Maynooth University
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An examination of cognitive and psychological outcomes of a neuroeducation programme for individuals living with Mild Cognitive Impairment and their families.

Thesis submitted to the Department of Psychology, Faculty of Science and Engineering, in fulfilment of the requirements for the degree of Master of Philosophy, Maynooth University.

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June 2022

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Acknowledgments

This project was completed as part of the requirements for a MSc in Psychology. This project was done with both the support of Maynooth University and also Tallaght University Hospital.

First of all, I would like to sincerely thank Tallaght University Hospital, and Prof. Sean Kennelly for allowing me the opportunity to work with him and his amazing clinician team in conducting this project. Under them I have learned so much.

I would like to thank both my supervisors Dr Richard Roche and Prof Sean Commins for their support and encouragement while writing this project. This project came with its issues not to mention doing it during a pandemic. I have learned so much under their guidance and I will be forever grateful. Also to my friends and family for supporting me and for not letting me give up no matter how many times I threatened to.

I decided to complete my masters for my kids, they are my reason for doing everything I do in my life to make theirs better. I never would have taken on the challenge of being a Masters student if not for you two. You both make me want to be better, and do better for you. I love you both more than I can ever tell you.

Abstract

Background

The definition of Mild Cognitive Impairment (MCI) is a cognitive decline more advanced than one would expect based on a person's age, but not severe enough to obtain a diagnosis of dementia. Current literature varies on potential causes for MCI, and also on the impact that depression, stress and anxiety may have on this neurodegenerative condition. Many MCI patients go on to develop Alzheimer's Disease (AD). However, research has indicated that MCI patients can benefit from different types of intervention programmes. This study had a number of aims including, (i) to examine the impact of a non-pharmacological intervention, a four-week neuroeducation programme, on both patients with MCI and their family members, on various tests of cognition, stress, depression and anxiety; (ii) to follow up and qualitatively explore, using semi-structured interviews, the general impact and usefulness of the neuroeducation programme; (iii) given the global impact of Covid-19, our third aim was to examine, again using semi-structured interviews and interpretative phenomenological analysis (IPA), the impact of the pandemic on patients with MCI and their family members.

Methods

The study involved testing a sample of five participants, three with MCI, and two family members (FM) who did not have MCI. This project used a mixed methods design in which to analysis the data collected. All participants were given an initial battery of cognitive and psychological tests including the Control Autonomy, Self-realisation and Pleasure scale (CASP-19), the Satisfaction with Life Scale (SWLS), the Hospital Anxiety and Depression Scale (HADS), the Community Integration Questionnaire (CIQ), the Cognitive Failures Questionnaire (CFQ), the Montreal Cognitive Assessment (MoCA) and the Mini Mental

State Exam (MMSE). Following this, participants were provided with a 40-minute video file weekly to watch, over a 4-week period and began in February 2021; this was conducted online due to the Covid-19 pandemic. Weekly topics included: MCI and what it is; MCI and its relationship to AD; MCI and life satisfaction; community integration; and MCI and its relationship to diet and exercise. Following this four-week neuroeducation programme, participants were asked to complete the same battery of cognitive and psychological tests (with alternative versions where possible). Then, in a semi-structured interview, participants were asked to provide an assessment of the programme, whether they felt that it had had an impact, whether they found it useful and whether they would change aspects of their lifestyle as a direct result of the programme. Finally, patients were asked to assess the impact that Covid-19 was having on their lives, including restrictions and fear around the disease.

Results

Results from the pre- and post-intervention battery of tests showed minimal and limited changes in either cognitive (CFQ, MMSE, MoCA) or psychological measures (HADS, CASP-19, SWLS). In terms of the assessing the programme itself, IPA revealed three key themes which included Understanding, Lack of Time/Confidence and Intention to make lifestyle changes after the intervention. Although most participants (both MCI patients and family members) stated that they wouldn't change their current lifestyle in terms of diet or exercise, they understood the importance of these factors via the programme. Six common themes emerged following our qualitative analysis on the questions relating to the impact of Covid-19, these included: Family; Negative Emotions; Acceptance and Resilience; Anxiety; and Restriction/Confinement. The interviews highlighted the importance of family, social and care-networks in providing support and encouraging resilience.

However, despite this, the patients reported much anxiety around the disease itself, their own situation (especially MCI patients), and anger due to restrictions imposed and the limited contact allowed, brought about through the various government preventative measures.

Discussion and Conclusions

Although the participant numbers in the current study are small, and any definitive conclusions are difficult to make, we have shown that a neuroeducation programme may be a useful tool to provide patients with MCI and their family members with an additional understanding of the disorder and possible ways to improve lifestyles. In addition, the study highlights the importance of talking to patients and family members to better understand their worries and situation. As might be expected, Covid-19 had a particular impact that led to anger and anxiety among all participants, but also led to a better appreciation of family and an emerging sense of resilience. Such themes should be further explored among other clinical populations as well as in the general society. Future research in this area should aim to expand the numbers in both the MCI and family members, systematically compare a neuroeducation programme to other types of interventions, and conduct follow-up interviews that track changes in themes across time for both patients and families.

Chapter 1

Introduction

1.1 Ageing

Older adults are defined as those who are 60 years of age and over (Kot, & Kurkiewicz, 2004, United Nations, 2019). Currently, the proportion of the world's older adults is approximately 12% of the global population; by 2050, this number will have almost doubled, to approximately 22% of the global population. Therefore by 2050 an estimated 2 billion people will be 60 years of age (Cohen, 2003). The majority of older adults are considered to be healthy, both mentally and physically (Ohrnberger, Fichera, & Sutton, 2017). However, as one ages, the risk of developing mental disorders, neurological disorders, or substance abuse problems and various other health conditions increases significantly (Richardson, Lee, Berg-Weger, & Grossberg, 2013; Prince et. al., 2015; Widlitz, & Marin, 2002; Barile et. al., 2013; Patel et. al., 2016). Furthermore, as individuals age, they can experience several conditions consecutively - over 60% of adults over the age of 60 years of age suffer from two or more illnesses. (World Health Organisation 2017). Mental health and physical health often have a bi-directional relationship. For example, an older adult who is living with heart disease, has a higher risk of developing depression, or an individual who experienced chronic stress, can develop hypertension (Jiang et. al., 2002; Fiske, Wetherell, & Gatz, 2009; Zhang, Chen, & Ma, 2018). If more can be done to understand how people develop mental and physical health issues, more can be done to prevent them occurring initially.

1.2 Age-related Disorders of Cognition

According to the World Health organisation (WHO, 2017), for people over 60 years of age an estimated 20% have been diagnosed with some form of mental or neurological disorder, with the most common being dementia. Dementia is an umbrella term that incorporates a multitude of degenerative neurological brain conditions which include but are not limited to Alzheimer's

Disease (AD), Lewy Body Dementia, frontotemporal Dementia and Parkinson's Disease (PD) (National Collaborating Centre for Mental Health (UK) 2007; Aarsland, Andersen, Larsen, & Lolk, 2003; Ballard, O'Brien, James, & Swann, 2003). Currently, it is estimated that there are approximately 50 million people worldwide, who are living with a form of dementia, and the figures are set to rise significantly in the next 20 years (Wortmann, 2012; Alzheimer's Association, Thies, & Bleiler, 2013; World Health Organization. 2019). Dementia is normally associated with individuals who are 65 years and over and is classed as being a progressive neurodegenerative disorder, which causes decline in cognitive abilities such as memory problems, issues with processing language, inability to concentrate, impaired judgment, and can also affect an individual's ability to learn (Rosen, 2011; Krinsky-McHale, & Silverman, 2013; Fymat, 2018). For individuals living with this neurodegenerative condition, the changes are severe enough to affect their day to daily lives (Sandilyan, & Dening, 2015). Further, an individual living with dementia may not want to feel like a burden on their family, so they do not go seek medical attention, and this can result in them feeling unsure, alienated and separated from their peers and family members (Gove, et. al., 2016), exuberating the condition even further.

There is no one cause for an individual to develop any of the different types of dementia but stroke, traumatic brain injury (TBI), cardiovascular disease, hypertension and diabetes have all been suggested as potential contributing factors (Stampfer, 2006; Reitz, et. al., 2007; Iadecola, 2014). In a recent comprehensive review, Livingston et al. (2020) highlighted a number of other variable risk factors for dementia, including (but are not limited to) level of education, alcohol misuse, obesity, smoking, lack of physical activity, social isolation and air pollution. For example, for a person who achieves lifelong higher education accomplishment, this can significantly reduce their chances of developing dementia. While cognitive stimulation is important in early life, lifelong cognitive activity is also impactful (Kremen et. al., 2019).

Preventative measures, that have worked to various degrees, have mainly focused on pharmacological interventions (such as acetylcholinesterase (ACh) inhibitors), cognitive stimulation therapy, and cognitive rehabilitation (Spector et. al., 2003; Choi, & Twamley, 2013; Eldufani, & Blaise, 2019). However, early detection and early intervention, so that support is put in place as soon as possible, is vitally important to help reduce the impact of age-related disorders (Mukadam, & Livingston, 2012; Mukadam, Cooper, & Livingston, 2013; Robinson, Canavan, & O'Keeffe, 2014). In this respect, research over the last decade has focused on identifying prodromal stages of degenerative conditions. For example, Sperling (2011) argues that identifying these stages is imperative to ensure that treatment is effective, and aids in the prevention of further decline for individuals with neurological degenerative conditions. One possible early target for intervention is those with a condition termed Mild Cognitive Impairment (MCI).

1.3 Mild Cognitive Impairment (MCI)

Bondi (2017) suggested that the signs for dementia are evident up to 20 years before the full onset of the disorder (Beason-Held et. al., 2013; Bondi et. al., 2017). Mild Cognitive Impairment (MCI) is a clinical condition whereby the individual experiences a higher degree of memory loss than one would expect to see for normal ageing, but they fall short of reaching the criteria to receive an AD diagnosis (Petersen, et. al., 2001). The literature is inconclusive with MCI; some studies report that the transition rate from MCI to dementia is as little as 3% overall, where others report a progression rate of 40% (Shiri- Panza et. al., 2005; Feshki, 2009; Gao et. al., 2014).

The term MCI was first introduced into research in 1988 by Resiberg and was meant to refer to stage three of the Global Deterioration Scale (GDS), and to help people understand

what to expect when caring for someone with dementia (Reisberg et. al., 2008). This scale explores issues with navigation, problem solving, and minor memory issues, and when it was paired with the Clinical Dementia rating (CDR) - which investigates a person's performance on judgement, problem solving, hobbies and personal care - it was discovered that a transitional stage of dementia was evident, as some individuals were scoring poorly on these tests, but not significantly enough to obtain a diagnosis of dementia (Hughes et. al., 2000; Woolf et. al., 2016). People diagnosed with MCI are still able to live independently, partake in daily activities, and work, as they normally would have (Larrieu et. al., 2002). When MCI was first discovered, it was used as a predicting factor of progressive cognitive decline in the older adult population (Flicker, Ferris, & Reisberg, 1991).

Interest in MCI has increased in recent years due to the growing emphasis on identifying the early features of cognitive disorders such as AD (Petersen et. al., 2009). Gauthier (2006) argued that it is potentially too late to treat the core process of disorders like Alzheimer's Disease, but if individuals can be treated before it gets to AD, it is potentially possible to halt the progression, or even reduce the severity of the symptoms experienced by people. In order for an individual to receive a diagnosis for MCI, they are required to be able to function normally in their daily lives, unlike individuals with dementia (Petersen, 2004; Winblad, et al., 2004). A major issue with obtaining an MCI diagnosis is that not all clinicians have the same diagnostic criteria for MCI (Schinka et. al., 2010; Díaz-Mardomingo et. al., 2017). According to Petersen and colleagues (1997), the criteria for MCI were defined as follows: 1) individual must present with a memory complaint, 2) an objective memory disorder must be present, 3) absence of other cognitive disorders or repercussions to patients' daily life, 4) normal general cognitive function, and 5) absence of dementia. In 1997, the criteria were altered to the compulsory presence of a memory complaint and disorder. In 1999 the criteria were further clarified whereby MCI was to be defined solely in clinical terms, and it was also

decided that the absence of impaired cognitive function in any other domain except memory was needed for a diagnosis of MCI to be given (Petersen et. al., 1999).

Research has now indicated that MCI is often a pathology-based condition with progression to other neurodegenerative disorders such as AD as deemed to be high (Panza et. al., 2005). Recent research has shown that individuals who were categorised as having MCI were frequently shown to have impairments in other cognitive domains, not just memory, leading to the criteria for an MCI diagnosis to include both amnestic and non-amnestic presentations and additionally to include the involvement of both single and multiple domains (Petersen et. al., 2010; Hughes, et. al.,2011). MCI can be broadly defined as amnestic MCI (aMCI), and non-amnestic (naMCI); within these definitions they have been further defined as either being present in a single domain, or multiple domains - aMCI can be subdivided into single domain subtype with a pronounced memory deficit, or a multiple-domain subtype which includes a memory deficit but also includes an impairment on other cognitive domains such as language, or executive function. This is also the same for naMCI; it can be subdivided into single and multiple domain subtypes (Panza et. al., 2010).

While the causes of MCI are still unclear, studies have indicated that other degenerative diseases can be a contributing factor to MCI developing. Studies have shown that Parkinson's disease and frontotemporal lobe degeneration (a degeneration within the frontal and anterior temporal lobes, resulting in a decline in behaviour and language) can all contribute to an individual developing MCI later in life. (Bird et. al., 2010; Domoto-Reilly et. al., 2012; Monastero et. al., 2018). Non-degenerative diseases can also potentially cause MCI; these include, but are not limited to, brain tumours or certain types of medications, cerebrovascular pathologies such as stroke, restrictions in blood flow or clots. Haemorrhages or aneurysms have been linked as potential causes for MCI (Ihle-Hansen et. al., 2011; Consoli, Pasi, & Pantoni, 2012; Cramer et. al., 2019).

1.3.1 MCI: Neurological Bases and Varieties

Investigating the structural changes within the brain of an individual that has MCI has proven difficult, due to the fact the global atrophy varies greatly in older individuals (Fan et. al., 2008; Peterson, et. al., 2014). Using both fMRI and MRI studies, results have shown that the hippocampus and other regions of the brain are different for individuals with MCI compared to healthy normal controls (see Fellgiebel, & Yakushev, 2011; Foy et. al., 2011); that said, it can still be difficult to differentiate MCI from normal ageing. For example, Laakso and colleagues (1998) conducted a study to investigate the difference in hippocampal volumes using 166 participants; of these, 43 presented with MCI, 62 were controls, and 55 had a diagnosis of AD. This study showed that while there was evidence of hippocampal volume decrease with participants who had an AD diagnosis, none was found between the controls and the patients with MCI. Structural changes in the brain according to this study were more evident with individuals who presented with aMCI as they showed a larger reduction in hippocampal volume as well as changes in the amygdala in comparison to the cognitively healthy normal participants (Soininen et. al., 1994; Peng et. al., 2015; Joko et. al., 2016).

In recent years Volumetric-Magnetic Resonance Imaging (vMRI) has been used to investigate the brain areas affected by MCI (Bottino et. al., 2002; Fleisher, et. al., 2008). This is a non-invasive procedure, and its primary use is to look at atrophy within a person's brain. This technique is sensitive enough that it can detect the differences between AD, MCI, and general deterioration that one would expect to see from the normal ageing process. For example, Bottino (2002) showed that the amygdala, hippocampus, and parahippocampal gyrus were all significantly different for AD patients in comparison to those with MCI and controls. Additionally, the study also showed a significant reduction in the left hemisphere volumetric measures for the amygdala, hippocampus and parahippocampal gyrus for those with MCI

versus the healthy controls. The results indicated that measures of the medial temporal lobe regions could be helpful in aiding in the identification of people with MCI and also help with diagnosing those with mild to moderate AD due to the sensitivity of vMRI (Bottino et. al., 2002).

By using fMRI imaging on individuals with MCI, it has been shown that individuals with MCI show greater activation in the hippocampus compared with healthy normal participants (Dickerson et. al., 2005). Other studies that have used executive tasks have shown increased activation in the parietal lobes but decreased activation in the prefrontal cortex and the anterior cingulate gyrus (Rosano et. al., 2005). Furthermore, by using perfusion MRI scans results have shown that individuals with MCI have increased cerebral blood flow in anterior cingulate and basal ganglia as well as hippocampal regions, but they have decreased cerebral blood flow in their temporal and precuneus parietal regions (Clark et. al., 2011). Being able to combine multiple neuroimaging techniques such as fMRI and MRI has allowed researchers to conduct a more an in-depth examination of the pathophysiology of the transition from MCI to dementia.

Finally, while aMCI and naMCI are clinically different, little research has been done to investigate the exact neural differences between both. One study conducted used a sample of 62 participants with both aMCI and naMCI, as well as healthy normal participants. The study showed that of the individuals that presented with aMCI; their hippocampus, entorhinal cortex and amygdala were all decreased in size in comparison to participants who had presented with naMCI. Additionally, other structural changes were noted such as a reduction in the size of the cortical thickness of the entorhinal cortex, precuneus, the fusiform gyrus, and the isthmus of the cingulate gyrus. The hippocampus had decreased by 18% in aMCI compared to only a 5% decrease for individuals with naMCI. Furthermore, aMCI individuals' neuropsychological tests showed a decline in anterograde and retrograde memory, as well as category fluency

performance. The participants with naMCI showed deficits in letter fluency compared to controls. Both aMCI and naMCI groups showed deficits in executive functioning in comparison with controls; this was measured using the Trail-making Test (TMT). This study showed that aMCI and naMCI exhibit differences and the condition appear to affect individuals differently (Csukly et. al., 2016)

1.4 Cognitive, Non-cognitive and Psychological Issues in MCI

1.4.1 Cognitive Symptoms

Individuals with MCI typically experience several cognitive symptoms and not all patients will experience the same ones. For example, some individuals will experience problems with memory, language comprehension and understanding, attention, executive functions issues, problems with making decisions, and impaired judgement (Tarawneh, & Holtzman, 2012) and the symptoms will depend on whether they have been classified as aMCI or naMCI. Furthermore as discussed above, these can be further defined as either being present in a single domain, or multiple domains - aMCI can be subdivided into single domain subtype with a pronounced memory deficit, or a multiple-domain subtype which includes a memory deficit but also includes an impairment on other cognitive domains such as language, or executive function. This is also the same for naMCI, which can be subdivided into single and multiple domain subtypes. (Panza et. al., 2010).

1.4.2 MCI and Depression

Depression is a common disorder for older individuals to experience, and it is also significantly underdiagnosed in the general population. It is thought that 3.8% of the general population experience depression and this number rises to 5.7% in adults over 60 (WHO, 2017). This underdiagnosis may be potentially due to the stigma that surrounds having a diagnosis of depression (Barney et. al., 2006; Frederiksen & Waldemar, 2021). Furthermore, depression is also severely underdiagnosed in primary care settings due to symptoms often being missed because they can co-occur with other health problems (Davidson, & Meltzer-Brody, 1999; Nierenberg, 2001; Mergl et. al., 2007). Research has indicated that depression and MCI are connected, and for an individual who experiences recurring bouts of depression, this can increase their chances of developing MCI, and further increase their chances of progressing on to various forms of dementia (Panza et. al., 2010; Ma, 2020). However, based on the fact that depression is often overlooked as being a confounding factor for cognitive impairment issues, it is often excluded as part of the criteria when researching conditions such as MCI (Aalten et. al., 2007; Mangialasche et. al., 2009; Song et. al., 2019). For people who have already been diagnosed with MCI, they can experience bouts of depressive symptoms, and more recent research has now suggested that repeated experience with depressive symptoms with MCI accelerates an individual's progression from MCI to various forms of dementia such as AD (Modrego & Ferrández, 2004; Richard et. al., 2013). Research has suggested that the lack of empirical evidence in relation to the impact that depression has on MCI progressing onto dementia was due to the poor characterisation of cognitive performance and cognitive decline when depression was the focus of the initial research; this was further limited by the fact that studies often exclude people from participating in MCI research if there have depression or there is a history of depression for them or within their immediate family (Steffens, 2012).

A population-based epidemiological study conducted by Lyketsos and colleagues (2002) showed that neuropsychiatric symptoms were present in individuals who were living with MCI. This study used 3608 participants with MCI and was conducted over a ten year period. Within this study 824 participants were classified as having dementia, 320 had MCI, and 142 as being cognitively healthy normal controls. The study showed that of the 682 participants with MCI and dementia, 43% of those with MCI demonstrated neuropsychiatric symptoms; 29% of these were considered as being clinically significant, with 20% of these showing signs of depressive moods. For participants with dementia, 75% showed neuropsychiatric symptoms and 62% of these were clinically significant. Of the dementia patients, 32% demonstrated depression with 30% showing signs of agitation and aggression. The study showed that 50% of participants with MCI exhibited at least one neuropsychiatric symptom. The study indicated that there was a high prevalence associated with MCI and neuropsychiatric symptoms and more research was needed in this area to understand the impact on neuropsychiatric symptoms and the impact they had on individuals who were diagnosed with MCI.

Lee & Lyketsos (2003) further explored the link between depressive symptoms MCI and the risk of individuals with MCI progressing on to Alzheimer's Disease. Their study used 243 patients with MCI and involved a two-year follow-up. The results of this study demonstrated that individuals with MCI who had persistent depressive symptoms were shown to have a higher conversion to AD compared to those that had no neuropsychiatric symptoms. Additional patients with MCI who had more comorbid depressive symptoms showed more frontal, temporal, parietal and white matter atrophy compared with neuropsychiatric asymptomatic participants.

Research has suggested that depressive symptoms in MCI patients could contribute to different neurocognitive characteristics when compared to MCI patients without depression (Ma, 2020). One study recruited 153 MCI patients and divided them into two groups: MCI with

depression, and MCI without depression. Results demonstrated that of the 153 patients, 94 MCI with depression and 59 MCI without depression showed no significant difference for general cognitive status, but they did show a significant difference in cognitive performance tasks such as memory recall, Trail Making Test, and palm task for those with MCI and depression, compared to those with MCI and no depression. They concluded that participants with MCI and depression demonstrated greater deficits in neurocognitive functions including memory, executive function, attention, and visual memory than those with MCI without depression.

1.4.3 MCI and Anxiety

Current literature seems to be in agreement when it comes to the question of whether anxiety is common in people with cognitive deterioration (Ma, 2020; Martin, & Velayudhan, 2020; Santabárbara et. al., 2020). However, the literature seems to be conflicted over the prevalence of anxiety in individuals with MCI (Geda, 2004; Ma, 2020). Bierman (2004) showed that 11% of individuals with MCI display anxiety symptoms, whereas Rozzini and colleagues (2008) demonstrated that the occurrence of anxiety was 74% of individuals that had been diagnosed with MCI. Depression, anxiety, and apathy are common neuropsychiatric features for individuals with MCI; these have been linked to cognitive and functional decline in the daily lives of people with MCI, in an individual progressing onto other neurodegenerative disorders. However, anxiety symptoms for individuals with MCI have been researched less than depressive symptoms, and as with depression, the relationship between anxiety and cognition is complex (Ma, 2020). There is conflicting evidence as to the impact that anxiety has on people with MCI, and whether it increases the chances of a person developing Alzheimer's Disease. Some studies have reported the prevalence of anxiety for those with MCI ranging from 9.99% to 52% (Lyketsos et. al., 2002; Palmer et. al., 2007; Chan, et al., 2011). Additionally, a meta-analysis showed that the prevalence of anxiety for participants with MCI

was 14.3% for individuals within the community, and 31.2% for clinical-based samples (Chen et. al., 2018). Gallagher (2011) argued that these significant discrepancies in findings could be attributed to differences in recruitment strategies, methodology, and environmental factors. According to Rozzini and colleagues (2009), anxiety symptoms have been found to have severe interactions with executive functions in MCI; therefore, they are potentially a marker for cognitive decline in MCI. Generalised Anxiety Disorder (GAD) is the main anxiety disorder that is linked to poor global cognitive functioning (Potvin et. al., 2011). Anxiety is also a risk factor for Alzheimer's Disease developing in older adults with MCI.

