; Post $M=3.50$, $SD=3.02$; $t(5)=1.19$, $p=0.15$). DT effect sizes were small in PWD ($g_{av}=0.15$; 95% CI [-0.57, 0.92]) and small to moderate in caregivers ($g_{av}=0.42$; 95% CI [-0.12, 1.09]). DTPFQ showed that DT was perceived as tolerable and acceptable in both PWD and caregivers, with no significant differences between the two groups. While this study had limited inferential capacity due to small sample size, it proved useful in establishing a dyadic DT approach is feasible and acceptable in this population. The quantitative findings on anxiety and depression show that whilst not significant, they were promising considering that confidence intervals were weighted towards positive effect (especially on the depression subscale in caregivers). This implies that future dyadic DT research with larger sample sizes has potential to ascertain significant positive outcomes in both PWD and caregivers.

*“Though those with Alzheimer’s might forget us,
We as a society must remember them”*

Scott Kirschenbaum, Filmmaker

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LIST OF ABBREVIATIONS/ ACRONYMS/ SYMBOLS

AD	Alzheimer's Dementia
ADL	Activity of Daily Living
BPSD	Behavioural and Psychological Symptoms of Dementia
DT	Dignity Therapy
DTPFQ	Dignity Therapy Patient Feedback Questionnaire
DTQP	Dignity Therapy Question Protocol
ESD	Early-Stage Dementia
FTD	Frontotemporal Dementia
GD	Generativity Document
HADS	Hospital Anxiety and Depression Scale
KGRH	Karin Grech Rehabilitation Hospital
LBD	Lewy Body Dementia
LSB	Life Story Books
MCI	Mild Cognitive Impairment
MDT	Multidisciplinary Team
MoCA	Montreal Cognitive Assessment
NPI	Non-Pharmacological Intervention
PWD	People with Dementia
QoL	Quality of Life
RT	Reminiscence Therapy
VD	Vascular Dementia

CHAPTER 1 – INTRODUCTION

1.1 The Demographics of Ageing

Demographic studies have made it abundantly clear that the 20th century has been witness to the phenomenon of population ageing. By the year 2050, it is predicted that one in six people will be over 65 (16%), when compared with the current ratio of one in 11 in 2019 (9%) (United Nations, 2019). 2018 was the first year in recorded history that the global population over 65 started to outnumber the global population of children under the age of 5 (United Nations, 2019). When considered from the aspect of gender, ageing has often been deemed to be a female phenomenon, as gender distribution to date remains weighted towards females, especially in the oldest old. However, this gender difference in longevity has been noted to be narrowing over recent years, with more older people now spending longer periods as couples as they age (Westerhof, Dittmann-Kohli, Bond, & Peace, 2007). It is a success story for humanity, through the improvement of public health and medicine, socioeconomic development, disease control, and reduction in premature death.

Malta is no exception to the demographic trends being faced in other countries worldwide. The Maltese population has increased 3.6 times in size between 1842 and 2011. In just over a century, the over 65 age group has increased from 5.4% (in 1901) to 19.0% (in 2015), with the younger than 14 group going from 34.1% (1901) to 14.2% (2015) with the median age rising to 40.5 years in 2011. Longevity in the Maltese islands has also increased considerably. In 1948, the average lifespan of a Maltese citizen stood at 43 and 46 years for males and females respectively. In 2016, this had gone up to 80.6 and 84.4 years for males and females respectively. Females continue to outnumber males, most significantly in the oldest cohorts, with over-representation of married men and widowed women (Formosa & Scerri, 2015).

1.2 Epidemiology of Dementia

1.2.1 International perspective

Dementia is a condition which predominantly afflicts older people, with age being the greatest risk factor for the development of cognitive impairment (Livingston et al., 2020). The substantial increase in longevity (especially in developing countries) driven by population growth and overall demographic ageing has thus led to the inevitable and considerable increase

in the total number of people being diagnosed with mild cognitive impairment or dementia worldwide. The figures have been projected to reach 75.6 million by the year 2030 and to then double by the year 2050 (Prince, Guerchet, & Prina, 2013). This has rightly led the World Health Organisation to define dementia as a ‘global public health priority’ (World Health Organization, 2012).

The financial ramifications of this demographic shift are expected to be significant. In 2010, the world’s expenditure on dementia was estimated to total to around 1% of the global gross domestic product (which equates to about 604 billion American dollars), with around 42% of these costs being contributed by informal and societal care (Alzheimer's Disease International, 2010).

This has led to a concerted international effort in the drafting of new policies which strive to be more comprehensive in their understanding of dementia and in improving the provision of care for this vulnerable population. An example of such policies is the European Collaboration on Dementia (EuroCoDe), a project led by Alzheimer Europe to gain a thorough understanding of the cost related to dementia, its prevalence, diagnosis and treatment. Moreover, it also focused on the gathering of information about prevention of this condition, psychosocial interventions employed in its management and social support systems implemented in EU member states (Alzheimer Europe, 2011).

The working group which focused on psychosocial interventions reflected that whilst pharmacological therapies are routinely subject to rigorous testing through double-blinded and controlled studies, non-pharmacological interventions are seldom tested with the same rigor. The project aimed to perform a review of reviews available and compile a collection of European guidance on non-pharmacological interventions. The review concluded that the most effective psychosocial interventions were those which were directed towards both the patient with dementia and their caregiver. Appraisal of guidelines from various European member states evidenced an increased awareness of the importance of psychosocial interventions, yet (at the time) only 5 countries had provided recommendations for such interventions in their guidance (Alzheimer Europe, 2011). This led to a collaborative evaluation of available guidelines and collation of 15 quality indicators that may prove helpful to policy makers of European member states ameliorating psychosocial care in dementia.

1.2.2 Local Perspective

The prevalence rates obtained from data collected at the time of the EuroCoDe project showed that the number of older persons with dementia in the Maltese islands was 5,198 in 2010 and was estimated to double by the year 2030 (Scerri & Scerri, 2012). In the local context, dementia and its consequent care investment has also had significant socioeconomic impact, costing the Maltese government approximately between €63.1 to €96.2 million in 2009 (Wimo et al., 2011).

The importance of addressing dementia in view of its significant public health impact has also been appreciated locally. In response to the above, the Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing launched the National Strategy for Dementia in the Maltese Islands (2015-2023) in April 2015. This Strategy was the result of an amalgamation of works from local experts in the field. The aim of this publication was to better understand and improve the quality of life of persons with dementia, whilst also safeguarding their close relatives or those that play a caregiving role. This strategy was structured such that it laid out a series of plans over 9 years aimed at targeting dementia awareness, timely diagnosis, augmenting the specialist workforce employed in this sector and encouraging continuous development and betterment of dementia care and research (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015).

The National Strategy for Dementia echoes international recommendations, that whilst pharmacological therapy plays a role in the holistic approach towards dementia care, there is limited evidence in literature for its exclusive use (Krishnamoorthy & Anderson, 2011). It advocates for the transition from the traditional institutional policies that encourage restraint (be it chemical, mechanical or environmental) to increased use of non-pharmacological intervention. Such an approach has been found to have a small yet significant impact on cognition, behavioural symptoms and reduced use of antipsychotics (Richter, Meyer, Möhler, & Köpke, 2012). However, locally there is still no protocol in the use of medication for management of BPSD and non-pharmacological interventions are still utilised infrequently (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015).

The Strategy established a number of objectives, which included the promotion of research initiatives focusing on non-pharmacological interventions targeted towards management of

BPSD and cognitive stimulation, using models which not only involve the PWD, but also their caregivers and family members (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015). It is in light of these proposals and the dearth of psychosocial interventions in dementia that this research question was formulated and this project carried out.

1.3 Defining Dementia

From a clinical perspective, dementia is considered to be a progressive neurodegenerative clinical syndrome, where symptoms tend to run a gradual and persistent course. The consequence of these changes is the loss of a number of cognitive functions, such as memory, attention, language skills, interpretation of visual information and solving problems amongst others. This loss of function can progress to an extent that it starts having an adverse impact on an individual's ability to perform daily activities and life in general (NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center, 2017). The following are the definitions of neurocognitive disorders as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, often abbreviated to DSM-5.

Dementia, or Major Neurocognitive Disorder (DSM-5), is a syndrome that is characterised by cognitive decline which is registered in multiple domains including memory, learning, executive function and language. This presentation is observed beyond occurrence of delirium and interferes with the ability of an individual to function adequately in personal and independent activities of daily living (ADLs) (American Psychiatric Association, 2013).

Dementia is most often preceded by a precursor state of cognitive decline which is known as Mild Cognitive Impairment (MCI) (World Health Organization., 2004) or Mild Neurocognitive Disorder (DSM-5). It is typified by a modest decline in cognitive function, without significantly interfering with the ability of an individual to function adequately in personal and instrumental ADLs, including performance of more complex tasks (American Psychiatric Association, 2013).

It is worth highlighting that the redefinition of dementia and MCI into Major and Mild Neurocognitive Disorders respectively in the DSM-5 was an important step in the classification of dementias. This is because in doing so, these redefinitions allow for the inclusion of

conditions that may result in cognitive dysfunction beyond that of memory loss in their initial stages.

There is a plethora of aetiologies that can lead to an array of symptoms in keeping with a clinical diagnosis of dementia. As elaboration on all aetiologies goes beyond the scope of this literature review, I shall limit my description to the four commonest types of dementia that constitute the vast majority of cases encountered in clinical practice.

1.3.1 Alzheimer's Dementia

Alzheimer's dementia (AD) is the most common form of dementia, making up between 60 to 80% of total cases. The principal pathological features observed in AD are thought to occur secondary to the accumulation of neurofibrillary tangles and beta amyloid plaques in the brain. This accumulation usually starts in the entorhinal and hippocampal cortices, leading to neuronal injury and subsequent death. This loss of neurons (which are of a cholinergic nature) correlates with the clinical symptoms of memory loss and other dysfunctional components of cognition. As the pathological changes spread to other cortical regions of the brain, the general clinical picture deteriorates accordingly (Weerasak Muangpaisan, 2017).

The onset of AD is generally an insidious and gradual one, with loss of short-term memory being often the first clinical symptom noted by relatives or clinicians. In the earlier stages of the condition, deficits are usually noted primarily in memory and visuospatial functions (for example getting disorientated in a familiar place such as the home environment or the community). As the disease progresses, other difficulties may start to be encountered with the individual's personality and behaviour. The final stages of AD may be characterised by complete inability to communicate or to function independently, even in the most basic personal ADLs (Duong, Patel, & Chang, 2017).

1.3.2 Vascular Dementia

Vascular dementia (VD) is the second-most common type of dementia, contributing to around 20% of total cases. It is believed to occur as the result of poor (or occluded) cerebral circulation, causing neurons to become deprived of oxygen and dying. Cerebrovascular accidents are the most common cause of VD. The presentation of this dementia type depends largely on the area

of the brain which is affected and the severity of the hypoxic brain injury. VD is characterised by a sudden and significant deterioration in executive function, although it can often run a more gradual course when it occurs in the context of multiple small infarcts. VD can occur concurrently with AD, a condition known as *Mixed-type Dementia* (Weerasak Muangpaisan, 2017).

1.3.3 Lewy Body Dementia

Lewy Body dementia (LBD) is responsible for approximately 5-15% of total cases. The main pathological feature in this type of neurocognitive disorder is the abnormal inclusion of alpha synuclein protein (known as Lewy bodies) in neurons. The hallmark features of LBD are fluctuating cognitive impairment, accompanied by visual hallucinations as well as Parkinsonian features. In the earlier stages of LBD, presenting features might include Rapid Eye Movement (REM) sleep behavioural disorders, where the body is not paralysed during REM phases of sleep, resulting in the acting out of dreams which are often distressing (Duong et al., 2017; Högl & Iranzo, 2017).

LBD can be differentiated from Parkinson's Disease Dementia (PDD) by the chronology in which the symptoms present. To diagnose LBD, cognitive features have to be present for a period of at least 12 months before the onset of parkinsonian (movement) symptoms. When the cognitive symptoms have been present under 12 months, a diagnosis of PDD is usually made. Furthermore, postural stability and gait problems tend to be more common in LBD (Weerasak Muangpaisan, 2017).

1.3.4 Frontotemporal Dementia

Frontotemporal dementia (FTD) is an umbrella term that includes a number of variants which primarily affect the frontal and temporal regions of the cerebral cortex. FTD, when compared with other types of dementia, occurs much more frequently in adults under the age of 65, making it the commonest type of younger-onset dementia. The primary features of this type of dementia are changes in personality and disturbance of behaviour, with other cognitive domains being adversely affected as the disease progresses (Weerasak Muangpaisan, 2017).

1.4 Behavioural and Psychological Symptoms of Dementia

The cognitive component of dementia is managed pharmacologically through the use of cholinesterase inhibitors, such as donepezil, and NMDA antagonists, such as memantine, which agents are used in the vast majority of cases except in the earlier and the most severe stages of cognitive decline. However, the non-cognitive component that accompanies dementia is also deserving of the attention of healthcare professionals.

Behavioural and psychological symptoms of dementia (BPSD), also known as neuropsychiatric symptoms, are present in around 98% of dementia cases (and 35% to 85% of MCI cases (Gallagher, D., Fischer, & Iaboni, 2017)) and are considered by both people with dementia and their caregivers alike to be the more distressing aspect of the condition, more than the decline in cognitive function itself (Kales, Gitlin, & Lyketsos, 2014).

BPSD can constitute a wide variety of symptoms and these include depression, anxiety, apathy, sleeping disorders, agitation, aggression and psychotic features such as hallucinations and delusions amongst others (Phan, Osa, Morgan, Inyang, & Fagan, 2019). Depression and apathy are believed to be the commonest symptoms which are observed in the earlier stages of neurocognitive disorders (Lyketsos et al., 2011), with depression very commonly occurring concurrently with anxiety (Van der Mussele et al., 2014).

The presence of psychological symptoms has been identified as an independent factor in negatively impacting on the Quality of Life (QoL) and general level of function of older persons (Grassi et al., 2020), only to be further exacerbated by the presence of cognitive decline. Various researchers have stated that in the context of the dementia care-dyad, BPSD are significant contributors to reduced QoL (Banerjee, S. et al., 2006), with anxiety and depression being correlated with a decrease in QoL in both PWD (Selwood, Amber, Thorgrimsen, & Orrell, 2005) and their caregivers (Covinsky et al., 2003).

1.5 Informal Caregiving in Dementia

Neurocognitive disorders have been identified as being one of the most frequent causes for admission into long term care, with up to 90% of people who suffer with dementia reportedly ending up admitted into such institutions at some stage of their disease (Yaffe et al., 2002).

Dementia is in fact one of the strongest longitudinal predictors to institutionalisation (Hajek et al., 2015). However, the vast majority of people with dementia live in their own homes and in fact wish to continue doing so. In order to make this possible, they usually require help (i.e., informal caregiving) to perform ADLs from their immediate social support network, which is comprised primarily of family members and friends (Laver, Milte, Dyer, & Crotty, 2017).

Support is often required to perform personal ADLs (e.g., washing, dressing, eating and toileting) and instrumental ADLs (e.g., chores, shopping, cooking, managing money and making decisions about healthcare). Another important aspect of caregiving is the provision of supervision so as to ensure the safety of the person with dementia (Laver et al., 2017).

It is understandable that the role of the caregiver evolves as the disease progresses, with support in instrumental ADLs being more typical of the earlier stages of dementia, transitioning into provision of personal ADLs and management of challenging behaviours in the latter stages of the illness (Huang, Huei-Ling et al., 2015), resulting in increased levels of burden and consequent reduction in their QoL (Laver et al., 2017). Caregiver burden and distress often results in psychological sequelae, with symptoms of depression and anxiety being frequently associated with the occurrence of burden (Mahoney, Regan, Katona, & Livingston, 2005).

From the healthcare systems perspective, one of the primary goals in dementia care remains the avoidance, or at least delay of institutionalisation. To be able to achieve this, healthcare professionals must work together with informal caregivers in order to adequately cater for the needs of PWD (Huang, Huei-Ling et al., 2015) and ultimately, the needs of the caregivers themselves.

However, to be able to achieve this quality of care, healthcare professionals must be cognisant of the fact that the needs of an individual are not simply limited to the physical domain, but tend to encompass other facets of the human experience, including psychosocial, spiritual and existential aspects of care (World Health Organisation / Worldwide Palliative Care Alliance, 2014). It is therefore imperative that healthcare systems, in their objective to cater for the non-medical needs of people with cognitive impairment, integrate the provision of dignity-conserving care as a regular component of general practice.

1.6 The Patient and Caregiver as a Dyad

When considering the patient with dementia and their caregiver, it is imprudent to think of them as two independent individuals. From the prediagnostic and diagnostic stages of dementia, the experience of this condition becomes a mutual one (Orsulic-Jeras, Whitlatch, Powers, & Johnson, 2020). As the disease progresses, a number of transitional challenges occur, which influence various aspects of the patient's as well as their family's lives (Orsulic-Jeras, Whitlatch, Szabo, Shelton, & Johnson, 2019). The dementia care dyad becomes co-dependent in communication, decision-making and emotions amongst other factors (Orsulic-Jeras et al., 2020). For this reason, the dyad should not be considered as two separate entities. Rather, the patient and their caregiver should be approached as a single interdependent unit, where to ensure the health of the dyad, the health of both parties must be safeguarded (Lyons & Lee, 2018). Failure to do this can result in worsened lived experiences for both patient and caregiver (Orsulic-Jeras et al., 2019).

In recent years, a growing body of literature is concentrating on the way illness is experienced by the dyad and how deeply this influences the extant rapport (Whitlatch, 2013). A number of psychosocial interventions with a dyadic focus have been reviewed and generally found to be tenable, tolerable (Moon & Adams, 2013) and effective in patients, caregivers or both (Leven et al., 2013). However, even though there has been an increase in interest in researching dyads in dementia care, a gap remains in the consideration of combined outcomes in caregiver-patient dyads (Gellert et al., 2018).

1.7 Theoretical Foundations of the Study

1.7.1 Dignity

The concept of dignity has been at the centre of human evaluation for centuries and a great number of publications have been written in its regard. Researchers are in general agreement that dignity can be considered as having two main components: human dignity, which is inherent to human beings and is not prone to alteration by other factors; and personal dignity, which is susceptible to being influenced by context and can be altered by both internal factors (such as the worth and respect that one gives oneself) or external factors (i.e., a social component where an individual is attributed value by those around him) (van Gennip, W. Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2016).

Whilst the importance of dignity in care has been widely advocated for in literature, the main challenge lies primarily in the operationalisation of this concept, so as to provide guidance for its implementation in systemic practice (Johnston et al., 2015). Part of this difficulty lies with the fact that the significance of dignity and how it is affected can vary markedly from one individual to another (Chochinov, Harvey M. et al., 2006). Furthermore, the experience of loss of dignity may also vary depending on the condition leading towards end of life, given that different conditions follow different trajectories (Chochinov, Harvey Max et al., 2017).

1.7.2 Dignity in Older Persons with Cognitive Impairment

In older persons, the gradual loss of independence and function in activities of daily living can result in an insult to an individual's sense of dignity (Gallagher, A., Li, Wainwright, Jones, & Lee, 2008). This can be further complicated by the onset of cognitive impairment. For many years, the opinion of individuals with cognitive decline was not actively sought in dementia research, although in recent years there have been remarkable efforts to gain insight into this condition from those who experience it themselves (van Gennip et al., 2016). On the intrapersonal level, apart from the loss of function that comes with the increasing frailty that often accompanies ageing, as previously mentioned, the decline of autonomous decision-making (Holst & Hallberg, 2003) and loss of abilities and skills may negatively affect an individual's notion of self-worth and identity (van Gennip et al., 2016). On an interpersonal level, individuals with cognitive impairment regard the value they are attributed by others as an important aspect of their dignity (Steehan, E., Tournoy, Grypdonck, Godderis, & Casterlé, 2013), finding negative remarks from others more demeaning to their sense of worth than their cognitive problems per se (Clare, 2003).