However, Palmer (2007) and Devier (2009) have argued that this is only in population samples, and not in clinical samples. A study by Biringer (2005) reported that high anxiety levels were related to cognitive functioning, *only* when the participants were experiencing depressive symptoms concurrently, but Paterniti (1999) found this not to be the case; their findings report that high anxiety levels were associated with poor global cognitive functioning in non-depressed males only. According to Palmer and colleagues, anxiety symptoms aid in the predictive validity of MCI for identifying future AD, and they stated that mood-related depression in preclinical AD may be related to the neuropathological mechanism. Furthermore, anticipatory anxiety is also significantly linked with conversions to AD, but the significance is reduced once a cognitive status at the baseline occurs; for example, the participants become less anxious once the event occurs. Devier (2009) argued that different risk profiles have been put forward for state and trait anxiety. Devier stated that state anxiety was not a significant predictor for an individual to progress onto AD later in life; however, higher trait anxiety predicted lower risk for individuals progressing onto Alzheimer's Disease later in life. However, not all research has been consistent in their findings, and the results can vary greatly (for example, see Robert, 2008).

Various reasons have been presented to explain the differences in results for the prevalence of anxiety in people with MCI. Some have argued that it could be attributed to the differentiation between anxiety as a personality feature, and as a reaction to memory deterioration. Additionally, there are also issues caused by subjective anxiety and objective anxiety. Regardless of the various tools that are available to measure anxiety, the majority of studies have opted to use self-reported measures which tap into subjective anxiety and not objective anxiety. Gigi & Papirovitz (2021) explored whether anxiety levels in patients with MCI would vary depending on either objective or subjective anxiety. They recruited 50 older adults and split them into two groups. The first group had nine participants with MCI; the control group had 41 people. The study showed that while both cognitively healthy normal participants and memory-impaired participants showed elevations in physiological arousal in the memory test, only the cognitively normal participants demonstrated an enhanced state of anxiety. This finding suggested that individuals with MCI possibly have impaired awareness of their emotional state.

1.4.4 MCI and Stress

For decades it has been known that stress harms people's health (Peavy et. al., 2013). Recently researchers have explored the impact that chronic stress has on the brain. The most commonly measured of these are life events, hormone cortisol and the levels of stress experienced by individuals (Lupien et. al., 2004; Rosnick et. al., 2007). Theories suggest that stress must be chronic or sustained for it to have a physiologically harmful impact on the individual (McEwen, 1998; Brosschot, Gerin, & Thayer, 2006). Literature has suggested that cognitive decline due to stress is related to the effects of prolonged elevations of cortisol, which is a hypothalamic-pituitary-adrenocortical (HPA) axis response to high levels of stress (Beluche et. al., 2010; Peavy et. al., 2013). The areas affected by this response are the hippocampus, the amygdala,

and the prefrontal cortex (Lupien et. al., 2004; Li et. al., 2006). The hippocampus is a vital part of the human brain for certain types of memory; it is also thought to be the originating site of the neuropathology of AD, and to be compromised in people with MCI (Bird et. a., 2008; Fellgiebel, & Yakushev, 2011). Older adults are more susceptible to HPA axis dysfunction (Scheff et. al.,2006; Costafreda et. al., 2011), putting them at higher risk of developing conditions such as MCI and AD (Gil-Bea et. al., 2010; Escher et. al., 2019).

Peavy and colleagues explored the link between stress and neuropathology connected with dementia showed that stress relates to synapse loss and increases in amyloid β-peptide (Tata et. al., 2006) as well as tau accumulation and phosphorylation (Green et. al., 2006). A longitudinal study showed that highly stressful events were connected to memory decline for individuals with MCI over a two-to-three-year period. The study also showed that higher levels of cortisol were not connected to a decline in participants with MCI. The results of this longitudinal study suggested that the differential effect of cortisol level on cognition depended on the neuropathological change. They argued that identifying methods to better define chronic stress in ageing could have an important effect on the relevance of these associations. Peavy and colleagues (2012), conducted a study to explored the relationship between chronic stress and diagnostic change in 62 participants over 2.5 years, concluding that prolonged experience of highly stressful events was linked to progression from MCI to dementia.

As stated, the prevalence of AD and pre-dementia states like MCI is on the rise (Hebert et. al., 2013). With the lack of effective disorder-modifying treatments for dementia, research is focusing on early interventions, by way of identifying remediable risk factors and trying to develop preventive interventions to stop conditions like MCI from progressing to other neurodegenerative disorders such as Alzheimer's Disease (Anstey, Cherbuin, & Herath, 2013). While studies have investigated the relationship between chronic stress and its impact on AD (Johansson et. al., 2013), very few have explored the impact between stress and MCI in

community-based samples (Wilson et. al., 2007). Katz and colleagues (2016) argue that to understand the complicated association of stress with cognitive decline, depression must also be considered (see section above). Individuals who carry the APOE ε4 allele are at an even higher risk of receiving a diagnosis of aMCI and AD (Lee et. al., 2008; Fei et. al., 2013). Katz et. al. (2016) recently explored if chronic stress led to the onset of aMCI, and whether chronic stress, APOE genotype, and depressive symptoms were factors of individuals being diagnosed with aMCI, and if the stress was a remediable risk factor for aMCI. The study concluded that 30% of their participants were at higher risk of the onset of aMCI with perceived stress. These findings were further supported by Koyanagi et. al. (2019) who showed that the perceived stress score (PSS) was 1.14 times higher for individuals with MCI compared to cognitively healthy normal participants across six countries (Ghana, India, Mexico, South Africa, Russia, and China). The study concluded that perceived stress potentially has a significant impact on those with MCI and could be a factor for progressing on to a diagnosis of dementia.

1.5 Family members and MCI

Historically, family members were expected to care for individuals in their family who had ailing health or were suffering from various disorders (Schulz, & Eden, 2016). In previous years, caregivers did not care for the ailing family members for long, due to the lower life expectancy because of poor health care, socioeconomic status, and various other reasons (Roser, Ortiz-Ospina, & Ritchie, 2013). With medical intervention, people who are sick are now living longer (Brown, 2015; Mishra, 2016). For individuals who chose to take on the role of caring for their loved ones, they are prone to experiencing financial issues, chronic stress levels, anxiety, depression, as well as physical strain (Schulz, & Sherwood, 2008; Brodaty, & Donkin, 2009). Literature has demonstrated that individuals who provide care for long periods

to family members who are chronically ill or have neurological conditions put their own physical health and mental wellbeing at risk (Vitaliano et al., 2003; Schulz, & Sherwood, 2008). They experience social isolation, their quality of life shows a significant decrease, emotional distress, and on average 50% of caregivers meet the diagnostic criteria for major depression (Dekel, Solomon, & Bleich, 2005; Gallagher-Thompson, & Coon, 2007; Chang, Chiou, & Chen, 2010; Blanco et. al. 2014). Currently there is extensive literature on the impact that caring for individuals with AD or various other types of dementia has on their families and caregivers (Dunkin & Anderson-Hanley, 1998; Waite, 2004). However, not much is known about individuals who care for someone who has been diagnosed with MCI (Petersen et. al., 2004). The lack in research within this area could be due to the fact that caring for an individual with MCI is significantly different to caring for someone with dementia. Research indicates that caring for someone with MCI can lead a caregiver to experience emotional distress, sleep problems, and disruption of daily tasks (Garand et. al., 2005; Blieszner & Roberto, 2010; Fisher et. al., 2011; Kelleher et. al., 2016; Carlozzi et. al., 2018). Family members also face the added strain of worrying if the person they are caring for could progress on to developing dementia; this potential for a long disease is an extra challenge that family members for individuals living with MCI face (Bruce et. al.2008; Fisher et. al., 2011). For example, using focus groups Carlozzi et. al. (2018) explored the impact that caring for someone with MCI has on individuals. Topics that emerged included social health, changes in their social roles, their need for more social support, and also their own mental health concerns, particularly focused around anger, frustration, anxiety and patience. Carlozzi (2018) concluded that health related quality of life (HRQOL) for carers caring for someone with MCI are severely impacted, and more support services are needed. Indeed, Keller (2008) argued that more education and awareness around the needs of those living with MCI are needed.

Garand (2005) interviewed 27 partners of individuals who had been given a diagnoses of MCI and found that 11.1% had clinical depression, 11.1% had clinically significant anxiety and these were linked to caregiver burden. However, this study only had a small sample size, and identified that more needed to be done to explore the impact on caregiven burden to those living with someone who has MCI. In a related study Bruce et. al. (2008) demonstrated that 30% (n=51) of the caregivers showed a clinically significant burden which was associated with longer course of cognitive symptoms. These results are significant in highlighting the fact that individuals with MCI can experience behavioural and emotional difficulties which in turn impacts those that are caring for them.

Despite this, family members are a vital part of helping individuals with complex chronic care needs. Family members can help to slow down the risk of individuals with long term issues being moved into long term care facilities, in turn reducing the impact and financial burden these have on the health system (Gaugler, 2005). It also helps to create a more stable relationship between the clinicians and the patients themselves (Delbanco et. al., 2012; van der et. al., 2017). Mild Cognitive Impairments and other forms of long-term illness not only impact those living with the condition but also their family members. These conditions have an extensive impact on social interactions, and economic consequences for those living with conditions such as MCI and those helping them (Feinberg et. al., 2011; Liu et. al., 2012).

1.6 Interventions for MCI

Currently there are a multitude of pharmacological and non-pharmacological interventions that are being used to target MCI, and in particular to prevent the symptoms worsening or progressing on to various forms of dementia. These non-pharmacological interventions include, but are not limited to, cognitive intervention programmes (Faucounau et. al., 2010; Sherman et. al., 2017), exercise and psychotherapeutic interventions (Rodakowski et. al., 2015;

Karssemeijer et. al., 2017). Some interventions are memory-based, and focus on memory rehabilitation. For example, one systematic review that explored the effect of these memory-based interventions and looked at how effective they were for individuals living with MCI was done by Stott & Spector (2011). However, their results, based on 10 studies, were not promising. Although they concluded that individuals with MCI can learn specific information, the evidence that memory training could be generalised was poor at best. They also stated that there was some evidence of a person with MCI having the ability to learn to compensate for memory difficulties, but again this was also limited.

Another systematic review that analysed seven studies focusing on the impact of non-pharmacological interventions on cognition for older adults living with MCI was conducted by Teixeira et al. (2012). Six of the studies used a cognitive intervention aimed at improving memory, and one study explored the impact of physical activity. The authors concluded that both physical and cognitive exercise could potentially improve memory and also executive functioning, but they suggested that a standardisation of protocol for exercise was necessary in order to show general improvements in the cognitive functioning in older adults with MCI.

In a more recent umbrella review Demurtas et. al. (2020) conducted analysis of 27 studies that examined the impact of physical activity/exercise on cognition and (non-cognitive functioning) in those living with MCI. The authors found that mind-body interventions and mixed physical interactions had a small effect on global cognition for those with MCI, whereas resistance training had a greater impact. In addition, the authors found that exercise proved to be effective in improving cognition in Alzheimer disease and other types of dementias. Exercise also improved non-cognitive functioning; participants showed less falls and improved neuropsychiatric symptoms.

While it is evident that some non-pharmacological interventions for treating MCI show great promise, current literature continues to suggest that more needs to be done in this area, to

design a programme that will substantially benefit all those affected by this neurological disorder.

1.7 Neuroeducation and MCI

Most research in relation to people with MCI has explored pharmacological treatments and some researchers have argued that the effect of pharmacological treatments for MCI is still uncertain (Cooper, Li, Lyketsos, & Livingston, 2013; Gordon & Martin, 2013; Petersen et al., 2014). Very little research has explored the impact that non-pharmacological treatments can have on this condition, and an even smaller amount has explored the impact of neuroeducation or psychoeducation in relation to this condition. A psycho-educational intervention is designed to provide information to those living with illnesses and disorders and show them ways of managing these conditions, whereas a neuroeducation based programme is designed to aid in the understanding of what is currently happening to a person with a diagnosis of MCI by providing information about the brain and neurodegeneration, while also showing them ways in which to manage symptoms. This project chose to use a neuroeducation programme as few of these studies combine neurological and education factors in connection to MCI (Ekhtiari, et. al., 2017: Longley, Tate, & Brown, 2022). Horr and colleagues (2015) argued that individuals living with MCI can in fact benefit from nonpharmacological treatment that improves their cognitive abilities as well as reducing their risk of longer, more severe bouts of depression and anxiety; this theory has also been supported by other research (Cooper, Li, Lyketsos, & Livingston, 2013; Gordon & Martin, 2013). Barrios (2013) argued that improvements in Quality of Life (QoL) are just as vitally important for those living with MCI as finding a way to improve their cognitive abilities. Recent research reports that individuals with MCI have a lower QoL of than people without MCI (Muangpaisan, Assantachi, Intalapapron, & Pisansalakij, 2008; Teng et al., 2012: Barrios et al., 2013). Further research using non-

pharmacalogical approaches such as psychoeducation and social groups has shown promising results for improving QoL for those living with MCI (Pitkala, Routasalo, Kautiainen, Sintonen, & Tilvis, 2012: Dannhauser et al., 2014). Young (2019) conducted a study which explored the impact of a psychoeducation group-based on an eastern approach to health care and explored the impact it had on improving QoL in a Chinese cohort. The study used a Randomised Controlled Trial (RCT), and they recruited a total of 40 participants. The participants were randomly allocated to either the control group, or the treatment group which received 10 sessions of psychoeducation. Analysis showed improved scores for the treatment group for QoL. The authors concluded that there is some evidence to suggest potential benefits from using psychoeducation with individuals with MCI.

Alescio-Lautier and colleagues (2019) argued that in the early stages of AD the brain is still able to show plasticity and that adapted cognitive training programmes should be explored, as currently cognitive stimulation is underexplored. They conducted a study using patients who had AD or aMCI. Their study also included family members. They had a small sample size (n=12). Participants were given a training programme (15 sessions from 90 to 120 minutes every two weeks) as well as sematic tasks, and memory and attention tasks. The results from this study showed that individuals showed an improvement for memory recall with the training programme, and also an improvement in verbal fluency. Alescio-Lautier argued that the results from this study demonstrate that individuals who are in the early stages of AD can benefit from cognitive training programmes, and therefore, it could be argued that – if MCI is a prodromal stage of MCI, as research has indicated – then so too may individuals with a diagnosis of MCI before it progresses to AD (Reisberg et. al., 2018; Breton, Casey, & Arnaoutoglou, 2019).

Very little is available in relation to neuroeducation studies that have been conducted on individuals with MCI and the impact that it could potentially have. Therefore this project

was devised to explore this, and to determine if educating people with MCI would show a reduction in anxiety and depression, as well as giving them a better understanding of this condition for both those living with MCI and also their loved ones.

Health education is a critical part of managing a disease. It provides patients with knowledge of their condition, helps their understanding of how the disease may progress, and helps patients in terms of self-management and how to make any required adjustments (Liu et al, 2021). Despite this, there are many studies that have shown older adults often lack knowledge about cognitive disorders. For example, in a recent study by Zhang et al. (2017) it was found that dementia literacy was only 55.5% among community-dwelling older adults in China. Similarly, Rimmer et al. (2005) found that although Europeans understood the effects of AD, few recognised early-stage symptoms. In addition, those with AD were found to react to their diagnosis with either a fatalistic attitude, a non-acceptance of the condition, or simply believe that the disease is linked to old age. Although it has been shown that older adults with MCI had lower knowledge of dementia compared to those with normal cognition (Lee et al., 2016), there is a general lack of education programmes for those with MCI (Du & Hu, 2016). Furthermore, even if health programmes were extensive, it is unknown how beneficial they might be (Liu et al., 2021). However, a recent study suggests that education programmes may not only have benefits in terms of increasing knowledge and management of the disease, but they may also prevent decline in cognition. For example, Sink et al. (2015) compared a long-term health education programme (60-90 minute weekly workshop) to a moderate-intensity exercise program (including walking) in older adults and found no difference in two tests of cognition (Digit Symbol Coding task and Hopkins Verbal Learning Test-Revised). Furthermore, MCI and dementia occurred at similar rates for both groups. The authors suggested that exercise intervention did not result in better cognition than an education

programme, and that elements of the programme may have improved or prevented cognitive decline.

1.8 Covid-19 and the impact of the pandemic

Covid-19 became a worldwide crisis shortly after the commencement of this project. Within the first 12 months of the pandemic it was beginning to become apparent that Covid-19 would have long reaching consequences on everybody. While research is still ongoing in relation to exactly the extent of the impact that this pandemic has, and will have, is still being discovered. One study explored the impact that the pandemic had on generalised anxiety and depression and used a sample size of n=1041 within the population of Ireland. The study used self-reported methods and March and April of 2020. The study found that 27.7% of the sample reported experiencing generalised anxiety and/or depression since the first week of restrictions in Ireland. Furthermore, generalised anxiety was found to be higher within the older cohort 65 years or older (Hyland, et. al., 2020). Murphy and colleagues (2021) also reported that individuals with pre-existing mental health issues are more vulnerable due to Covid-19 and lockdowns. Covid-19 not only poses a risk to an individual's physical well-being, but also their mental wellbeing, and due to the fact that this project was exploring the impact of a neurodegenerative condition and if a neuroeducation based intervention could aid in reducing psychological based symptoms such as anxiety, depression, and stressed, it was decided to include this as an aim of the thesis.

1.9 Aims of Current Thesis

Given the importance of general education programmes in (i) disease management and increasing knowledge, (ii) the possible benefits of such programmes in terms of cognition and prevention of disease progression, and (iii) the general lack of such programmes for MCI patients, we wished to pilot and assess a 4-week education programme in a small sample of patients living with MCI and their family. Through semi-structured interviews we wanted to examine the impact of the programme, specifically in terms of whether both patients and family members felt that their knowledge of the condition increased and whether the programme helped in the self-management of the condition (e.g. whether it might bring about a change in lifestyle or not). This would help determine whether the programme could be expanded and used for others living with MCI or other age-related diseases.

Furthermore, given the prevalence of psychological issues including depression, stress and anxiety among those living with MCI and family members (see above sections), as well as changes in cognition, we wanted to assess whether the programme might be beneficial in terms of these formal measures. Although we expected to see little or no change in terms of cognitive or psychological measures following such a brief intervention, given the recent Sink et al. (2015) study (see above) we wanted to explore this further, and provided all participants with a battery of tests pre- and post-intervention. These measures included the Control Autonomy, Self-realisation and Pleasure scale (CASP-19), the Satisfaction with Life Scale (SWLS), the Hospital Anxiety and Depression Scale (HADS), the Community Integration Questionnaire (CIQ), the Cognitive Failures Questionnaire (CFQ), the Montreal Cognitive Assessment (MoCA), the Mini Mental State Exam (MMSE), and the Trail Making Test (TMT).

Finally, 2020 and 2021 saw the devastating global impact of Covid-19. This disease has and continues to have severe consequences on the physical and psychological well-being

of all, but particularly older adults (Mueller et. al., 2020.;Wilkinson et. al., 2021). With restrictions on hospital appointments, movement, visitations and general fear in the community, it is currently unknown how the disease has and continues to impact on those with cognitive deficits and specifically those living with MCI. Again, using semi-structured interviews we wanted to explore how Covid-19 had affected the lives of both those living with MCI but also family members.

In brief, the aims of this project were:

1. To explore the impact of this specifically designed neuroeducation programme on those with MCI and their family members in terms of whether the programme enhanced the understanding of the condition and how best to manage it.
2. To investigate whether the programme had any impact on formal cognitive and psychological measures.
3. To explore the impact of Covid-19 on individuals living with MCI and their family members.

Chapter 2

Methods

2.1 Overview

The purpose of this chapter is to provide details of the study, the battery of tests, the participants and how they were recruited. In particular the chapter will provide a detailed account of the development and procedure of the intervention programme that the participants received. Details of the statistical analysis that have been used in this project will also be described.

2.2 Design

This study used a mixed methods design, with both qualitative and quantitative methods. For the quantitative portion of this study a series of cognitive and psychological tests were given to each participant both pre-and-post a 4-week neuroeducation intervention programme, these included: CASP-19, the HADS, CIQ, CFQ, MMSE, MoCA, TMT, SWLS. Following the 4-week programme, a series of semi structured interviews were then conducted for the qualitative part of this study. Questions focused on the neuroeducation programme, the impact of the disease and the impact Covid-19 had on each participant. The researcher used manual transcription for the qualitative data gathered from the semi structured interviews. Due to the small participant sample within this project MAXQDA or other analytical programmes were not used. Due to the relationship that the researcher had built between her and the participants, it was decided that analysing the data collected independently for each interview would be more beneficial for this project.

2.3 Participants

Participants were recruited through the memory clinic in Tallaght University Hospital (TUH) between January and March 2020; ethical approval for the study was granted from the ethics committees of both TUH (see **Appendix A**) and Maynooth University (see **Appendix B**). The researcher was invited to attend a number of memory clinics provided by the team in TUH, where she was able to meet and discuss the study with patients. The memory clinic was run weekly. Patients were asked by the nurse if they had any objections to the researcher being present during these consultations. The memory clinic was run by the clinical lead nurse and involved individuals that had been diagnosed with MCI. For the most part, these clinics were used to assess if there had been any changes for the patients, and their overall wellbeing. During the clinics, patients were asked about changes in health, sleeping, and eating habits. Once the clinic was concluded, the nurse introduced the researcher, and explained why she was there, and asked if any participant was interested in taking part in the study. All patients were not suitable for recruitment (see inclusion/exclusion criteria below) and the lead clinical nurse helped with this process. From this initially introduction the researcher was able to discuss the details of the project and asked for consent to contact each participant that agreed to take part in the study.

From this, and following the onset of Covid-19 lockdown and restricted hospital access, we were only able to recruit three individuals with MCI and two individual who were family members. The age and gender for those with MCI were as follows; 2 females (one aged 74 and the other 67) and 1 male (aged 78). The family members of those living with MCI who agreed to participate in the project included a male (spouse, aged 78) and a female (daughter, aged 34).

Originally this programme had been designed with the intention of inviting each participant to TUH and conducting the programme in a group setting, but as Covid-19 restrictions prevented this, a number of changes had to be made (see next sections for detail). For the safety of the participants, and also the researcher, this project was moved completely online. All 4 education sessions were pre-recorded using power point. The researcher contacted each participant, and obtained permission to use their email addresses and send them a link using WeTransfer which was a safe online platform for transferring files. Participants were also asked to have a pen and paper beside their laptops, so if any questions arose while they were watching the slides they could discuss these with the researcher when she called them after each week. Participants were also told that the researcher would contact them by telephone by the end of the week to discuss that week's session and answer any questions.

Since the researcher had met each participant in the Memory Clinic in TUH, it was decided that a follow-up phone call was needed to re-establish a relationship between all parties involved. A telephone call was made to each participant individually where the details of the project were given, and the procedure of how the project would work was explained. After completing this call, a pack was sent to each participant. This pack consisted of an invitation letter (see **Appendix C**), an information leaflet (see **Appendix D**), a consent form (see **Appendix E**), and the battery of tests (see Section 2.5, below).

2.4 Measures

A questionnaire was initially given to the five participants to assess education status, age, smoker/non-smoker, drinker/non-drinker and work status. Following this, a battery of cognitive measures was administered.

2.4.1. Cognitive Measures

The **Trail Making Test** (TMT) from the Delis-Kaplan Executive Function System (D-KEFS, Delis Kaplan & Kramer, 2001) was used to evaluate executive functioning skills of the participants involved in this study (See **Appendix F**). This version is a modified version of the original test first developed by Partington (Brown & Partington, 1942; Partington & Leiter, 1942). It later became a common tool to be used in the *Halstead-Reitan Neuropsychology Battery* for neuropsychology (HRNB; Reitan & Wolfson, 1995). This test has shown sensitivity in detecting issues with higher level executive functioning (Delis, Kaplan, & Kramer, 2001) and consists of a visual cancellation task, and also multiple connect-the-circle tasks. This test had two conditions. In part A participants were required to draw a line connecting 25 dots, as quickly and as accurately as possible. Each dot contained a letter, and participants had to connect them in alphabetical order. This condition was timed by the researcher. In part B of the TMT, participants were asked to connect dots again, only this time there was a mixture of both numbers and letters. Participants were instructed to connect a letter, to a number to a letter. They were also instructed that both numbers and letters needs to be in alphabetical, and numerical order. This was also a timed task. If participants made an error, the researcher instructed them and allowed them time to correct it. The number of errors were taking into account when the test was completed at the researcher was scoring the test. The scoring of the test was done when the time from trial A and trial B were subtracted from each other. This test

was used in this project, as it is sensitive when dealing with individuals with have brain damage or other impairments such as MCI (Reitan, & Wolfson, 1994).

The TMT is often used to assess executive functioning, particularly for those that may have damage to frontal lobes or connecting regions (Faria et. al., 2015; Varjacic et. al.,2015). As individuals with MCI often have issues with executive function (Kirova, Bays, & Lagalwar, 2015) the trail making task was deemed an appropriate test to examine this. This test has two parts, the first (Part A) Participants are asked to connect the dots in ascending numerical order. The second stage (Part B), individuals are required to switch between number and letters, requiring planning, attention, working memory and visual spatial abilities such processes require executive functioning which is impaired with individuals who have MCI (Archibald, & Fisk, 2000; Salthouse,2011)

Montreal Cognitive Assessment (MoCA: Nasreddine, et al., 2005**; See Appendix G).** The MoCA was used to evaluate individuals performances on orientation, short-term memory, executive function, visuospatial ability, language, and attention The MoCA is a rapid screening test to aid in the detection of MCI and other neurological degenerative disorders (Nasreddine et. al., 2005). It is considered more sensitive than the Mini Mental State Exam (MMSE, Mast, & Gerstenecker, 2010), and has a better detection of MCI for people who present with memory issues, but are not severe enough to be diagnosed with Alzheimer's disease (AD) (Hoops et. al., 2009). The test is designed to be short, it takes approximately 10 minutes for the participant to complete it. It consists of 30 items and assess multiple cognitive domains including memory, visual spatial, memory, attention, concentration, and visuoconstruction skills (Nasreddine et. al., 2005; Smith, Gildeh, & Holmes, 2007). Each domain is scored separately and the points are added up at the end of the test. Participants can obtain a maximum of 30 points.

The short term memory recall task consist of two learning trails of five nouns, and there is a delayed recall of approximately five minutes. This section has a maximum score of five points. Participants visuospatial ability is assessed by giving them a clock drawing task, and a three-dimensional cube copy. There are three marks and one mark for this task, respectfully. The MoCA assess multiple aspects of executive functions by using an alternation task which has been adapted from the trail Making Task B, there is one point for this. There is a verbal fluency tas which participants have to name as many words beginning with letter F in sixty seconds, there is one point associated with this task. Additionally there is a sentence repetition section which requires participants to repeat a sentence back to the tester accurately, there is one point associated with this task. Individuals are also tested on their attention, working memory and concentration by being given an attention task where they have to detect a moving target by tapping, there is one point allocated for this, a subtraction task whereby participants have to serial subtract seven from a number given to them by the researcher, this task is given three points for this and a version of the digit span task is used that has two conditions, one where participants have to remember a number sequence and repeat it back (forward condition), and the second condition where they have to remember and repeat the sequence backwards (Reverse condition) there is one point each for this. Individuals are also tested on their language, this is done by giving them a three-item confrontation naming task with low-familiarity animals (e.g. lion, rhinoceros, giraffe) and there are three points allowed for this, a fluency test which is given two points, and also a repetition of two syntactically complex sentences, which is also two points. Finally, participants are given an orientation task, this is where they are asked to name the time and the place, this is allocated 6 marks (Julayanont, & Nasreddine, 2017).

Cognitive Failures Questionnaire (CFQ: Broadbent, Cooper, FitzGerald, & Parkes, 1982; See **Appendix H**). The CFQ was used to investigate participants probability of making errors in tasks associated with their everyday lives, it also explores participants' attentiveness and memory. The CFQ was developed in 1982 by Broadbent and colleagues. Broadbent and colleagues argued that it could not be rationalised perceptual, action failures and memory were all connected to each other. The CFQ is used to investigate a number of issues such as; exploring the relationships between cognitive failure and individual differences. The CFQ was designed to assess a number of things such as; to explore the relation between cognitive failure and individual differences. The CFQ was designed to investigate how often individuals experienced cognitive failures such as memory lapses, motor function issues, errors with perception to name a few (Broadbent et. al., 1982: Wallace et. al., 2002). The test consists of 25 potential failures that can occur to individuals occasionally. Participants are giving 25 questions, and asked to respond how often these have occurred during the last six months. It is scored using a five point scale with zero being never and four being very often.

2.4.2 Psychological Measures

The Hospital Anxiety and Depression Scale (HADS; Zigmond, & Snaith, 1983; See **Appendix I**) is a widely used test to measure anxiety and depression in individuals. The HADS is a self-reported 14-item measure that is scored on a 4 point Likert Scale from 0-3. The HADS asks participants questions such as "I feel tense wound up" or "I have lost interest in my appearance. Participants are then asked to rate these statements using a Likert scale from 0-3. This is a simple and straight forward test for the participant, and it is also easy for the researcher to run. The HADS takes approximately seven minutes to administer. Seven of the questions are in relation to depression, and the other seven are associated with anxiety. Participants are

asked to consider their feelings within the last seven days and to score their answers from zero to three. Zero corresponded to Definitely as much; One, not quite as much; Two, only a little; Three, hardly at all. The HADS scale is widely used and has been found to be a dependable instrument in detecting states of depression and anxiety for individuals (Snaith, 2003). The scoring scale indicated that scores under seven are considered to be normal, anything form eight and above potentially indicates that the individual has clinical levels of anxiety and or depression. The scale also shows that those that score eleven or over, could potentially have a clinical disorder (Zigmond, & Snaith, 1983**)**. The correlation between both anxiety and depression with the HADS is .53, suggesting it is a reliable psychological assessment tool to use (Crawford, Henry, Crombie,& Taylor, 2001). Due to the fact that individuals with MCI are likely to experience depression (Panza et, al., 2010), the HADS is a sensitive and simple test to perform and it has been shown to be reliable and valid.

Community integration Questionnaire (CIQ; Willer, Ottenbacher, & Coad, 1994; See **Appendix J**) was originally developed to determine community integration after a traumatic brain injury. It focuses more on activities of daily living and includes questions such as "Who does the weekly shopping?" or "Who usually looks after the personal finances, such as paying the bills and banking?" (Willer, Ottenbacher, & Coad, 1994; Sander et. al., 1999). The CIQ contains 15-items designed to investigate areas such as Home Integration, Social Integration and Productivity. Each of these areas have sub categories that examine how well an individual performs their daily tasks, i.e. household chores, shopping, financial independence, relationships with peers and family, work commitments, and other social activities outside the home, to name a few (Hirsh et. al., 2011). The CIQ is a self-reported questionnaire and takes approximately seven minutes to complete. Participants find it simple to complete, and it is also a straightforward test for the researcher to administer. The answers are focused on if they

perform tasks alone, with someone, or if they get someone else to do these tasks for them. The CIQ has shown to be a valid and reliable method of testing community integration with a Cronbrach's alpha within an acceptable range of 0.7999 (Singh et. al., 2015; Razaob et. al., 2020). Using the CIQ with people who have MCI helps to form a better understanding of how they are integrating with their community.

Satisfaction with Life Scale (SWLS**;** Diener, et al., 1985; See **Appendix K**). The Satisfaction With Life Scale (SWLS) has been widely used to measure how satisfied an individual is with their subjective well-being (Pavot et. al., 2009). The SWLS scores have been shown to relate to measures of mental health and have also been predictive to future behaviours (Pavot, & Diener,2008). This SWLS is a simple psychological assessment tool to use. Participants find it easy to understand, and it takes approximately five to six minutes for the researcher to conduct it. The SWLS is a self-reported questionnaire 7-point items. Individuals are given five statements and are asked to rate them on how much they agree with the statements. An example of the statements that participants are asked are, "The conditions of my life are excellent". Participants are asked to score this statements, and other similar ones, using a seven point Linkert scale. On the Linkert scale one is attributed to the participant strongly disagreeing with the statement, and seven relates to the participant strongly agreeing with the statement; four is attributed to them neither agree or disagree with the statement present to them. Individuals can score between 5 and 35, and a score of 20 is the natural point on the scale (Diener, et al., 1985). A score of between five and nine is an indication that the individual is extremely unhappy with life, whereas scores of between 30-35 show that individuals are extremely happy with how their life is. The coefficient alpha for the SWLS is between 79-.89 showing that the scale has high internal consistency. Test retest correlations are also shown to be sufficient with between .84 being average after a month (Durak, Senol-Durak, & Gencoz, 2010).

CASP-19 (Hyde, Wiggins, Higgs, & Blane, 2003; See **Appendix L**). The Control, Autonomy, Self-realisation and Pleasure (CASP-19), is a quality of life, self-reporting questionnaire for older adults. It investigates the quality of life for older individuals in four domains which are; pleasure, self-realisation, control, and autonomy (Hyde, Wiggins, Higgs, & Blane, 2003). The CASP-19 is a 19-item scale, where individuals are asked to answer questions based on how it best applies to them. Typical questions include "I look forward to each day". The choices that they are given are Often, Sometimes, Not Often, and Never. Questions 1, 2, 4, 6, 8, and 9 are all negatively worded and are scored between 0-3, the rest of the items are positively worded and are scored between 3-0.Cronbach's alpha for the CASP-19 range between 0.6-0.8, and the correlations between the 4 domains are between 0.4-0.7. The CASP-19 has been shown to be accurate in measuring individuals health and happiness (Kim et. al., 2015).

The Mini Mental State Examination (MMSE: Folstein et. al., 1975; see **Appendix M**). The mini mental state examination (MMSE) was designed as a way of grading cognitive decline in patients. It is an simple test to administer taking approximately seven to ten minutes to give a patient. It is a self-reported questionnaire, with the most marks being five for any given question and a maximum score total for the entire test being 30 points (Folstein et. al., 1975). The MMSE allows clinicians to follow a patients decline once the cut off scores have been established. The MMSE can indicate an array of disorders including but not limited to manic depressive disorder, schizophrenia, delirium and dementia (Folstein, Robins, & Helzer, 1983). The MMSE is used to measure immediate recall, short-term memory, calculation, language, orientation to time-and -place and also a patients constructive ability (Molloy et. al., 1991). The MMSE has been reported as being reliable and valid for use for measuring cognitive

decline in individuals, however due to the fact that it is a brief test and the interpretation of the scoring of answers provided are vast and subjective this can vary from clinician to clinician and therefore, could affect the results.

2.4.3 Neuroeducation Programme

This project used a neuroeducation based programme as the intervention. This approach was taken as there are limited research done in the area of neuroeducation and the impact that it potentially can have on those living with MCI. This programme was designed around the available research, and where it was thought that a neuroeducation programme would have the most benefit such as teaching people about MCI, what it is, and also ways of managing it. The consensus behind this was to focus more on giving participants living with MCI and their family members the tools that would help them in further understanding MCI as a whole, and also ways to potentially reduce the risk of it developing further into another form of dementia. The neuroeducation programme consisted of approximately 40-minute talks provided each week over a 4-week period, comparable to other studies (see Section 1.7). The intervention began in January 2021 and continued until beginning of March. As this was done in the middle of the global Covid-19 pandemic the programme was carried out online for all participants. Each talk was given through a voice-over power-point presentation (see section below on Covid-19 adjustments). Each week's presentation focused on one specific topic. The presentations also allowed time for the participants to reflect and consider how that week's topic affected them. For example, week three discussed exercise and diet, and participants were asked to consider if and how this was implemented within their current routine. These topics were carefully chosen and agreed through multiple interactions between members of the memory unit at TUH, the researcher, and also their supervisors. The topics included MCI and

what it actually means to have this neurological condition. MCI and its relation to AD and other types of Dementia, diet and exercise, and social integration and lifestyle choices. The final week consisted of a question and answer session where the researcher focused on if any of the education programme had been adopted into the participants lifestyle, and how the education programme had benefited the participants. More detail on each week's talk is provided below.

Week 1: In the first session the researcher introduced herself to participants. The contact information for both herself, and her supervisors were provided. Participants were provided with an initial overview of what they might expect throughout the neuroeducation programme, such as: the topics to be covered, the duration of the course, and how long approximately each session will last. It was explained to participants, that due to the fact that the programme was online, they could listen to the presentation in their own time and take breaks where needed. Participants are also encouraged to write down any questions that they had throughout the presentation, and these would be answered during the telephone conversation with the researcher later in that same week.

Following introductions and general information the topic of **MCI** was introduced. The researcher described different aspects of cognition (including memory issues, navigation issues, and concentration problems) , and how MCI may impact some of these areas. The researcher explained that not everyone with MCI will experience the same symptoms, and that it is also possible to prevent symptoms becoming worse. Potential causes for MCI were discussed, such as protein build up within an individual's brain, and structural changes that can occur. Participants were also shown simple diagrams of the brain, and the different areas that are potentially affected by MCI. The link between MCI and various types of Dementia were also discussed, but the researcher stressed that not all people that are diagnosed with MCI will

go on to develop dementia. The researcher emphasized that the percentages of those developing AD or other forms of dementia varied widely, indicating that very little is known about MCI and its progression into various forms of dementia. The researcher concluded the session by discussing ways in which symptoms could potentially be minimized such as word search puzzles, and regular daily exercise. Information was given about various different supports such as the Alzheimer's society of Ireland and family Carer's Ireland. To close the session the researcher explained that she would call every participant by the end of the week, and any questions that they thought off they should write them down, and they could be discussed at this point.

At the ending of the first week, the participants were contacted by telephone. This was to assess how they had found the information that had been discussed, and to identify any issues, or to answer any questions that they had. For this week, no questions were asked, but participants did give general feedback. The feedback stated that participants felt that they understood the condition MCI better now compared to when they were initially diagnosed with it, as they were scared and unsure of what that meant for them. At the end of the telephone conversations, the researcher explained that the slides for week two, would be sent off the following week, and at the end of that week another telephone call would take place. All participants were happy to continue with both the slides, and receiving the telephone calls.

Week 2: The researcher opened the session with a recap of what was discussed the previous week. Participants to have a pen and paper beside them, as this session would be more interactive than the previous week. Participants were asked to take a minute and to think about last week's session to see if anything resonated with them. If there were area's that they struggled with, or wanted more information on. The topics covered in week two were **Diet**, and

Exercise. For this, participants received information about the importance of eating healthy, reducing the consumption of red meat, reducing alcohol and cigarettes, are important for a healthy body and help aid in cognitive function (Scarmeas et. al., 2009; Singh et. al., 2014). The benefits of exercise was also discussed with them. Examples of what constitutes exercise was given (walking, swimming), with an emphasis placed on the fact that exercise should be enjoyable. Participants were also asked about their own hobbies, and what they found enjoyable prior to their diagnosis with MCI. Participants were asked to take a pen and paper to pause the presentation and to note things that they enjoy doing in the daily life. They were also asked to think about what obstacles they have encountered since being diagnosed with MCI in relation to their hobbies, and to mention these when the researcher telephoned them at the end of the week to discuss that week's topic. Participants were also asked to think about the diet they currently have, and if there was anything they could change. They were also asked to consider what prevented them from making these changes. The session was closed off by giving individuals the support information, thanking them for listening, and asking them if they had questions.. Furthermore, the researcher reminded participants that she would be contact them by telephone no later than Friday of that week to discuss they topic, and also go through any questions that might have arisen for them during that week's presentation.

At the end of the week, contact was made with each participant individually. No questions were asked at this point, but again participants identified that the slides were informative. The also mentioned that due to Covid-19 it was difficult to maintain any of their hobbies that they had enjoyed doing, but most of them had taken up walking. Participants were informed that week three would be sent out the following Monday, and that they would be contacted by telephone at the end of the following week to discuss the topic for that week.

Week 3: The researcher again opened the session with a re-cap of what was covered in the previous session. The researcher asked participants to take a minute and to think about what hobbies they currently enjoyed doing and to write them down. Participants were also asked to consider any groups that they may be involved in. The focus of this week's topic was about Lifestyle factors. The researcher opened this topic by discussing the negative impact that excessive drinking and smoking has, not only on the body, but on brain function as well. The researcher suggested different ways in which to aid memory and reduce day to day potential stresses for individuals. Some of the ways that were discussed between participants and they researcher were the benefits of word search puzzles and crosswords. These help to stimulate the brain (Pillai et. al., 2011; Eshkoor et. al., 2015). Participants were asked to consider potential barriers for lifestyle factors and what they themselves found they struggled with in this area. Finally, the researcher asked the participants if they had any questions. The researcher again closed the session by giving individuals the contact information of the Alzheimer's Society Ireland, and also the Family Carer's Ireland information. The researcher thanked participants for completing the session, and also informed them that she would be contacting them by telephone to discuss that week's topic and to help answer any questions that they had in relation to lifestyle factors, or anything that they had covered in the course to date.

At the end of the third week, contact was made with each participant individually. For this week, one HP and one MCI asked the researcher to discuss that topic from week two again which was the relationship between MCI and dementia. For the female with MCI, she did not fully understand what was happening in her brain, and identified that she felt fearful. The researcher went through this topic again, answering the questions that arose in relation to this, and at explaining the participants how important it is to discuss any and all changes with her clinician team. At the end of the call, the participant seemed less anxious, and explained that she understood, and would speak to her doctors the following week. All participants were told

that week four was their last week, and a phone call would be made at the end of that week, to discuss the neuroeducation programme in general, and to answer any questions that they had.

Week 4: This was the final week of the programme. In this session the researcher recapped on all topics covered so far. This session was designed slightly different to the others, as it was aimed at getting an overall feel for the course, gaging the participants opinions of the course, and also finding out what helped them and what they struggled with. Participants were asked a series of questions, these questions included but were not limited to "Did you take on any new hobbies during this period". Participants were asked to consider their answers. This session closed with a recap of the supports available for individuals with MCI such as the Alzheimer's Society, and the Family Carer's Ireland group. The researcher thanked the individual's for attending the four week course, and also told them that she would contact them by phone to by the end of the week to discuss the contents of the session, and to address any questions or issues that they had. The researcher also told participants that if at any point they had questions about anything that was covered to contact her, and she also reminded them, that the contact information for both herself, and her supervisors could be found on the information leaflet and consent forms.

The participants were contacted at the end of this week, and two requested that the previous weeks slides be sent to them again. The identified that the found the slides helpful both in the way that MCI was explained, and the information that was presented. The participants were told that if at any point in listening to the slides again they found they had questions to contact the researcher, and she would answer them. The participants were also asked if a follow up telephone call would be acceptable, and all volunteered to be contacted at any time.

2.4.4 Semi-Structured Interviews and Qualitative Approach.

A semi-structured interview was conducted with all participants following the neuroeducation programme. This was done on a one-to-one basis between the research and the participant and took place via telephone at a pre-agreed time. The aim of the interviews was to obtain feedback on the programme itself and to examine whether it was felt that the programme had been beneficial, both in terms of understanding MCI better as a condition and whether the participants were planning to make any lifestyle changes as a result of the programme. Several questions were specifically asked to address these aims, including:

- Did you find the programme helpful?
- How did you find the format and terminology of the programme?
- Did you try anything new in the last four weeks as a result of the programme? For example, did you try new hobbies, change your diet or increased exercise? What are the barriers that might have prevented you from making any lifestyle changes?
- Were their expectations of the programme met?

In addition, the interviews also explored how Covid-19 and the global pandemic had impacted each participant. To this end a number of questions were asked, including:

- How has Covid-19 impacted you?
- What do you find the hardest with the COVID-19 pandemic?
- How has Covid-19 impacted you in terms of mood, sleeping patterns or other aspects of your life?

Based on the same number of participants and the relationship that had been built between both the researcher and the participants, it was thought that a richer source of data could be collected if participants were given the ability to discuss their overall experience since receiving a diagnosis of MCI. This was demonstrated to be accurate, as it was clear from the results of the

semi structured interviews that participants were able to express their emotions to the researcher. The semi-structured interview that was conducted between the researcher and the participants allowed them to voice thoughts, feelings and emotions that the psychological and cognitive tests could not show. Therefore, it could be suggested that the semi structured interview, and the relationship that had been developed between both researcher and the participants, did in fact yield a more fruitful source of data, therefore making the project more ecologically valid. Finlay (2012) have argued that phenomenological research methods that are beneficial to both phenomenon and that of the subjective interconnection between both the researcher, and the participants that they are working with are paramount to understanding and creating a better understanding of the data that are collected and analysed.

2.5 Procedure

During participant recruitment, the researcher identified the following as inclusion criteria for this project; Inclusion Criteria were:

1. Participants were required to be over 40 with MCI or a family member of a person diagnosed with MCI (of any age).
2. Participants have normal or corrected vision and auditory abilities.
3. Participants agreed to participant in this study.

Exclusion criteria for this project were as follows; participants responded with Yes or No to each of the following:

1. History of drug or alcohol abuse.
2. History of acquired Brain Injury (ABI) or Traumatic Brain Injury (TBI).

3. History of psychiatric conditions.
4. Current diagnosis of depression and/or anxiety.
5. Motor function impairments.
6. Evidence of epilepsy.
7. Aphasia.
8. Evidence of heart conditions.

The battery of tests was as follows; the TMT (see **Appendix F**), MoCA (see **Appendix G**), CFQ (see **Appendix H**), HADS (see **Appendix I**), CIQ (see **Appendix J**), SWLS (see **Appendix K**), CASP-19 (see **Appendix L**) and MMSE (see **Appendix M**). Two weeks was allocated to allow for the packs to be delivered before contact was made again with the participants, the reason for this was that due to Covid-19 there had been a significant delay in post being received, and also to ensure that participants had sufficient time to read the paperwork that they received. Once the 14 days had passed, each participant was contacted individually, and a day and time was arranged which suited them for the battery of tests to be conducted via telephone. Participants were informed that the battery of tests should take approximately 45 minutes to do. These tests were done within the week. Participants were given instructions over the phone and answered the questions to the best of their ability based on these instructions. In addition, participants were informed as to how the programme would run over the coming weeks. The participants where asked what they hoped to gain from this programme, and the general consensus was that they needed to understand what this condition actually was, and how it would progress, and also what to expect. For those that had received the diagnosis of MCI (n=3), they really wanted to understand what was happening to them. For the family members who participated in the study (n=2), they wanted to learn how to be of help to their loved ones. The following week, the researcher sent Week 1 (see above), this was sent

using WeTransfer platform, and it was send to their email addresses. The file was sent on a Monday, and the researcher made arrangements with each participant to call them either on the Friday of that week, or the Monday of the following week. On average, the follow-up phone call lasted about 15 minutes. On completion of the four week intervention programme, the researcher contacted each participant on the fifth week, and arranged a time and day that suited them to complete the second battery of tests. This was done similarly to the first, with the only difference being the pack was not sent out this time. The researcher called out the questions, with the instructions attached, and the participant gave the response that was most accurate for them at the time. The interview began in February 2021 and were conducted over three months. It was not possible to conduct them within the week due to illnesses for some participants, and others who were working.

For the initial meeting, the researcher either met individuals in their own home, or via a telephone call (once lockdown was implemented). For participants that participated in the project by telephone a package was put together consisting of an Invitation Letter (**See Appendix C**), the Information Leaflet (**See Appendix D**), Consent form (**See Appendix E**), as well as a copy of the cognitive and psychological questionnaires that would be used. The consent form was then sent back to the researcher in a pre-paid stamped addressed envelope.

2.5.1 Changes in Procedure related to Covid-19 and adaptation of the programme

This project commenced prior to the outbreak of the Covid-19 pandemic. Initially this project was supposed to be done by recruiting participants via the memory clinic in TUH, and then meeting them one on one to administer the battery of tests. The project was then going to conduct four weeks of a neuroeducation programme, and this was due to be given in a group setting. However, due to the pandemic measures had to be taken to alter this project. The

researcher reapplied for an ethical amendment to both TUH and also Maynooth University to move the project from in person, to allow it to be conducted online, using the ability to record the participants where needed (see **Appendices A and B**). The researcher and her supervisors added a Covid-19 question once the pre and post psychological and cognitive battery of tests had been completed. Additionally it was decided to introduce the Interpretative phenomenological analysis (IPA) as a method in this project to analysis the information received from the questions relating to Covid-19.