In view of the above, one can appreciate that older people with cognitive decline are at significant risk of depletion of their dignity. Loss of dignity can result in feelings of hopelessness, worthlessness and feelings of life not being worth living (Chochinov, Harvey Max, 2002). It is therefore the responsibility of clinicians to strive for the preservation of dignity in people with dementia. Healthcare professionals hold an important role in this respect, due to the prominent influence that they wield on the patient's experience of their condition. This patient-professional rapport provides the chance for actively conserving an individual's dignity, not only through curing, but also caring (Grassi, Chochinov, Moretto, & Nanni, 2019).

1.7.3 Dignity-Conserving Care

Chochinov (2007) described a basic template for healthcare professionals in order to provide good dignity-conserving care, with a view for it to be generalisable and applicable to an array of clinical settings beyond cancer patient populations. He describes the ABCD of dignity-conserving care: A, the health professional's mindfulness of his/her own attitude towards patients; B, behaviour of respect and kindness in building trust and connection in the patient-professional relationship; C, compassion towards patients' suffering and a desire to alleviate it; and D, dialogue where the personhood beyond the patient's condition and the emotional toll it causes is acknowledged (Chochinov, Harvey Max, 2007).

Formalisation and expansion of the dialogue component of this framework has led to a number of trials using a variety of psychotherapeutic modalities in this particular patient population, such as life review and reminiscence therapies (Woods, O'Philbin, Farrell, Spector, & Orrell, 2018), where the scope of these interventions was to preserve an individual's identity through the ascription of societal value to that individual's personhood.

Another modality which has drawn much attention in this field and is worth consideration for use in people with cognitive impairment is Dignity Therapy (DT) (Chochinov, Harvey Max, 2012). This is because it has proven itself to be a suitable and effective means to deliver good patient-centred care. DT, unlike other life evaluation therapies, does not limit itself to the simple compilation of a series of life events in a chronological order utilising a biographical format. Rather, the primary objectives of DT are to emphasise particular moments and relationships in one's life which instil feelings of pride and enhance self-worth, to elicit significant roles played or achievements in life and to identify any important lessons learnt in life that the one might wish to pass on to his/her loved ones. In doing this, DT not only gives meaning and enhances the value of self through the exploration of important life events, but also provides the opportunity – through the creation of a written document (known as the Generativity Document, GD) – to produce a lasting legacy to be inherited by their relatives and loved ones.

1.8 Relevance of the Study

To date, DT has been studied primarily in cancer patient populations (for whom it was originally created) and has been proven widely acceptable, tolerable and beneficial (Chochinov, Harvey Max, Kristjanson, Breitbart, McClement et al., 2011; Mai et al., 2018; Martínez et al., 2017). However, there is a growing body of evidence that it is a modality which is applicable to other life-limiting conditions as well (Chochinov, Harvey Max et al., 2017).

Dementia qualifies as a terminal condition, in view of it being an incurable illness characterised by a series of progressive losses and eventually leads to the patient's demise (McInerney, Doherty, Bindoff, Robinson, & Vickers, 2018). Despite the fact that dementia remains under-recognised as a terminal illness (Ghneim & Diaz, 2021), this patient population has drawn the interest of researchers as a potential candidate for DT in previous years, with empirical yet promising results (Chochinov, Harvey Max et al., 2012; Hall, Goddard, Opio, Speck, & Higginson, 2012; Johnston et al., 2016).

When considering the importance that is attributed to the relational component in the preservation of dignity in dementia, one cannot ignore the central role that informal caregivers (who are most often close relatives) play in this aspect (Grassi et al., 2019). In fact, a positive relationship between the PWD and their caregiver already bolsters dignity through the provision of a framework that allows the former to lead as normal a life as possible, while also empowering them to continue ageing in place and supporting them in making decisions and at the same time where possible respecting their wishes (van Gennip et al., 2016).

DT research has elucidated that from the family members' point of view, the therapy was not only found to be useful in helping their loved one towards the end of life by improving their sense of dignity and purpose, but also reduced distress and improved hopefulness about the future in family members themselves, which effects could be perpetuated after their loved one passed through the legacy of the GD (Scarton et al., 2018). The importance of personal belongings of the grieved individual as an aid to facilitate the family's transition through the bereavement process has also been described (Gibson, 2004), emphasising the relevance of the GD as a transitional object.

1.9 Aim of the Study

In light of the loss of dignity associated with the neurocognitive decline in dementia experienced by the PWD as well as the significant caregiver burden, this project proposes that when carrying out meaning-centred interventions aimed at improving dignity in people with cognitive impairment, one cannot exclude the caregiver in this process given the relevance of the dyadic relationship on the mental health and quality of life in both involved parties.

Whilst caregivers have supported participants to varying degrees in the DT process in other studies (Scarton et al., 2018), the aim of this project is to assess whether it is feasible that the caregiver is formally involved as a direct participant in the therapeutic process rather than being given an ancillary role, using the dyadic component as a vehicle to improve wellbeing in both PWD and caregivers, with a focus on anxiety and depression as outcomes of interest.

1.10 Overview of Chapters

Chapter 2 will explore existing literature on the experience of dementia from both the patient and caregiver perspective, the occurrence of anxiety and depression in both groups and their management, with emphasis on non-pharmacological interventions. An argument for dementia being a terminal illness is made, justifying the use of Dignity Therapy. Chapter 3 provides an overview of the methodology employed in this study to test the hypotheses postulated to answer the research question, with the results being documented in Chapter 4. Chapter 5 outlines a discussion of the findings in the light of other studies and provides possible explanations for the results obtained. Chapter 6 concludes with an appraisal of the strengths and limitations of the study, implications for clinical practice and recommendations for future research.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This chapter gives a phenomenological account of the experience of dementia, from both the patient and the caregiver perspectives. This is followed by a description of the prevalence of anxiety and depression and their complex relationship with cognitive impairment, as well as anxiety and depression in caregivers and the importance of treating these symptoms in both groups. A review of the research available with regards to the pharmacological and non-pharmacological management of anxiety and depression in cognitive impairment is done, with reference to the role of reminiscence-based therapies and dyadic non-pharmacological interventions. The chapter concludes with an argument as to whether dementia can be considered a life-limiting illness, thus justifying the use of Dignity Therapy as a means of treating distress (and the psychological sequelae) caused by this condition.

2.2 Experiencing dementia – the patient and caregiver perspectives

One can appreciate how receiving a diagnosis of dementia is an experience that may have social, psychological and economic ramifications for an older person, their caregivers and other family members. Whilst it is common to explain dementia from a biomedical perspective, it is important to be cognisant of the phenomenological point of view of those living with dementia, be it the PWD or their caregivers.

From the perspective of the PWD, literature has often shown that living with dementia is an extremely personal and elaborate process transitioning through various stages, starting well before the formal diagnosis of the condition (Steeman, Els, de Casterle, Godderis, & Grypdonck, 2006). Several studies commonly describe a sense of loss (de Boer et al., 2007). This experience of loss is described by van Wijngaarden and colleagues (2019) as a disturbance in the relationship of the older person with their own bodies, those around them and the world they live in and interact with. PWD undergo a variety of biological and psychological symptoms, as well as experience a disconnection from their experienced reality, though impairment of consolidation of novel experiences due to impairment in their episodic memory (Ounalli et al., 2020).

These impairments are direct threats to an individual's self-agency and identity resulting in distress, shame and frustration which may in part contribute to the PWD hiding their difficulties from others until the degree of dysfunction becomes apparent. Other stages include a feeling of vulnerability and uncertainty about the future, as well as loss of control typified by solitude, dependence on their loved ones and feelings of guilt from becoming a burden and a wish to regain autonomy and value (Mazaheri et al., 2013; Xanthopoulou & McCabe, 2019). PWD do not experience this process passively, but rather engage in the transitions actively through emotion- (e.g., minimisation or denial, avoidance, etc) as well as problem-based (e.g., facing their diagnosis, compensating for losses, etc) coping mechanisms (de Boer et al., 2007).

From the caregiver perspective, the caring role is not only the provision of hands-on care for the PWD, but also includes other duties, including the forecast of future needs, ongoing supervision of the PWD, preserving the older person's sense of individuality and self and supporting the person in developing new roles that make them feel valued (Nolan, Keady, & Grant, 1995). It is therefore not surprising that this role is accompanied by changes in most of the caregiver's life aspects, be it social relationships, work and leisure amongst others.

There is perceived change in the relationship with the PWD, typified commonly by role reversal (in children), loss of reciprocity (in spouses) and appreciation (Daley et al., 2019). It is also felt to negatively impact the caregiver's freedom and ability to do things spontaneously. This can lead to some difficulties and resentment in accepting this role and may be associated with adverse health outcomes for the caregiver as well as causing significant anxiety with regards to the future (Daley et al., 2019).

Furthermore, caregivers undergo what has been outlined in research as the Two-Track Model of Dementia Grief. In this model, a distinction is made between the bereavement related to the physical end of life and the loss of personhood of a close relation, which significantly exacerbates the grieving experience (Rubin, Manevich, & Doron, 2019). The caregiver's process of grief starts shortly after diagnosis of a neurocognitive disorder and progresses as the PWD's cognitive and functional abilities decline, persisting after the PWD's death (Rubin et al., 2019).

The occurrence of anticipatory grief has been found to have a negative effect on caregiver burden independent from other contributors such as depression (Holley & Mast, 2009) and may

lead to dysfunctional coping strategies which result in an increased need of professional healthcare intervention (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). The difference of anticipatory grief in other terminal conditions is that the final stages allow for the opportunity to resolve conflicts and improve acceptance prior to death, an opportunity which is not possible for families of PWD due to decline in cognition and communication (Lindauer & Harvath, 2014). In fact, a study by Shah et al (2016) looking at the impact of death of a partner with dementia reported that spouses of PWD have an increased likelihood of depression and requirement of psychiatric medications when compared to spouses of people without dementia.

2.3 Patient Anxiety, Depression and MCI/Dementia

The occurrence of mood disorders is frequent in normal ageing. In fact, in the general (non-MCI/dementia) older population, the prevalence rates for depression may vary between 14.6% and 53% and for anxiety between 3.7% to 43% (Ma, 2020). Independent of MCI/dementia, anxiety and depression have a significant association with the development of worsened cognitive function (Sugarman, Alosco, Steinberg, Tripodis, & Stern, 2017).

The presence of neuropsychiatric illness is even more common in MCI and dementia and the relationship between these factors is a complex one. A number of studies have reported that symptoms of anxiety and depression occur in around 40-50% of people with MCI (Gallagher, D. et al., 2017), though these data need to be interpreted in light of the bidirectional relationship between affective disorders and cognitive decline.

Older people with normal cognitive function and higher frequency of affective disorders have an increased risk of developing MCI (Geda et al., 2014; Sugarman et al., 2017). Depression with first onset in later life has been especially correlated with MCI in this regard (Gallagher, D. et al., 2017), with an abundance of evidence that is correlated with doubling of the risk of dementia (Mirza et al., 2017). In fact, it has been posited that the occurrence of affective disorders may indicate prodromal stages of a neurocognitive disorder, with anxiety and depression being two of the initial behavioural indicators of the condition (Ismail et al., 2016; Lyketsos et al., 2011).

Conversely, there is a wealth of literature reporting that older people with MCI experience a higher incidence of depressive illness that is often accompanied by comorbid anxiety disorders, indicating a positive correlation between the two (Ma, 2020).

Furthermore, in persons with MCI experiencing comorbid affective disorders, there has been an association with more severe cognitive decline and development of dementia (Gallagher, D. et al., 2017; Kuring, Mathias, & Ward, 2018). A study by Lee et al. (2012), showed that in MCI patients with comorbid depression, the annual conversion rate to AD was 31%, compared to the 13.5% observed in MCI patients without depression. Also, depressed patients were found to have increased frontal, parietal and temporal atrophy compared to controls (Lee et al., 2012). It is therefore not surprising that in the early stages of dementia, anxiety and depression are the most common neuropsychiatric symptoms (Lyketsos et al., 2011).

2.4 Anxiety and Depression in Caregivers of People with Dementia

The caregivers of people with dementia have been described as “hidden victims” of this condition, in view of the marked challenges that they must endure (Zarit, Orr, & Zarit, 1985). Approximately 75% of the caregiver’s day is dedicated to providing some form of care, which increases as the condition progresses (Aguglia et al., 2004).

It is therefore understandable that these circumstances may lead to an increased caregiver psychological burden, which may have a negative impact on the caregiver’s mental health (Zarit et al., 1985). In fact, primary caregivers to people with dementia are at an increased risk of developing psychological morbidity, in particular depression and anxiety, when compared to non-caregivers (Pinquart, Martin & Sörensen, 2003) and the impact of the caregiver role has been found to be more pronounced in dementia than in other conditions (Daley et al., 2019; Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015). Also, the burden seems to be larger for those caring for patients with frontotemporal and Lewy-body dementia when compared to Alzheimer’s dementia (Liu et al., 2018).

There has been variation in the reporting of prevalence rates of depression (10.5% (Mahoney et al., 2005); 14.9% (Alfakhri et al., 2018); 34.0% (Sallim et al., 2015)) and anxiety (23.5% (Mahoney et al., 2005); 43.6% (Sallim et al., 2015)) in caregivers, which is likely due to the period of time covered, the population studied, the variability in definition of ‘caseness’ of

anxiety and depression and diagnostic tools used. However, what is clear is that there is a definite and significant positive association. It is very common that caregivers who are depressed also suffer from anxiety, whereas the opposite was found not to be the case (Mahoney et al., 2005).

The relationship between every caregiver and care-recipient is highly individualised and complex, marked with its own set of difficulties. However, a number of risk factors increase the risk of developing anxiety and depression including being a female caregiver, spousal caregivers, younger caregivers (<50 years of age), caring for a male care-recipient, greater severity of dementia, physical impairment in the care-recipient, presence of behavioural problems (which is one of the strongest predictors), higher number of caregiving hours, lack of additional caregivers, and lower education (Mahoney et al., 2005; Sallim et al., 2015; Wulff, Malmgren Fänge, Lethin, & Chiatti, 2020; Ying, Yap, Gandhi, & Liew, 2018).

Depression and anxiety are also related to a number of factors which are attributable to the caregiver's perceptions, experiences and behaviours. The greatest predictor of these has been the caregiver's perceived burden, which increases the risk of developing both depression and anxiety (Cooper, Balamurali, & Livingston, 2007; García-Alberca et al., 2012). Caregiver burden describes the adverse effect that provision of care has on the caregiver's mental and physical health, often having social and financial consequences (Cheng, 2017; Pinquart, Martin & Sörensen, 2007). Caregiver's poor perceived physical health, perceived poor quality of relationship with the care-recipient (Mahoney et al., 2005), having additional life stressors (Oyebode, 2003), caregiver abusive behaviours and decreased caregiver life satisfaction (Cooper et al., 2007) also have an impact on the development of psychological burden.

Furthermore, coping strategies employed by caregivers have been identified as playing a role in mediating how stress influences psychological health consequences. Coping is the ongoing cognitive and behavioural reactions that caregivers employ to face internal or external stressors that go beyond the individual's normal resources (García-Alberca et al., 2012). It was found that caregivers who use disengagement coping strategies such as being problem-avoidant, using wishful thinking, being self-critical and social withdrawal, were at increased risk of developing depression and anxiety (García-Alberca et al., 2012; Li, Cooper, & Livingston, 2014), whereas using more functional, emotion-/acceptance-focused strategies was found to be protective (Cooper, Katona, Orrell, & Livingston, 2008).

Other protective factors include focusing on the strengths of caregiving (e.g. feeling useful, appreciated), religiosity (Roff et al., 2004), greater self-esteem and self-concept (Vedhara, Shanks, Anderson, & Lightman, 2000) and a good sense of coherence, which is an individual's capability of efficiently making use of available resources (Orgeta & Sterzo, 2013).

Caregiver anxiety and depression also have an impact on the care-recipient, having been associated with a more rapid cognitive decline in the PWD (Norton et al., 2013), depression in the care-recipient (Teri, Logsdon, Uomoto, & McCurry, 1997) and higher rates of institutionalisation (Coehlo, Hooker, & Bowman, 2007; Gaugler et al., 2010). Notwithstanding the aforementioned, addressing anxiety and depression in the caregiver is important due to high rates of suicidal ideation which may manifest along the course of care (Joling, O'Dwyer, Hertogh, Cees M P M, & van Hout, Hein P J, 2018; O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016).

In consideration of all the above, management of BPSD in PWD is of utmost priority (and of public health interest), in order to reduce caregivers' perceived burden and psychological consequences which in turn is expected to improve outcome in the care-recipient.

2.5 Management of Anxiety and Depression in MCI/Dementia

The treatment of neuropsychiatric symptoms in neurocognitive disorders takes a multidimensional approach, often requiring the involvement of a number of different health professionals. To remain within the remit of this review, the focus will be on the management of anxiety and depression.

Management relies largely on the use of pharmacological and non-pharmacological therapeutic approaches which are derived from therapies used for psychiatric disorders in the general adult population. This may explain to an extent the limited effectiveness of established treatments, due to incomplete understanding of the organic changes that are responsible for the symptoms being exhibited (Nowrangi, Lyketsos, & Rosenberg, 2015).

2.5.1 Pharmacological treatment of Anxiety and Depression

When considering the pharmacological perspective, pro-cognitive drugs have been found to have a small but significant effect on symptoms of anxiety and depression. This is when considering both acetylcholinesterase inhibitors, such as donepezil (Cummings et al., 2016; Loi, Eratne, Kelso, Velakoulis, & Looi, 2018) and NMDA antagonists, such as memantine (McShane et al., 2019).

The mainstay of treatment of anxiety and depression is through the use of antidepressants. When the efficacy of antidepressants has been studied in PWD, mixed results have been obtained. Some reviews found these medications to be effective in this population (Magierski & Sobow, 2016) whilst others found only limited evidence, with sertraline and citalopram being preferred due to favourable safety profiles and the latter also having an effect on agitation and psychosis (Legesse, Babadi, & Forester, 2017; Seitz et al., 2013; Sink, Holden, & Yaffe, 2005). A number of studies, however, found no benefit over placebo (Dudas, Malouf, McCleery, Denning, & Dudas, 2018; Lozupone et al., 2018; Sepehry, Lee, Hsiung, Beattie, & Jacova, 2012; Wang et al., 2015).

Whilst pharmacological treatment may be quick and easy for the caregiver, through the simple administration of an oral agent, this therapeutic option comes with the risk of possible deleterious effects that medication have in older adults and potential interactions with other prescribed medications. Therefore, it is reasonable to consider non-pharmacological interventions (NPI) as first-line treatment in PWD, although frequently both approaches are used concurrently.

2.5.2 Non-Pharmacological Treatment of Anxiety and Depression

NPI are considered first-line interventions in BPSD because they aim to tackle the problematic precipitant factors from both the PWD and the caregiver, which give rise to the relevant symptomatic presentations. They also pose little to no risk when compared to pharmacological interventions. The aim of NPI is to prevent, control, mitigate or eliminate BPSD whilst improving the QoL in both the PWD and their caregiver (Gitlin, Kales, & Lyketsos, 2012).

A number of systematic reviews and meta-analyses have been carried out over the past few years to evaluate the studies available on the efficacy of psychological and psychosocial interventions in MCI and dementia. These have consistently showed that a variety of such interventions have evidenced a statistically significant effect in at least partially reducing symptoms of depression and anxiety in people with MCI/dementia (Noone, Stott, Aguirre, Llanfear, & Spector, 2019; Orgeta, Qazi, Spector, & Orrell, 2015) as well as improving caregiver reactions to the PWD (Brodaty & Arasaratnam, 2012). These findings are limited by study quality, small sample sizes, lack of blinding, randomisation and controls, low power and a large variety of interventions implemented (Legere, McNeill, Martin, Acorn, & An, 2018; Loi et al., 2018), with the most conclusive evidence advocating for bespoke, sensory-focused or person-centred interventions (Legere et al., 2018).