2.6 Analysis

Data from the test batteries pre- and post-intervention were collated into Excel and SPSS. Descriptive statistics were calculated for all participants (family members and patients). Due to the fact that the current sample size was small, inferential statistics where not conducted.

An in-depth analysis of interview content was conducted using Interpretative Phenomenological Analysis (IPA). IPA was introduced by Smith and colleagues (1999), and it has become a common way to analyse qualitative data, in particular in areas such as counselling and health psychology (Hefferon, & Gil-Rodriguez, 2011; Smith, & Shinebourne, 2012). Here, IPA was used as a means to explore two questions: 1) **what impact did the neuroeducation programme have on the lives of the participants**, and 2) **how did the global pandemic impact upon them**. IPA is a phenomenological approach due to the fact it focuses on detailed look at an individual's environment based on their lived experience (Smith, 1999). IPA joins both empathic hermeneutics with questioning hermeneutics, meaning the researcher must be able to interpret the date from the participants perspective (Smith, Jarman, & Osborn, 1999; Smith, 2004). IPA allows for a deeper in-depth analysis of the data collected. IPA is conducted using a series of semi- structured interviews, where the researcher not only listens to what the

participant says, but also is aware of the participants mood, and their physical reaction to questions being asked. This style of research allows for the researcher to ask questions as the conversation unfolds, thus in turn allowing for more information to be used later in the project (see Table 2.1; Pietkiewicz, & Smith, 2014).

Table 2.1: 5 steps to conduct IPA analysis on a dataset.

Stage	Activity	Action
1	The Interview transcriptions	Coding is done here. Key words, statements, sentences, and quotes are identified at this stage
2	Themes are Identified	Researcher labels major and minor themes based on stage one.
3	Structuring the Analysis	Themes are clustered, and labelled by the researcher
4	Production of summary table of the themes	Quotes are taken from the interviews. Themes are eliminated if there is not enough evidence to support them.
5	Cohesive Argument	Narrative is created based on the above steps. Quotes from the interviews are used. This creates depth and richness

2.6.1 IPA Analysis

IPA was used as a means to explore **two questions**: 1) what impact did the neuroeducation programme have on the lives of the participants, and 2) how did the global pandemic impact upon them. It has been suggested that IPA is better for projects with a small sample sizes due to the fact that each participant is dealt with individually instead of collectively (Finlay, 2012; Smith et. al., 2012). On completion of the post-intervention cognitive and psychology batteries of tests, the participants were asked if they would be willing to do a small semi-structured interview which would be conducted via telephone. A suitable date and time were arranged with each participant. The researcher then recorded the interviews using a phone app, with the

permission of the participants. Interviews lasted between 40 to 60 minutes depending on how long each participant wanted to talk. The researcher started off by asking: “How has your life changed since the diagnosis with MCI occurred?”; this was intended as an opening ice-breaker question, and the responses were not subjected to IPA analysis. A question was asked in the latter stage of the interview about the impact of Covid-19 on their medical care, and if they had noticed any other changes since the pandemic began. These questions where chosen as the researcher believed them to be open-ended, and would allow for the participants to discuss other aspects of how their lives had been potentially affected by both the diagnosis of MCI and also the current pandemic.

The five steps for using IPA were then followed by the researcher in order to extract the emergent themes pertaining to the aims of the project. **Stage 1** consisted of the researcher **transcribing each interview**. The interviews lasted approximately 40 minutes, and the transcription of each interview took in the region of 6 hours. The process was key to allowing words or sentences that multiple participants mentioned to be extracted. For example, all five participants discussed family, and how it was important to each of them. Quotes were also identified here that could support this as being a potential theme. Once this stage was complete, the researcher then moved on to the **Stage 2**, which was where we attempted to **identify themes** within this process. These themes were **clustered**, where appropriate, into “superordinate” themes, as per **Stage 3**.

The researcher then moved on to **Stage 4,** wherein all information was then complied, and quotes were selected from each interview that supported the themes the researcher had identified. In this stage, **a summary table** of the themes was produced, and **quotes** were taken from the interviews. Themes that did not have sufficient evidence to support them were eliminated. **Stage 5** - **Cohesive Argument** - was then implemented, whereby a narrative was

created based on the above steps and specific quotes from the interviews were selected to support this narrative.

2.7 Ethical Considerations

Since this project consisted of working with people that were classed as being within a vulnerable population, ethical considerations were discussed. The researcher considered any and all biases that she may have been aware off, and for this project and identified that there were none. Participants safety and wellbeing were paramount during this project, not only due to Covid-19 but also because for some of the participants within this study they were cognitively impaired. Participants were encouraged to take breaks were needed and as often as they felt was necessary. Participants were also encouraged to contact the researcher at any point if they felt unsure about any of the information contained within the slides. Furthermore, the researcher made a point of keeping in regular contact with each participant, due to the fact that no physical meetings were allowed, this allowed for a rapport to be built and to allowed for open communication between the participants and the researcher. Participants were also encouraged to keep in regular contact with their clinician team, if they were worried about any of the questionnaires that were conducted within this study, of if any new symptoms presented for them.

Ethical approval for this project was sought from both Tallaght University Hospital (TUH), Joint Research Ethics Committee (JREC) and also the Maynooth Social Sciences Research Ethics Sub-Committee (SSREC) (See **Appendix A and B,** respectively). An initial application for ethics was made to both TUH and MU in February 2019, this was granted 6 months later. A subsequent application was made in March 2020 when the current pandemic led to the country being shut down, and the hospitals and all research ceased due to health and

safety risks for all involved. This project was moved online, and ethical approval was granted by both committees.

Chapter 3

Results

3.1 General Demographics

In total five participants took part in the study; this involved 3 patients with mild cognitive impairment (MCI) and two family members, who participated as the controls for this study. Of the 5 participants three were female, and two were male. Three participants had presented with MCI (2 female, one male) and had been diagnosed at least 12 months prior to the start of the study two participants were family members (one male, one female), and were related to the patients. Due to not having access to their medical records, it is unclear how long it had been since each participant had received their diagnosis of MCI; for all participants, a minimum of 12 months had elapsed since diagnosis. The average age for the patients was 69.66 [range: 67 to 74]. The two control participants were 78 and 34. Three of the participants (two with MCI and 1 FM) had attended a second level technical school. The additional two (1 with MCI and 1 FM) had attended third-level college. All participants were married and had children. For the three individuals with MCI, their families were all grown and did not reside with them. A granddaughter was living with one patient and his wife on a full-time basis. For HP2 her family were young, and she was caring for them as well as her mother who had MCI (see Table 3.1).

Table 3.1: Participant characteristics for MCI patients and their family members.

Code	Category	Gender	Age	Marital Status	Education level
MCI01	MCI	Female	74	Married	Some College
MCI02	MCI	Male	68	Married	Secondary School
MCI03	MCI	Female	67	Married	Secondary School
FM01	FM	Male	78	Married	Secondary School
FM02	FM	Female	34	Married	Some College

The researcher explored lifestyle factors with each of the participants. None of the participants were current smokers, of those that had MCI all three had been ex-smokers, but

had not smoked in ten years or more. Both FM were non-smokers and had never smoked. Furthermore, for the three participants with MCI, one was a non-drinker and had been for 20 years, one drank very occasionally, and one drank weekly. Both FMs stated that they drank occasionally. Of the five participants, four enjoyed exercise and partook in some form of exercise on a daily bases, only one did not. The exercises ranged from running, walking, and the gym, and also one participant who had MCI had also taken up word search puzzles. The frequency of how often the participants exercised was daily, and only one participant who had MCI did not exercise as she did not like to (see Table 3.2).

Table 3.2: Lifestyle Characteristics for MCI patients and their family members.

Code	Category	Gender	Smokes	Exercise	Exercise Type	Amount	Alcohol consumed?
MCI01	MCI	Female	No	Yes	Walking. Aqua aerobics	Daily	No
MCI02	MCI	Male	No	Yes	walking.	Outdoors daily with work	No
MCI03	MCI	Female	No	No	None	None	Yes
FM01	FM	Male	No	Yes	Running Walking	Daily	Yes
FM02	FM	Female	No	Yes	Gym walking	3 times weekly	Yes

3.2 Cognitive changes pre- and post-intervention

Each participant was given a series of cognitive tests before and immediately after the neuroeducation programme. The results for these can be found in Table 3.3 below and table 3.4. Note: only two participants took the Montreal Cognitive Assessment (MoCA), as it was difficult to complete this test on-line during Covid-19. The scores for the individual patients and the FMs are provided in Table 3.3. As there were only five participants, it was decided that inferential statical analyses were inappropriate. In general, the scores on the CFQ were slightly higher in the MCI cohort compared to healthy participants, but we note that for one healthy participant the score on this measure increased from 8 to 22 post-intervention – these unusually low scores cannot be easily explained. Scores for the MMSE were at their maximum (30/30) for the healthy participants but slightly lower for the MCI group (see Table 3.3).

Table 3.3: Cognitive tests conducted on participants pre-and-post intervention.

Code	**CFQ**		**MMSE**		**MoCA**	
	Pre	**Post**	**Pre**	**Post**	**Pre**	**Post**
MCI01	30	42	-	28	21	21
MCI02	21	23	28	25		
MCI03	35	35	26	28		
Mean (SEM)	28.6 (3.6)	33.3 (7.7)	27	27 (1.2)	-	-
FM01	33	33	-	30	21	30
FM02	8	22	30	30		
Mean (SEM)	**20.5 (10.2)**	**27.5 (4.5)**	**-**	**30**	**-**	**-**

3.3 Psychological changes pre- and post-intervention

Similarly, each participant was given a series of psychological tests pre- and post-intervention. These included the Community Integration Questionnaire (CIQ), the Hospital Anxiety and Depression Questionnaire (HADS), the Control, Autonomy, Self-Realisation and Pleasure Questionnaire (CASP-19), and the Satisfaction with Life Scale Questionnaire (SWLS). The scores for the individual patients and the FM participants are provided in Table 3.4. Again, as there are too few participants to analyse formally, only descriptive statistics are provided. In general, the scores for the MCI participants decreased across all measures (apart from the HADS-depression, which showed a slight increase) post-intervention. The scores for the FM participants remained stable.

Table 3.4: Psychological tests given pre- and post-intervention

Code	HADS Depression		HADS Anxiety		CIQ		CASP-19		SWLS	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
MCI01	6	6	7	6	17	17	42	35	24	21
MCI02	1	3	2	1	16	14	38	36	35	26
MCI03	10	13	7	7	17	11	38	25	31	26
Mean (SEM)	5.6 (2.6)	7.3 (2.9)	5.3 (1.6)	4.67 (1.85)	16.67 (0.33)	14 (1.7)	39.3 (1.3)	32 (3.5)	30 (3.2)	24.3 (1.6)
FM01	4	6	7	1	15	8	47	47	34	35
FM02	7	6	3	7	23	22	37	37	29	29
Mean (SEM)	5.5 (1.5)	6 -	5 (2)	4 (3)	19 (4)	15 (7)	42 (5)	42 (5)	31.5 (2.5)	32 (3)

3.4 Qualitative Analysis - Impact of the Neuroeducation Programme

The final week of the intervention consisted of a question-and-answer session. This section examined how participants felt about the neuroeducation programme, whether they felt it was

beneficial or not, and their expectations. Furthermore, the session attempted to explore whether any of the participants had implemented anything (e.g. lifestyle changes) that had been discussed during the four weeks of the programme, as well as obtaining general thoughts on the delivery of the programme, the topics covered, and the terminology used throughout the slides.

3.4.1 Expectations of the Programme

Additionally, the researcher asked the participants a question both pre- and post-intervention: "What do you hope to get out of this programme?" (Pre-intervention) and "Did this programme meet your expectations" (post-intervention). For the pre-intervention question, the participants mostly identified a need to *understand* the condition that they had been diagnosed with "I just want to know what it is, and what it means" said MCI03, another stated that "I want to help others if I can" MCI01. All five participants expressed the need to understand what having MCI meant for the participants living with the condition. In addition, the FMs wanted to understand the condition more, so they could help their loved ones if they needed to. Another area identified was that all five of them wanted to know what it meant for the *future*, and the researcher understood that there was a fear of the unknown for the progression of MCI. For the post question, again the general feedback of the intervention was positive and all participants said that they felt "they understood what MCI was" with one of the HP's saying "now I feel like I can support my mam better", one of the participants with MCI stated that "Now I think I understand what is going on inside my brain now".

3.4.2 Feedback on the Programme

Overall the feedback from the participants was positive. One participant reported that the language from the slides was "easy to understand" with another stating that "they helped me

and explained this mild cognitive thing". This suggested to the researcher that the wording of the slides had been successful and that the participants were able to relate to how the information on the slides was presented "*It was really good, I was actually able to understand what my mam had*". Of the five participants, all of them reported that the found the slides helpful. Furthermore, all participants had expressed that they felt very overwhelmed at the beginning, and clinicians had provided a lot of information to them, but they still found it hard to understand what a diagnosis of MCI actually meant. One non-patient participant expressed how she now felt better able to help her loved one, and that she had a better understanding of what MCI was since doing participating in the intervention: "I can help my mam better, I feel like I understand this a bit better"; another participant expressed that she did not feel uncertain now. The main consensus from participants was that they now understood MCI better, and the fact that they were allowed to process the information and could ask questions, resulted in their feeling better able to deal with the diagnosis of MCI. For family members, they felt better equipped at helping where needed, and had a better understanding of the condition overall. On further exploration of this question, they also stated that having regular contact with the researcher was extremely helpful to them. This underscored the value of the relationship between the participant and the researcher, as the researcher was able to gain a better understanding of living with MCI and helping a loved one with the condition.

3.4.3 Impact of Programme on Lifestyle

The intervention focused on a number of issues including social integration, lifestyle choices, diet and exercise; the researcher wanted to assess the impact of the programme on participants lifestyle choices. Of the five participants none of them joined a new *hobby*, but the intention was there. When asked if they had taken up a new hobby, two stated no, but had gotten a new crossword book, and word search puzzle book, both of these were participants who were living with MCI, the remaining three stated they hadn't taken up a new hobby, reasoning that they were active enough currently. When the researcher approached the topic of food, and their *diet*, all five stated the same, that they would eat relatively healthily and currently felt no need to approach their food intake differently. Furthermore, when the conversation came to *exercise* and what could possibly prevent them from engaging more than they do currently, one participant identified that it is a lack of confidence for her "I don't have confidence, and I don't like doing things alone", another participant stated that she "just doesn't like exercise and I find it boring". The last three participants were considerably active with one participant (HP) walking or running 10km daily, and the second HP exercising three to four times a week. Finally the researcher wanted to identify if participants or their family members had noticed any changes for them since the project began. Of the five, two both with MCI identified that they felt their memory issues had gotten progressively worse, and both their family members supported this. The last participant reported an improvement in his memory since the time the project began (see Table 3.5).

Table 3.5 Summary of the Questions and Answers from each participant regarding the impact of the neuroeducation programme.

Questions	MCI01	MCI02	MCI03	FM01	FM02
Did you find this helpful?	Yes	Yes	Yes	Yes	Yes
How was the terminology?	Easy to understand and informative.	It was good. It was easy	It helped me and explained this Mild Cognitive thing	I could follow it.	It was really good, I was actually able to understand what my mam had
Did you try anything new in the last four weeks?	No, not yet, but I have signed up for an exercise class.	No no, but I have signed up to do classes twice a week now	No, not really, but I do go walking a little more	No, I am active enough and I have work too	No, I have no time between mam, work and my own kids
Did you try new hobbies?	No, I used to crochet but I don't now. I did do the word search puzzles	No, not yet, but maybe	No, but I got a crossword book	No.	No, I didn't
What prevents you from changing your diet?	No point, I eat good now.	No, I eat good, I don't have a sweet tooth	No, but I eat my three meals a day	No we would eat healthily	No, but I don't feel the need to
What prevents you from joining a new group?	Lack of confidence	I don't know really	I don't like groups	Lack of time	Time
What stops you from exercise?	I don't like doing things alone, and Covid-19	I get out a lot with work	It's boring	I exercise every day	I exercise as much as I can
Have your family noticed a change since doing this project?	Yea, my concentration and memory were worse, and my mood was very down and depressed	Eh no. not really, cause like nothing has changed	Yes I think so, they said my mood is lower	Yea with MCI01 I have, her memory and her mood	Yea with my mam (MCI03) I have her memory is worse

3.4.4 Qualitative IPA analysis of the Impact of the Programme

An IPA analysis was conducted on the above table to extract common themes that emerged between all participants involved. While there are five stages involved in doing IPA (see Table

2.1), only four of these were followed here due to not having access to interviews to transcribe. Therefore the analysis was based upon the contents of Table 3.5, which allowed common themes to be extracted. The following themes were identified. One of the questions probed whether participants had taken up any new activities. Out of the five participants, three identified that they planned to start a new hobby, with one saying she would go back to crochet again. This theme was labelled as **Intention.** Only two participants stated they had not considered any new activities; one said that this was due to the fact that he was already quite active, and the second due to her hating exercise of any kind. Both of these views also were identified in the second IPA analysis that was conducted during this study in relation to the pandemic.

A second theme was identified which was labelled **Lack of time/confidence**. This theme connected with the above one of Intention as participants were asked why they had not joined any new groups or clubs up to that point. Having the confidence to attend activities was a problem for participants. For those with MCI, there was the lack of confidence in relation to being around other individuals who would not understand or know how to empathise with them. The lack of time was identified for some of the participants that were still working, and for one who was working and had a small family, as well as caring for her mother who was living with MCI.

Another theme that emerged was that of **Understanding.** All five participants identified that the terminology in the programme was easy to understand and the slides were easy to follow, and one participant who was a FM stated that she was able to understand what her mother had, and felt that she could help her better. Other participants had talked about how, on leaving the hospital after getting their diagnosis they had questions, and sometimes didn't fully understand what MCI meant for them and their family, and now they had slides that they could access,

which were both easy to understand and informative. This suggests that using simpler language and keeping the slides positive had a positive effect for all those involved in the project.

3.5 Impact of Covid-19 on Participant Experience of MCI.

A further aim of the study was to explore the impact that the pandemic was having on the participants within this project, and also how the pandemic itself had affected them living with MCI, both as a patient and as a caregiver. To achieve this, a number of questions were asked during a semi-structured interview including (i) how has Covid-19 impacted you? (ii) what do you find the hardest with the COVID-19 pandemic? and (iii) how has Covid-19 impacted you in terms of mood, sleeping patterns or other aspects of your life? Using IPA, a thorough analysis was performed on the date collected from these semi-structured interviews. This was done manually and no other computer-based programmes where used. The interviews were recorded, and then transcribed by the researcher (**Stage 1**). Only this was completed, they were read and assessed for any common themes between the five interviews (**Stage 2**).

It quickly became apparent that significant overlaps were present in some of the themes, such as *anger, frustration, disappointment*. The themes that were not shared by all five participants were thought to be minor themes within the IPA analysis; these were *anger and confinement*, *frustration*. These were **clustered** into a superordinate theme, as per **Stage 3**, and were labelled as "negative emotions" due to the similarities between them, and also the fact that for some of these themes tone of voice, or the way in which the participant expressed themselves, aided the researcher in identifying if this was irritation, frustration or anger. For example, if participants expressed an unhappiness with everything being closed due to Covid-19 restrictions, but tone of voice determined if this was anger or frustration, and for two

participants, it was evident that one was angry about this disruption to her life, and one was mildly irritated/frustrated because of it.

The following four were identified as reoccurring themes, these were as follows: family, negative emotions, anxiety, acceptance and resilience.

3.5.1 Family

The theme of **family** presented itself in four out of five of the interviews that the researcher conducted. When the researcher spoke to each participant individually about how their lives had changed since learning of MCI or how the impact of COVID-19 had on them, this theme emerged quickly. The participants discussed that Covid-19 had impacted them significantly especially in relation with their ability of seeing their loved ones or to spend time with them. One participant stated that "*I miss being able to go to Kerry and Waterford to spend time with my family, and my grandchildren*". Another stated "*I am so lucky to have my daughter and my family, I would be honestly lost without them*". A male participant said not seeing his family did not impact him so much, however he did state "*my granddaughter lives with us so we are happy with that*". When it came to looking at how the diagnosis of MCI had affected them, one participant expressed how she felt in relation to this news on her family "*I don't know what this means for me with my family, or how things will change for me",* while another had expressed that the idea of being a burden to her family troubled her "*I have this thing in my brain, and I don't want to be relying on my family…. I don't want to be a burden".* The fact that family emerged as such as strong theme throughout this stage of the project suggests that family was a core factor for majority of the participants within this study, and also that the loss of this contact with family members due to Covid-19 was felt substantially. Additionally when it came to MCI and what it meant for the future, family was still a common factor, even though

it was coupled by fear and uncertainty. One participant, who was used to travelling to Kerry and Waterford to see her two of her children who did not live close to her, and she would spend a few weeks at a time with them, and also her grandchildren. She spoke very fondly of her family and her time away with them. However, Covid-19 prevented her from being able to travel to see them "*I couldn't see my family, I miss my grandchildren, and helping where I could we talk on the video thing, but it's not the same, you know, but it's not the same*". For one of the FMs, even though family didn't come out as strongly for him he did notice a change in his wife not being able to see their children and grandchildren "*Covid-19 didn't really affect me because of my work, but not seeing the family and grandchildren, now that, that really affected herself*". Another participant in the study had a daughter living in the UK who had a baby close to the beginning of the pandemic. Not being able to have her daughter come home had an effect on her, and she mentioned this numerous times throughout the conversations that were had between the researcher and herself. Family for her was also a support system as she had been very sick throughout the pandemic and had been hospitalised also "*I really know how lucky I am to have my family, they are so supportive even after all this mild cognitive thing and me not being able to do my own things*". Additionally, another participant who was part of the FM participant group, identified how important family was for her, she herself has a young family, and also helps her mother where and when she can "*mam is only around the corner from me, so Covid-19 made it hard, the kids missed being able to see her, but I couldn't risk it for her*" and also discussed how they help each other out where needed "*we are a close family, plus she is my mam, I'll help where I can I just want her to be okay you know*". The emergence of the family theme was strong for both all participants. The lack of family contact for both groups seemed to have impacted them more negatively with some feeling it in their moods with one participant identifying how she noticed changes in her mother *"I noticed she seemed more depressed with all this Covid-19 stuff*" and also the loss of support reported by more than one

participant "*I missed seeing them*". During the course of the interviews the researcher began to notice the emergence of the second theme which was identified as Anger and Resentment.

3.5.2 Negative Emotions

The second theme that was identified was **negative emotions**. This theme was a more difficult one, it was not present in all five participants, and covered a mixture of emotions including anger, resentment, frustration, worry and confinement. It was coined as negative emotions as some of the quotes that are used encompass all of these, however, the tones in which they were said were different, and the way in which these emotions presented were not the same for all participants. These negative emotions were demonstrated considerably early within the interview process and when they were shown by the participants they were deemed by the researcher to be extremely strong based on the way in which the participant talked. For example, one participant who was a control within the study, discussed continuously about how she was worried about her mother and her fears in relation to her mother having obtained a diagnosis of MCI and also the current pandemic and how that had impacted both herself and her mother. "*I am worried about her and what she does. I was glad for Covid-19, because she couldn't go out*", this participant was not only worried about her mother wanting to go out during the pandemic, but also about some behavioural changes that she had noticed, including excessive spending and the consumption of alcohol. Unfortunately, at times it was difficult to separate this participants anger towards Covid-19 and towards her mother. The researcher concluded that these were both linked for this participant and it came across extremely prominent throughout her interview "*I am pi**ed off, she doesn't listen, I have a life and a family too".* Another participant repeatedly stated that she was anger that "*everything is closed, and I can't go out when I want to*". The fact that people were confined indoors, and were cut

off from family and friends defiantly seemed to have come out in the forms of anger and resentment for these participants, especially in the initial stages of the pandemic.