Additionally, interventions that included the caregiver were found to be more efficacious in managing BPSD (Ayalon, Gum, Feliciano, & Areán, 2006; Brodaty & Arasaratnam, 2012; Gitlin et al., 2012). There is also strong evidence for NPI in caregivers, where through a spectrum of multicomponent and psychoeducational interventions it is possible to alleviate caregiver depression, anxiety and burden (Kishita, Hammond, Dietrich, & Mioshi, 2018; Piersol et al., 2017; Selwood, A., Johnston, Katona, Lyketsos, & Livingston, 2006).

A study by Gellert et al. (2018) explored how dyadic coping – coping mechanisms which are based on mutual efforts of the caregiver and the PWD – is significantly associated with reduction of depressive symptoms and promotes further research on dyadic-based interventions. Dyadic coping was also associated with improved relationship satisfaction (Falconier, Jackson, Hilpert, & Bodenmann, 2015). However, a weakness that is still notable in the available literature is that interventions for PWD and caregivers are often provided separately (Judge, Yarry, Looman, & Bass, 2013).

2.6 Reminiscence-based Therapies in managing Anxiety and Depression

Reminiscence therapy (RT) is a NPI modality which has garnered interest in dementia. It finds its origins in the work carried out by Butler in the 1960s on Life Review, a therapy which emphasises how looking back at one's past experiences fosters a feeling of integrity (Butler, 1963).

So, on a similar note, RT involves the exploration of past memories to stimulate cognitive function and foster wellbeing. It can take either an individualised or group format and is usually done with the aid of stimuli such as photos, videos, items and music that are familiar to the PWD. It is appropriate for use in depression and dementia, in view of these individuals having easier retrieval of long-term memory and preserved memories of their younger years.

A vast amount of research has been carried out to evaluate the use of RT in PWD. Findings have always been consistent in that RT has at least a small to moderate effect in alleviating depressive symptoms (Huang, Hui-Chuan et al., 2015; Park, Lee, Yang, Song, & Hong, 2019; Pinquart, M., Duberstein, & Lyness, 2007; Syed Elias, Neville, & Scott, 2015; Woods et al., 2018), as well as a potential to prevent onset of depression (Pot et al., 2010). The evidence is less clear with regards to the effect that RT has on anxiety (Syed Elias et al., 2015), although a recently published trial has obtained positive results (Indarwati, Fauzi, & Asmoro, 2020).

It is worth mentioning that Life Story Books (LSB), are one promising approach to RT, where memories are collected into a tangible end product, a physical book. A systematic review by (Elfrink, Zuidema, Kunz, & Westerhof, 2018) confirmed that LSB in dementia have both qualitative (evoking positive memories and improving relations with PWD) as well as quantitative effects (positive impact on autobiographical memory, depression and caregiver burden).

2.7 Is Dementia a terminal illness?

Dementia is a chronic and progressive illness which to date has no known cure. In spite of this, many are still unable to accept dementia as a terminal illness, be it relatives or health professionals (Bayer, 2006; Kumar & Kuriakose, 2013). People suffering with dementia experience a host of symptoms, be it cognitive, behavioural or perceptual, which inevitably progress into physical symptoms and accompanying complications (McInerney et al., 2018).

Research has made it abundantly clear that dementia in itself is a life-limiting disease (Kane, Shamliyan, Talley, & Pacala, 2012; Koller et al., 2012), where people experience an increased sense of frailty and dependence that adversely impacts their sense of dignity (van der Geugten & Goossensen, 2020; van Gennip et al., 2016) through the threat that this condition poses to the notion of self and personhood (Nowell, Thornton, & Simpson, 2013; Zeiler, 2014). People

with dementia have been found to suffer a symptom burden which is similar to people with malignant diseases (Moens, Higginson, & Harding, 2014).

Dementia, compared to other terminal illness such as cancer however, varies in the disease trajectory that it takes. Whilst in patients with cancer, there is a well-defined, foreseeable and substantial functional decline over weeks to months, this is not the case in dementia. Neurocognitive disorders run a variable course of deterioration, with progressive disability and suffering which may take years. Studies give survival rates ranging between 3 and 10 years (Zanetti, Solerte, & Cantoni, 2009), where there may be either death due to the illness itself or secondary to conditions that develop in dementia (e.g., pneumonia, reduced oral intake). Recognition of end-of-life is also remarkably difficult in this population, with health professionals tending to overestimate the time that PWD have left (Eisenmann, Golla, Schmidt, Voltz, & Perrar, 2020). One study highlighted how staff in a nursing home predicted the death of 1% of dementia residents in 6 months, with 71% actually dying in that period (Mitchell, Kiely, & Hamel, 2004).

Keeping in mind the above, experts in the field have been calling for the implementation of tailored palliative care targeting specifically people with dementia (van der Steen, Jenny T et al., 2014). The World Health Organisation defines palliative care as

“an approach that improves the quality of life of patients and their families, who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”

(World Health Organisation, 2020)

In spite of this, even though the dementia population is eligible to such care services, enforcement through national policies and translation into practice has remained challenging, primarily due to paucity of high-quality evidence that is available (Murphy et al., 2016). Another major issue is that caregivers for PWD generally lack a good understanding of the concept of palliative care, especially in the context of dementia (McInerney et al., 2018).

Whilst there are several challenges to address in the provision of palliative care in dementia, most stem from an underlying concept that is crucial to effective care, which is the conservation

of dignity of the person with dementia (Alzheimer Europe, 2008), with the scope of maintaining and enhancing factors which are considered important by the older population, including quality of life (Grassi et al., 2020) and meaning of life (Volkert et al., 2019).

2.8 Dignity Therapy

Dr Harvey Max Chochinov, the pioneer of Dignity Therapy who has done extensive research on this topic, rightly states that dying with dignity should be the common denominator of all care interventions (Chochinov, Harvey Max, 2002). This is because by keeping the conservation of dignity as the principal aim of palliative care, interventions expand to include not only symptomatic management but also incorporate the physical, psychological, spiritual and existential challenges faced by the individual (Chochinov, Harvey Max, 2002).

The definition of dignity, in the context of end-of-life care, has been a remarkably challenging endeavour. What was identified, however, was that dignity was “an elusive concept” that required defining by the patients themselves (Turner et al., 1996).

A study by Chochinov et al. (2002) embarked on this task, through qualitative analysis of 50 interviews with patients at the end of life on their opinion of dignity (Chochinov, Harvey Max, Hack, McClement, Kristjanson, & Harlos, 2002). Three main themes were derived from this data, which were believed to have a bearing on a person’s dignity:

- *Illness-Related Concerns*: problems that arise as a direct result of the illness. These include symptomatic distress in the context of disease progression, as well as the illness’ impact on level of independence and functional capacity.
- *Dignity-Conserving Repertoire*: challenges secondary to an individual’s psychological and spiritual qualities. This repertoire depends on dignity-conserving perspectives, which refer to the person’s inherent personality traits when it comes to coping with illness, and dignity-conserving practices, which describe activities carried out to maintain dignity.
- *Social Dignity Inventory*: the environmental factors which may affect dignity. This includes the impact that social challenges and relationship dynamics may have on the

notion of dignity such as privacy, tenor of care, sense of being a burden to others and concerns about the aftermath.

The most salient features elicited were the highly subjective nature of dignity (in that the weight on each aspect varied from one individual to the other) and the wish for generativity or legacy (i.e., to be remembered). An inability to adequately address these areas was found to be related with psychosocial and spiritual distress, with consequent depression and anxiety (Chochinov, Harvey Max et al., 2005).

In light of the above, Dignity Therapy (DT) was created. DT is a brief, time-sensitive and individualised psychotherapeutic modality aimed at alleviating the psychological and existential distress that patients with terminal illness experience.

It takes the form of a semi-structured interview, where the patients are asked a series of questions revolving around what they feel is important to tackle at this stage of their life and what they want their loved ones to remember about them. The aim of DT is not to produce a chronological biography, but rather to highlight memories that the individual holds with pride, important roles and accomplishments and life lessons that he or she may wish to pass on. These sessions are audio-recorded and transcribed into a narrative manuscript, called the Generativity Document (GD), which serves as a lasting legacy that is then returned to the patient for them to share with whoever they wish (Chochinov, Harvey Max et al., 2005).

DT was found to be tolerable and effective by both patients and their relatives, improving an overall sense of dignity and purpose in the patient and helping relatives in their grieving process (Chochinov, Harvey Max et al., 2005; McClement et al., 2007). These findings have remained consistent as DT was studied in the following years (Chochinov, Harvey Max, Kristjanson, Breitbart, McClement et al., 2011).

A systematic review by Martínez et al. (2017) looked at various outcomes in relation to DT and its utilisation in life-threatening conditions in general. When reviewing the impact of DT on anxiety and depression, they reported that results were somewhat inconclusive. This is because there were randomised control trials which found statistically significant improvements in only depression (Chochinov, Harvey Max et al., 2011), only anxiety (Rudilla, Galiana, Oliver, & Barreto, 2016), none (Hall et al., 2011) or both (Julião, Oliveira, Nunes,

Vaz Carneiro, & Barbosa, 2014). These results convey a strong message that further research in the field is required for better understanding.

As a model, DT was hypothesised to be “elastic enough to support its consideration for broad application among patients nearing death”, meaning that it is theoretically applicable to other terminal illnesses (Chochinov, Harvey Max, 2002). DT has now been explored with a number of patient populations, such as Motor Neuron Disease (Bentley, O'Connor, Kane, & Breen, 2014), End-stage Renal Disease, Amyotrophic Lateral Sclerosis and Chronic Obstructive Pulmonary Disease (Chochinov, Harvey Max et al., 2017). However, the group of interest for the purpose of this study is that of frail older persons, with focus on those with cognitive impairment.

In the older adult, loss of function in daily activities and independence already leads to impairment of dignity (Gallagher, A. et al., 2008; Lothian & Philp, 2001). This is often compounded by institutionalisation, which hampers not only intrapersonal dignity, but also interpersonal, or relational dignity (dignity inferred by social interaction) (Pleschberger, 2007).

Factors that are considered as dignity-conserving by older people include: remaining active till the very end; having one's will be respected; being allowed a dignified death; being pain-free; and being with loved ones (Anderberg, Lepp, Berglund, & Segesten, 2007).

In 2008, Chochinov made an argument that older persons face loss of dignity and quality of life as their lives draw to an end, advocating for timely palliative care approaches for them and their families (Chochinov, Harvey Max, 2008). A feasibility study was carried out in a group of older persons in long-term care (Chochinov, Harvey Max et al., 2012), with both cognitively intact and impaired individuals, the latter accompanied by relatives who would provide support where the PWD encountered any difficulties. The majority found the intervention helpful for themselves and their relatives. DT however was found to be ineffective in participants with low levels of baseline distress (Hall et al., 2012). It is important to highlight that in both studies, the number of participants was very small, limiting the generalisability of the findings.

DT was also trialled with a small number of patients with Early-Stage Dementia (ESD) in residential care (Johnston et al., 2016). Whilst the intervention took longer than other populations and greater skill was required in transcribing the interview, DT was felt to be acceptable by PWD, relatives and professionals alike.

2.9 Dignity therapy as a dyadic psychotherapeutic intervention for the patient and the caregiver

Considering all the above, the proposal for this study is to adapt DT from an individualised psychotherapy to a dyadic intervention due to the potential of involving the caregivers, who are usually their close relatives, in keeping with the concept of person-centred care (Edvardsson, Winblad, & Sandman, 2008; Grassi et al., 2019).

Dyadic approaches in community-based ESD have been associated with better communication, rapport and QoL in PWD and their caregivers (Moon & Adams, 2013) as well as improved behavioural and mood disturbances and caregiver burden (Leven et al., 2013). A systematic review by Poon (2019) identified that dyadic interventions show promise in treating anxiety (with no significant effects on depression), improving caregiver burden and quality of life in PWD. However, she reflects on the principal limitation of such interventions being that they are not uniformly applicable across the variables of interest (Poon, 2019). This means that in view of the potential of dyadic interventions in terms of anxiety and depression, lack of evidence of efficacy does not equate with inefficacy, such that further research is warranted.

Using a dyadic approach provides greater consistency and improved caregiver acceptance of the intervention due to perception of it meeting dyadic needs, resulting in a more effective outcome with regards to mental health and QoL (Hennings & Froggatt, 2019; Judge et al., 2013). The latter is of importance as it boosts a caregiver's satisfaction in care provision, which may include "the sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life" (Yu, Cheng, & Wang, 2018).

The potential of administering DT in this patient population has been identified by others, with a number of psychosocial interventions based on the person-centred care concept already having been devised, with the aim of conservation of personhood (Fazio, Pace, Flinner, & Kallmyer, 2018; Johnston & Narayanasamy, 2016).

Even though there are studies where there was caregiver involvement in DT with older persons, this research project is the first study to formally include the caregiver as a direct participant in the therapeutic process. In this adaptation, the Dignity Therapy Question Protocol (DTQP) was

edited to include both the patient and caregiver's perspectives, to produce a joint generativity document. The aim of the 'joint' or 'dual voice' document is to capture the dynamic relationship between the caregiver and the care-recipient, drawing from the reciprocal role model used in Cognitive Analytical Therapy (Denman, 2001).

It is believed that this model would be beneficial to the patient in improving the sense of dignity and value of self through narrative, improving the PWD's communication with their caregiver, through deepening of knowledge about their loved one and providing comfort in processing the gradual loss of their loved one. By enhancing the relationship in the dyad, positive outcomes are expected in both care recipient and caregiver in terms of anxiety and depression.

2.10 Conclusion

This chapter reviewed various studies in the treatment of anxiety and depression of PWD and their caregivers with particular emphasis on the use of non-pharmacological management, dyadic interventions and reminiscence-based therapies. Considering the effectiveness of these interventions, the aim of this present study was to test the feasibility and acceptability of DT as an effective therapeutic modality in the treatment of anxiety and depression in the patient-caregiver dyad.

CHAPTER 3 – METHODOLOGY

3.1 Introduction

This chapter gives an overview of the rationale of the study design, the aims of the study and hypotheses tested, a list of inclusion criteria required for participants, exploration of the recruitment process, description of the method of data collection and validity of the assessment tools used, elaboration of the study procedure, ethical considerations and outline of the statistical analysis employed.

3.2 Aims and Hypotheses of the Study

This pilot study strived to evaluate the feasibility and impact of Dignity Therapy (DT) delivered concurrently to both patient with Mild Cognitive Impairment (MCI) or Early-Stage Dementia (ESD) and caregiver (i.e., patient-caregiver dyads) on anxiety and depression in both care-giver and care-recipient. The project postulated three main aims:

Aim 1: To improve anxiety and depression in patients with MCI/ESD

Aim 2: To improve anxiety and depression in caregivers of patients with MCI/ESD

Aim 3: To ascertain that dyadic DT is feasible, tolerable and acceptable in the patient-caregiver dyad

In line with these aims, the following hypotheses were formulated:

H₁: DT significantly improves anxiety and depression in patients with MCI/ESD

H₀: DT does not significantly improve anxiety and depression in patients with MCI/ESD

H₂: DT significantly improves anxiety and depression in caregivers of patients with MCI/ESD

H₀: DT does not significantly improve anxiety and depression in caregivers of patients with MCI/ESD

Null hypotheses would be rejected at 0.05 level of significance ($p \leq 0.05$).

The third hypothesis was not tested statistically but was formulated as follows:

H₃: Dyadic DT is a feasible and acceptable intervention in the patient-caregiver dyad

H₀: Dyadic DT is not a feasible and acceptable intervention in the patient-caregiver dyad

3.3 Methodology used in the Study

A quantitative methodology approach was employed to address this research question, as it allows for the objective measurement of any change produced by the proposed intervention on the variables of interest, through the use of validated and reliable screening tools. A quasi-experimental single-group pretest-posttest design was utilised to carry out this study.

Participants were recruited through the use of convenience sampling, which is a type of nonprobability sample where subjects who are representative of the population of interest are identified and recruited through sites where they are readily available (Salkind, 2010).

3.4 Inclusion criteria

Participants were deemed eligible to participate in the study if they met the following criteria:

- Age 60 years or older.
- Community-dwelling (i.e., not currently hospitalised or in long term care).
- Person with MCI/ESD should have a Montreal Cognitive Assessment score of 20 or more.
- Person with MCI/ESD must be able to choose the informal caregiver to participate in the study independently.
- Informal caregivers should have no known cognitive impairment, i.e., a Montreal Cognitive Assessment score of 26 or more.
- All participants must be fluent in Maltese and English to take part in this study.

3.5 Montreal Cognitive Assessment (MoCA)

The Montreal Cognitive Assessment (MoCA) (Appendix A) was the neuropsychological test chosen to assess the cognitive function of the research participants. It is a 10-minute test scored out of 30 points. It tests short-term memory recall, visuospatial abilities, attention, working memory, concentration, language, multiple aspects of executive function and orientation to time and place.

The Mini Mental State Examination (MMSE), whilst being one of the most commonly used cognitive screening tools in dementia, has been proven time and time again to have difficulties in the detection of earlier stages of cognitive decline, especially in MCI (Arevalo-Rodriguez et

al., 2015; Nasreddine et al., 2005). The MoCA was devised to cater for those individuals with cognitive impairment who would score in the normal range of the MMSE. In a comparative study between MoCA and MMSE, the former was found to have significantly better specificity and sensitivity in detecting both MCI and dementia when compared with the latter (Nasreddine et al., 2005). Thus, the decision was made to utilise the MoCA in view of the population of interest, in that the participants to be recruited had a diagnosis of either MCI or ESD.

3.6 Recruitment Process

Sampling was carried out in the Day Hospital at Karin Grech Rehabilitation Hospital (KGRH). The Day Hospital is an outpatient department which provides assessment and management for community-dwelling older people. These services take a multidisciplinary team (MDT) approach and include geriatric medicine, geriatric psychiatry, psychotherapy, occupational and physical therapy, social services and other allied health professionals.

Recruitment occurred through the dissemination of relevant information about the project via personal and electronic communication to the MDT professionals working in the Day Hospital. The MDT professionals then acted as gatekeepers to invite patient-caregiver dyads who were deemed eligible as per the above criteria.

When patient-caregiver dyads expressed interest to participate, the MDT informed the researcher. The researcher then set a meeting with the patient and caregiver to ensure eligibility and to obtain informed consent (Appendix B). During this meeting, in-depth information (both verbal and written) was provided about the research project (Appendix B) and the participants had the opportunity to ask any questions with regards to the study.

3.7 Method of Data Collection

3.7.1 Hospital Anxiety and Depression Scale (HADS)

The HADS (Appendix C) was created to serve as a screening tool aimed at identifying significant depression and anxiety in clinical contexts (Zigmond & Snaith, 1983). The HADS is divided into the Anxiety subscale (HADS-A) and the Depression subscale (HADS-D). It takes around 2-5 minutes to complete and has a total of 14 items, 7 of which are related to depressive symptoms and 7 related to anxious symptoms (Table 1). Each item is then coded

from 0 to 3, meaning that scores from 0 to 21 can be obtained in both the anxiety and depression subscales, higher scores implying worsening severity. Severity was classified by the authors as follows: minimal symptomatology, not clinically significant (0-7); mild symptomatology, doubtful clinical significance (8-10); and clinically significant symptoms (11-21) (Zigmond & Snaith, 1983) with 11-14 being considered moderate and 15-21 severe (Stern, 2014).

HADS-A	HADS-D
I feel tense or 'wound up'	I still enjoy the things I used to enjoy
I get a sort of frightened feeling as if something awful is about to happen	I can laugh and see the funny side of things
Worrying thoughts go through my mind	I feel cheerful
I can sit at ease and feel relaxed	I feel as if I am slowed down
I get a sort of frightened feeling like 'butterflies' in the stomach	I have lost interest in my appearance
I feel restless as I have to be on the move	I look forward with enjoyment to things
I get sudden feelings of panic	I can enjoy a good book or radio or TV program

Table 1 – HADS Anxiety (HADS-A) and Depression (HADS-D).

3.7.2 HADS Reliability and Validity

The validity of an instrument is the ability of that instrument to accurately measure a specific outcome of interest in a specific population (Sullivan, 2011), whereas reliability is the reproducibility of the results obtained (Gjørup, 1997). The HADS has been validated in a variety of languages, patient populations and settings, ranging from inpatient to community practice (Stern, 2014).

A rigorous literature review of the HADS was carried out by Bjelland et al. (2002). They found good evidence for the bidimensionality of the HADS, exploring the dimensions of anxiety and depression through the two respective subscales. It was found to have a mean Pearson correlation coefficient of 0.56 between HADS-A and HADS-D, which has been hailed as a feature of good discriminant validity for two conditions that tend to be comorbid. The mean Cronbach's alpha coefficient of internal consistency was 0.83 for HADS-A and 0.82 for

HADS-D, implying good internal consistency as the coefficient exceeds the value of 0.6 (Bjelland et al., 2002).

The cut-off scores for caseness were found to have specificity and sensitivity scores of 0.78 and 0.9 for anxiety and 0.79 and 0.83 for depression respectively. When the HADS subscales were correlated with other validated tools for anxiety and depression, they were found to have correlations of 0.6-0.8, indicating good concurrent validity (Bjelland et al., 2002).

All the above features make the HADS a valid and reliable tool for initial diagnosis and monitoring of symptom progression or resolution, including populations with physical and mental health problems.

A more recent psychometric evaluation tested whether the HADS is a valid measure of anxiety and depression in the general older (65-80) population. Once again it showed that the HADS was a two-factor model with good internal consistency and no variance with gender, confirming its use in the older population (Djukanovic, Carlsson, & Årestedt, 2017). Similar results were also noted when considering carers of PWD (Stott, Orrell, & Charlesworth, 2017).

The potential of the HADS has been identified for the dementia population, in view of its brevity and ease of use resulting in its widespread application in clinical practice as well as dementia research (Clare et al., 2012). However, the abovementioned findings are not thought to be as easily extrapolated to the dementia population (Cosco, Doyle, Ward, & McGee, 2012). Some challenges include the variability in presentation of anxiety and depression in PWD (Banerjee, Sube et al., 2011), together with some items being confounding in cognitive impairment (Haugan & Drageset, 2014).

A study by Stott et al. (2017) aimed to test the validity of the HADS in PWD. They concluded that it is feasible to use the HADS as a screening tool in mild to moderate cognitive impairment, but results may be more difficult to interpret when comparing amongst individuals with more severe degrees of cognitive decline (Stott et al., 2017). This is another reason which strengthened the choice to limit recruitment to individuals with MCI/ESD, as explained above.

3.8 Study Procedure

The study utilised a pre-experimental single-group pretest-posttest design. Given that the minimum clinically important difference of HADS in a number of clinical populations was a mean reduction of 1.5-1.7 (Lemay, Tulloch, Pipe, & Reed, 2019; Pais-Ribeiro et al., 2007; Puhan, Frey, Büchi, & Schünemann, 2008), in this study the mean HADS reduction was set at 1.75. Assuming a type I error of 5% ($\alpha = 0.05$), power of 80% ($\beta = 0.2$) and a standard deviation of 2.5, a target effect size of 0.7 should be detectable using a sample size of 20 subject pairs to compare paired differences in mean HADS before and after DT.

The study was performed over a total of five sessions (including the eligibility assessment session) and was carried out by therapists qualified in DT. Each dyad was attended to by two DT therapists, one of whom was the researcher.

During the first session (T0), a pre-intervention HADS was performed by the researcher with both the patient and the caregiver.

The first session of DT (T1) was carried out within one week of T0. The Dignity Therapy Question Protocol (DTQP) (Appendix D) was administered by a DT therapist to the caregiver and the PWD separately. Whilst the original DTQP (i.e., as written by Chochinov) was used with the PWD, a modified version of the DTQP was devised by the researcher such that it could be utilised with the caregiver while maintaining the focus on the PWD. The session was recorded using a voice recorder. Two separate transcripts were created from the two respective audio recordings obtained during T1, which were the drafts of the Generativity Document (GD).

The editing process was completed by the therapists and consisted of the elimination of colloquialisms, non-starters, and interruptions, whilst also correcting obvious chronological errors. In the case of any discordance between patient and designated caregiver, both perspectives were retained in the combined generativity document at the participants' discretion.

To ensure pacing and prevention of subject fatigue, the possibility for the DT session to be completed over two sessions within one week of one another (1_i and 1_{ii}) was offered to the dyad.

The second session (T2) was scheduled within one week of T1. The scope of this session was such that the therapists could present the transcripts to the PWD and the caregiver, by reading it out loud to them, though both retained the option to also read through the document if their condition allowed. The patient and caregiver were given the opportunity to suggest any amendments they felt were required. Following amendments, the two GD drafts were merged together to form the final joint GD.

Another session (T3) was planned within one week of T2, to present the final GD (i.e., the product of the two separate transcripts) to the dyad. The patient and caregiver were given the chance as a dyad to suggest any final amendments.

The final session (T4) was organised two weeks after T3. Physical copies of the combined GD were provided such that the PWD could share them with whoever they deem fit. Furthermore, the HADS was repeated post-intervention for both PWD and caregiver. This was once again carried out by the researcher.

In view of this study being the first of its kind (in that DT was administered to the patient and the caregiver in a dyadic modality), its feasibility and acceptability were assessed quantitatively, using a brief version of the Dignity Therapy Patient Feedback Questionnaire, or DTPFQ (Appendix E) (Chochinov, Harvey Max et al., 2011), which has been used in other DT feasibility studies (Mai et al., 2018).

3.9 Quality Assurance

Various exercises of quality assurance were implemented so as to ensure that the therapy being delivered for this research project was of good quality.

The therapists carrying out the sessions in this study received formal training in administering Dignity Therapy. Certification was obtained in July 2019 by attending a course which was organised by Prof L. Grassi and Prof M.G. Nanni, who are accredited DT trainers at the

University of Ferrara, Italy. This course consisted of a series of lectures which outlined the theoretical aspects of the intervention, followed by practical demonstration of DT as well as an in-depth overview of the transcription and editing process. Following this theoretical course, the therapists also attended a number of virtual follow-up sessions, which served as supervision for cases carried out locally, to ensure that the process remained faithful to the DT framework. These supervision sessions were carried out over 2019 and 2020.

Once that sufficient experience was obtained in the administration of DT locally and the study protocol for this project was completed, a trial dyad case was carried out to ensure that it was logistically feasible, that the modified caregiver DTQP concurred well with the original DTQP and to ensure that the creation of a joint generativity document was achievable.

3.10 Ethical Approval

The data obtained from the participants was of a personal nature, pertaining to their health and private information, thus requiring approval from relevant bodies. Consequently, a proposal containing the study protocol, tests performed, as well as the information sheets and consent forms were submitted for review by the Faculty Research Ethics Committee (FREC) of the Faculty of Social Wellbeing (University of Malta) on the 3rd of May 2020. Following a number of amendments, the study was approved on the 3rd of August 2020 (Appendix F). As recruitment was to be carried out through a service offered by KGRH, institutional approval from the Research Committee at KGRH was also obtained prior to initiating this project (Appendix F).

It was emphasised to all participants that they were free to withdraw from the study at any stage with no repercussions to their regular care. Any private information was stored anonymously. Each participant was assigned a code and these codes were documented on the data collection forms. Codes and personal information were saved in a secure place that was only accessible by the researcher. Audio recordings and transcripts were stored virtually on the researcher's password-protected personal computer and in the case of hard-copy forms of information stored in a locked cupboard to which only the researcher had access. Once the study was completed and the results published, the data were retained in anonymous form. Any personal details were destroyed.

All data was collected in accordance with the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning the participant to be erased.

3.11 Method of Data Analysis

Data analysis was carried out using the facilities of the IBM Statistical Package for the Social Sciences (SPSS) version 24 for Windows. Data was inputted and analysed by the researcher. From the data collected, descriptive statistics were derived and tested for normality using the Shapiro-Wilk and Kolmogorov-Smirnov tests.

Mean differences between the Pre- and Post-intervention HADS scores were analysed using the relevant comparative statistical test (paired T-test or Wilcoxon rank sum, depending on the data distribution). Data was analysed for persons with dementia and caregivers respectively and was evaluated in its respective subscales where relevant.

The hypotheses postulated by the research question are directional. This means that DT is expected to result either in a positive effect on the outcomes of interest or no positive effect, with negative effects being considered to be unlikely. For this reason, one-tailed tests were performed. When the tests yielded a p-value of less than 0.05 level of significance, it would indicate a significant association.

Effect size and power derived from this study were also included. Mean scores marked by the PWD and Caregiver groups for each item on the DTPFQ were compared to test for any significant differences.

3.12 Conclusion

This chapter outlined the methodology utilised to investigate the hypotheses posed by the research question. The rationale and aims for this project were presented. The inclusion criteria for patient recruitment and the process through which recruitment was carried out were explained. The principal data collection tool used (the HADS) was described in detail and its reliability and validity as a screening tool for the outcomes of interest in this participant

population discussed. The study protocol was provided, together with the ethical approval required and the statistical analysis employed for the data collected.

CHAPTER 4 – RESULTS

4.1 Introduction

This chapter constitutes the results obtained from the statistical analysis of the data procured before and after the administration of DT, in order to test the hypotheses posed by this study. Further detail is provided with regards to the participant recruitment process and demographics of research subjects. This is followed by documentation of statistical testing and results, including normality testing and comparison of means through paired T-test. Statistical testing was carried out for both the Anxiety and the Depression subscales of the HADS, and the participants were divided into PWD and Caregiver groups where relevant.

4.2 Participant Recruitment and Attrition

11 patient-caregiver dyads expressed initial interest with various members of the MDT at KGRH Day Hospital in participating in this study and were forwarded for eligibility assessment with the researcher. 4 of these dyads were not enrolled into the study, 3 who refused to participate on provision of further information and 1 dyad was deemed ineligible due to the caregiver not meeting the requirement of having a MoCA over 26/30.

7 participant dyads were enrolled to participate in the study. 1 dyad was excluded from the study in the initial stages (T0) due to concerns about the caregiver's mental health. On deliberation, it was decided to discontinue intervention for this dyad and to refer to mental health services for further management. 6 dyads completed the intervention and provided complete data for analysis.

A summary of the above is provided in Figure 1.

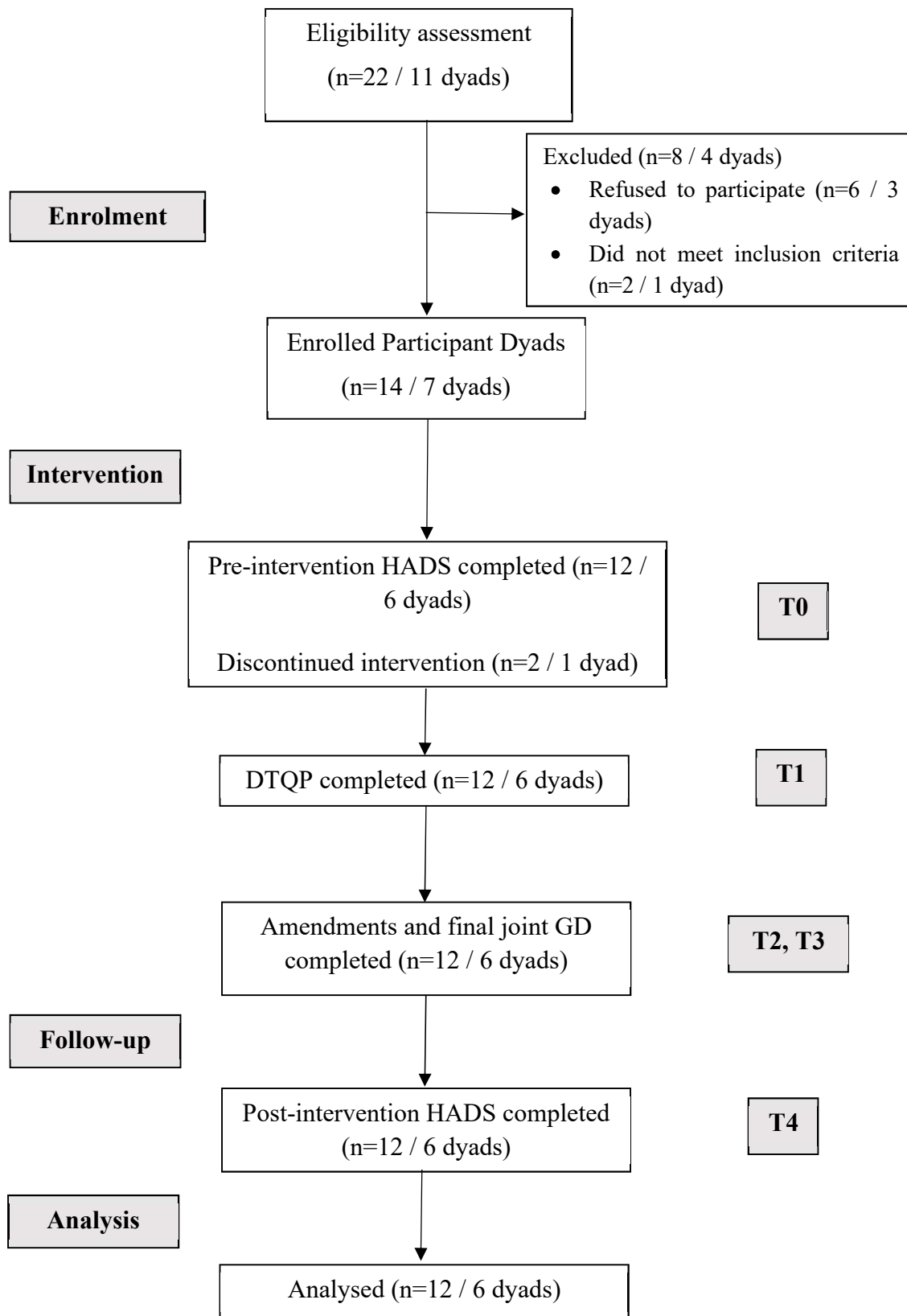


Figure 1 – Summary of patient recruitment and attrition

4.3 Participant Demographics

The research sample consisted of 6 participant dyads (i.e., 6 PWD and 6 caregivers).

In the PWD group, the mean age was of 76 years (SD 8.24; range 67-87 years). The gender distribution was 67% (n=4) male and 33% (n=2) female. 67% (n=4) achieved education to a tertiary level, and 33% (n=2) to a secondary level. In this group, 50% (n=3) had a diagnosis of Alzheimer's type dementia, 33% (n=2) were diagnosed with Mild Cognitive Impairment and 17% (n=1) had a diagnosis of Parkinson's Disease Dementia. The mean MoCA score was of 22 (SD 1.26; range 20-23).

In the Caregiver group, the mean age was of 74 years (SD 8.75; range 65-87 years). The gender distribution was 33% male (n=2) and 67% female (n=4). 33% (n=2) achieved education to a tertiary level, 50% (n=3) to a secondary level and 17% (n=1) to a primary level. All caregivers had a spousal relationship with the PWD. The mean MoCA score was of 28.5 (SD 1.05; range 27-30).

PWD	Age	Gender	Educational level	Diagnosis	MoCA
1	87	Male	Tertiary	PDD	20
2	86	Male	Secondary	MCI	21
3	71	Female	Secondary	AD	23
4	67	Female	Secondary	AD	23
5	73	Male	Secondary	AD	22
6	74	Male	Tertiary	MCI	23
Caregivers	Age	Gender	Educational level	Relation to PWD	MoCA
1	87	Female	Secondary	Wife	27
2	82	Female	Primary	Wife	28
3	72	Male	Secondary	Husband	28
4	66	Male	Tertiary	Husband	29
5	65	Female	Tertiary	Wife	29
6	73	Female	Secondary	Wife	30

Table 2 – Participant Demographics

4.4 Normality Testing

The use of parametric statistical tests depends on the assumption that the data being utilised has a normal distribution. It is this assumption of normality that allows for the generation of reliable conclusions from the data (Ghasemi & Zahediasl, 2012). In the case of the paired samples t-test, the normality assumption is held for the difference between the paired values.

To test for normality, one can either make use of visual plots or tests of normality. The latter method has been employed in this study, using the two tests offered on SPSS, Kolmogorov-Smirnov and Shapiro-Wilk tests.

Both tests compare the numbers in the data to a corresponding set of scores with an equal mean and standard deviation. A p-value of more than 0.05 assumes normal distribution (which is the Null hypothesis). The Kolmogorov-Smirnov (K-S) has a limitation in that it is sensitive to outlying data, such that the Lilliefors correction is used in conjunction to it to render it less sensitive. The Shapiro-Wilk (S-W) test provides better power than K-S (Ghasemi & Zahediasl, 2012).

As can be seen displayed in Table 3, on normality testing, both K-S and S-W yielded p-values which were larger than 0.05 (even when dividing the data into the Anxiety and Depression subscales). This implies that distribution of the data can be assumed to be normal and therefore parametric tests can be used.

PWD / Caregiver		Kolmogorov-Smirnov			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
HADS	PWD	.225	6	.200	.876	6	.252
HADS-A	PWD	.241	6	.200	.902	6	.387
HADS-D	PWD	.185	6	.200	.974	6	.918
HADS	Caregiver	.309	6	.075	.864	6	.204
HADS-A	Caregiver	.205	6	.200	.961	6	.830
HADS-D	Caregiver	.252	6	.200	.916	6	.480

Table 3 – Tests of Normality using the Kolmogorov-Smirnov and Shapiro-Wilk Tests.

4.5 Descriptive Statistics

4.5.1 Anxiety

In both the PWD and Caregiver groups, prior to administration (Pre-Intervention), the mean scores of the Anxiety subscale (HADS-A) were below the ‘caseness’ level, i.e., less than 8, as described by the authors of the HADS (Zigmond & Snaith, 1983). Post-Intervention, changes were noted in the mean scores for both groups, with some improvement of the HADS-A in the PWD group (0.67) and in the Caregiver group (0.83), as outlined in Table 4.

	Pre-Intervention			Post-Intervention		
	Mean	Median	Std. Deviation	Mean	Median	Std. Deviation
PWD	6.00	6.50	3.795	5.33	5.50	3.724
Caregiver	4.33	4.00	2.658	3.50	3.50	3.017

Table 4 – HADS-A descriptive statistics for PWD and Caregiver groups, pre- and post-intervention

4.5.2 Depression

In both groups, once again Pre-Intervention scores for the Depression subscale (HADS-D) were below the “caseness” level of 8. The Post-Intervention scores showed improvements in both groups, with changes being larger in the Caregivers group (1.33) than the PWD group (0.33), as shown in Table 5.

	Pre-Intervention			Post-Intervention		
	Mean	Median	Std. Deviation	Mean	Median	Std. Deviation
PWD	3.67	3.50	2.944	3.33	3.50	2.944
Caregiver	3.00	2.50	2.098	1.67	1.00	1.751

Table 5 – HADS-D descriptive statistics for PWD and Caregiver groups, pre- and post-intervention

4.6 Comparison testing of Pre- and Post-intervention data

The inferential statistics test used to compare the means of the paired values obtained through this pretest-posttest design was the Paired Samples t-test, in view of the normality assumption confirmed on testing.