One participant who was very forthcoming in relation to other health issues that she suffered with during Covid-19 stated that "*I was glad that I was sick during the pandemic, cause I couldn't go anywhere so it was ok kinda*". This was identified at the beginning of this project, however over time the researcher noticed how this participant was beginning to resent not being able to go where she wanted to, again it was difficult to separate this from the actual pandemic and her living with MCI "*I hate having to rely on everyone, I feel like a burden*". The researcher had to look at things as a whole and identified that for some participants Covid-19 only amplified their feelings in some areas. The main area for this participant that resulted in her anger and resentment was her inability to drive since being diagnosed with epilepsy, she was extremely resentful towards this, so when Covid-19 began, her health began to improve towards the latter stages of the pandemic, and her anger and irritation was then directed towards her diagnosis and also what she felt like she had lost because of Covid-19 "I *just wish things would go back to normal, but I do still get out for my shopping… but I want to go myself".* When this was said the participant's tone was agitated and unhappy. It also appeared to be the loss of her independence that was mostly responsible for her anger and resentment, not just the pandemic. This participant also mentioned numerous times that "*Cause I can't drive places being shut, and this whole Covid-19 thing didn't affect me too much, you know*", however this did change later with her saying "*I wish places would open and things could go back to normal, you know*". For her daughter, who was one of the controls within the project she revealed that some of her stress lessened at the beginning of the pandemic as her mother was confined and couldn't travel so she wasn't afraid of her mother contracting Covid-19 "*she couldn't drive, I didn't have to worry about where she was and who she was with, Covid-19 meant that she wasn't getting others to bring her places*".

For another participant the anger was present, but only slightly, and more in relation to the lack of physical contact with her family "*I feel stuck, and I don't like it I want to be able to do what I was doing and go see my family, you know what that's like*". Hospital care was also affected by the pandemic and this is something that two of the participants did experience. It also seemed to create a lot of anger especially for one of the control participants. Her mother had spent a long period during the pandemic in hospital "*the hospital was a nightmare when mam was in….we couldn't see her, or drop stuff up to her… we couldn't get her GP on the phone… I think she would have recovered quicker if she had of been allowed see people*". For individuals living with MCI and also their family members, the pandemic was an emotional time. With restricted access to medical personal and hospitals, inability to see their loved ones who were in a hospital dealing with unrelated Covid-19 problems, and also not being able to see their loved ones when they wanted to, created a lot of anger and resentment among the participants. This was not only evident in the examples that have been shown here, but it also came across in their tones during the interview with the researcher. The researcher was able to tap into this due to the fact she had built up a strong and stable rapport with each participant within the study. In some ways this theme had a mixed reaction for the participants who identified anger and resentment in their interviews, it was both a negative and a positive thing, and in some occasions it was difficult to separate the anger and resentment in relation to MCI that some of the participants were living with and their loved ones, and also the pandemic that the world was facing. The researcher also was able to identify that another theme was also mixed up with anger and resentment, and this was Frustration.

One participant who had mentioned her inability to drive said that later on in the pandemic she began to start " *I want to go places, but they are closed, and I can't… I like to go out, you know*". Another participant identified that she found the pandemic and that she just felt frustrated and irriated with the entire situation. There was an expression of helplessness

during this interview and uncertainty with when or if things with ever return to normal for her and her family"*…it's so frustrating, I can't travel and see my grandchildren*" "*You know I went to see my grandchildren whenever I could, I just wish things would go back to normal"*, another participant stated that his life had not been affected by Covid-19 but he did express a sense of helplessness and sympathy for his wife who couldn't see their grandchildren when she wanted, and he had stated that he knew that the pandemic was difficult for her "*frustrated for my wife cause she can't go away like she does, the grandchildren make her happy*", so even though frustration did not impact him directly it was still apparent that he experienced it. Furthermore, one of the participants who was part of the healthy participants group did identify that she felt very frustrated with not only the pandemic but also her mother's diagnosis with MCI "*she drinks a lot, her memory is worse… I'm frustrated with her and everything, why should I bother*". While the question was in relation to Covid-19, this seems to be entwined with other issues for one of the participants, it is evident in how she talked, and in the way she stated things. Based on the fact that Covid-19 had begun fairly near to the beginning of this project, the researcher had been in constant contact with the participants, so during this project the participants were extremely open with her, and she had adapted to understand not only what they said but also in relation to the way it was said. For one health control participant in this project, her frustration was very evident she would continually say phrases such as "*why do I bother*" "*why am I trying if she isn't*", her inability to be allowed in to see her mother while she was seriously ill in hospital during Covid-19, had also caused a lot of issues for this participant, and she had voiced this during the course of this project. Also her mother's behavioural changes had also been a cause for not just anger but also frustration for this participant "*I am just so so fed up, like why?*". Additionally for her mother who was also a participant in this project, she also appeared to be just as frustrated with the entire situation and had identified at various times how "*I hate asking them to bring me places*", and she was also

frustrated that her husband had called her lazy and had told her to "*just do things herself*", also a loss of independence had created its own level of frustration for this participant "*I just want to bring myself places, I miss driving*". The frustration is clear in not only what she says but also her voice. She is clearly frustrated about the pandemic, but also in relation to her mother's behaviour i.e. "*she drinks so much, like three or four bottles a night, and her memory is so much worse, why do I bother*". Covid-19 seems to have amplified underlying issues for some participants. This theme could also be linked to anger and resentment, as it also seems to link to some of the previous statements. For other participants, there seems to be a level of frustration in relation to them being confined and stuck in their homes, this led to the theme confinement being identified as a factor.

Participants discussed how the travel restrictions, lack of physical contact with family, and places being closed impacted them. One participant identified how she "*felt stuck, I couldn't go where I wanted to"* while another stated *"I felt stuck, it wasn't nice, and it was scary for everyone"*. Another discuss how "*it's the hardest thing, you know being stuck at home all the time*". Throughout their interviews this theme was reiterated repeatedly, with the participants identifying that the did not like the restrictions of being confined to their homes. Also for this theme, it seemed to be strongly connected to the family theme, based on the fact of the participants where frustration was identified there was evidence of it also being around the inability for participants to see their families "*it's the hardest thing, being stuck at home, and not seeing my family, it's frustrating*". For one participant this seemed to cause her a lot of distress and it appeared that this was something she was really struggling with feeling confined at home and her inability to go to Kerry and Waterford where some of her family are. Another participant identified that confinement seemed to have a negative impact on participants and left them feeling confined to their residence with little physical contact with friends and family. While this theme was not present in all participants, it presented strongly in the participants

who have experienced that feeling of confinement and being trapped, and in some cases affected symptoms and moods of participants "*I didn't like being stuck at home, I felt sad*" and another participant identified that she "*felt my memory get worse, and I know have this Alzheimer's thing*". With people being at home it does seem to have amplified a lot of how they were felt potentially making symptoms of MCI more pronounced such as memory impairments. Due to the way that the confinement theme was discussed by the participants, it became clear that anxiety was also a factor for these individuals. Therefore the researcher identified anxiety as being a theme in this analysis.

3.5.3 Anxiety

A further theme that was identified within this interview process was **anxiety.** This was present in three out of the five of participants. It was also a theme that emerged quickly, and came from talking things out with the researcher. One way the researcher was able to explore if anxiety was present for any of the participants, was with a question in relation to the mood of each participant during the pandemic. One participants was able to identify that she felt significantly anxious when it came to doing anything out doors currently "*I have Covid-19 anxiety… I don't like going out…. When friends ask I don't want to go anymore*". From talking to this participant, it was apparent that she enjoyed her trips with her friends prior to Covid-19, and had stated that even if money was tight she would also find it. She also iterated that "*I was always afraid of not going in case I missed something*". This participant had been affected negatively in this regard with Covid-19 and also in relation to her mother's health "*I am afraid of being around her sometimes in case she gets Covid-19*" Two other participants identified that for them their mood "felt different", with one saying " *I feel anxious sometimes, but I eh I don't know why*", another said that sometimes her mood "Felt different*, I kinda feel like maybe I'm a bit more*

anxious that I was, even to describe it to you I couldn't, but like normally I am happy go lucky, and I find I'm more anxious now, I find it hard to relax".

For these individuals they could identify that something was wrong but there were uncertain as to why, or in what way. Participants did state that they did think this was due to Covid-19, and two who are living with MCI also identified that their memory issues had progressively got worse, with one also explaining that "…*I don't think this is just Covid-19, I think I am getting worse with this em Alzheimer's so em I'm conscious of it like you know*". This participant did not have AD, and was not diagnosed with AD since the start of this project, she did, however, report to the researcher on multiple occasions throughout the course of this project that she felt her memory issues were getting worse, and when she said it there was an element of fear and uncertainty in her voice. It is worth mentioning that for one participant, even though she identified that she was experiencing Covid-19 anxiety, she also was able to see this as a positive thing, she repeatedly stated throughout the interview how Covid-19 taught her to be able to say no to her friends, when prior to Covid-19, she could not do this "*I have learned to say no",* and she also identified another positive, which was her ability to save money. Furthermore, one of the participants did identify how on some days "*I found it hard to get out of bed, I didn't want to, but I was sick too, it was a scary time for everyone*". It is unclear whether she just didn't have the strength to get out of bed due to being sick, was experiencing low mood, or was feeling anxious on these days. However, the researcher concluded that based on pervious conversations, and tone of voice, that potentially this was partially about her being sick, and also about her experiencing anxiety-like symptoms due to the global pandemic. For this participant, anxiety was present at the beginning of the pandemic, but towards the later stages, she seems to have transitioned into acceptance about the situation. What does need to be mentioned is that of the participants that identified that they had experienced anxiety or "Covid-19 anxiety" this was not evident in the psychological tests that they underwent, even

though three out of five of the participants did identify feel anxious. The fact that all five participants have since learned to accept what is happening with the current global pandemic led to the researcher it helped to identify the fifth theme which was acceptance and resilience.

3.5.4 Acceptance and Resilience

Another theme that emerged was **Acceptance and Resilience.** This theme was present in all five participants, and presented in different ways. The participants seemed to all be at a stage where they were resigned and accepting to the global pandemic, and this also seemed to transfer over to MCI for those that were living with the condition. One participant stated that "*most of the time I can't control it, so I just let it go, I am trying to live by that",* another participants said that "*if I can't control it, I try and accept it".* For participants that had continued to work unaffected by Covid-19 they seemed to have accepted the changes with the pandemic easier. One participant said "*It didn't affect me, I was still working outdoors, so I didn't notice any difference at all*". Additionally one participants said "*I was still able to go for his run and his walk during the pandemic as well as work, so it hadn't affected me*" With another participant also stating similar "Nope, I eh, I still went to work every day, so I just tried to make the most of the situation". One participant who stated that Covid-19 was good for her in some ways as "I was really sick during Covid-19, and if not for being sick I think the pandemic would have been worse for me" she support this by saying if she had not have been sick, places being closed, and an inability to go where she wanted to would have impacted her more substantially, but due to various illness that she experienced, this was not a factor for her. For another participant after having a lengthy discussion with the researcher she identified that she had accepted Covid-19 and it was good for her " *I learned to say no, I didn't feel a need to go everywhere*" this participant stated multiple times, that even in financially difficult times, she

would find money to go places, but now "*I don't feel I have to do that now, I have actually saved money so Covid-19 has been positive in some ways*". Covid-19 does seem to have a positive benefits in some respects in some ways for people, it is possible that for those that have learned to accept it, have learned to see the positives in the situations that they have been faced with, therefore making it easier for them to have a more positive outlook on the global pandemic.

3.5.5 Coherent Argument

After conducting a quantitative analysis using IPA guidelines on the data that was collected, **four themes** were identified that were strongly present in the set of interviews that were conducted. These were **Family, Negative Emotions, Anxiety, Resilience and Acceptance** (see Table 3.6 for a summary). While these themes were not present in all participants at any one time, there were present in over half, and most of these themes were present in at least two of the three MCI participants. For two participants in particular anger and frustration were considerably strong in their interviews. However as noted, at some parts of the interviews it was difficult to separate some of the themes from living with MCI and the global pandemic that the world has faced since March 2020. In some cases, the themes seemed to lead into each other, such as confinement and the inability to see family, throughout both of these themes the participants identified that their confinement meant they could not see their loved ones, and vice versa. Furthermore, anger and frustration seemed to be quite closely linked for the participants that experienced it with them being able to identify that they were feeling frustrated by the situation but expressing their anger in different ways including tone. It is worth noting that for two participants, both male, one with MCI, and one FM, their routines had both stayed consistent during the pandemic and had continued to work, and live their lives the way they

had prior to the pandemic. For both of these males, they were the least to express either anger, resentment or frustration. In fact, from the beginning they seemed to be more accepting towards the Covid-19 was now a factor of life, and they seemed to be able to process the changes easier than the other three participants in the study. For one of the females in the study her main themes were family, and anxiety, but the inability to see her loved ones seemed to have a profound negative impact at her and she repeatedly stated this through the conversations with the researcher, with her husband supporting the fact that he had observed mood changes with her since Covid-19 began. For the latter stages of this project, this participant did seem to experience less frustration with the current situation and she had begun to go walking more, and once the lockdown had eased she had been able to see her family, resulting in her being able to accept the current situation with the pandemic.

Each participant discussed the pandemic in detail in the ways that they had been impacted by the global pandemic, for one participant who was female and a FM, her hours had been reduced in work, and she had been able to identify that Covid-19 had caused her to experience Covid-19 anxiety. She was fearful of passing it on to her mother, and had identified that she did not like going out now. What is evident that Covid-19 has had both positive and negative impacts on each participant, with each being able to identify this for themselves. It is clear that regardless Covid-19 has had an impact on each participant that was involved in this study.

Overall, it appears that the presence of the global Covid-19 pandemic exacerbated the range of negative emotions associated with a diagnosis of MCI – these included fear, confinement, anger and frustration; an increase in anxiety was also reported. However, these negative effects were offset by the support and comfort provided by family, which in turn led to feelings of resilience and eventual acceptance of the situation.

Table 3.6: Summary of Covid-19 Questions and Themes.

Themes	MCI01	MCI02	MCI03	HP01	HP02
Family	Grandkids "Travel to see my family, I can't"	"Grand-daughter lives with me so I am ok with family cause she is with us"	"I would be lost without my family and my friends"	"My wife misses going to see the grandkids,"	"She has a good family around her"
Negative Emotions (Frustration)	"I felt trapped, I couldn't see my family,		"I couldn't go out when I wanted"		"I am just so frustrated"
Negative Emotions (Anger/Resentment/Fear)					"I do absolutely everything, and I have my own family to worry about"
Negative Emotions (Confinement/restricted)	"I can't move"				I didn't like not being able to go out at the beginning
Anxiety	"I feel different, I don't want to go out, I guess you could call it anxiety"				"I feel anxious in large groups now" "I've Covid-19 anxiety, but I am getting a little better now"
Acceptance/Resilience	"I just have to accept it and move on"	"I've just tried to make the most of the situation"	"I think if I had of been driving Covid-19 would have affected me more"	"I was working like normal, it didn't impact me"	"In some ways Covid-19 helped, cause she has to stay home"

Chapter 4

Discussion

The current thesis had a number of different aims. The first was to pilot the effects of a 4-week neuroeducation programme in small sample of patients living with MCI and their family. Through semi-structured interviews we wanted to examine the impact of the programme in terms of whether both patients and FMs felt that their knowledge of the condition increased and whether the programme benefited them in the self-management of the condition. Second, given the prevalence of psychological issues (including depression, stress and anxiety) for individuals living with MCI and their family members, as well as changes in cognition, we wanted to assess whether the programme might be beneficial for these processes by using well-established psychological and cognitive measures. Finally, using semi-structured interviews, we wanted to explore how Covid-19 had affected the lives of both those living with MCI and their family.

4.1 Piloting the effects of a neuroeducation programme

The first aim of the thesis explored the effects of a 4 week programme on individuals with MCI and their FMs. Overall results from this were positive. At the beginning participants had identified a fear of the unknown, and had expressed their desire of wanting to understand their disorder more, what it entailed, and how it could potentially affect them. Participants identified that some terminology used within a clinical setting was confusing and often scared them. Following the programme, participants were asked a series of questions concerning the programme itself. They were asked to consider the wording in the slides, and how they found the explanation of MCI, and various other factors. All participants said that they found the slides easy to understand. They liked the fact that they could easily access the slides, and re-read them if they found they had forgotten something, or needed to re-listen to them again. For this project, it was important to keep the language of the slides simple and straightforward, and

to focus on the more positive aspects of living with a condition like MCI. Literature suggests that individuals who are more positive and optimistic show a significant reduction in depressive, anxiety and stress symptoms than those who have a more pessimistic outlook (Robinson-Whelen et. al., 1997; Giltay et. al., 2006). In this respect, all five participants identified this programme as being helpful in relieving some of the fear they had felt around MCI, and said it aided in their understanding of this neurological condition.

The programme also focused on diet, lifestyle factors such as exercise, and social integration. The reasoning behind including these factors into this intervention was based on the literature that suggests that a healthy diet, regular exercise, a reduction in smoking and drinking, and also potentially taking up a new hobby can all aid in the improvement of cognitive functions (Kalmijn et. al., 2002; Tao et. al., 2019; Klimova et. al., 2020). This is particularly important for individuals with MCI, where there is a notable decline in capacities such as memory retention, attention, language comprehension among others. For example, Singh et al. (2014) suggests that high adherence to the Mediterranean Diet (MeDI), which is a diet that encourages the higher intake of vegetables, fish, fruits, cereals and unsaturated fatty acids, has shown to have a positive impact on MCI groups and for non-clinical individuals; it could also potentially decrease the risk of developing MCI later in life. Participants in our study identified that for the most part they followed a healthy eating plan - having three meals a day which included vegetables, carbohydrates, and a form of protein or fish. The majority of the participants identified that they were happy with their current diet, and did not want to change. None of the participants involved in the study smoked, but all were ex-smokers, and had not smoked in ten years or more. Furthermore, of the five participants, four drank socially and only one drank on a more regular basis. Overall, all participants reported having not changed their eating habits during this project. When asked why, they reported that their eating habits were healthy enough for them to be happy with them.

This study also examined lifestyle factors such as exercise. Participants within this project, irrespective of their diagnosis, were all considerably active. Of the five MCI participants, only one did not exercise regularly prior to beginning this project. This participant (who had MCI) had discussed on numerous occasions that she found exercise boring and did not like doing it alone. Of the other participants, one male (MCI), had an active job, but did not do any additional exercise. The other three participants, one (MCI) walked daily regardless of the weather, one went to the gym regularly, and the other either ran or walked seven days a week. On completion of the intervention, the three MCI participants stated that they were all doing more exercise, with two having joined a gym for people with cognitive impairment, set up by Tallaght University Hospital. One patient suggested that he felt that his memory had improved since beginning the programme, and another MCI participant said that her and her family members had mostly noticed an improvement in her mood. This supports the current literature suggesting that exercise can have benefits on cognitive function and also depressive and anxiety symptoms (Dillon et. al., 2018; Klimova et. al., 2020). Indeed, Klainin-Yobas (2019) recently argued that education-based health programmes paired with other types of programmes, such as mindfulness, can have a significant effect on reducing anxiety and depressive moods, benefiting both an older adult population and those living with MCI. Other studies suggest that exercising as little as three times per week for a minimum of 15 mins at a time can improve cognitive function overall, aids in better sleep patterns, and also improves mood (Voss et. al., 2010; Devenney et. al., 2017; Demurtas et. al., 2010).

Of the five MCI participants, none took up a new hobby, but the intention to do so was there. It is important to note that that the world was in the midst of a global pandemic where many services were shut down. Some of the participants over the course of this project had discussed that they would consider joining a club, and missed some of their normal social activities, and if not for Covid-19 they would consider restarting them. At the time of

completion of this project, the pandemic restrictions were still in place, and also time limits did not permit a follow-up of this to see if participants had re-joined their previous hobbies, or in fact joined new ones.

4.2 Impact on Psychological and Cognitive Measures

Previous studies have shown changes in attention and memory following an intervention, with some reporting on MCI patients that have returned to normal cognitive function (Alescio-Lautier et al., 2019). For example, Alescio-Lautier and colleagues (2019) used an intervention that was conducted for 90-120 minutes every two weeks and found improvements in verbal fluency and semantic tests. However, improvements in cognitive function for individuals with MCI vary substantially, depending on the type of intervention. For example, interventions that include exercise show cognitive improvements (see Teixeira et al., 2012; Demurtas et. al., 2020), other studies which looked at memory rehabilitation showed no improvement for cognitive function adults with MCI (Stott & Spector 2011). Furthermore, research has suggested that the some cognitive measures (e.g. the MMSE) have extremely poor sensitivity and using this test for people with cognitive deficits will not give a true account of those deficits (Olson et. al., 2011). Given the low numbers of participants in our study we did not conduct any statistical analysis but in general we found minimal impact. In addition, for this project it was not clear which type of MCI with each individual had been diagnosed. For example, not all people with MCI experience the same symptoms; some people will not experience issues with memory, but may show difficulties with other cognitive functions. This depends on the type of MCI that a person has been diagnosed with (e.g. amnestic MCI (aMCI) or not), and also if it is single domain (which might affect memory only) or multiple domain MCI (which is memory plus another cognitive function deficit such as impairments in executive function

(Panza et. al., 2010). It is important to note, however, that the studies mentioned above were not identical to the four-week neuroeducation programme that was attempted here, and many of them were implemented for longer periods or at greater intensity (i.e. multiple sessions per week).

Of the psychological tests conducted within this project, only one showed signs of a slight change, which was the Community Integration Questionnaire. This test explored the well-being of the individual within their community, their lifestyle, and also how independent they are (Willer, Ottenbacher, & Coad, 1994) The participants within this study were all community-dwelling residents. Finding that the scores on the CIQ decreased following the programme is not supportive of current literature that suggests that people with MCI are capable of living a normal independent lifestyle within their communities, and are still capable of maintaining their hobbies, family commitments, and jobs should they choose to (Larrieu et. al., 2002). The CIQ scores were higher prior to the intervention and showed that they decreased after participants completed the neuroeducation programme, this indicates that the participants were not as integrated within their community as research suggests they should be. While this finding is surprising, this could potentially be attributed to the global pandemic Covid-19, and how the pandemic impacted on people and their social integration. Based on current guidelines, people have been unable to interact with their families and their peers; it is therefore, highly likely that this is reflected by our results. However, more research would need to be carried out to examine and validate this, especially as the CIQ is a reliable and valid test for use with an older population.

Currently, research indicates that people who are living with MCI are more likely to experience depressive moods, and anxiety-like symptoms compared to healthy normal individuals (Lee, & Lyketsos, 2003; Fiske, Wetherell, & Gatz, 2009; Santabárbara et. al., 2020). Furthermore, caregivers and family members are also more susceptible to experiencing

higher levels of stress, which in turn leaves them at increased risk of developing depression, anxiety or other conditions (Brodaty, & Donkin, 2009; Camak, 2015). However, we did not find any changes in scores on the HADS post-intervention, experienced by either family members or those that are living with MCI. We note that the mean scores pre- and post-intervention on the HADs were within the normal range. While the HADs is widely used, Djukanovic (2017) argued that the measure is not sufficient, and Snaith (2003) argues that this test should only be used in a hospital setting and given by experienced clinicians. This project was not conducted in a hospital setting, and was delivered via telephone, so this could be a factor as to why the HADS did not show any major changes. Poole & Morgan (2006) also argued that while the depression scale in the HADS is reflective of what participants report, the anxiety scale is less accurate and less reliable. Interestingly, although the HADS did not show changes, three out of five participants identified that they experienced both depressive and anxiety-like symptoms when they were interviewed (see below).