4.6.1 PWD Group

Table 6 contains the results of the paired samples t-test for the PWD group, which resulted in no changes of statistical significance when considering both the Anxiety and Depression subscales, as well as the HADS score as a whole. This can be ascertained through the fact that the t values derived are not larger than the critical t value (2.015 at $df = 5$, $\alpha = 0.05$) on the one-tailed Student's t distribution table, the p-values being more than 0.05 and the confidence intervals overlapping the 0 threshold.

	Pre	Post	Mean Difference	Paired Differences			t	df	Sig. (1-tailed)
				Std. Deviation	Std. Error Mean	95% CI			
HADS	9.67	8.67	1.00	5.020	2.049	-4.268, 6.268	.488	5	.323
HADS-A	6.00	5.33	0.67	3.559	1.453	-3.068, 4.402	.459	5	.333
HADS-D	3.67	3.33	0.33	1.751	0.715	-1.504, 2.171	.466	5	.331

Table 6 – Paired Samples t-Test - PWD for total HADS score and Anxiety and Depression subscales

4.6.2 Caregiver Group

Despite there being larger improvements in the caregiver scores (when considering both total HADS score and subscales), the one-tailed paired samples t-test in this group still did not yield statistically significant findings, as outlined in Table 7, but it is worth noting that significance was almost achieved on the Depression subscale in this group. However, once again, the t values are not larger than the critical t value (2.015 at $df = 5$, $\alpha = 0.05$) on the one-tailed Student's t distribution table, the p-values are more than 0.05 and the confidence intervals overlap the 0 threshold.

	Pre	Post	Mean Difference	Paired Differences			t	df	Sig. (1-tailed)
				Std. Deviation	Std. Error Mean	95% CI			
HADS	7.33	5.17	2.167	2.787	1.138	-.758, 5.091	1.904	5	.058
HADS-A	4.33	3.50	0.83	1.722	.703	-.974, 2.641	1.185	5	.145
HADS-D	3.00	1.67	1.33	1.633	.667	-.380, 3.047	2.000	5	.051

Table 7 – Paired Samples t-Test - Caregivers for total HADS score and Anxiety and Depression subscales

4.7 Effect Size

The effect size is the degree of improvement for a variable of interest in the population, using standard deviations (SD) as a measure (Ellis, 2010). The effect size in repeated measures designs is calculated using Cohen's d , which is calculated by dividing the difference of the means of the paired values by the standard deviation of the difference (York, 2016). Effect sizes were classified by Cohen as follows: 0.2 is considered a small effect size, 0.5 is a medium effect size and 0.8 is a large effect size (Cohen, 1988). In view of the sample size in this study and to correct for bias in estimating population effect size, Hedge's g average (g_{av}) was utilised, which weights the SD by its sample size and controls for correlation of measurements (Lakens, 2013).

The effect sizes obtained in this study are displayed in Table 8. In the PWD group, the effect sizes derived were small (< 0.2), both when looking at the total HADS score and its respective subscales. In the Caregiver group, larger effect sizes were noted, with a small effect size on the Anxiety subscale, near-medium effect size on the total HADS score and a medium effect size on the Depression subscale. However, these findings have to be interpreted with caution, considering that the confidence interval overlaps with 0.

		Hedge's g_{av}	95% CI	
PWD	HADS	0.154	-0.567	0.915
	HADS-A	0.150	-0.595	0.935
	HADS-D	0.097	-0.371	0.591
Caregivers	HADS	0.424	-0.116	1.087
	HADS-A	0.246	-0.236	0.795
	HADS-D	0.580	-0.129	1.458

Table 8 – Effect size calculations using Hedge's g_{av} with 95% confidence intervals

4.8 Power Analysis

Power, in statistical terms, is the likelihood that a test will correctly reject the null hypothesis or rather, the likelihood not to commit a Type II error (i.e., report a false negative) (Salkind, 2010). Therefore, it calculates the probability that a study is able to detect an outcome when it is genuinely present.

A two-tailed post-hoc analysis of the power achieved in this study was computed using G*Power version 3.1.9.6. The results for both PWD and Caregivers are displayed in Table 9. The power levels obtained are considerably lower than the a priori estimation of 80%, which was to be expected considering that the estimation was calculated on a larger sample size.

	Power
PWD	6.1%
Caregivers	13.6%

Table 9 – Power analysis

4.9 Dignity Therapy Patient Feedback Questionnaire (DTPFQ)

Out of the 12 participants, all completed and returned feedback questionnaires. This data was tabulated for PWD and Caregivers separately (Tables 10 and 11 respectively).

In the case of PWD, the administration of DT was overall perceived to be a tolerable and acceptable process, with means for all question scores being over 3. The highest mean scores (4+) were obtained in 4 items, where PWD found DT to be useful, satisfactory, improved meaning in their lives and decreased their sense of suffering. DT was perceived as least beneficial in altering healthcare professionals’ perspectives of them.

For the Caregivers group, administration of DT was perceived in an overall similar manner, that is it was considered to be a generally tolerable and acceptable experience, considering every item on the questionnaire had a mean score of more than 3. Three items had a mean score of 4+, where caregivers found DT to be useful, satisfactory and found it to be a helpful addition in overall psychosocial care. Once again, it was considered least helpful in changing how participants are perceived by healthcare professionals.

The scores achieved by Caregivers and PWD were compared to see whether the replies in the two groups were significantly different from one another. As this data was found to be non-normal in distribution, the Mann-Whitney U test was used. As documented in Table 12, no statistically significant differences were elicited for any of the items in the DTPFQ.

4.10 Conclusion

In summary, this chapter described the population enrolled and analysed in this study and their demographics, the data was tested for normality and was found to have normal distribution. Means of the Anxiety and Depression subscales were compared for both the patient and the caregiver groups, using the paired t-test and showed no statistically significant differences between the paired values (with near significant results attained on the HADS-D in caregivers). Small to medium effect sizes were derived using Hedge's g_{av} and low power was computed using post-hoc testing.

On the DTPFQ, both PWD and Caregivers perceived DT as a generally feasible and acceptable experience, with means for all items on the questionnaire scoring over 3. Both groups found DT to be useful and satisfactory. PWD felt it improved meaning in their lives and reduced their sense of suffering. Caregivers perceived it as a good addition to overall psychosocial care. Both PWD and Caregivers found it least relevant in changing the way healthcare professionals perceive them. No significant differences were found in the scores obtained in both groups.

	Mean	SD	Strongly Agree or Agree, n (%)	Neither Agree nor Disagree, n (%)	Disagree or Strongly Disagree, n (%)
I have found Dignity Therapy to be useful to me.	4.00	0.632	5 (83)	1 (17)	0
I have found Dignity Therapy to be satisfactory.	4.00	0.632	5 (83)	1 (17)	0
Dignity Therapy made me feel that my life currently is more meaningful.	4.17	0.408	6 (100)	0	0
Dignity Therapy has given me a heightened sense of purpose.	3.83	0.983	5 (83)	0	1 (17)
Dignity Therapy has given me a heightened sense of dignity.	3.83	0.983	5 (83)	0	1 (17)
Dignity Therapy has lessened my sense of suffering.	4.00	0.632	5 (83)	1 (17)	0
Dignity Therapy has increased my will to live.	3.67	1.033	4 (67)	1 (17)	1 (17)
I believe Dignity Therapy has or will be of help to my family.	3.67	1.366	4 (67)	1 (17)	1 (17)
I believe my participation in Dignity Therapy could change the way my family sees or appreciates me.	3.67	1.033	4 (67)	1 (17)	1 (17)
I believe my participation in Dignity Therapy could change the way my healthcare providers see or appreciate me.	3.33	1.211	3 (50)	1 (17)	2 (34)
In general, I have been satisfied by my psychosocial care.	3.83	0.753	4 (67)	2 (34)	0

Table 10 – DTPFQ in PWD

	Mean	SD	Strongly Agree or Agree, n (%)	Neither Agree nor Disagree, n (%)	Disagree or Strongly Disagree, n (%)
I have found Dignity Therapy to be useful to me.	4.00	1.095	5 (83)	0	1 (17)
I have found Dignity Therapy to be satisfactory.	4.17	0.408	6 (100)	0	0
Dignity Therapy made me feel that my life currently is more meaningful.	3.83	1.169	4 (67)	1 (17)	1 (17)
Dignity Therapy has given me a heightened sense of purpose.	3.67	1.033	4 (67)	1 (17)	1 (17)
Dignity Therapy has given me a heightened sense of dignity.	3.83	1.169	4 (67)	1 (17)	1 (17)
Dignity Therapy has lessened my sense of suffering.	3.50	1.225	2 (34)	3 (50)	1 (17)
Dignity Therapy has increased my will to live.	3.50	1.049	3 (50)	2 (34)	1 (17)
I believe Dignity Therapy has or will be of help to my family.	3.83	1.169	4 (67)	1 (17)	1 (17)
I believe my participation in Dignity Therapy could change the way my family sees or appreciates me.	3.50	1.049	3 (50)	2 (34)	1 (17)
I believe my participation in Dignity Therapy could change the way my healthcare providers see or appreciate me.	3.33	1.033	2 (34)	3 (50)	1 (17)
In general, I have been satisfied by my psychosocial care.	4.00	1.095	5 (83)	0	1 (17)

Table 11 – DTPFQ in Caregivers

	U	Asymp. Sig. (2-tailed)	Exact Sig. [2*(1-tailed Sig.)]
Q1	16.000	.719	.818*
Q2	15.500	.598	.699*
Q3	16.000	.719	.818*
Q4	16.000	.720	.818*
Q5	17.500	.931	.937*
Q6	12.000	.357	.394*
Q7	16.000	.737	.818*
Q8	17.000	.867	.937*
Q9	16.000	.737	.818*
Q10	18.000	1.000	1.000*
Q11	14.500	.546	.589*

Table 12 – Mann-Whitney U test comparing DTPFQ scores in PWD and Caregivers.
*not corrected for ties

CHAPTER 5 – DISCUSSION

5.1 Introduction

The primary aims of this research study were to ascertain whether the dyadic model of DT is a feasible and acceptable intervention and to evaluate whether its administration has a significant effect on symptoms of Anxiety and Depression in persons with MCI or dementia and their caregivers respectively.

This chapter will provide a summary of the findings, followed by interpretation of the statistical analysis of these outcomes in the context of the hypotheses formulated. A discussion on how these findings compare to published literature and other possible causes for the results obtained will be made.

5.2 Summary of Findings

As described previously, 12 participants (6 PWD-caregiver dyads) successfully completed the study and provided data for analysis. The data was found to have a normal distribution on testing with Kolmogorov-Smirnov and Shapiro-Wilk tests. Comparison of means using paired t-test yielded no significant results for either subscale in PWD. In the Caregiver group, changes in the Anxiety subscale were insignificant whilst changes in the Depression subscale were bordering on statistical significance ($p = 0.051$). Small-to-medium, non-significant effect sizes were obtained in both groups and the post-hoc power analysis revealed low levels of power. DTPFQ results showed DT to be a feasible and acceptable intervention in both PWD and Caregivers.

5.3 Project overview

5.3.1 Participant recruitment

The first point to emphasise is that the researcher was unable to recruit the target amount of participant dyads, as described in the methodology. Rather than the originally stipulated sample size of 20 participant dyads, only 11 participant dyads expressed initial interest in the project. Furthermore, a 36% refusal rate was experienced following the initial eligibility assessment,

resulting in a total of 6 participant dyads successfully completing the study to the point of data analysis.

The main challenge encountered in the recruitment of a larger sample size was due to the impact that the COVID-19 pandemic has had on geriatric care. Literature has evidenced a general, worldwide phenomenon of reduced healthcare utilisation (Moynihan et al., 2021). Some reasons that may have led to this occurrence is the reluctance to engage with health services due to fear of infection with the virus and a consequent increase in the tolerance threshold of mental and physical health symptoms in both patients and relatives. This is further exacerbated in older persons by worsened social isolation through public health directives (Vahia et al., 2020), challenges with technological literacy and public transport restrictions (Yang et al., 2020). All the above may have made the prospect of participating in a research project through multiple contacts with healthcare services appear more risky than beneficial in the current circumstances.

Apart from the reduction in healthcare utilisation by service users as described above, for a period of several months, the outpatient department in Karin Grech Rehabilitation Hospital was closed as a risk mitigation exercise, only to be reopened late last year with a reduction in patient list allowance to reduce overcrowding in waiting areas. Furthermore, a restructuring of the Geriatric Medicine physicians' work across different sites occurred during the trial period further contributing to a decreased referral base at the level of the gatekeeper. This led to a drastic reduction in the available number of subjects that may have expressed interest in participating in this study.

5.3.2 Tolerability and Feasibility

Considering the fact that all 6 participant dyads enrolled successfully completed the study with no attrition following the eligibility assessment points towards DT being a tolerable and feasible intervention in older persons with cognitive impairment and their caregivers.

All sessions were carried out in under an hour and in all cases, there was no need to introduce an extra session to cater for subject fatigue. Participants with higher MoCA scores (i.e., caregivers and participants with MCI) were noted to be able to give clear and relevant replies

to the questions posed and their replies also tended to be of good length and detail. On the other hand, participants with lower MoCA scores (i.e., participants with more significant cognitive decline) were noted to give shorter replies, sometimes even single sentences and required more support in answering the questions posed in a relevant manner, through the use of a number of close-ended, clarifying questions.

In certain cases, some questions were not adequately answered. Due to this, during the editing of the transcript unanswered questions were merged with completed questions to ensure continuity and completeness of the document. As a result, the editing process tended to take longer in the latter cohort, requiring more skill and effort to be able to produce a coherent and well-structured generativity document draft. These findings are in keeping with the experiences that other researchers have reported through their use of DT with older persons with cognitive impairment (Chochinov, Harvey Max et al., 2012; Johnston et al., 2016).

The generativity documents required little to no editing when presented to the participants for amendment, as they were largely satisfied with the content already provided, which they perceived to be representative of their own narrative. The process of combining the PWD and caregiver drafts into a combined generativity document did not result in any unexpected difficulties which was likely a result of the manner in which the two sets of questions were formulated to complement each other. As expected, the reading of the final generativity document to the dyad proved to be an emotional experience in most cases, especially for caregivers.

5.3.3 Acceptability

From the results obtained through the feedback questionnaire completed by the participants, DT was perceived by both PWD and their caregivers as an acceptable experience. This was indicated by the fact that the majority perceived positive outcomes in most items explored by the DTPFQ, especially with regards to DT being both useful and satisfactory.

The usefulness of DT for the PWD's family is also worth noting, as this finding has been replicated consistently in other DT studies (Scarton et al., 2018), through the generation of a document which is perceived as a legacy of the PWD and a source of comfort for the family as

the illness progresses and when the patient eventually passes (Chochinov, Harvey Max et al., 2012; McClement et al., 2007). The fact that the lower scores were obtained on the item with regards to the way they are perceived by health professionals may be due to the fact that being in the earlier stages of cognitive decline, the need to engage with healthcare services is not yet as marked as it would be in later stages of the condition.

Caregivers noted that DT not only benefits the PWD, but also provides solace for them as relatives when the disease progresses. This, again, is in keeping with what previous research with this patient population has reported (Chochinov, Harvey Max et al., 2012). Both PWD and caregivers expressed gratitude at being given the opportunity to participate in this project.

Whilst PWD generally tended to score marginally higher on the DTPFQ than caregivers did, this difference was not noted to be significant on testing the data with Mann-Whitney U test.

5.4 Interpretation of Statistical Analysis

5.4.1 Normality testing

With a total sample of 12 participants further divided into two groups, the risk is that the power of the sample is too small to challenge the normality assumption, giving a false result (Ghasemi & Zahediasl, 2012). A normal distribution was assumed following testing using K-S and S-W, the latter being used primarily due to the fact that it offers more power when testing smaller samples, thus mitigating this risk.

5.4.2 Paired Samples t-test

Visual inspection of the means in both the PWD and Caregiver groups evidenced a larger improvement in the Caregiver scores when compared to the PWD scores. However, the HADS mean differences of neither group reached the Minimal Clinically Important Difference (MCID) set for this study, which was set at 1.75.

Furthermore, limited inferences can be made from these findings in view of the fact that the results did not reach statistical significance, even though near-significance is noted on the depression subscale for caregivers. For this reason, in the 2 hypotheses formulated by the

research question requiring statistical analysis, the alternative hypothesis is refuted and the null hypothesis accepted, meaning that DT did not result in significant improvement of anxiety or depression in patients with MCI/ESD or their caregivers.

Having said this, the fact that in both groups the MCID falls within the CI implies that whilst the point estimate achieved in the study sample did not reach the MCID, it is still contained within the CI of the population. This means that further research using larger sample sizes is warranted.

5.4.3 Effect Size

While the paired samples t-test analyses the data for statistical significance, it is important to elicit the practical significance of research findings as well. One way of doing this is through the calculation of effect size. The computation of an effect size is a means of standardisation of one's findings, thus allowing for the comparison of effect on a particular variable of interest from one study to another, even though measurement tools used may have been different (Lakens, 2013).

As previously described, the magnitude of the effect sizes obtained were noted to be small in PWD and small to medium in caregivers, with the most promising findings being on the Depression subscale ($g_{av} = 0.58$) in caregivers.

Even though the confidence intervals obtained were wide (reflective of the small sample size), they were noted to lie more in the positive range, implying the possibility that the intervention had an overall positive effect but requires larger sample sizes to be elicited with increased certainty.

Similar findings have been reported by other researchers who have studied the impact of DT on anxiety and depression in patients with (non-dementia) terminal conditions and their caregivers. In a recent meta-analysis on the effects of DT on patients with terminal illness, 3 RCTs reported non-significant findings in both anxiety ($d: -0.26$, 95% CI, -0.97 to 0.46 , $p = 0.48$) and depression ($d: -0.24$; 95% CI, -0.48 to 0.00 , $p = 0.05$), although there have been

quasi-experimental studies that have reported significant outcomes in this regard (Xiao, Chow, Liu, & Chan, 2019).

In the case of caregivers, only two studies were found which quantified the effect of DT on anxiety and depression using validated scales. In both studies, a modest reduction in anxiety and depression was noted but was not found to be statistically significant (partly due to small sample sizes) (Aoun, Chochinov, & Kristjanson, 2015; Bentley, O'Connor, Breen, & Kane, 2014). The applicability of this comparison is also limited due to this study being the first to have included the caregiver as a formal participant in DT rather than a proxy contributor. Nevertheless, the promising results obtained imply a potential focus for further research using DT in caregivers, which as yet remains an unexplored aspect in DT literature.

5.4.4 Power Analysis

The power of a test is dependent on three principal factors: statistical significance, effect size and sample size, where the larger the value of each factor, the higher the power level (Salkind, 2010). However, in the case of statistical significance, a larger alpha level comes with increased risk of Type I error (false positive - rejecting the null hypothesis when it is true), so it is often arbitrarily set at 0.05, whereas the effect size depends entirely on the magnitude of effect of the variable of interest which is being studied.

The greatest challenge that was encountered in this study is the limited sample size obtained due to the circumstances previously described. In small study samples, it is frequently difficult to reach statistical significance (Ellis, 2010). The theoretical risks of carrying out a study with such a sample size is that one can either erroneously conclude that there were no effects to be found when effects were present (Type II error) due to the study being underpowered, or believing that effects are present when they are not (Type I error) due to the sample not being an accurate reflection of the population it was derived from and which consequently would not be reproducible in future research (Salkind, 2010). In the case of this project, Type I error was not of concern, in view of the fact that previous research has already elicited an effect of DT on anxiety and depression. It is more likely that a Type II error was observed in this study.

5.5 Alternative Explanation of Findings

The most prominent fact worth commenting on with regards to the HADS baseline scores obtained is that in the case of both the persons with cognitive impairment and their caregivers, the scores were noted to be remarkably low (refer to Tables 4 and 5 for the Anxiety and Depression subscale scores respectively). As Chochinov rightly reflected in his writings, the presence of distress has been shown to be associated with anxiety and depression (Chochinov, Harvey Max, 2008). Therefore, it is reasonable to conclude that in the absence of distress, there is the possibility that symptoms of anxiety and depression may not be present. The following are a number of factors that may explain the nature of the findings reported above.