Additionally, the Satisfaction With Life Scale (SWLS) revealed a score that was also trending towards being reduced. While the scores decreased slightly for the patients, most still remained in the 'satisfied' category. It could be argued that the reason the SWLS did not show any change was also due the impact that the pandemic has had on people, but this cannot be stated with certainty. This was confirmed by speaking to the participants; each of them identified that they were generally satisfied with their lives currently. All five participants identified that if they could change anything it would be their MCI diagnoses and also the global pandemic. Research suggests that the SWLS is a useful tool for group comparison, but in order to utilise it fully it is important to understand the core values a person holds. Given that 'Family' emerged as a strong theme (see below) among all participants, it is probably no surprise that all participants scored highly on this questionnaire. Research has indicated that people who score high on the SWLS tend to have strong supportive peer and family networks

(Pavot, & Diener, 2009). Living with both MCI and Covid-19 had a major impact on the lives of each participant, but most showed a level of acceptance (another theme that emerged – see below); this acceptance may have contributed to the relatively high scores on the SWLS and their stability across time. Future research should examine this more closely using a larger sample of participants.

4.3 Qualitative Analysis: Impact of Covid-19 on the Experience of MCI

The final part of the thesis focused on the impact that Covid-19 had on each participant. Multiple common themes emerged for all participants. While the questions were structured toward the impact of Covid-19 on their mental health and wellbeing, the answers were also reflective of their experiences and feelings in relation to MCI. Of the five MCI participants, three identified that **anxiety and low moods** were problematic for them both in relation to Covid-19 and for living with MCI. This theme emerged despite not finding any difference in either the depression or anxiety aspects of the HADS test. Recent literature has identified that individuals living with conditions such as MCI are at higher risk of experiencing anxiety and mood disorders (Panza et. al., 2010; Ma, 2020). There is also a higher probability of this occurring for those who care for individuals with neurodegenerative conditions, due to additional stress that caregivers and family members can experience (Chang, Chiou, & Chen, 2010; Blanco et. al. 2014). Therefore, it is not surprising that this theme was identified, but it was hoped that this would have been supported by the psychological tests that were used to measure participants responses.

Another sub-theme that was identified and came through strongly was that of **anger and resentment**. This was unexpected. While anger can be experienced by people who have been diagnosed with MCI or other type of dementias, this theme was also present in the family

members. It appears that very limited research has been done in this area. However, research has shown that high stress levels brought about by caregiving can also result in anger and resentment (Rudd et. al., 1999; Adams, 2006), and this is particularly observed if the caregiving is done by partners or close family members (Adams, 2006). The participants identified various different reasons for being angry and resentful, and these ranged from the diagnosis itself, to the impact that Covid-19 had on their lives, including the inability to see friends, family and grandchildren. Research is seriously lacking in this area and more should be done to explore the emotional impact that receiving a diagnosis in relation to a neurodegenerative disorder should explore

Another theme that emerged was **resilience and acceptance,** and we have mentioned this above in terms of being generally satisfied. Resilience in itself is a new concept, and like anger and resentment, research is relatively limited. In psychological terms, resilience is often defined as a person's ability to recover from stressful situations (Thomassen, 2018). Each participant identified that they had learned to accept both their MCI, and also the current pandemic, and all five had been vocal about making the most of their situation. One participant had identified that by accepting the current pandemic, and also her initial diagnosis with MCI, she felt better able to cope. However, she also expressed anxiousness about the future and her risks of progressing into other forms of dementia.

4.4 Limitations & Recommendations

This project had a number of limitations. To begin with, the sample (N=5) was low. This limited the number statistical analysis that we were able to conduct. The reasoning behind the sample being low was that the recruitment process had to be halted on numerous occasions due to Covid-19, and for the health and safety of all involved it was impossible to recruit more participants. The pandemic began to have an impact globally just after the researcher began

collecting data. Therefore, the project had to be restructured and ethical approval had to be reapplied for on two separate occasions to allow for the changes that were made, such as the tape recording of the information that was to be used for the qualitative analysis. Furthermore, due to the restructuring of this project, some participants were unable to complete the full battery of cognitive and psychological tests. For example, the MoCA and TMT where not used with all participants, as these had to be conducted in person. In addition, the intervention contained a lifestyle factor section this focused on the hobbies participants enjoyed. Again due to Covid-19, all activities had ceased, so it was difficult to gauge if this part of the intervention had an impact. Furthermore, it is worth mentioning that during the IPA process, the transcription and analysis of the themes was carried out solely by the researcher; due to time constraints and isolation imposed by the pandemic restrictions, a second independent rater could not be involved. This constitutes a significant limitation, and under normal circumstances an additional researcher would carry out the same analysis and emergent themes would be compared for overlap.

Another potential limitation of this study was the duration of the project. It is possible that a long course possible six weeks, would have yielded more valid results than we have shown here, and also allowed for a more productive relationship to be achieved between the researcher and the participants. Initially this project should have been conducted in person, with the week that focused on AD and its connection to MCI being conducted by the researcher as well Dr Richard Roche and Professor Sean Commins. This would have allowed for a more in-depth focus on the relationship between these conditions. It could be argued that this could have had a significantly negative impact on the project overall. It could be argued also that due to the impersonal nature of the intervention with it being held online and not in person, it possibly did not have the desired impact that was hypotheses within the aims of the project. Few neuroeducation programmes have been done in relation to MCI, and none have been

conducted solely online, therefore it should be considered that this impacted this project in a negative way.

Another limitation of the project was that there was no access given for previous medical records, and therefore time since diagnosis of MCI was not known. Participants were able to estimate that they had been 12 months+ since they had been told they had MCI, but nothing more specific than that. The time since diagnosis could have possibly impacted the success of the intervention, and potentially even affected the results of the pre- and post-intervention battery of tests that were conducted. Additionally, this was the first project of its kind that focused solely on the neuroeducational aspect of neurodegenerative conditions such as MCI. Other studies have not examined this, and many have paired interventions like this with other tasks such as walking exercises, cognitive tasks, and/or aerobics (Faucounau et. al., 2010; Rodakowski et. al., 2015: Karssemeijer et. al., 2017; Sherman et. al., 2017; Alescio-Lautier et. al., 2019). Further, it is also possible that, if such an intervention as we employed here does indeed result in lifestyle-based changes (for example to exercise, diet, social interaction etc.) the possibility of longer-term cognitive gains as a result of these lifestyle changes may be worth testing for; this is perhaps even likely given the well-established links between lifestyle factors and cognitive function (see Livingston et al., 2020).

While Covid-19 had a predominantly negative impact, it also had some positive implications, at least for this project. Due to the fact that people were confined to their homes for almost two years, it meant that people were more willing to engage with both the researcher and the content that she was presenting. She was a point of human contact with people and this was repeatedly stated by the participants throughout this project. Additionally, the researcher may never have gotten access to the kind of in-depth information that she was able to extract from participants if this project had of been conducted in a group setting as was originally planned. Furthermore, the participants within this project were very open and honest in relation

to both how living with a condition like MCI affected them emotionally, physically and mentally, and also how the global pandemic was affecting them. This level of openness and honesty would not have been obtained in a group setting. Due to the project being conducted online via telephone, and video chat, both participant and researcher formed a unique type of relationship where trust was established participants were more engaged with the topics and the questions that were presented to them.

4.5 Future Research

This study shows that more needs to be done to determine the most beneficial form of intervention for those with MCI. Furthermore, interventions in relation to caregivers and family members are just as important, and very little has been done in relation this area. Based on the fact that people are living longer, and currently it is estimated that approximately 50 million people worldwide are living with a form of dementia, with this number set to increase significantly in the next 20 years (Wortmann, 2012; Alzheimer's Association, Thies, & Bleiler, 2013; World Health Organization. 2019), it is vital that research examine the various prodromal stages of dementia and potential interventions. Intervening earlier could help reduce the chances of individuals progressing on to Alzheimer's Disease, or other types of dementia. Despite many different types of interventions (e.g. exercise, diet), results from if these improve cognitive function or reduce symptoms from MCI or other types of dementia vary extensively, therefore, more needs to be done in these areas in order to create an intervention that prevents people from progressing from MCI to other types of dementia.

Although only quantitative measure showed a slight change pre- to post-intervention (the CIQ), some of the other tests did show a trend towards significance (e.g. Casp-19 and the HADS, depression sub-scale only). A larger sample may have helped to clarify whether the

intervention would impact on other measures. Furthermore, given the complexities around the neurological basis of MCI and the different types of MCI, it is possible that some interventions might have a greater impact on some sub-types compared to others. Future studies may wish to explore this aspect more. Finally, although we included a small number of family members in our study, future research would benefit from a more focused intervention that is solely oriented towards this group, as well as some of the interesting themes that emerged in our research, including anger/resentment and resilience.

While this neuroeducation programme did not quantitatively reduce the experience of depression, stress and anxiety in our participants with MCI and their family members, it did help clarify and reduce the confusion around the disease. Furthermore, it re-affirmed the importance of living a healthy lifestyle, and encouraged all to continue with both exercise and a good diet. Finally, through the interviews, this study highlighted the importance of family, social and care-networks in providing support and encouraging resilience. As identified above participant sample size was an issue for this project; perhaps further research could consider using longitudinal studies and using more participants, and exploring neuroeducation on a larger scale over a longer period of time to see if a enhancement in psychological wellbeing and also an improvement in cognitive function may be evident.

4.6 Conclusion

Here we present tentative evidence that a non-pharmacological intervention in this instance a neuroeducation programme, may represent a promising avenue for future approaches to conditions associated with memory impairment and cognitive decline. In a small sample of people with a diagnosis of MCI, as well as their FMs, we observed minimal objective evidence of improvements on anxiety, depression, satisfaction with life or other self-report measures;

however, qualitative analysis and examination of semi-structured interviews did reveal a pattern of subjective improvements and increased satisfaction, coupled with reduced fear or anxiety around the diagnosis, as a result of the intervention. Findings suggest that, in the absence of an effective drug treatment for dementias or related conditions, education- or lifestyle-based intervention may be a viable approach to enhance the lived experience of those with a diagnosis, and that for small samples and case series studies at least qualitative approaches may represent a more valid indicator of change than quantitative.

References

Aalten, P., Verhey, F. R., Boziki, M., Bullock, R., Byrne, E. J., Camus, V., & Robert, P. H. (2007). Neuropsychiatric syndromes in dementia. *Dementia and geriatric cognitive disorders*, *24*(6), 457-463.

Aarsland, D., Andersen, K., Larsen, J. P., & Lolk, A. (2003). Prevalence and characteristics of dementia in Parkinson disease: an 8-year prospective study. *Archives of neurology*, *60*(3), 387-392.

Adams, K. B. (2006). The transition to caregiving: the experience of family members embarking on the dementia caregiving career. *Journal of gerontological social work*, *47*(3-4), 3-29.

Alescio-Lautier, B., Sambucchi, N., Michel, B-F., Chambon, C. (2019). Multifactorial Cognitive Training can Slow Down the Cognitive Decline in Early Alzheimer Patients. Journal of Alzheimer's Disease & Parkinsonism, OMICS International, 9(4), 1000470. ⟨hal-02305523⟩.

Amieva, H., Ouvrard, C., Meillon, C., Rullier, L., & Dartigues, J. F. (2018). Death, depression, disability, and dementia associated with self-reported hearing problems: a 25-year study. *The Journals of Gerontology: Series A*, *73*(10), 1383-1389.

Ancoli-Israel, S., & Alessi, C. (2005). Sleep and aging. *The American Journal of Geriatric Psychiatry*, *13*(5), 341-343.

Anstey, K. J., Cherbuin, N., & Herath, P. M. (2013). Development of a new method for assessing global risk of Alzheimer's disease for use in population health approaches to prevention. *Prevention Science*, *14*(4), 411-421.

Archibald, C. J., & Fisk, J. D. (2000). Information processing efficiency in patients with multiple sclerosis. *Journal of clinical and experimental neuropsychology*, *22*(5), 686-701.

Armstrong, N. M., Carlson, M. C., Schrack, J., Xue, Q. L., Carnethon, M. R., Rosano, C., & Gross, A. L. (2018). Late-life depressive symptoms as partial mediators in the associations between subclinical cardiovascular disease with onset of mild cognitive impairment and dementia. *The American Journal of Geriatric Psychiatry*, *26*(5), 559-568.

Ballard, C. G., O'Brien, J., James, I., & Swann, A. (2003). Dementia: management of behavioural and psychological symptoms. *Nordic Journal of Psychiatry*, *57*(2), 159-160.

Barile, J. P., Thompson, W. W., Zack, M. M., Krahn, G. L., Horner-Johnson, W., & Bowen, S. E. (2013). Multiple chronic medical conditions and health-related quality of life in older adults, 2004–2006. *Preventing chronic disease*, *10*.

Barney, L. J., Griffiths, K. M., Jorm, A. F., & Christensen, H. (2006). Stigma about depression and its impact on help-seeking intentions. *Australian & New Zealand Journal of Psychiatry*, *40*(1), 51-54.

Beason-Held, L. L., Goh, J. O., An, Y., Kraut, M. A., O'Brien, R. J., Ferrucci, L., & Resnick, S. M. (2013). Changes in brain function occur years before the onset of cognitive impairment. *Journal of Neuroscience*, *33*(46), 18008-18014.

Beluche, I., Carrière, I., Ritchie, K., & Ancelin, M. L. (2010). A prospective study of diurnal cortisol and cognitive function in community-dwelling elderly people. *Psychological medicine*, *40*(6), 1039-1049.

Bierman, E. J., Comijs, H. C., Rijmen, F., Jonker, C., & Beekman, A. T. (2008). Anxiety symptoms and cognitive performance in later life: results from the longitudinal aging study Amsterdam. *Aging and Mental Health*, *12*(4), 517-523.

Bird, C. M., & Burgess, N. (2008). The hippocampus and memory: insights from spatial processing. *Nature Reviews Neuroscience*, *9*(3), 182-194.

Bird, C. M., Chan, D., Hartley, T., Pijnenburg, Y. A., Rossor, M. N., & Burgess, N. (2010). Topographical short-term memory differentiates Alzheimer's disease from frontotemporal lobar degeneration. *Hippocampus*, *20*(10), 1154-1169.

Blanco, V., Rohde, P., Vázquez, F. L., & Torres, Á. (2014). Identification of caregivers at greatest risk of major depression in two prevention studies. *Psychotherapy Research*, *24*(5), 578-593.

Blieszner, R., & Roberto, K. A. (2010). Care partner responses to the onset of mild cognitive impairment. *The Journals of Gerontology*, *50*(1), 11-22.

Bond, J., Stave, C., Sganga, A., Vincenzino, O., O'connell, B., & Stanley, R. L. (2005). Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. *International Journal of Clinical Practice*, *59*, 8-14.

Bondi, M. W., Edmonds, E. C., & Salmon, D. P. (2017). Alzheimer’s disease: past, present, and future. *Journal of the International Neuropsychological Society*, *23*(9-10), 818-831.

Bottino, C. M., Castro, C. C., Gomes, R. L., Buchpiguel, C. A., Marchetti, R. L., & Neto, M. R. L. (2002). Volumetric MRI measurements can differentiate Alzheimer's disease, mild cognitive impairment, and normal aging. *International Psychogeriatrics*, *14*(1), 59-72.

Broadbent, D. E., Cooper, P. F., FitzGerald, P., & Parkes, K. R. (1982). The cognitive failures questionnaire (CFQ) and its correlates. *British journal of clinical psychology*, *21*(1), 1-16.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217.

Brosschot, J. F., Gerin, W., & Thayer, J. F. (2006). The perseverative cognition hypothesis: A review of worry, prolonged stress-related physiological activation, and health. *Journal of psychosomatic research*, *60*(2), 113-124.

Brown, R. R., & Partington, J. E. (1942). A psychometric comparison of narcotic addicts with hospital attendants. *The Journal of General Psychology*, *27*(1), 71-79.

Brown, G. C. (2015). Living too long: the current focus of medical research on increasing the quantity, rather than the quality, of life is damaging our health and harming the economy. *EMBO reports*, *16*(2), 137-141.

Bruce, J. M., McQuiggan, M., Williams, V., Westervelt, H., & Tremont, G. (2008). Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia and geriatric cognitive disorders*, *25*(4), 385-390.

Butters, M. A., Young, J. B., Lopez, O., Aizenstein, H. J., Mulsant, B. H., Reynolds III, C. F., & Becker, J. T. (2008). Pathways linking late-life depression to persistent cognitive impairment and dementia. *Dialogues in clinical neuroscience*, *10*(3), 345.

Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of clinical nursing*, *24*(17-18), 2376-2382.

Carlozzi, N. E., Sherman, C. W., Angers, K., Belanger, M. P., Austin, A. M., & Ryan, K. A. (2018). Caring for an individual with mild cognitive impairment: a qualitative perspective of health-related quality of life from caregivers. *Aging & mental health*, *22*(9), 1196-1204.

Chan, W. C., Lam, L. C., Tam, C. W., Lui, V. W., Leung, G. T., Lee, A. T., & Chan, W. M. (2011). Neuropsychiatric symptoms are associated with increased risks of progression to dementia: a 2-year prospective study of 321 Chinese older persons with mild cognitive impairment. *Age and ageing*, *40*(1), 30-35.

Chang, H. Y., Chiou, C. J., & Chen, N. S. (2010). Impact of mental health and caregiver burden on family caregivers' physical health. *Archives of gerontology and geriatrics*, *50*(3), 267-271.

Chen, C., Hu, Z., Jiang, Z., & Zhou, F. (2018). Prevalence of anxiety in patients with mild cognitive impairment: a systematic review and meta-analysis. *Journal of affective disorders*, *236*, 211-221.

Choi, J., & Twamley, E. W. (2013). Cognitive rehabilitation therapies for Alzheimer's disease: a review of methods to improve treatment engagement and self-efficacy. *Neuropsychology review*, *23*(1), 48-62.

Clark, C. M., Schneider, J. A., Bedell, B. J., Beach, T. G., Bilker, W. B., Mintun, M. A., & AV45-A07 Study Group. (2011). Use of florbetapir-PET for imaging β-amyloid pathology. *Jama*, *305*(3), 275-283.

Cohen, J. E. (2003). Human population: the next half century. *science*, *302*(5648), 1172-1175.

Consoli, A., Pasi, M., & Pantoni, L. (2012). Vascular mild cognitive impairment: concept, definition, and directions for future studies. *Aging clinical and experimental research*, *24*(2), 113-116.

Costafreda, S. G., Dinov, I. D., Tu, Z., Shi, Y., Liu, C. Y., Kloszewska, I., & Simmons, A. (2011). Automated hippocampal shape analysis predicts the onset of dementia in mild cognitive impairment. *Neuroimage*, *56*(1), 212-219.

Cramer, C. K., McKee, N., Case, L. D., Chan, M. D., Cummings, T. L., Lesser, G. J., & Rapp, S. R. (2019). Mild cognitive impairment in long-term brain tumor survivors following brain irradiation. *Journal of neuro-oncology*, *141*(1), 235-244.

Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, *40*(4), 429-434.

Crowley, K. (2011). Sleep and sleep disorders in older adults. *Neuropsychology review*, *21*(1), 41-53.

Dartigues, J. F. (2002). Incidence and outcome of mild cognitive impairment in a population-based prospective cohort. *Neurology*, *59*(10), 1594-1599.

Davidson, J. R., & Meltzer-Brody, S. E. (1999). The underrecognition and undertreatment of depression: what is the breadth and depth of the problem?. *Journal of clinical psychiatry*, *60*(7), 4-11.

Dekel, R., Solomon, Z., & Bleich, A. (2005). Emotional distress and marital adjustment of caregivers: Contribution of level of impairment and appraised burden. *Anxiety, Stress & Coping*, *18*(1), 71-82.

Delbanco, T., Gerteis, M., Aronson, M. D., & Park, L. (2012). A patient-centered view of the clinician-patient relationship. *Uptodate*.

Delis, D. C., Kaplan, E., & Kramer, J. H. (2001). Delis-Kaplan executive function system.

Demurtas, J., Schoene, D., Torbahn, G., Marengoni, A., Grande, G., Zou, L., & Veronese, N. (2020). Physical activity and exercise in mild cognitive impairment and dementia: an umbrella review of intervention and observational studies. *Journal of the American Medical Directors Association*, *21*(10), 1415-1422.

Devenney, K. E., Sanders, M. L., Lawlor, B., Rikkert, M. G. O., & Schneider, S. (2017). The effects of an extensive exercise programme on the progression of Mild Cognitive

Impairment (MCI): study protocol for a randomised controlled trial. *BMC geriatrics*, *17*(1), 1-10.

Devier, D. J., Pelton, G. H., Tabert, M. H., Liu, X., Cuasay, K., Eisenstadt, R., & Devanand, D. P. (2009). The impact of anxiety on conversion from mild cognitive impairment to Alzheimer's disease. *International journal of geriatric psychiatry*, *24*(12), 1335-1342.

Devlin, E., MacAskill, S., & Stead, M. (2007). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of nonprofit and voluntary sector marketing*, *12*(1), 47-58.

Díaz-Mardomingo, M. D. C., García-Herranz, S., Rodríguez-Fernández, R., Venero, C., & Peraita, H. (2017). Problems in classifying mild cognitive impairment (MCI): one or multiple syndromes?. *Brain sciences*, *7*(9), 111.

Dickerson, B. C., Salat, D. H., Greve, D. N., Chua, E. F., Rand-Giovannetti, E., Rentz, D. M., & Sperling, R. A. (2005). Increased hippocampal activation in mild cognitive impairment compared to normal aging and AD. *Neurology*, *65*(3), 404-411.

Dijkers, M. (1997). Measuring the long-term outcomes of traumatic brain injury: a review of the community integration questionnaire. *The Journal of Head Trauma Rehabilitation*.

Dillon, C. B., McMahon, E., O'Regan, G., & Perry, I. J. (2018). Associations between physical behaviour patterns and levels of depressive symptoms, anxiety and well-being in middle-aged adults: a cross-sectional study using isotemporal substitution models. *BMJ open*, *8*(1), e018978.

Djukanovic, I., Carlsson, J., & Årestedt, K. (2017). Is the Hospital Anxiety and Depression Scale (HADS) a valid measure in a general population 65–80 years old? A psychometric evaluation study. *Health and quality of life outcomes*, *15*(1), 1-10.

Domoto-Reilly, K., Sapolsky, D., Brickhouse, M., Dickerson, B. C., & Alzheimer's Disease Neuroimaging Initiative. (2012). Naming impairment in Alzheimer's disease is associated with left anterior temporal lobe atrophy. *Neuroimage*, *63*(1), 348-355.

Du, L., & Hu, J. (2016). The effects of health education on knowledge about Alzheimer's disease and health-promoting behaviours of older Chinese adults in a nursing home: A pilot study. *International journal of nursing practice*, *22*(1), 31-42.

Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology*, *51*(1 Suppl 1), S53-S60.

Durak, M., Senol-Durak, E., & Gencoz, T. (2010). Psychometric properties of the satisfaction with life scale among Turkish university students, correctional officers, and elderly adults. *Social indicators research*, *99*(3), 413-429.

Ekhtiari, H., Rezapour, T., Aupperle, R. L., & Paulus, M. P. (2017). Neuroscience-informed psychoeducation for addiction medicine: A neurocognitive perspective. *Progress in brain research*, *235*, 239-264.

Eldufani, J., & Blaise, G. (2019). The role of acetylcholinesterase inhibitors such as neostigmine and rivastigmine on chronic pain and cognitive function in aging: A review of recent clinical applications. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *5*, 175-183.

Escher, C. M., Sannemann, L., & Jessen, F. (2019). Stress and Alzheimer's disease. *Journal of Neural Transmission*,*1 26*(9), 1155-1161.

Eshkoor, S. A., Hamid, T. A., Mun, C. Y., & Ng, C. K. (2015). Mild cognitive impairment and its management in older people. *Clinical interventions in aging*, *10*, 687.

Evans, S. C. (2018). Ageism and dementia. In *Contemporary perspectives on ageism* (pp. 263-275). Springer, Cham.

Everson-Rose, S. A., Mendes de Leon, C. F., Bienias, J. L., Wilson, R. S., & Evans, D. A. (2003). Early life conditions and cognitive functioning in later life. *American journal of epidemiology*, *158*(11), 1083-1089.

Fan, Y., Batmanghelich, N., Clark, C. M., & Davatzikos, C. Initiative tAsDN (2008) Spatial patterns of brain atrophy in MCI patients, identified via high dimensional pattern classification, predict subsequent cognitive decline. *Neuroimage*, *39*, 1731-1743.