Firstly, the end-of-life experience can vary greatly from one older person to another. Some older persons may not consider themselves as individuals that are dying (Chochinov, Harvey Max et al., 2012) or even that they have a condition which can be considered terminal (McVey, McKenzie, & White, 2014).

Age confers a degree of life experience, which may lead to a change in outlook towards the end of life. This can result in improved mental health, consequent to adaptation developed over years of experience (Chochinov, Harvey Max, 2008). In fact, literature has shown that being able to make use of coping skills such as emotional stability, conscientiousness and optimism results in a host of health benefits, be it physical and mental (Steptoe & Wardle, 2017). As people age, even though optimism tends to become less common, it is noted that the aforementioned benefits persist (Jacobs, Maaravi, & Stessman, 2021). Furthermore, as people get older, most show less concern about death itself and more about the process of dying (Fleming, Farquhar, Brayne, & Barclay, 2016; Tjernberg & Bökberg, 2020). Thus, personal resilience may explain why at baseline both caregivers and PWD scored low on the HADS Anxiety and Depression subscales.

The pre-intervention levels of anxiety and depression must also be considered in the context of the population that participated in this study, i.e., persons with cognitive impairment and their caregivers in the earlier stages of their illness (MCI and ESD).

From the patient perspective, a reduced level of distress secondary to their illness may stem from the fact that cognitive impairment can give rise to varying degrees of anosognosia, which

is lack of appreciation of having a condition. It is also referred to as reduced self-awareness or lack of insight. Anosognosia affects an individual's metacognitive skills (i.e., knowledge of one's own memories, perceptions, choices and actions), thus possibly negatively affecting awareness of one's disease status as well as specific aspects or deficits of the condition, such as memory loss (Sunderaraman & Cosentino, 2017). Anosognosia may also be accompanied by anosodiaphoria, better known as *la belle indifférence*, or the minimisation or indifference to a functional deficit (Lindau & Bjork, 2014).

Even in the earlier stages of cognitive decline (including at the MCI stage), individuals were noted to overestimate their cognitive capabilities when compared to the general population (Lin et al., 2010). In fact, some studies have shown that there are no significant differences in the occurrence of reduced self-awareness when comparing MCI and established dementia (Galeone, Pappalardo, Chieffi, Iavarone, & Carlomagno, 2011; Vogel, Hasselbalch, Gade, Ziebell, & Waldemar, 2005). Having said this, it is important to note that the severity of the anosognosia tends to positively correlate with the severity of cognitive decline (Lehrner et al., 2015; Lindau & Bjork, 2014). Anosognosia has also been found to cause an altered appreciation of mood symptoms (i.e., affective anosognosia), with individuals who lack insight into their cognitive function tending to lack insight into their affective experiences. In fact, a well-established negative correlation between anosognosia and distress and/or mood symptoms has been identified throughout years of research (Conde-Sala et al., 2014; Kashiwa et al., 2005; Maki, Amari, Yamaguchi, Nakaaki, & Yamaguchi, 2012; Mograbi & Morris, 2014; Verhülsonk, Quack, Höft, Lange-Asschenfeldt, & Supprian, 2013).

In those individuals where awareness about their cognitive decline is intact, distress may still not be marked. Van Gennip (2016) carried out a qualitative study with persons with mild to moderate dementia to understand how their cognitive state affected their dignity. In most participants, whilst expressing a degree of reduction in dignity due to their gradual loss of function and increased dependence, they still reported a relatively intact sense of dignity and were still able to find meaning in their daily lives. This preservation of dignity relied heavily on the support they received from their caregiver, who created an environment where the care recipient could still feel valued and (where possible) autonomous.

Furthermore, as previously described, a pivotal aspect of dignity in dementia relies on the social component. In social situations, PWD may feel ashamed of their deficits in the fear of being

criticised by others. This often leads to social withdrawal as a coping mechanism, limiting interaction to family members and close friends who are understanding (van Gennip et al., 2016).

In support of this theory, the dyads who participated in this study were all married couples. The intact spousal relationship between PWD and caregiver are likely to have contributed significantly to the provision of a safe and comfortable environment for the PWD to maintain a dignified life through the respect and acceptance afforded to them by their spouse. Such close and stable relationships can result in mutually reduced levels of distress. In addition to this, current public health restrictions may have accentuated the limitation in social interaction beyond close relatives, resulting in avoidance of societal insults to personal dignity in these individuals.

From the caregiver perspective, levels of distress must be understood from the aspect of which stage of disease their care recipients are in. The PWD who participated in the study sample were either diagnosed with MCI or in the early stages of dementia. Patient factors that have been linked with exacerbation of caregiver distress include cognitive impairment, worsening functional decline (with consequent increase in dependence) and neuropsychiatric symptoms, with the first being the least consistent and the last being the most potent indicator (Gallagher, D. et al., 2011; Reed et al., 2020). Patients in early stages are least likely to be experiencing marked functional decline. This is based on the findings of longitudinal studies that have outlined positive correlation between cognitive and functional decline (Black & Rush, 2002; Green, Mohs, Schmeidler, Aryan, & Davis, 1993; Suh, Ju, Yeon, & Shah, 2004). Furthermore, neuropsychiatric symptoms tend to become more significant contributors to caregiver burden in moderate to severe stages of the disease (Gallagher, D. et al., 2011). Thus, considering the above, one can appreciate why the recruited caregivers may have exhibited low levels of distress, and therefore low levels of anxiety and depression prior to intervention.

The floor effect that was observed on the HADS prior to intervention may explain why no significant differences were observed following intervention. This is because if distress, anxiety and depression were not considered to be a problem prior to the administration of DT, then there was little improvement to be gained from intervention. This phenomenon has been encountered previously in other studies looking at DT (Chochinov, Harvey Max et al., 2011). In fact, it was found that DT had better outcomes when it was administered to individuals who

had an increased level of distress at baseline, with significant improvements in both anxiety and depression following intervention (Julião et al., 2014).

Having said this, in spite of the floor effect observed, the intervention did result in a medium effect on depressive symptoms in the caregiver group. This improvement in depressive symptoms may be suggestive that DT did, in fact, address an unmet need in the psychosocial care of those caring for individuals with cognitive impairment, even though caregivers perceived their levels of distress as low. This finding ties in with previous research findings outlining DT as a positive experience for caregivers (Scarton et al., 2018).

5.6 Conclusion

This chapter provided an in-depth review highlighting the findings obtained in this study. It consisted of an evaluation of the responses from the Feedback Questionnaire, confirming that DT was overall deemed to be satisfactory, tolerable and acceptable in persons with cognitive impairment and their caregivers in its dyadic form. Additionally, reflections on the tests carried out were included, with possible reasons as to why mean differences obtained from pre-test post-test analysis yielded no statistically significant results. Comparison with findings from other DT studies was done and distinction between statistical and practical significance of the results was made and the potential for yielding significant results through larger sample sizes described.

CHAPTER 6 – CONCLUSION

6.1 Introduction

This research project postulated three hypotheses in light of the research question. The first two hypotheses were tested through the use of a single group pre-experimental pretest-posttest design and comparison of means on completion of data collection. The third hypothesis was answered through the administration of the DTPFQ.

Whilst statistical testing on the data collected was inconclusive, most likely due to the small sample size, confidence intervals for mean differences included the MCID, whereas confidence intervals for the effect sizes were weighted towards the positive range. This inferred the potential of attaining significant positive outcomes through the recruitment of a larger sample size, with findings being most encouraging for the Depression subscale in caregivers. As a therapeutic intervention, DT was perceived as both feasible and acceptable in both PWD and caregivers.

This chapter will provide a description of the strengths and limitations of this study, whilst discussing implications for clinical practice and outlining recommendations for possible future research.

6.2 Strengths and Limitations of the Study

6.2.1 Strengths

The research question set by this study is the first of its kind when it comes to the utilisation of Dignity Therapy. This is because, as previously outlined in the literature review, whilst a number of studies have been carried out using DT as the therapeutic modality of choice, there is a dearth in literature with regards to the use of DT in older persons, especially those with cognitive impairment, which was the researcher's population of interest. Furthermore, this is the first attempt to formally include the caregivers to persons in the early stages of cognitive decline as direct participants in the therapeutic process beyond the provision of support to the care recipient in answering the questions, as has been done in past studies. This was done by modifying the traditional DT format from an individualised therapeutic approach and administering it as a dyadic intervention. From the feedback received, it appears that this novel

format was well-tolerated and deemed useful and satisfactory by the majority of the participants.

When considering the study design, the adoption of a single-group pretest-posttest design allowed for the possibility that all participants were administered the therapeutic intervention of choice, whilst being carried out in the limited time frame of around 6 months, considering that the administration of DT, editing and amendments of the transcripts and creation of the final joint generativity document is quite a time-intensive and laborious process which was further complicated by the challenges faced due to the COVID-19 pandemic.

6.2.2 Limitations

Even though a number of strengths were identified in this study, it also presented a number of limitations. The first and most significant limitation that this study suffered was the fact that size of the sample participating was small. The reasons for the challenges faced during recruitment have been outlined previously in the discussion and were unfortunately beyond the control of the researcher. However, due to this fact, the study ended up not having sufficient power to reach statistical significance, likely resulting in a Type II error.

A number of possible limitations also stem from the choice of study design, i.e., a single-group pretest-posttest design. The most salient to mention is that this design does not have a control group. The scope of such a group is to provide the possibility to randomly assign participants to either receive the intervention being investigated (the experiment group) or standard care (the control group). The absence of a control group makes it particularly difficult to infer with certainty as to whether a finding is due to the intervention used or whether it was confounded by another variable, even if statistically significant results are obtained between pretest and posttest data (Knapp, 2016).

The use of single-group pretest-posttest designs is accompanied by a number of factors which remain uncontrolled and thus once again pose a threat to both the internal and external validity of the study.

Internal validity describes the accuracy of any statements made with regards to the causal relationship between the manipulated and dependent variable (in this case, the intervention and the outcome of interest, respectively) (Salkind, 2010). Some pertinent factors outlined by Knapp (2016), which may have jeopardised internal validity in this study include:

- a) History, which describes the chance that while the study sample's exposure to the manipulated variable, a confounding variable may be exerting its effect on and causing change in the dependent variable during the same time period.
- b) Maturation, where the participants may undergo developmental changes in the period between the pretest and posttest that may affect the outcome of interest. The effect of maturation was mitigated in this study in view of the relatively short timeframe in which it was carried out (over 4 weeks or less), which is also in line with the dogmatic principles of DT to carry out the therapy in as short a time as possible.
- c) Instrumentation describes the risk of variability in scoring pre- and post-intervention, be it through the use of different measurement tools or administration of tools by different researchers. In this study, the same tool was used to measure the outcomes of interest and it was administered by the researcher pre- and post-intervention to avoid inter-rater variability.
- d) Statistical regression to the mean, where participants who obtain low scores on pretest are likely to score better on posttest and vice versa. However, this change, rather than being due to the intervention, may simply be due to inaccuracy in measurement at pretest. Having said this, the low scores obtained on the HADS in this case are not a question of participants having performed poorly on testing, but rather this was more likely due to low levels of distress.

External validity refers to the generalisability of the findings of a study to a wider group of people (or rather, a population of interest) (Salkind, 2010). In this study design, external validity could have been affected by either pretesting or sampling.

- a) The effect that pretesting may have on the outcome of interest is that it may sensitise the participants to the intervention carried out, in that they will be aware of what the outcome of the intervention should be. As a result, any findings may not be generalisable beyond a pretested population (Knapp, 2016). However, not making use of pretesting would have made it a lot more difficult to document any observable changes brought about by the intervention. Furthermore, this effect was mitigated to an extent in individuals with cognitive impairment by the very nature of their condition.

- b) External validity may also have been affected by the fact that non-random sampling was utilised for recruiting participants. Convenience sampling has the advantage of facilitating finding subjects at relatively low cost and effort (in this case through the geriatric outpatient clinics at Karin Grech Rehabilitation Hospital). This makes it an excellent tool to use in pilot studies such as this one (Salkind, 2010). However, the disadvantage of this type of sampling is that its findings may not necessarily be generalisable. This is because a convenience sample may not be fully reflective of the general population, thus making convenience sampling a threat to external validity (Sedgwick, 2013). A practical example of this is that the patient-caregiver dyads who chose to participate in this study were sufficiently motivated and interested in doing so. Those dyads who may not have had the motivation to express interest in participating could have been suffering from more prominent symptoms of anxiety and/or depression, thus being missed. Whilst the power of the study would have increased through the use of random sampling, the practicality of this choice would have been questionable.

Other limitations that may adversely affect the findings of this study is through the presence of bias. Bias is when an error occurs during the collection of data on a systematic level, as opposed to random errors which balance out in a population. Errors of this nature may lead to the researcher making overestimations or underestimations when measuring an outcome of interest (Salkind, 2010).

Some forms of bias have already been mentioned when discussing the study design, principally that of sampling bias through the use of non-random sampling and selection bias, where

participants may have different traits to the general population. The latter is often assumed in quasi-experimental designs due to the fact that subjects are non-randomly assigned to experimental conditions (Salkind, 2010).

Experimenter expectancy effects may also have been recorded in view of the fact that blinding of researcher and participant was not possible. In this kind of bias, the researcher's knowledge of what outcome is expected for the intervention may lead the researcher to behave in such a manner that leads to the participant's actions confirming the researcher's hypotheses (Salkind, 2010). Another aspect of this expectancy is what is known as the Hawthorne effect, where the participants, through their wish to exhibit socially desirable behaviour and conform to the researcher's expectations, may alter their performance such that it is more in keeping with said expectations (McCambridge, Witton, & Elbourne, 2014).

6.3 Recommendations for Future Research

Whilst the findings of this study were inconclusive with regards to the significance of DT effect on anxiety and depression in the patient-caregiver dyad, interpretation of the data suggests that in spite of this, there is potential for this therapy to have beneficial effects, in particular in depressive symptoms of caregivers. Future research should focus on addressing the limitations encountered in this study to be able to characterise better the nature and extent of the impact that DT has on anxiety and depression.

To address the sample size concern, if one were to use the combined effect size (of both PWD and caregivers) obtained from this study – which was 0.31 – to perform a two-tailed a priori power analysis (using G*Power version 3.1.9.6), a sample size of 84, or rather 42 dyads, should give a power level ($1-\beta$) of 0.8 at a level of significance (α) of 0.05. However, one must treat these estimations with caution, as the accuracy of calculations derived from smaller sample sizes may be impaired when generalising them to population effect sizes (Ellis, 2010). Additionally, future studies should introduce a control group, or rather a crossover design, such that any inferences on the causal relationship between DT and outcomes of interest can be made with greater certainty, whilst all participants have the opportunity to experience DT and compare it to standard care.

Another factor that may improve outcomes in future research would be to address the role that the presence (or absence) of distress is believed to play in the efficacy and effectiveness of DT. It is likely that more meaningful changes would be observed in participants found to have a higher level of baseline distress prior to intervention, so pretesting should take this element into consideration. Thus, subsequent studies should focus on whether DT is effective in actually reducing levels of distress (and therefore accompanying psychological sequelae such as anxiety and depression) where it is present.

Finally, whilst the DTPFQ allowed us to quantitatively observe how DT was experienced by patients and caregivers, a qualitative component would help future researchers better understand which aspects were perceived as useful from both perspectives, thus further informing the implementation of this novel therapeutic approach.

6.4 Implications for Clinical Practice

In view of the brevity of the psychotherapeutic intervention, as well as the positive feedback received from the participants (both caregivers and their care recipients) with regards to its tolerability and general levels of satisfaction and feelings of usefulness, DT presents itself as an interesting and potentially impactful adjunctive therapy to be assimilated into the holistic care model of individuals with neurocognitive disorders. DT allows for the strengthening of the dyadic rapport between the person with dementia and their caregiver through the improvement of the quality of life of the involved parties by the potentiation of dyadic coping. DT promotes the perpetuation of meaningful relations between the person with dementia and their loved ones, even when the ability to communicate starts to gradually decline.

Moreover, DT may provide an opportunity for the patient to feel more valued in their regular clinical care. However, the DT can be mutually beneficial in the clinical rapport, as it gives healthcare professionals the chance to better appreciate the personhood of the individual they are treating, fostering increased respect and more meaningful, humane interactions. Considering that the training to administer DT is relatively short, its incorporation into general geriatric care is feasible, by training nursing staff and other allied health professionals who work with this patient population to deliver it, thus enhancing the psychosocial aspects of care.

6.5 Conclusion

This study has contributed to paving the way for DT research in individuals with cognitive impairment, through the employment of a novel approach that invites the caregiver to actively participate in the therapeutic process, thus not only aiming to target patient distress, but also distress in their caregivers. Dyadic intervention is a model that is drawing great interest in dementia research, making this psychotherapeutic modality worthy of study and relevant to dementia care. While this study was a small one, with limited capability of making inferences of great significance, it proved useful in establishing that the dyadic approach is a feasible, tolerable and satisfactory experience in the population of interest. Additionally, the preliminary quantitative findings derived from this project with regards to its influence on anxiety and depression show that, whilst not significant, confidence intervals were weighted towards positive effect, implying potential to ascertain positive outcomes in future research.

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APPENDICES

Appendix A – Montreal Cognitive Assessment

A.1 MoCA - English

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

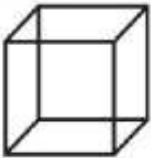
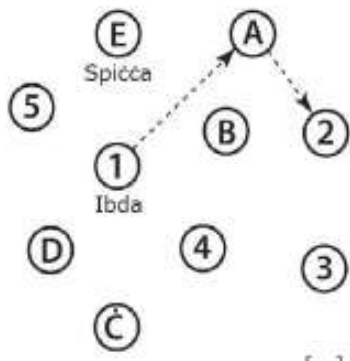
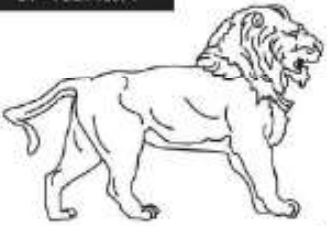
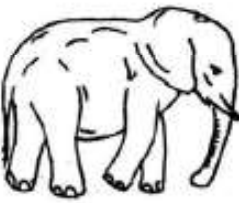
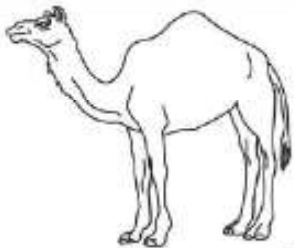
NAME :
Education :
Sex :

Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE							POINTS	
	Copy cube	Draw CLOCK (Ten past eleven) (3 points)					___/5	
NAMING								
							___/3	
MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.					No points	
			FACE	VELVET	CHURCH	DAISY	RED	
		1st trial						
		2nd trial						
ATTENTION		Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2					___/2	
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					___/1	
		Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts , 2 or 3 correct: 2 pts , 1 correct: 1 pt , 0 correct: 0 pt					___/3	
LANGUAGE		Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []					___/2	
		Fluency / Name maximum number of words in one minute that begin with the letter F [] ____ (N ≥ 11 words)					___/1	
ABSTRACTION		Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler					___/2	
DELAYED RECALL		Has to recall words WITH NO CUE					Points for UNCUE recall only	
		FACE	VELVET	CHURCH	DAISY	RED		
Optional		Category cue						
		Multiple choice cue						
ORIENTATION		[] Date [] Month [] Year [] Day [] Place [] City					___/6	
© Z.Nasreddine MD www.mocatest.org		Normal ≥ 26 / 30			TOTAL ___/30			
Administered by: _____		Add 1 point if ≤ 12 yr edu						

A.2 MoCA – Maltese

MONTREAL COGNITIVE ASSESSMENT - MALTESE (MOCA-M) ISEM: _____
IT-TEST KONOXXITTIV MONTREAL Livell ta' edukazzjoni: _____ Sess: _____
 Data tat-twelid: _____ Data: _____

IL-HILA VIŽISPAZZJALI/EZEKUTTIVA				Ikkopja l-kaxxa (3 punti)	Pingi arloġġ (Il-hdax u ghaxra) (3 punti)	PUNTI			
		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	___/5			
IT-TISMIJA				<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>	___/3
IL-MEMORJA		Aqra l-lista tal-kliem u l-persuna trid tirrepetihom. L-eżerċizzju jrid isir darbtejn, anke jekk fl-ewwel prova il-persuna tkun gabet kollox tajjeb. Wera hames minuti erga staqsi lill-persuna tirrepeti l-istess kliem.		WICC	BELLUS	KNISJA	WARDĀ	AHMAR	Ebda punti
L-ATTENZJONI		Staqsi lill-persuna bliema lingwa juża n-numri <input type="checkbox"/> Malti <input type="checkbox"/> Inġliż		Il-persuna trid tirrepetihom wara xulxin kif ikunu ntqalu [] 2 1 8 5 4		Il-persuna trid tirrepetihom bil-meqjub ta' kif ikunu ntqalu [] 7 4 2		___/2	
L-ASTRAZZJONI		Aqra l-lista tal-ittri. Kull darba li jisma' l-ittra A, il-persuna trid ittaptaq b'idejha. Edha punti jekk ≥ 2 zbalji		[] FBAĈMNAAJKLBAFAKDEAAAJAMOFAB		___/1			
L-ASTRAZZJONI		Naqqas serje ta' 7 (sebgħat) minn 100. [] 93 [] 86 [] 79 [] 72 [] 65		4 jew 5 tajbin - 3 punti ; 2 jew 3 tajbin - 2 punti ; 1 tajba - punt ; ebda tajbin - 0 punti		___/3			
IL-HILA LINGWISTIKA		Irrepeti: Nef biss li llum Ġanni huwa l-persuna li rridu nġinu. [] Il-qattus dejjem stahba taht is-sufan meta l-klieb kienu għal-kamra. []		___/2					
L-ASTRAZZJONI		Heffa fil-kliem / Semmi n-numru massimu ta' kliem fminuta li jibdeu bl-ittra F [] _____ (N ≥ 11 il-kelma)		___/1					
L-ASTRAZZJONI		Xebh bejn eż banana u laringa = frott [] dghajsa = karozza [] riga = arloġġ		___/2					
IL-FTAKIR		Il-persuna trid tiftakar il-kliem BLA RIJEL		WICC []	BELLUS []	KNISJA []	WARDĀ []	AHMAR []	___/5
L-ORJENTAZZJONI		Mhux obligatorju Bi riġel tal-kategorija Minn għażla ta' twegġibiet						Il-punti jingħataw biss jekk il-persuna tiftakar il-kliem BLA MA TINGĦATA RIJEL	
TAZ-ZMIEN U L-POST		[] Data [] Xahar [] Sena [] Ġurnata [] Post [] Raġel		___/6					
© Z.Nasreddine MD		www.mocatest.org		In-normal ≥ 26 / 30		TOTAL: ___/30			
Adattat u tradott minn R. Vella (2012)									
Amministrat minn: _____									
								Żkl punt jekk il-persuna Ballha ≤ 12-il sena oħr	

Appendix B – Informed Consent Forms

B.1 Informed Consent Form – Patient (English)

Participants` Information Sheet – Patient

Dear Participant,

My name is Fabian Bonello and I am currently reading for a Master in Gerontology and Geriatrics at the University of Malta. As part of my course requirements, I am conducting a research study entitled, “The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia”. The aim of this study is to explore the effect of a form of psychotherapy called Dignity Therapy on improving symptoms of depression and anxiety in persons with early-stage dementia and their caregivers. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

Should you decide to take part in this study, you will be asked to choose a person who you consider to be your main caregiver. This person shall also be invited to take part in the study with you. Both you and your identified caregiver will sign an informed consent form separately, and you are both free to participate or withdraw your consent at any time of the study.

The study shall be carried out over a maximum of 6 weeks and will include five sessions, each lasting up to one hour. During this time, both you and your caregiver shall have a paper and pencil test done in which you will be asked questions related to your mood and wellbeing.

You shall also take part in a session where you will be asked a number of questions about important aspects of your life, including the roles you played and lessons learnt in your life. Your caregiver shall also be asked a similar set of questions to obtain their perspective about you and help you give the full picture. This session will be audio-taped and the researcher will then transcribe it and offer you both a chance to edit it during your next session. The final joint document shall be given to you and you are free to share it with whoever you please.

You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason. Furthermore, withdrawal from the study will not have any negative repercussions on you and any data collected will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised). I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised, meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data may only be accessed by the researcher. The academic supervisor/s and the examiners will typically have access to coded data only. There may be exceptional

circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. The coded audio-recordings, and transcripts will be stored on the researcher's personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard.

The main risk of the study is that you may get tired answering the questions. At any point of the study you may have breaks and you will be offered the chance to extend the session to another date. In the event that you feel distressed due to participation in the interview, you will be directed to seek support from appropriate healthcare professionals at no financial cost on your part.

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. As a participant, you have the right, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased. Once the study is completed and the results are published, the data will be retained in anonymous form. Any personal details will be destroyed.

This study has been approved by the Research Ethics Committee of the Faculty for Social Wellbeing at the University of Malta.

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on [REDACTED] or by e-mail [REDACTED] or my supervisor **Prof David Mamo** on [REDACTED]

Yours Sincerely,

Fabian Bonello
Researcher

Prof David Mamo
Research Supervisor

Participants` Consent Form – Patient

The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia

I, the undersigned, give my consent to take part in the study conducted by Fabian Bonello. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in five sessions over a span of six weeks. During this time a number of pen and pencil tests will be carried out.
3. I am aware that one session will be an interview lasting up to an hour. I understand I will be asked a number of questions about important aspects of my life.
4. I am aware that the aforementioned session will be audio recorded and transcribed (written down as it has been spoken).
5. I am aware that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.
6. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes.
7. I am also aware that the coded audio-recordings and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.
8. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
9. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on myself and that any data collected from me will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).
10. I also understand that my contribution will serve to better understand the effect of a form of psychotherapy called Dignity Therapy on improving symptoms of depression and anxiety in persons with early-stage dementia and their caregivers.
11. If I feel that the interview has distressed me in any way, I will be directed to seek support from appropriate healthcare professionals at no financial costs on my part.
12. I understand that under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, I have the right to access, rectify, and where applicable ask for the data concerning me to be erased.
13. I also understand that once the study is completed and results are published the data will be retained in anonymous form. Any personal details will be destroyed.
14. I will be provided with a copy of the information letter and consent form for future reference.

15. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: _____

Signature: _____

Date: _____

Fabian Bonello
Researcher

Prof David Mamo
Research Supervisor

B.2 Informed Consent Form – Patient (Maltese)

Formula ta' Informazzjoni għall-Parteċipanti - Pazjent

Għażiż/a Parteċipant/a,

Jiena Fabian Bonello, fil-prezent qed insegwi 'Master' għal Ġerontologija u l-Ġerjatrija fi hdan l-Universita' ta' Malta. Bħala parti mir-rekwiżiti tal-kors, qed nagħmel riċerka bit-titlu, "The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia". L-għan ta' dan l-istudju hu li ninvestiga l-effett ta' tip ta' psikoterapija li tissejjaħ Terapija tad-Dinjita', li ttejjeb sintomi ta' depressjoni u ansjeta' f'persuni fl-istadji inizjali tad-dimensja u f'dawk li jiehdu hsiebhom. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.

Jekk tiddeciedi li tiegħu sehem f'dan l-istudju, se tiġi rikjest/a li tagħzel persuna li skontok l-aktar li tiegħu hsiebek. Din il-persuna se tiġi mistiedna biex tiegħu sehem fl-istudju miegħek. Int u l-persuna li tagħzel tintalbu tiffirmaw formula ta' kunsens separatament, u t-tnejn tkunu hielsa sabiex tipparteċipaw jew tirtiraw il-kunsens f'kull mument f'dan l-istudju.

L-istudju se jiegħu massimu ta' 6 ġimgħat u se jinkludi hames laqgħat, li jistgħu jiehdu madwar siegħa. Tul dan il-perjodu, int u min jiegħu hsiebek se tagħmlu xi testijiet fejn isir mistoqsijiet dwar il-burdata.

Se tiegħu sehem ukoll f' laqgħa fejn se tiġi mistoqsi/ja dwar affarijiet importanti f'haġtek, bħal irwoli li kellek u lezzjonijiet li tgħallim f'haġtek. Il-persuna li tagħzel se tiġi mistoqsija affarijiet simili biex tinkiseb perspettiva oħra dwar li tkompli żżewwaq ir-rendikont tiegħek. Din il-laqgħa se tkun irrikordjata biex ir-riċerkatur imbagħad jittraskriviha. Fil-laqgħa ta' wara din, intom ikollkom ċans taqraw din it-traskrizzjoni u tiddluha skond kif taħsbu li jkun hemm bżonn. Id-dokument finali mbagħad jingħata lilek u tista' tagħzel li taqsmu ma' min tixtieq.

M'intix obligat/a li twieġeb il-mistoqsijiet kollha u tista' twaqqaf l-istudju fi xhin trid mingħajr ma tagħti l-ebda raġuni. Dan mhux ha jkollu riperkussjonijiet negattivi fuqek u l-informazzjoni li tingabar mingħandek tithassar. Id-data se tinhażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata). Nassigurak li se tinzamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhuma se jiġu żvelati mkien fit-teżi, ir-rapporti, il-prezentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha. Kull tagħrif miġbur se jiġi psewdonomizzat, jiġifieri id-data kollha se tkun protetta permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali.

Ir-Riċerkatur / Riċerkatriċi biss ser ikollu / ikollha aċċess għall-informazzjoni miġbura, filwaqt li s-Superviżur/a akkademiku/a (jew is-Superviżuri akkademiċi) u l-eżaminaturi se

jkollhom biss aċċess għal data kkodifikata. Is-Supervizuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika. L-awdjo rrekordjat u d-data kollha se jinħażnu fuq il-kompjuter personali tar-Riċerkatur/Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, il-materjal stampat se jinqafel f'post sigur.

Ir-riskju prinċipali ta' dan l-istudju hu li jista' jkun tgħajja tirrispondi l-mistoqsijiet. F' kwalunkwe punt tista' tieqaf tistrieħ u tista' tiġi offrut ukoll l-opportunita' li testendi sessjoni għal data oħra. F'każ li tħoss li l-istudju holoqlok diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonist/a mill-qasam tal-kura tas-saħħa, se tkun ipprovdut b'direzzjonijiet kif tikseb servizz ta' għajna mingħajr hlas min-naħa tiegħek.

Il-partecipazzjoni tiegħek f'dan l-istudju hija għażla għal kollox volontarja u inti hieles/hielsa li taċċetta jew tirrifjuta li tieħu sehem mingħajr ma jkun hemm konsegwenzi fil-konfront tiegħek. Se tingħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex tkun tista' taċċessahom fil-futur. Barra minn hekk, skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġislazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, inti għandek id-dritt li taċċessa, tirretifika, u fejn japplika titlob sabiex titħassar id-data li tikkonċerna lilek. L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-rizultati miksuba.

Dan l-istudju ġie approvat mill-Kumitat għall-Etika fir-Riċerka fi hdan il-Fakultà tal-Benesseri Soċjali fl-Università ta' Malta.

Grazzi ħafna tal-hin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq [REDACTED] jew tibgħatli email fuq [REDACTED]. Tista' wkoll tikkuntattja lis-Supervizur/a **Prof David Mamo** fuq [REDACTED].

Dejjem tiegħek,

Fabian Bonello

Prof David Mamo

The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia

Jien, hawn taht iffirmat/a, nagħti l-kunsens tiegħi biex niehu sehem fl-istudju mmexxi minn Fabian Bonello. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazzjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twieġbu.
2. Nifhem li ġejt mistieden biex niehu sehem f'ħames laqgħat tul medda ta' sitt ġimghat u tul dan iż-żmien se jsiru xi testijiet ta' mistoqsijiet fuq il-burdata.
3. Naf li dawn il-laqgħat jistgħu idumu sa siegħa. Nifhem li se jsiru mistoqsijiet dwar affarijiet importanti f'ħajti.
4. Jien konxju/a li r-risposti tiegħi se jkunu qed jiġu rrekordjati permezz ta' tagħmir awdjo u se jinkitbu r-risposti fuq formuli apposta.
5. Naf ukoll li se ssir kodifikazzjoni tad-data u din se tinzamm separatament mill-informazzjoni personali.
6. Naf ukoll li r-Riċerkatur / Riċerkatriċi hu/hi l-uniku/a persuna li se jkollu/jkollha aċċess għal din l-informazzjoni, filwaqt li s-Supervizur/a akkademiku/a (jew is-Supervizuri akkademiċi) u l-eżaminaturi se jkollhom aċċess għal data kkodifikata biss. Is-Supervizuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.
7. Barra min hekk, naf li l-awdjo rrekordjat u d-data se jinħażnu fuq il-kompjuter personali tar-Riċerkatur jew Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.
8. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.
9. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-parteċipazzjoni f'kull hin bla ma nagħti raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuqi. Nifhem ukoll li la darba nirtira minn dan l-istudju, l-informazzjoni miġbura se tithassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata).
10. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex jiġi investigat l-effett ta' tip ta' psikoterapija li tissejjaħ Terapija tad-Dinjita', li ttejjeb sintomi ta' depressjoni u ansjeta' f'persuni fl-istadji inizjali tad-dimensja u f'dawk li jieħdu ħsiebhom.
11. Madanakollu, jekk inħoss li l-istudju holoqli diffikultà u nixtieq li niddiskuti x'qed inħoss, naf li se nkun ipprovdut b'direzzjonijiet kif nikseb servizz ta' għajjnuna tas-saħħa professjonali mingħajr hłas min-naha tiegħi.
12. Nifhem ukoll, li skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġizlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, jiena għandi d-dritt li naċċessa, nirretifika, u fejn japplika nitlob sabiex tithassar id-data li tikkonċernani.

13. Naf ukoll li meta jintemm l-istudju u r-rizultati jkunu ppubblikati, l-informazzjoni personali miġbura tithassar.
14. Fl-aħħar nett, naf ukoll li se ninghata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.
15. Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din il-formula. Inħossni sodisfatt/a bit-twegibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċetta minn jeddi li nipparteċipa f'dan l-istudju.

Parteċipant: _____

Firma: _____

Data: _____

Fabian Bonello
Riċerkatur

Prof David Mamo
Supervizur tar-Riċerka

B.3 Informed Consent Form – Caregiver (English)

Participants' Information Sheet – Caregiver

Dear Participant,

My name is Fabian Bonello and I am currently reading for a Master of Gerontology and Geriatrics at the University of Malta. As part of my course requirements I am conducting a research study entitled, “The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia”. The aim of this study is to explore the effect of a form of psychotherapy called Dignity Therapy on improving symptoms of depression and anxiety in persons with early-stage dementia and their caregivers. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

You are being invited as _____ identified you as his/her primary caregiver. If you choose to take part of the study you shall be invited to sign an informed consent form. Both you and the person you care for will sign an informed consent form separately, and you are both free to participate or withdraw your consent at any time of the study.

The study shall be carried out over a maximum of 6 weeks and will include five sessions, each lasting up to one hour. During this time, both of you shall have a paper and pencil test done in which you will be asked questions related to your mood and wellbeing.

You shall also take part in a session where you will be asked a number of questions about the important aspects of the life of the person you care for, including the roles the person played and lessons learnt in his/her life. This session will be audio-taped and the researcher will then transcribe it and offer you both a chance to edit it during your next session. The final document shall be given to _____ who will be free to share it with those closest to him/her.

You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason. Furthermore, withdrawal from the study will not have any negative repercussions on you and any data collected will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised). I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised, meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data may only be accessed by the researcher. The academic supervisor/s and the examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. The coded audio-recordings, and transcripts will be stored on the

researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard.

The main risk of the study is that you may get tired answering the questions. At any point of the study you may have breaks and you will be offered the chance to extend the session to another date. In the event that you feel distressed due to participation in the interview, you will be directed to seek support from appropriate healthcare professionals at no financial cost on your part.

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. As a participant, you have the right, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased. Once the study is completed and the results are published, the data will be retained in anonymous form. Any personal details will be destroyed.

This study has been approved by the Research Ethics Committee of the Faculty for Social Wellbeing at the University of Malta.

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on [REDACTED] or by e-mail [REDACTED] or my supervisor **Prof David Mamo** on [REDACTED]

Yours Sincerely,

Fabian Bonello
Researcher

Prof David Mamo
Research Supervisor

Participants` Consent Form – Caregiver

The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia

I, the undersigned, give my consent to take part in the study conducted by Fabian Bonello. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in five sessions over a span of six weeks. During this time a number of pen and pencil tests will be carried out.
3. I am aware that one session will be an interview lasting up to an hour. I understand I will be asked a number of questions about important aspects of the person I care for's life.
4. I am aware that the aforementioned session will be audio recorded and transcribed (written down as it has been spoken).
5. I am aware that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.
6. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes.
7. I am also aware that the coded audio-recordings and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.
8. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
9. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on myself and that any data collected from me will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).
10. I also understand that my contribution will serve to better understand the effect of a form of psychotherapy called Dignity Therapy on improving symptoms of depression and anxiety in persons with early-stage dementia and their caregivers.
11. If I feel that the interview has distressed me in any way, I will be directed to seek support from appropriate healthcare professionals at no financial costs on my part.
12. I understand that under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, I have the right to access, rectify, and where applicable ask for the data concerning me to be erased.
13. I also understand that once the study is completed and results are published the data will be retained in anonymous form. Any personal details will be destroyed.

14. I will be provided with a copy of the information letter and consent form for future reference.
15. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: _____

Signature: _____

Date: _____

Fabian Bonello
Researcher

Prof David Mamo
Research Supervisor

B.4 Informed Consent Form – Caregiver (Maltese)

Formula ta' Informazzjoni għall-Parteċipanti - Kurant

Għażiż/a Parteċipant/a,

Jiena Fabian Bonello, fil-preżent qed insegwi 'Master' għal Ġerontologija u l-Ġerjatrija fi hdan l-Universita' ta' Malta. Bħala parti mir-reqwiziti tal-kors, qed nagħmel riċerka bit-titlu, "The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia". L-għan ta' dan l-istudju hu li ninvestiga l-effett ta' tip ta' psikoterapija li tissejjaħ Terapija tad-Dinjita' ('Dignity Therapy'), li ttejjeb sintomi ta' depressjoni u ansjeta' f'persuni fl-istadji inizjali tad-dimensja u f'dawk li jieħdu hsiebhom. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.

Qed tiġi mistieden/mistiedna għax ġejt magħżul/a minn _____ bħala l-kurant primarju tiegħu/tagħha. Jekk tagħzel li tiegħu sehem f'dan l-istudju, se tiġi mitlub/a tiffirma formula ta' kunsens. It-tnejn se tintalbu tiffirmaw formula ta' kunsens separatament, u tkunu hielsa sabiex tipparteċipaw jew tirtiraw il-kunsens f'kull mument f'dan l-istudju.

L-istudju se jieħu massimu ta' sitt gimgħat u se jinkludi hames laqgħat, li jistgħu jieħdu madwar siegħa. Tul dan il-perjodu, it-tnejn se tagħmlu xi testijiet fejn isir mistoqsijiet dwar il-burdata.