Faria, C. D. A., Alves, H. V. D., & Charchat-Fichman, H. (2015). The most frequently used tests for assessing executive functions in aging. *Dementia & neuropsychologia*, *9*(2), 149-155.

Farias, S. T., Mungas, D., Reed, B. R., Harvey, D., & DeCarli, C. (2009). Progression of mild cognitive impairment to dementia in clinic-vs community-based cohorts. *Archives of neurology*, *66*(9), 1151-1157.

Faucounau, V., Wu, Y. H., Boulay, M., De Rotrou, J., & Rigaud, A. S. (2010). Cognitive intervention programmes on patients affected by mild cognitive impairment: a promising intervention tool for MCI?. *The journal of nutrition, health & aging*, *14*(1), 31-35.

Fei, M., & Jianhua, W. (2013). Apolipoprotein ε4-allele as a significant risk factor for conversion from mild cognitive impairment to Alzheimer's disease: a meta-analysis of prospective studies. *Journal of Molecular Neuroscience*, *50*(2), 257-263.

Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. *Washington, DC: AARP Public Policy Institute*, *32*, 2011.

Fellgiebel, A., & Yakushev, I. (2011). Diffusion tensor imaging of the hippocampus in MCI and early Alzheimer's disease. *Journal of Alzheimer's Disease*, *26*(s3), 257-262.

Finlay, L. (2012). Debating phenomenological methods. In *Hermeneutic phenomenology in education* (pp. 17-37). Sense Publishers, Rotterdam.

Fisher, G. G., Franks, M. M., Plassman, B. L., Brown, S. L., Potter, G. G., Llewellyn, D., & Langa, K. M. (2011). Caring for individuals with dementia and cognitive impairment, not dementia: findings from the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, *59*(3), 488-494.

Fiske, A., Wetherell, J. L., & Gatz, M. (2009). Depression in older adults. *Annual review of clinical psychology*, *5*, 363-389.

Fleisher, A. S., Sun, S., Taylor, C., Ward, C. P., Gamst, A. C., Petersen, R. C., & Thal, L. J. (2008). Volumetric MRI vs clinical predictors of Alzheimer disease in mild cognitive impairment. *Neurology*, *70*(3), 191-199.

Foy, C. M., Daly, E. M., Glover, A., O'Gorman, R., Simmons, A., Murphy, D. G., & Lovestone, S. (2011). Hippocampal proton MR spectroscopy in early Alzheimer's disease and mild cognitive impairment. *Brain topography*, *24*(3), 316-322.

Folstein MF, Folstein SE, McHugh PR: Mini-mental state: "A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975; 12;189-198.

Folstein, M. F., Robins, L. N., & Helzer, J. E. (1983). The mini-mental state examination. *Archives of general psychiatry*, *40*(7), 812-812.

Frederiksen, K. S., & Waldemar, G. (2021). Disclosure of Diagnosis in MCI and Dementia. In *Management of Patients with Dementia* (pp. 57-72). Springer, Cham.

Gabryelewicz, T., Styczynska, M., Luczywek, E., Barczak, A., Pfeffer, A., Androsiuk, W., & Barcikowska, M. (2007). The rate of conversion of mild cognitive impairment to dementia: predictive role of depression. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, *22*(6), 563-567.

Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and aging*, *22*(1), 37.

Gallagher, D., Coen, R., Kilroy, D., Belinski, K., Bruce, I., Coakley, D., & Lawlor, B. A. (2011). Anxiety and behavioural disturbance as markers of prodromal Alzheimer's disease in patients with mild cognitive impairment. *International journal of geriatric psychiatry*, *26*(2), 166-172.

Gallo, J. J., & Lebowitz, B. D. (1999). The epidemiology of common late-life mental disorders in the community: themes for the new century. *Psychiatric Services*, *50*(9), 1158-1166.

Ganguli, M., Dodge, H. H., Shen, C., & DeKosky, S. T. (2004). Mild cognitive impairment, amnestic type: an epidemiologic study. *Neurology*, *63*(1), 115-121.

Gao, S., Unverzagt, F. W., Hall, K. S., Lane, K. A., Murrell, J. R., Hake, A. M., & Hendrie, H. C. (2014). Mild cognitive impairment, incidence, progression, and reversion: findings from a community-based cohort of elderly African Americans. *The American Journal of Geriatric Psychiatry*, *22*(7), 670-681.

Gates, N. J., & Sachdev, P. (2014). Is cognitive training an effective treatment for preclinical and early Alzheimer's disease?. *Journal of Alzheimer's disease*, *42*(s4), S551-S559.

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & mental health*, *9*(2), 105-118.

Gauthier, S., Reisberg, B., Zaudig, M., Petersen, R. C., Ritchie, K., Broich, K., & Cummings, J. L. International Psychogeriatric Association Expert Conference on mild cognitive impairment, 2006. Mild cognitive impairment. *Lancet*, *367*(1262), e1270.

Geda, Y. E., Smith, G. E., Knopman, D. S., Boeve, B. F., Tangalos, E. G., Ivnik, R. J., & Petersen, R. C. (2004). De novo genesis of neuropsychiatric symptoms in mild cognitive impairment (MCI). *International psychogeriatrics*, *16*(1), 51-60.

Gibson, R. H., Gander, P. H., & Jones, L. M. (2014). Understanding the sleep problems of people with dementia and their family caregivers. *Dementia*, *13*(3), 350-365.

Gigi, A., Papirovitz, M., Vakil, E., & Treves, T. (2020). Medical help-seekers with anxiety from deterioration in memory are characterized with risk factors for cognitive decline. *Clinical gerontologist*, *43*(2), 204-208.

Gigi, A., & Papirovitz, M. (2021). Association of anxiety awareness with risk factors of cognitive decline in MCI. *Brain Sciences*, *11*(2), 135.

Gil-Bea, F. J., Aisa, B., Solomon, A., Solas, M., del Carmen Mugueta, M., Winblad, B., & Ramirez, M. J. (2010). HPA axis dysregulation associated to apolipoprotein E4 genotype in Alzheimer's disease. *Journal of Alzheimer's disease*, *22*(3), 829-838.

Gabryelewicz, T., Styczynska, M., Luczywek, E., Barczak, A., Pfeffer, A., Androsiuk, W., & Barcikowska, M. (2007). The rate of conversion of mild cognitive impairment to dementia: predictive role of depression. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, *22*(6), 563-567.

Garand, L., Amanda Dew, M., Eazor, L. R., DeKosky, S. T., & Reynolds III, C. F. (2005). Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International journal of geriatric psychiatry*, *20*(6), 512-522.

Giltay, E. J., Zitman, F. G., & Kromhout, D. (2006). Dispositional optimism and the risk of depressive symptoms during 15 years of follow-up: The Zutphen Elderly Study. *Journal of affective disorders*, *91*(1), 45-52.

Gimson, A., Schlosser, M., Huntley, J. D., & Marchant, N. L. (2018). Support for midlife anxiety diagnosis as an independent risk factor for dementia: a systematic review. *BMJ open*, *8*(4), e019399.

Gove, D., Downs, M., Vernooij-Dassen, M. J. F. J., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & mental health*, *20*(4), 391-400.

Green, K. N., Billings, L. M., Roozendaal, B., McGaugh, J. L., & LaFerla, F. M. (2006). Glucocorticoids increase amyloid-β and tau pathology in a mouse model of Alzheimer's disease. *Journal of Neuroscience*, *26*(35), 9047-9056.

Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*, *80*(19), 1778-1783.

Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis *The Psychologist*.

Hely, M. A., Reid, W. G., Adena, M. A., Halliday, G. M., & Morris, J. G. (2008). The Sydney multicenter study of Parkinson's disease: the inevitability of dementia at 20 years. *Movement disorders*, *23*(6), 837-844.

Hirsh, A. T., Braden, A. L., Craggs, J. G., & Jensen, M. P. (2011). Psychometric properties of the community integration questionnaire in a heterogeneous sample of adults with physical disability. *Archives of physical medicine and rehabilitation*, *92*(10), 1602-1610.

Hoops, S., Nazem, S., Siderowf, A. D., Duda, J. E., Xie, S. X., Stern, M. B., & Weintraub, D. (2009). Validity of the MoCA and MMSE in the detection of MCI and dementia in Parkinson disease. *Neurology*, *73*(21), 1738-1745.

Hu, J. P., Guo, Y. H., Wang, F., Zhao, X. P., Zhang, Q. H., & Song, Q. H. (2014). Exercise improves cognitive function in aging patients. *International journal of clinical and experimental medicine*, *7*(10), 3144.

Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (2000). Clinical dementia rating (CDR) scale. *Task force for the Handbook of Psychiatric Measures*, 446-450.

Hyde, M., Wiggins, R. D., Higgs, P., & Blane, D. B. (2003). A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging & mental health*, *7*(3), 186-194.

Hyland, P., Shevlin, M., McBride, O., Murphy, J., Karatzias, T., Bentall, R. P., & Vallières, F. (2020). Anxiety and depression in the Republic of Ireland during the COVID-19 pandemic. *Acta Psychiatrica Scandinavica*, *142*(3), 249-256.

Iadecola, C. (2014). Hypertension and dementia. *Hypertension*, *64*(1), 3-5.

Ihle-Hansen, H., Thommessen, B., Wyller, T. B., Engedal, K., Øksengård, A. R., Stenset, V., & Fure, B. (2011). Incidence and subtypes of MCI and dementia 1 year after first-ever stroke in patients without pre-existing cognitive impairment. *Dementia and geriatric cognitive disorders*, *32*(6), 401-407.

Jack, C. R., Petersen, R. C., Xu, Y. C., O'Brien, P. C., Smith, G. E., Ivnik, R. J., & Kokmen, E. (1999). Prediction of AD with MRI-based hippocampal volume in mild cognitive impairment. *Neurology*, *52*(7), 1397-1397.

Jack Jr, C. R., Lowe, V. J., Weigand, S. D., Wiste, H. J., Senjem, M. L., Knopman, D. S., & Alzheimer's Disease Neuroimaging Initiative. (2009). Serial PIB and MRI in normal, mild cognitive impairment and Alzheimer's disease: implications for sequence of pathological events in Alzheimer's disease. *Brain*, *132*(5), 1355-1365.

Jefferson, A., & Benjamin, E. (2009). Cardiovascular disease, cognitive decline and dementia. *Vascular cognitive impairment in clinical practice. Cambridge*, 166-77.

Jia, J., Zhou, A., Wei, C., Jia, X., Wang, F., Li, F., & Chu, L. (2014). The prevalence of mild cognitive impairment and its etiological subtypes in elderly Chinese. *Alzheimer's & Dementia*, *10*(4), 439-447.

Jiang, W., Krishnan, R. R., & O'Connor, C. M. (2002). Depression and heart disease. *CNS drugs*, *16*(2), 111-127.

Johansson, L., Guo, X., Hällström, T., Norton, M. C., Waern, M., Östling, S., & Skoog, I. (2013). Common psychosocial stressors in middle-aged women related to longstanding distress and increased risk of Alzheimer's disease: a 38-year longitudinal population study. *BMJ open*, *3*(9), e003142.

Joko, T., Washizuka, S., Sasayama, D., Inuzuka, S., Ogihara, T., Yasaki, T., & Amano, N. (2016). Patterns of hippocampal atrophy differ among Alzheimer's disease, amnestic mild cognitive impairment, and late-life depression. *Psychogeriatrics*, *16*(6), 355-361.

Julayanont, P., & Nasreddine, Z. S. (2017). Montreal Cognitive Assessment (MoCA): concept and clinical review. In *Cognitive screening instruments* (pp. 139-195). Springer, Cham.

Kalmijn, S., Van Boxtel, M. P., Verschuren, M. W., Jolles, J., & Launer, L. J. (2002). Cigarette smoking and alcohol consumption in relation to cognitive performance in middle age. *American journal of epidemiology*, *156*(10), 936-944.

Karssemeijer, E. E., Aaronson, J. J., Bossers, W. W., Smits, T. T., & Kessels, R. R. (2017). Positive effects of combined cognitive and physical exercise training on cognitive function in older adults with mild cognitive impairment or dementia: A meta-analysis. *Ageing research reviews*, *40*, 75-83.

Katz, M. J., Derby, C. A., Wang, C., Sliwinski, M. J., Ezzati, A., Zimmerman, M. E., & Lipton, R. B. (2016). Influence of perceived stress on incident amnestic mild cognitive impairment: Results from the Einstein Aging Study. *Alzheimer disease and associated disorders*, *30*(2), 93.

Kelleher M, Tolea MI, & Galvin JE (2016). Anosognosia increases caregiver burden in mild cognitive impairment. *Int J Geriatr Psychiatry*, 31(7), 799–808. doi: 10.1002/gps.4394

Kim, G. R., Netuveli, G., Blane, D., Peasey, A., Malyutina, S., Simonova, G., & Pikhart, H. (2015). Psychometric properties and confirmatory factor analysis of the CASP-19, a

measure of quality of life in early old age: the HAPIEE study. *Aging & Mental Health*, *19*(7), 595-609.

Kirova, A. M., Bays, R. B., & Lagalwar, S. (2015). Working memory and executive function decline across normal aging, mild cognitive impairment, and Alzheimer's disease. *BioMed research international*, *2015*.

Klainin-Yobas, P., Kowitlawakul, Y., Lopez, V., Tang, C. T., Hoek, K. E., Gan, G. L., & Mahendran, R. (2019). The effects of mindfulness and health education programs on the emotional state and cognitive function of elderly individuals with mild cognitive impairment: a randomized controlled trial. *Journal of Clinical Neuroscience*, *68*, 211-217.

Klimova, B., Dziuba, S., & Cierniak-Emerych, A. (2020). The Effect of Healthy Diet on Cognitive Performance Among Healthy Seniors–A Mini Review. *Frontiers in human neuroscience*, *14*.

Köhler, A. C., Magalhaes, T., MMP Oliveira, J., S Alves, G., Knochel, C., Oertel-Knöchel, V., & F Carvalho, A. (2016). Neuropsychiatric disturbances in mild cognitive impairment (MCI): a systematic review of population-based studies. *Current Alzheimer Research*, *13*(10), 1066-1082.

Kot, S. M., & Kurkiewicz, J. (2004). The new measures of the population ageing. *Studia Demograficzne*, *2*, 17-29.

Koyanagi, A., Oh, H., Vancampfort, D., Carvalho, A. F., Veronese, N., Stubbs, B., & Lara, E. (2019). Perceived stress and mild cognitive impairment among 32,715 community-dwelling older adults across six low-and middle-income countries. *Gerontology*, *65*(2), 155-163.

Kremen, W. S., Beck, A., Elman, J. A., Gustavson, D. E., Reynolds, C. A., Tu, X. M., & Franz, C. E. (2019). Influence of young adult cognitive ability and additional education on

later-life cognition. *Proceedings of the National Academy of Sciences*, *116*(6), 2021-2026.

Laakso, M. P., Soininen, H., Partanen, K., Lehtovirta, M., Hallikainen, M., Hänninen, T., & Riekkinen Sr, P. J. (1998). MRI of the hippocampus in Alzheimer's disease: sensitivity, specificity, and analysis of the incorrectly classified subjects. *Neurobiology of aging*, *19*(1), 23-31.

Lai, X., Wen, H., Li, Y., Lu, L., & Tang, C. (2020). The Comparative Efficacy of Multiple Interventions for Mild Cognitive Impairment in Alzheimer's Disease: A Bayesian Network Meta-Analysis. *Frontiers in Aging Neuroscience*, *12*, 121.

Lambert, M. A., Bickel, H., Prince, M., Fratiglioni, L., Von Strauss, E., Frydecka, D., & Reynish, E. L. (2014). Estimating the burden of early onset dementia; systematic review of disease prevalence. *European journal of neurology*, *21*(4), 563-569.

Larrieu, S., Letenneur, L., Orgogozo, J. M., Fabrigoule, C., Amieva, H., Le Carret, N., & Lautenschlager, N. T. (2002). Is it possible to prevent dementia?. *Brazilian Journal of Psychiatry*, *24*, 22-27.

Lee, B. K., Glass, T. A., Wand, G. S., McAtee, M. J., Bandeen-Roche, K., Bolla, K. I., & Schwartz, B. S. (2008). Apolipoprotein e genotype, cortisol, and cognitive function in community-dwelling older adults. *American Journal of Psychiatry*, *165*(11), 1456-1464.

Lee, J. Y., Park, S., Kim, K. W., Kwon, J. E., Park, J. H., Kim, M. D., & Cho, M. J. (2016). Differences in knowledge of dementia among older adults with normal cognition, mild cognitive impairment, and dementia: a representative nationwide sample of Korean elders. *Archives of gerontology and geriatrics*, *66*, 82-88.

Li, G., Cherrier, M. M., Tsuang, D. W., Petrie, E. C., Colasurdo, E. A., Craft, S., & Wilkinson, C. W. (2006). Salivary cortisol and memory function in human aging. *Neurobiology of aging*, *27*(11), 1705-1714.

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., et al.. (2020) Dementia prevention, intervention and care: 2020 report of the Lancet Commission. *Lancet*. 2020; 396: 413-446.

Litvan, I., Goldman, J. G., Tröster, A. I., Schmand, B. A., Weintraub, D., Petersen, R. C., & Aarsland, D. (2012). Diagnostic criteria for mild cognitive impairment in Parkinson's disease: Movement Disorder Society Task Force guidelines. *Movement disorders*, *27*(3), 349-356.

Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., & Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of clinical nursing*, *26*(9-10), 1291-1300.

Liu, X., Wang, L., Tao, H., Ge, C., Zhen, X., Sun, X., & Su, L. (2021). Effects of a Trans-Theoretical Model-Based Health Education Program on the Management of Cognitive Dysfunction in Older Adults With Mild Cognitive Impairment: Study Rationale and Protocol Design for a Randomized Controlled Trial. *Frontiers in psychiatry*, 1562.

Longley, W. A., Tate, R. L., & Brown, R. F. (2022). The psychological benefits of neuropsychological assessment feedback as a psycho-educational therapeutic intervention: A randomized-controlled trial with cross-over in multiple sclerosis. *Neuropsychological Rehabilitation*, 1-30.

Lupien, S., Lecours, A. R., Lussier, I., Schwartz, G., Nair, N. P., & Meaney, M. J. (1994). Basal cortisol levels and cognitive deficits in human aging. *Journal of Neuroscience*, *14*(5), 2893-2903.

Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. *Jama*, *288*(12), 1475-1483.

Ma, L. (2020). Depression, anxiety, and apathy in mild cognitive impairment: current perspectives. *Frontiers in aging neuroscience*, *12*, 9.

Martin, E., & Velayudhan, L. (2020). Neuropsychiatric symptoms in mild cognitive impairment: a literature review. *Dementia and geriatric cognitive disorders*, *49*(2), 146-155.

Maruff, P., Lim, Y. Y., Darby, D., Ellis, K. A., Pietrzak, R. H., Snyder, P. J., & Masters, C. L. (2013). Clinical utility of the cogstate brief battery in identifying cognitive impairment in mild cognitive impairment and Alzheimer's disease. *BMC psychology*, *1*(1), 1-11.

Mast, B. T., & Gerstenecker, A. (2010). Screening instruments and brief batteries for dementia. *Handbook of assessment in clinical gerontology*, 503-530.

McColl, M. A., Davies, D., Carlson, P., Johnston, J., & Minnes, P. (2001). The community integration measure: development and preliminary validation. *Archives of physical medicine and rehabilitation*, *82*(4), 429-434.

McEwen, B. S. (1998). Protective and damaging effects of stress mediators. *New England journal of medicine*, *338*(3), 171-179.

McMurtray, A., Clark, D. G., Christine, D., & Mendez, M. F. (2006). Early-onset dementia: frequency and causes compared to late-onset dementia. *Dementia and geriatric cognitive disorders*, *21*(2), 59-64.

Mergl, R., Seidscheck, I., Allgaier, A. K., Möller, H. J., Hegerl, U., & Henkel, V. (2007). Depressive, anxiety, and somatoform disorders in primary care: prevalence and recognition. *Depression and anxiety*, *24*(3), 185-195.

Miller, L. A., Spitznagel, M. B., Busko, S., Potter, V., Juvancic-Heltzel, J., Istenes, N., & Gunstad, J. (2011). Structured exercise does not stabilize cognitive function in individuals with mild cognitive impairment residing in a structured living facility. *International Journal of Neuroscience*, *121*(4), 218-223.

Mishra, S. (2016). Does modern medicine increase life-expectancy: Quest for the Moon Rabbit?.

Molloy, D. W., Alemayehu, E., & Roberts, R. (1991). Reliability of a standardized mini-mental state examination compared with the traditional mini-mental state examination. *Am J Psychiatry*, *148*(1), 102-105.

Monastero, R., Mangialasche, F., Camarda, C., Ercolani, S., & Camarda, R. (2009). A systematic review of neuropsychiatric symptoms in mild cognitive impairment. *Journal of Alzheimer's disease*, *18*(1), 11-30.

Monastero, R., Cicero, C. E., Baschi, R., Davì, M., Luca, A., Restivo, V. & Nicoletti, A. (2018). Mild cognitive impairment in Parkinson's disease: the Parkinson's disease cognitive study (PACOS). *Journal of Neurology*, *265*(5), 1050-1058.

Mueller, S. G., Weiner, M. W., Thal, L. J., Petersen, R. C., Jack, C. R., Jagust, W., & Beckett, L. (2005). Ways toward an early diagnosis in Alzheimer's disease: the Alzheimer's Disease Neuroimaging Initiative (ADNI). *Alzheimer's & Dementia*, *1*(1), 55-66.

Mueller, A. L., McNamara, M. S., & Sinclair, D. A. (2020). Why does COVID-19 disproportionately affect older people?. *Aging (albany NY)*, *12*(10), 9959.

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, *8*(4), 377-386.

Mukadam, N., Cooper, C., & Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current opinion in psychiatry*, *26*(4), 409.

Murphy, L., Markey, K., O'Donnell, C., Moloney, M., & Doody, O. (2021). The impact of the COVID-19 pandemic and its related restrictions on people with pre-existent mental health conditions: A scoping review. *Archives of Psychiatric Nursing*, *35*(4), 375-394.

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, *53*(4), 695-699.

National Collaborating Centre for Mental Health (UK. (2007). Dementia. *Dementia: A NICE-SCIE Guideline on Supporting People With Dementia and Their Carers in Health and Social Care*.

Nierenberg, A. A. (2001). Current perspectives on the diagnosis and treatment of major depressive disorder. *American Journal of Managed Care*, *7*(11; SUPP), S353-S366.

Olson, R. A., Iverson, G. L., Carolan, H., Parkinson, M., Brooks, B. L., & McKenzie, M. (2011). Prospective comparison of two cognitive screening tests: diagnostic accuracy and correlation with community integration and quality of life. *Journal of neuro-oncology*, *105*(2), 337-344.

Palmer, K., Berger, A. K., Monastero, R., Winblad, B., Bäckman, L., & Fratiglioni, L. (2007). Predictors of progression from mild cognitive impairment to Alzheimer disease. *Neurology*, *68*(19), 1596-1602.

Panza, F., D'Introno, A., Colacicco, A. M., Capurso, C., Del Parigi, A., Caselli, R. J., & Solfrizzi, V. (2005). Current epidemiology of mild cognitive impairment and other predementia syndromes. *The American Journal of Geriatric Psychiatry*, *13*(8), 633-644.

Panza, F., D'Introno, A., Colacicco, A. M., Capurso, C., Del Parigi, A., Capurso, S. A., & Solfrizzi, V. (2006). Cognitive frailty: predementia syndrome and vascular risk factors. *Neurobiology of aging*, *27*(7), 933-940.

Panza, F., Frisardi, V., Capurso, C., D'Introno, A., Colacicco, A. M., Imbimbo, B. P., & Solfrizzi, V. (2010). Late-life depression, mild cognitive impairment, and dementia: possible continuum?. *The American Journal of Geriatric Psychiatry*, *18*(2), 98-116.

Partington, J. E., & Leiter, R. G. (1949). Partington's Pathways Test. *Psychological Service Center Journal*.

Patel, V., Chisholm, D., Dua, T., Laxminarayan, R., & Medina-Mora, M. E. (2016). Mental, Neurological, and Substance Use Disorders: Disease Control Priorities, (Volume 4).