Se tiegħu sehem ukoll f' laqgħa fejn se tiġi mistoqsi/ja dwar affarijiet importanti f'hajjet min tiegħu hsieb, bħal irwoli li kellu/ha u lezzjonijiet li tgħallem/tgħallmet f'hajtu/hajjitha. Din il-laqgħa se tkun irrikordjata biex ir-riċerkatur imbagħad jitraskriviha. Fil-laqgħa ta' wara din, intom ikollkom ċans taqraw din it-traskrizzjoni u tiddluha skond kif taħsbu li jkun hemm bżonn. Id-dokument finali mbagħad jingħata lil _____ biex j/taqsmu ma min j/tixtieq.

M'intix obligat/a li twieġeb il-mistoqsijiet kollha u tista' twaqqaf l-istudju fi xhin trid mingħajr ma tagħti l-ebda raġuni. Dan mhux ha jkollu riperkussjonijiet negattivi fuqek u l-informazzjoni li tingabar mingħandek tithassar. Id-data se tinhażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata). Nassigurak li se tinzamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhuma se jiġu żvelati mkien fit-tezi, ir-rapporti, il-preżentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha. Kull tagħrif miġbur se jiġi psewdonomizzat, jiġifieri id-data kollha se tkun protetta permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali.

Ir-Riċerkatur / Riċerkatriċi biss ser ikollu / ikollha aċċess għall-informazzjoni miġbura, filwaqt li s-Superviżur/a akkademiku/a (jew is-Superviżuri akkademiċi) u l-eżaminaturi se

jkollhom biss aċċess għal data kkodifikata. Is-Supervizuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika. L-awdjo rrekordjat u d-data kollha se jinħażnu fuq il-kompjuter personali tar-Riċerkatur/Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, il-materjal stampat se jinqafel f'post sigur.

Ir-riskju prinċipali ta' dan l-istudju hu li jista' jkun tgħajja tirrispondi l-mistoqsijiet. F' kwalunkwe punt tista' tieqaf tistrieħ u tista' tiġi offrut ukoll l-opportunita' li testendi s-sessjoni għal data oħra. F'każ li tħoss li l-istudju holoqlok diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonist/a mill-qasam tal-kura tas-saħħa, se tkun ipprovdut b'direzzjonijiet kif tikseb servizz ta' għajna mingħajr hlas min-naħa tiegħek.

Il-partecipazzjoni tiegħek f'dan l-istudju hija għażla għal kollox volontarja u inti hieles/hielsa li taċċetta jew tirrifjuta li tieħu sehem mingħajr ma jkun hemm konsegwenzi fil-konfront tiegħek. Se tingħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex tkun tista' taċċessahom fil-futur. Barra minn hekk, skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġislazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, inti għandek id-dritt li taċċessa, tirretifika, u fejn japplika titlob sabiex titħassar id-data li tikkonċerna lilek. L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-risultati miksuba.

Dan l-istudju ġie approvat mill-Kumitat għall-Etika fir-Riċerka fi hdan il-Fakultà tal-Benesseri Soċjali fl-Università ta' Malta.

Grazzi ħafna tal-hin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq [REDACTED] jew tibgħatli email fuq [REDACTED]. Tista' wkoll tikkuntattja lis-Supervizur/a **Prof David Mamo** fuq [REDACTED].

Dejjem tiegħek,

Fabian Bonello

Prof David Mamo

The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early-Stage Dementia

Jien, hawn taht iffirmat/a, naghti l-kunsens tiegħi biex niehu sehem fl-istudju mmexxi minn Fabian Bonello. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazzjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twieġbu.
2. Nifhem li ġejt mistieden biex niehu sehem f'ħames laqgħat tul medda ta' sitt ġimgħat u tul dan iż-żmien se jsiru xi testijiet ta' mistoqsijiet fuq il-burdata.
3. Naf li dawn il-laqgħat jistgħu idumu sa siegħa. Nifhem li se jsiru mistoqsijiet dwar affarijiet importanti f'ħajjet min niehu ħsieb.
4. Jien konxju/a li r-risposti tiegħi se jkunu qed jiġu rrekordjati permezz ta' tagħmir awdjo u se jinkitbu r-risposti fuq formuli apposta.
5. Naf ukoll li se ssir kodifikazzjoni tad-data u din se tinzamm separatament mill-informazzjoni personali.
6. Naf ukoll li r-Riċerkatur / Riċerkatriċi hu/hi l-uniku/a persuna li se jkollu/jkollha aċċess għal din l-informazzjoni, filwaqt li s-Supervizur/a akkademiku/a (jew is-Supervizuri akkademiċi) u l-eżaminaturi se jkollhom aċċess għal data kkodifikata biss. Is-Supervizuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.
7. Barra min hekk, naf li l-awdjo rrekordjat u d-data se jinħażnu fuq il-kompjuter personali tar-Riċerkatur jew Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.
8. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.
9. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-parteċipazzjoni f'kull hin bla ma nagħti raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuqi. Nifhem ukoll li la darba nirtira minn dan l-istudju, l-informazzjoni miġbura se tithassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata).
10. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex jiġi investigat l-effett ta' tip ta' psikoterapija li tissejjah Terapija tad-Dinjita', li ttejjeb sintomi ta' depressjoni u ansjeta' f'persuni fl-istadji inizjali tad-dimensja u f'dawk li jieħdu ħsiebhom.
11. Madanakollu, jekk inhoss li l-istudju holoqli diffikultà u nixtieq li niddiskuti x'qed inhoss, naf li se nkun ipprovdut b'direzzjonijiet kif nikseb servizz ta' għajjnuna tas-saħħa professjonali mingħajr hłas min-naha tiegħi.
12. Nifhem ukoll, li skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġizlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, jiena għandi d-dritt li naċċessa, nirretifika, u fejn japplika nitlob sabiex tithassar id-data li tikkonċernani.

13. Naf ukoll li meta jintemm l-istudju u r-rizultati jkunu ppubblikati, l-informazzjoni personali miġbura tithassar.
14. Fl-aħħar nett, naf ukoll li se ninghata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.
15. Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din il-formula. Inħossni sodisfatt/a bit-tweġibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċetta minn jeddi li nipparteċipa f'dan l-istudju.

Parteċipant: _____

Firma: _____

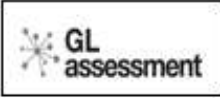
Data: _____

Fabian Bonello
Riċerkatur

Prof David Mamo
Supervizur tar-Riċerka

Appendix C – Hospital Anxiety and Depression Scale

C.1 HADS – English



Hospital Anxiety and Depression Scale (HADS)

Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.
 This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.
 Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A	D			A	D
3		I feel tense or 'wound up'	I feel as if I am slowed down	3	
2		Most of the time	Nearly all the time	2	
1		A lot of the time	Very often	1	
0		From time to time, occasionally	Sometimes	0	
		Not at all	Not at all		
	0	I still enjoy the things I used to enjoy	I get a sort of frightened feeling like 'butterflies' in the stomach	0	
	1	Definitely as much	Not at all	1	
	2	Not quite so much	Occasionally	2	
	3	Only a little	Quite often	3	
		Hardly at all	Very often		
3		I get a sort of frightened feeling as if something awful is about to happen	I have lost interest in my appearance	3	
2		Very definitely and quite badly	Definitely	2	
1		Yes, but not too badly	I don't take as much care as I should	1	
0		A little, but it doesn't worry me	I may not take quite as much care	0	
		Not at all	I take just as much care as ever		
0		I can laugh and see the funny side of things	I feel restless as if I have to be on the move	3	
1		As much as I always could	Very much indeed	2	
2		Not quite so much now	Quite a lot	1	
3		Definitely not so much now	Not very much	0	
		Not at all	Not at all		
3		Worrying thoughts go through my mind	I look forward with enjoyment to things	0	
2		A great deal of the time	As much as I ever did	1	
1		A lot of the time	Rather less than I used to	2	
0		Not too often	Definitely less than I used to	3	
		Very little	Hardly at all		
3		I feel cheerful	I get sudden feelings of panic	3	
2		Never	Very often indeed	2	
1		Not often	Quite often	1	
0		Sometimes	Not very often	0	
		Most of the time	Not at all		
0		I can sit at ease and feel relaxed	I can enjoy a good book or radio or television programme	0	
1		Definitely	Often	1	
2		Usually	Sometimes	2	
3		Not often	Not often	3	
		Not at all	Very seldom		

Now check that you have answered all the questions

	TOTAL	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 50px; height: 20px;"></td> <td style="width: 50px; height: 20px;"></td> </tr> </table>		

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C.2 HADS – Maltese

Skala ta' Ansjetà u Dipressjoni għall-Isptarijiet (HADS)



Isem: _____ Data: _____

ITWI HAWN

It-tobba jafu li l-emozzjonijiet għandhom rwol importanti f'haflna mard. Jekk it-tabib/a tiegħek t/ikun t/jaf b'dawn l-emozzjonijiet, t/jkun t/jista t/jgħinek aktar.

Dan il-kwestjonarju huwa magħmul biex jgħin lit-tabib/a tiegħek t/ikun t/jaf kif qed thossok. Aqra l-mistoqsijiet t'haawn taht u **aqta' linja taht it-twegġibiet** li jaqblu l-aktar ma' kif kont qed thossok fl-ahhar sebat ijiem. Tagħtis kaz in-numri li hemm fil-gem.

Iddamx taħsiha hafna dwar it-twegġibiet, ir-reazzjoni immedjata tiegħek għal kull mistoqsija jaf tkun aktar preċiża milli jekk toqgħod taħsiha fit-tul

NUMRI TAHT

A	D			A	D
		Inhożni nervuż/a u mimlija tensjoni	Qed inhożni li naqqast ir-ricmu		
3		Kwazi l-hin kollu	Kwazi dejjem		3
2		Ta' spiss	Spiss hafna		2
1		Kultant	Kultant		1
0		Lanqas qatt	Lanqas xejn		0
		Għadni niehu gost bl-affarijiet li kienu jtuoni pjaċir qabel	Inhoż certu beqgħat, bħal "friefet" fl-istonku		
0		Definitivament daqs qabel	Lanqas xejn		0
1		Mhux daqs qabel	Kultant		1
2		Frit biss	Sikwit		2
3		Frit li xejn	Ta' spiss		3
		Inhoż certu beqgħat, bħal donnha se tigri xi haġa kerha	Tliif l-interess fid-dehra tiegħi		
3		Iva, definitivament u gravi	Iva definitivament		3
2		Iva, imma mhux daqshekk gravi	Ma nilux hsieb kemm suppost		2
1		Daqsxejn, imma l-haġa ma tinkwetani	Jista' jkun li naqqast xi fitt milli niehu hsieb		1
0		Lanqas xejn	Għadni niehu hsieb daqs kemm kont qabel		0
		Kapaci nidhak u nara l-lar divertenti ta' l-affarijiet	Inhożni bla sabar, donnu l-hin kollu rrid magħmel xi haġa		
0		Daqs qabel	Hafna		3
1		Frit inqas minn qabel	Pjanost hafna		2
2		Hafna inqas minn qabel	Mhux hafna		1
3		Lanqas qatt	Lanqas xejn		0
		Jgħadduli hsibijiet inkwetanti minn moħħi	Nixteanu l-affarijiet b'certu herqa		
3		Kwazi l-hin kollu	Daqs kemm kont qabel		0
2		Ta' spiss	Daqsxejn inqas minn qabel		1
1		Mhux spiss hafna	Definitivament inqas minn qabel		2
0		Frit li xejn	Kwazi xejn		3
		Ninsab f'burdata tajba	F'daqqa wahda, inhoż certu paniku		
3		Qatt	Ta' spiss		3
2		Ma tantx	Sikwit		2
1		Kultant	Ma tantx		1
0		Sikwit	Lanqas qatt		0
		Kapaci noqgħod bi kwieti u nhożni rilaxxat/a	Kapaci niehu gost naqra ktieb tajjeb, jew programmi tar-radju u tat-televiżjoni tajbin		
0		Definitivament	Ta' Spiss		0
1		Ta' spiss	Kultant		1
2		Rari	Rari		2
3		Qatt	Rari hafna		3

Qis li wegġib għall-mistoqsijiet kollha

TOTAL

A	D

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 Kull dent minnha, iktar ta' informazzjoni.

HADS - Malta/Maltese - Version of 13 Mar 17 - Modj.
125824/HADS_MAL01_v13-07.doc

Appendix D – Dignity Therapy Question Protocol

D.1 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 dawk 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 your family to know about you, and are there particular things you would want them to remember? **Hemm xi affarijiet partikolari li tixtieq il-familja tieghek tkun taf dwarek, 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-iktar irwoli importanti li kellek f'hajtek (familjari, vokazzjonali, servizzi fli-komunita', eċċ)? Ghaliex kienu importanti ghalik, u x'tahseb li ksibt f'dawn l-irwoli? Bhal pereżempju qed nghidu ahna, fuq il-familja, fuq ix-xoghol, kif tkellimna tigha', 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 kishiet importanti tieghek, u biex thossok l-aktar kburi?**
5. What are your hopes and dreams for your loved ones? **X'holm jew xewqat ghandek ghal mahbubin tieghek?**
6. What have you learned about life that you would want to pass along to others? **Tghallimt xi haga 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, ragel tieghek, 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 ghandek trid tghid lil mahbubin tieghek, jew xi affarijiet li tixtieq tiehu l-hin biex terga' tghidilhom?**
9. Are their words or perhaps 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 taghati 'l familtek, sabiex tghin hom jippreparaw ghal futur?**
10. In creating this permanent record, are there other things that you would like included? **Hemm xi affarijiet ohra li tixtieq jigu mizjuda fid-dokument finali?**

D.2 Dignity 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 f'it 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' tahseb f'xi żmien jew mument fejn int hassejtek ferhan/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 f'it dwar is-sehem li _____ kellu f'hajtek?**
5. What are the most important accomplishments that you reached in your life thanks to _____? **Meta tahseb dwar dak li ksibt int f'hajtek, 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 tghid jew thoss li trid tghid lil _____, kemm jekk għidhom qabel u kemm jekk le, jew tixtieq li terġa' tghidhom?**
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'hajtek 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'hajtek?**
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 hsibijiet importanti ohra dwar _____ li tixtieq li jitnizzlu f'dan id-dokument?**

Appendix E – Dignity Therapy Patient Feedback Questionnaire

Participant: _____

Date: _____

Assessor: _____

Item	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I have found Dignity Therapy to be useful to me.					
I have found Dignity Therapy to be satisfactory.					
Dignity Therapy made me feel that my life currently is more meaningful.					
Dignity Therapy has given me a heightened sense of purpose.					
Dignity Therapy has given me a heightened sense of dignity.					
Dignity Therapy has lessened my sense of suffering.					
Dignity Therapy has increased my will to live.					
I believe Dignity Therapy has or will be of help to my family.					
I believe my participation in Dignity Therapy could change the way my family sees or appreciates me.					
I believe my participation in Dignity Therapy could change the way my healthcare providers see or appreciate me.					
In general, I have been satisfied by my psychosocial care.					

Strongly disagree=1; Disagree=2; Neither agree nor disagree=3; Agree=4; Strongly agree=5

Appendix F – Ethical Approvals

F.1 FREC Approval



Fabian Bonello

RE Research Ethics Proposal

1 message

SWB FREC

To: Fabian Bonello

3 August 2020 at 12:31

Unique Form ID:

Dear

Your ethics proposal with regards to your research titled *The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early Stage Dementia* has been **approved**.

Faculty Research Ethics Committees are authorised to review and approve research ethics applications on behalf of the University of Malta, except in the case of sensitive personal data. In this regard, your ethics proposal **does not need to be sent to UREC**. Hence, **you may now start your research**.

Regards,



Dr Claire Azzopardi Lane | FREC Chairperson

Faculty for Social Wellbeing

um.edu.mt/socialwellbeing/students/researchethics



F.2 Karin Grech Hospital Institutional Approval



Fabian Bonello <fab

Re: [EXTERNAL] - Request for institutional approval of dissertation project

2 messages

Fiorini Anthony at Rehabilitation Services-Health <
To: Fabian Bonello <
Cc: Messina Roberta at Rehabilitation Services-Health <

17 April 2020 at 08:07

Dear Dr Bonello,

The members of the Research Committee of KGH have agreed that you can proceed with your planned study at the hospital.

Dr Anthony Fiorini,
on behalf of the Research Committee KGH.

From: Fabian Bonello <
Sent: 09 April 2020 10:33
To: Fiorini Anthony
Subject: [EXTERNAL] - Request for institutional approval of dissertation project

Dear Sir/Madam,

I am a student sitting for the Master in Gerontology and Geriatrics with the University of Malta. I am writing to you in your capacity as Research Committee for Karen Grech Rehabilitation Hospital (KGRH) to request institutional approval to perform a study in KGRH as my dissertation project. Professors David Mamo and Marvin Formosa will be my supervisors in this project.

The title of my research project is "The Impact of Dignity Therapy on Depression and Anxiety in the Patient-Caregiver Dyad, in the context of Mild Cognitive Impairment and Early Stage Dementia".

Dignity therapy (DT) is a brief individualised validated psychotherapy which was originally created as a life-review therapy to enhance end of life experience in palliative care patients. It consists of 3-5 sessions where the participant is asked a series of questions related to personal dignity (Dignity Therapy Question Protocol) and these responses are recorded (using a voice recorder) and transcribed by the researcher. The transcript is then read back to the patient who may edit the document, and a final document ('generativity document') is presented to the patient who may choose to share it with anyone he/she wishes.

Our proposal is to carry out a feasibility study where DT is adapted from an individualised psychotherapy to a dyadic intervention due to the potential of involving the caregiver. It will aid patients to enhance their sense of dignity through deeper understanding of important roles they have held in their lives.

Furthermore, it boosts caregiver's satisfaction in care provision, which may include the sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life.

My dissertation will focus on evaluating whether this psychological intervention will have an impact on neuropsychiatric symptoms and caregiver distress, focusing on anxiety and depression as outcome measures of interest.

Participants are deemed eligible if patients are 60 years or older and community-dwelling, with a Montreal Cognitive Assessment (MoCA) score of $\geq 20/30$. Informal caregivers are to be selected independently by the patient, and have no known cognitive impairment (MoCA $>25/30$). All participants must be fluent in Maltese and English to take part in this study. 20 participant dyads will be recruited.

Sampling will be carried out in the Day Hospital at KGRH. The Day Hospital is an outpatient department which provides rehabilitation services for community-dwelling older people. These services take a multidisciplinary team (MDT) approach and include geriatric medicine, geriatric psychiatry, psychotherapy, physical and occupational therapy, social services and other allied health professionals.

Recruitment shall occur by disseminating information about the project via personal and electronic communication to the MDT working in the Day Hospital. MDT members will act as gatekeepers to invite eligible dyads. Should interest be expressed to participate, the MDT will inform the project lead to set a meeting with the patient to ensure eligibility and obtain informed consent. During this meeting, in-depth information shall be provided about the project as well as written information.

The intervention shall then be undertaken by certified Dignity therapists. The Hospital Anxiety and Depression Scale (HADS) shall be performed at baseline and 2 weeks post-intervention.

Please find attached my dissertation proposal, recruitment letters and consent forms. Please do not hesitate to contact me should you need further information.

Thank you for taking your time to review my request and I look forward to your response.

Kind regards,

Fabian Bonello

Messina Roberta at Rehabilitation Services-Health <
To: Fabian Bonello <

18 April 2020 at 07:39

Dear Dr.Bonello

Thank you for your email. I hereby forward approval as Data Protection Officer. Kindly note that you are to abide by all clauses in the Data Protection Act including the sections related to Research. You are to ensure that the officer in charge of the section that you are retrieving information from is updated on the progress of your research at all times. You are to declare the retention time for the data collected prior to starting data collection. Do not hesitate to contact me should you require any further guidance.

Regards

Roberta Messina