Paterniti, S., Dufouil, C., Bisserbe, J. C., & Alperovitch, A. (1999). Anxiety, depression, psychotropic drug use and cognitive impairment. *Psychological Medicine*, *29*(2), 421-428.

Pavot, W., & Diener, E. (2008). The satisfaction with life scale and the emerging construct of life satisfaction. *The journal of positive psychology*, *3*(2), 137-152.

Pavot, W., & Diener, E. (2009). Review of the satisfaction with life scale. In *Assessing well-being* (pp. 101-117). Springer, Dordrecht.

Peavy GM, Salmon DP, Jacobson MW, et al. Effects of chronic stress on memory decline in cognitively normal and mildly impaired older adults. *Am J Psychiatry.* 2009 Dec;166(12):1384–1391

Peavy, G. M., Jacobson, M. W., Salmon, D. P., Gamst, A. C., Patterson, T. L., Goldman, S., & Galasko, D. (2012). The influence of chronic stress on dementia-related diagnostic change in older adults. *Alzheimer disease and associated disorders*, *26*(3), 260.

Peng, G. P., Feng, Z., He, F. P., Chen, Z. Q., Liu, X. Y., Liu, P., & Luo, B. Y. (2015). Correlation of hippocampal volume and cognitive performances in patients with either

mild cognitive impairment or Alzheimer's disease. *CNS neuroscience & therapeutics*, *21*(1), 15-22.

Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Kokmen, E., & Tangelos, E. G. (1997). Aging, memory, and mild cognitive impairment. *International psychogeriatrics*, *9*(S1), 65-69.

Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Tangalos, E. G., & Kokmen, E. (1999). Mild cognitive impairment: clinical characterization and outcome. *Archives of neurology*, *56*(3), 303-308.

Petersen, R. C., Doody, R., Kurz, A., Mohs, R. C., Morris, J. C., Rabins, P. V., & Winblad, B. (2001). Current concepts in mild cognitive impairment. *Archives of neurology*, *58*(12), 1985-1992.

Petersen, R. C. (2004). Mild cognitive impairment as a diagnostic entity. *Journal of internal medicine*, *256*(3), 183-194.

Petersen, R. C., Roberts, R. O., Knopman, D. S., Boeve, B. F., Geda, Y. E., Ivnik, R. J., & Jack, C. R. (2009). Mild cognitive impairment: ten years later. *Archives of neurology*, *66*(12), 1447-1455.

Petersen, R. C., Roberts, R. O., Knopman, D. S., Geda, Y. E., Cha, R. H., Pankratz, V. S., & Rocca, W. A. (2010). Prevalence of mild cognitive impairment is higher in men: The Mayo Clinic Study of Aging. *Neurology*, *75*(10), 889-897.

Peterson, R. C., Caracciolo, B., Brayne, C., Gauthier, S., Jelic, V., & Fratiglioni, L. (2014). Mild cognitive impairment: a concept in evolution. *Journal of Internal Medicine*, *275*(3), 214-228.

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal*, *20*(1), 7-14.

Pillai, J. A., Hall, C. B., Dickson, D. W., Buschke, H., Lipton, R. B., & Verghese, J. (2011). Association of crossword puzzle participation with memory decline in persons who develop dementia. *Journal of the International Neuropsychological Society: JINS*, *17*(6).

Poole, N. A., & Morgan, J. F. (2006). Validity and reliability of the Hospital Anxiety and Depression Scale in a hypertrophic cardiomyopathy clinic: the HADS in a cardiomyopathy population. *General hospital psychiatry*, *28*(1), 55-58.

Potter, G. G., & Steffens, D. C. (2007). Contribution of depression to cognitive impairment and dementia in older adults. *The neurologist*, *13*(3), 105-117.

Potvin, O., Forget, H., Grenier, S., Préville, M., & Hudon, C. (2011). Anxiety, depression and incident cognitive impairment in community-dwelling older adults.

Potvin, O., Hudon, C., Dion, M., Grenier, S., & Préville, M. (2011). Anxiety disorders, depressive episodes and cognitive impairment no dementia in community-dwelling older men and women. *International journal of geriatric psychiatry*, *26*(10), 1080-1088.

Prince, M. J., Wu, F., Guo, Y., Robledo, L. M. G., O'Donnell, M., Sullivan, R., & Yusuf, S. (2015). The burden of disease in older people and implications for health policy and practice. *The Lancet*, *385*(9967), 549-562.

Rasquin, S. M., Lodder, J., Ponds, R. W., Winkens, I., Jolles, J., & Verhey, F. R. (2004). Cognitive functioning after stroke: a one-year follow-up study. *Dementia and geriatric cognitive disorders*, *18*(2), 138-144.

Ray, J., Popli, G., & Fell, G. (2018). Association of cognition and age-related hearing impairment in the English longitudinal study of ageing. *JAMA Otolaryngology–Head & Neck Surgery*, *144*(10), 876-882.

Razaob, N. A., Tham, S. Y., Mohd Rasdi, H. F., Wan Yunus, F., & Kadar, M. (2020). Translation, Validation and Reliability Testing of Community Integration Questionnaire-Revised (CIQ-R) Malay Version: A Preliminary Study. *Occupational therapy in health care*, *34*(1), 32-47.

Reisberg, B., Ferris, S. H., Kluger, A., Franssen, E., Wegiel, J., & De Leon, M. J. (2008). Mild cognitive impairment (MCI): a historical perspective. *International Psychogeriatrics*, *20*(1), 18-31.

Reitan, R. M., & Wolfson, D. (1994). Dissociation of motor impairment and higher-level brain deficits in strokes and cerebral neoplasms. *The Clinical Neuropsychologist*, *8*(2), 193-208.

Reitan, R. M., & Wolfson, D. (1995). Category Test and Trail Making Test as measures of frontal lobe functions. *The Clinical Neuropsychologist*, *9*(1), 50-56.

Reitz, C., Tang, M. X., Manly, J., Mayeux, R., & Luchsinger, J. A. (2007). Hypertension and the risk of mild cognitive impairment. *Archives of neurology*, *64*(12), 1734-1740.

Richard, E.; Reitz, C.; Honig, L.H.; Schupf, N.; Tang, M.X.; Manly, J.J.; Luchsinger, J.A. Late-Life depression, mild cognitive impairment, and dementia. JAMA Neurol. 2013, 70, 383

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: health of caregivers of Alzheimer's and other dementia patients. *Current psychiatry reports*, *15*(7), 367.

Rimmer, E., Wojciechowska, M., Stave, C., Sganga, A., & O'Connell, B. (2005). Implications of the Facing Dementia Survey for the general population, patients and caregivers across Europe. *International Journal of Clinical Practice*, *59*, 17-24.

Robert, P. H., Berr, C., Volteau, M., Bertogliati-Fileau, C., Benoit, M., Guerin, O., & PréAL Study Group. (2008). Importance of lack of interest in patients with mild cognitive impairment. *The American Journal of Geriatric Psychiatry*, *16*(9), 770-776.

Roberts, R. O., Knopman, D. S., Mielke, M. M., Cha, R. H., Pankratz, V. S., Christianson, T. J., & Petersen, R. C. (2014). Higher risk of progression to dementia in mild cognitive impairment cases who revert to normal. *Neurology*, *82*(4), 317-325.

Robinson, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *64*(6), 788-798.

Robinson, S. M., Canavan, M., & O'Keeffe, S. T. (2014). Preferences of older people for early diagnosis and disclosure of Alzheimer's disease (AD) before and after considering potential risks and benefits. *Archives of gerontology and geriatrics*, *59*(3), 607-612.

Robinson-Whelen, S., Kim, C., MacCallum, R. C., & Kiecolt-Glaser, J. K. (1997). Distinguishing optimism from pessimism in older adults: Is it more important to be optimistic or not to be pessimistic?. *Journal of personality and social psychology*, *73*(6), 1345.

Rodakowski, J., Saghafi, E., Butters, M. A., & Skidmore, E. R. (2015). Non-pharmacological interventions for adults with mild cognitive impairment and early stage dementia: An updated scoping review. *Molecular aspects of medicine*, *43*, 38-53.

Rosano, C., Aizenstein, H. J., Cochran, J. L., Saxton, J. A., De Kosky, S. T., Newman, A. B., & Carter, C. S. (2005). Event-related functional magnetic resonance imaging investigation of executive control in very old individuals with mild cognitive impairment. *Biological psychiatry*, *57*(7), 761-767.

Roser, M., Ortiz-Ospina, E., & Ritchie, H. (2013). Life expectancy. "Life Expectancy". Published online at OurWorldInData.org.

Retrieved from: 'https://ourworldindata.org/life-expectancy' [Online Resource].

Rosnick, C. B., Small, B. J., McEvoy, C. L., Borenstein, A. R., & Mortimer, J. A. (2007). Negative life events and cognitive performance in a population of older adults. *Journal of Aging and Health*, *19*(4), 612-629.

Rozzini, L., Chilovi, B. V., Peli, M., Conti, M., Rozzini, R., Trabucchi, M., & Padovani, A. (2009). Anxiety symptoms in mild cognitive impairment. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, *24*(3), 300-305.

Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *The International Journal of Aging and Human Development*, *48*(3), 217-240.

Salthouse, T. A. (2011). What cognitive abilities are involved in trail-making performance?. *Intelligence*, *39*(4), 222-232.

Sander, A. M., Fuchs, K. L., High Jr, W. M., Hall, K. M., Kreutzer, J. S., & Rosenthal, M. (1999). The Community Integration Questionnaire revisited: an assessment of factor structure and validity. *Archives of physical medicine and rehabilitation*, *80*(10), 1303-1308.

Sandilyan, M. B., & Dening, T. (2015). Brain function, disease and dementia. *Nursing Standard (2014+)*, *29*(39), 36.

Santabárbara, J., Lipnicki, D. M., Villagrasa, B., Lobo, E., & Lopez-Anton, R. (2019). Anxiety and risk of dementia: Systematic review and meta-analysis of prospective cohort studies. *Maturitas*, *119*, 14-20.

Santabárbara, J., Lipnicki, D. M., Olaya, B., Villagrasa, B., Bueno-Notivol, J., Nuez, L., & Gracia-García, P. (2020). Does anxiety increase the risk of all-cause dementia? An updated meta-analysis of prospective cohort studies. *Journal of clinical medicine*, *9*(6), 1791.

Sapolsky, R. M. (2001). Depression, antidepressants, and the shrinking hippocampus. *Proceedings of the National Academy of Sciences*, *98*(22), 12320-12322.

Satizabal, C. L., Beiser, A. S., Chouraki, V., Chêne, G., Dufouil, C., & Seshadri, S. (2016). Incidence of dementia over three decades in the Framingham Heart Study. *New England Journal of Medicine*, *374*(6), 523-532

Scarmeas, N., Stern, Y., Mayeux, R., Manly, J. J., Schupf, N., & Luchsinger, J. A. (2009). Mediterranean diet and mild cognitive impairment. *Archives of neurology*, *66*(2), 216-225.

Scheff, S. W., Price, D. A., Schmitt, F. A., & Mufson, E. J. (2006). Hippocampal synaptic loss in early Alzheimer's disease and mild cognitive impairment. *Neurobiology of aging*, *27*(10), 1372-1384.

Schinka, J. A., Loewenstein, D. A., Raj, A., Schoenberg, M. R., Banko, J. L., Potter, H., & Duara, R. (2010). Defining mild cognitive impairment: impact of varying decision criteria on neuropsychological diagnostic frequencies and correlates. *The American Journal of Geriatric Psychiatry*, *18*(8), 684-691.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, *44*(sup3), 105-113.

Schulz, R., & Eden, J. (Eds.). (2016). *Families caring for an aging America* (pp. 2-6). Washington, DC: National Academies Press.

Shaw, W. S., Patterson, T. L., Ziegler, M. G., Dimsdale, J. E., Semple, S. J., & Grant, I. (1999). Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. *Journal of psychosomatic research*, *46*(3), 215-227.

Sherman, D. S., Mauser, J., Nuno, M., & Sherzai, D. (2017). The efficacy of cognitive intervention in mild cognitive impairment (MCI): a meta-analysis of outcomes on neuropsychological measures. *Neuropsychology review*, *27*(4), 440-484.

Shiri-Feshki, M. (2009). Rate of progression of mild cognitive impairment to dementia-Meta-analysis of 41 robust inception cohort studies.

Singh, U., & Sharma, V. (2015). Validity and reliability of community integration questionnaire in elderly. *International Journal of Health and Rehabilitation Sciences*, *4*(1), 1-9.

Sink, K. M., Espeland, M. A., Castro, C. M., Church, T., Cohen, R., Dodson, J. A., LIFE Study Investigators. (2015). Effect of a 24-month physical activity intervention vs health education on cognitive outcomes in sedentary older adults: the LIFE randomized trial. *Jama*, *314*(8), 781-790.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. *Qualitative health psychology: Theories and methods*, 218-240.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, *1*(1), 39-54.

Smith, T., Gildeh, N., & Holmes, C. (2007). The Montreal Cognitive Assessment: validity and utility in a memory clinic setting. *The Canadian Journal of Psychiatry*, *52*(5), 329-332.

Smith, J. A., & Shinebourne, P. (2012). *Interpretative phenomenological analysis*. American Psychological Association.

Snaith, R. P. (2003). The hospital anxiety and depression scale. *Health and quality of life outcomes*, *1*(1), 1-4.

Soininen, H. S., Partanen, K., Pitkänen, A., Vainio, P., Hänninen, T., Hallikainen, M., & Riekkinen, P. J. (1994). Volumetric MRI analysis of the amygdala and the hippocampus in subjects with age-associated memory impairment: Correlation to visual and verbal memory. *Neurology*, *44*(9), 1660-1660.

Solfrizzi, V., Panza, F., Colacicco, A. M., D'introno, A., Capurso, C., Torres, F., & Capurso, A. (2004). Vascular risk factors, incidence of MCI, and rates of progression to dementia. *Neurology*, *63*(10), 1882-1891.

Solfrizzi, V., Colacicco, A. M., D'Introno, A., Capurso, C., Del Parigi, A., Capurso, S. A., & Panza, F. (2006). Dietary fatty acids intakes and rate of mild cognitive impairment. The Italian Longitudinal Study on Aging. *Experimental gerontology*, *41*(6), 619-627.

Solfrizzi, V., D'Introno, A., Colacicco, A. M., Capurso, C., Del Parigi, A., Caselli, R. J., & Panza, F. (2007). Incident occurrence of depressive symptoms among patients with mild cognitive impairment–the Italian longitudinal study on aging. *Dementia and geriatric cognitive disorders*, *24*(1), 55-64.

Spector, A., Thorgrimsen, L., Woods, B. O. B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *The British Journal of Psychiatry*, *183*(3), 248-254.

Sperling, R. A., Aisen, P. S., Beckett, L. A., Bennett, D. A., Craft, S., Fagan, A. M., & Phelps, C. H. (2011). Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & dementia*, *7*(3), 280-292.

Stampfer, M. J. (2006). Cardiovascular disease and Alzheimer's disease: common links. *Journal of internal medicine*, *260*(3), 211-223.

Steffens, D. C. (2012). Depressive symptoms and mild cognitive impairment in the elderly: an ominous combination. *Biological psychiatry*, *71*(9), 762.

Stott, J., & Spector, A. (2011). A review of the effectiveness of memory interventions in mild cognitive impairment (MCI). *International Psychogeriatrics*, *23*(4), 526-538.

Studer, J., Donati, A., Popp, J., & von Gunten, A. (2014). Subjective cognitive decline in patients with mild cognitive impairment and healthy older adults: Association with personality traits. *Geriatrics & Gerontology International*, *14*(3), 589-595.

Tao, J., Liu, J., Chen, X., Xia, R., Li, M., Huang, M., & Kong, J. (2019). Mind-body exercise improves cognitive function and modulates the function and structure of the hippocampus and anterior cingulate cortex in patients with mild cognitive impairment. *NeuroImage: Clinical*, *23*, 101834.

Tarawneh, R., & Holtzman, D. M. (2012). The clinical problem of symptomatic Alzheimer disease and mild cognitive impairment. *Cold Spring Harbor perspectives in medicine*, *2*(5), a006148.

Tata, D. A., Marciano, V. A., & Anderson, B. J. (2006). Synapse loss from chronically elevated glucocorticoids: relationship to neuropil volume and cell number in hippocampal area CA3. *Journal of Comparative Neurology*, *498*(3), 363-374.

Teixeira, C. V. L., Gobbi, L. T. B., Corazza, D. I., Stella, F., Costa, J. L. R., & Gobbi, S. (2012). Non-pharmacological interventions on cognitive functions in older people with mild cognitive impairment (MCI). *Archives of gerontology and geriatrics*, *54*(1), 175-180.

Thies, W., & Bleiler, L. (2013). Alzheimer’s Association. *Alzheimer’s disease facts and figures. Alzheimers Dement*, *9*(2), 208e245.

Thomassen, Å. G., Hystad, S. W., Johnsen, B. H., Johnsen, G. E., & Bartone, P. T. (2018). The effect of hardiness on PTSD symptoms: A prospective mediational approach. *Military Psychology*, *30*(2), 142-151.

Tifratene, K., Robert, P., Metelkina, A., Pradier, C., & Dartigues, J. F. (2015). Progression of mild cognitive impairment to dementia due to AD in clinical settings. *Neurology*, *85*(4), 331-338.

United Nations. (2019) World Population ageing 2019: Rethinking population aging in the SDG era page 3 United Nations Department of Economic and Social Affairs, Population Division.

Van der Flier, W. M., Kunneman, M., Bouwman, F. H., Petersen, R. C., & Smets, E. M. (2017). Diagnostic dilemmas in Alzheimer's disease: room for shared decision making. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *3*(3), 301-304.

Varjacic, A., Mantini, D., Demeyere, N., & Gillebert, C. R. (2018). Neural signatures of Trail Making Test performance: Evidence from lesion-mapping and neuroimaging studies. *Neuropsychologia*, *115*, 78-87.

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological bulletin*, *129*(6), 946.

Waite, A., Bebbington, P., Skelton-Robinson, M., & Orrell, M. (2004). Social factors and depression in carers of people with dementia. *International Journal of Geriatric Psychiatry*, *19*(6), 582-587.

Waldemar, G., Dubois, B., Emre, M., Georges, J., McKeith, I. G., Rossor, M., & Winblad, B. (2007). Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline. *European Journal of Neurology*, *14*(1), e1-e26.

Wallace, J. C., Kass, S. J., & Stanny, C. J. (2002). The cognitive failures questionnaire revisited: dimensions and correlates. *The Journal of general psychology*, *129*(3), 238-256.

Ward, A., Arrighi, H. M., Michels, S., & Cedarbaum, J. M. (2012). Mild cognitive impairment: disparity of incidence and prevalence estimates. *Alzheimer's & Dementia*, *8*(1), 14-21.

Widlitz, M., & Marin, D. B. (2002). Substance abuse in older adults. An overview. *Geriatrics (Basel, Switzerland)*, *57*(12), 29-34.

Wilkinson, L., Masters, J., & Boron, J. (2021). COVID-19 and Its Impact on Older Adults' Routine and Urgent Health Care Visits. *Innovation in Aging*, *5*(Suppl 1), 723-723.

Willer, B., Ottenbacher, K. J., & Coad, M. L. (1994). The community integration questionnaire. A comparative examination. *American journal of physical medicine & rehabilitation*, *73*(2), 103-111.

Wilson, R. S., Schneider, J. A., Boyle, P. A., Arnold, S. E., Tang, Y., & Bennett, D. A. (2007). Chronic distress and incidence of mild cognitive impairment. *Neurology*, *68*(24), 2085-2092.

Winblad, B., Palmer, K., Kivipelto, M., Jelic, V., Fratiglioni, L., Wahlund, L. O., & Petersen, R. C. (2004). Mild cognitive impairment–beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *Journal of internal medicine*, *256*(3), 240-246.

Woolf, C., Slavin, M. J., Draper, B., Thomassen, F., Kochan, N. A., Reppermund, S., & Sachdev, P. S. (2016). Can the clinical dementia rating scale identify mild cognitive impairment and predict cognitive and functional decline?. *Dementia and Geriatric Cognitive Disorders*, *41*(5-6), 292-302.

World Health Organization. (2015). *World health statistics 2015*. World Health Organization.

World Health Organization. (2017). *Global diffusion of eHealth: making universal health coverage achievable: report of the third global survey on eHealth*. World Health Organization.

World Health Organization. (2019). *Global status report on alcohol and health 2018*. World Health Organization.

Wortmann, M. (2012). Dementia: a global health priority-highlights from an ADI and World Health Organization report. *Alzheimer's research & therapy*, *4*(5), 1-3.

Zarit, S. H., & Zarit, J. M. (2011). *Mental disorders in older adults: Fundamentals of assessment and treatment*. Guilford Press.

Zhang, H., Loi, S. M., Zhou, S. A., Zhao, M., Lv, X., Wang, J., & Wang, H. (2017). Dementia literacy among community-dwelling older adults in urban China: a cross-sectional study. *Frontiers in public health*, *5*, 124.

Zhang, Y., Chen, Y., & Ma, L. (2018). Depression and cardiovascular disease in elderly: current understanding. *Journal of Clinical Neuroscience*, *47*, 1-5.

Zhou, H., Sabbagh, M., Wyman, R., Liebsack, C., Kunik, M. E., & Najafi, B. (2017). Instrumented trail-making task to differentiate persons with no cognitive impairment, amnestic mild cognitive impairment, and Alzheimer disease: A proof of concept study. *Gerontology*, *63*(2), 189-200.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, *67*(6), 361-370.

Zwan, M. D., Bouwman, F. H., Konijnenberg, E., Van Der Flier, W. M., Lammertsma, A. A., Verhey, F. R., & Scheltens, P. (2017). Diagnostic impact of [18 F] flutemetamol PET in early-onset dementia. *Alzheimer's research & therapy*, *9*(1), 1-8.

Appendices

Appendix A Tallaght Ethical Approval

Tallaght University Hospital | Ospidéal Ollscoile Thamhlachta

An Academic Partner of Trinity College Dublin

SJH/TUH Research Ethics Committee Secretariat
email: researchethics@tuh.ie

Ms Serena Marley,
NUI Maynooth,
Co Kildare

12th November 2019

REF: An examination of Cognitive and Psychological outcomes of a neuro-education programme for individuals living with mild cognitive impairment

REC: 2019-11 Chairman's Action (5)
(Please quote reference on all correspondence)

Date of Valid Submission to REC: 30.05.2019
Date of Ethical Review: 11.11.2019
Research and Innovation Application Number: N/A

Dear Ms Marley,

The REC is in receipt of your recent request to TUH/SJH Research Ethics Committee in which you queried ethical approval for the above named study.

The Chairman, Prof. Richard Dean, on behalf of the Research Ethics Committee, has reviewed your correspondence given full approval for this study to proceed. If Ms Marley is to be on site in TUH please ensure she registers with TUH HR.

Applicants must submit an annual report for ongoing projects and an end of project report upon completion of the study. It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018. ***Additionally, please note for documents submitted for GDPR purposes that the REC and the Chair are not confirming that you're documents are GDPR compliant, they are approving the document from an ethical perspective.***

Yours sincerely,

Sadhbh O'Neill

REC Officer – Dr Sadhbh O'Neill
SJH/TUH Research Ethics Committee

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

Appendix B Maynooth University Ethical Approval

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Maynooth University
National University of Ireland Maynooth

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

17 July 2019

Serena Marley
Department of Psychology
Maynooth University

RE: Application for Ethical Approval for a project entitled: An examination of cognitive and psychological outcomes of a neuro-education programme for individuals living with Mild Cognitive Impairment

Dear Serena,

The Ethics Committee evaluated the above project and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 01 August 2021.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Dr Richard Roche, Department of Psychology
Dr Sean Commins, Department of Psychology

Appendix C Letter of Invitation

Letter of Invitation to Participate

National University of Ireland Maynooth,

Maynooth,

Co. Kildare.

29th January 2020.

To whom it may concern,

My name is Serena Marley, and I am a psychology masters student in Maynooth university. I wish to invite you to participate in a project that will investigate the cognitive and psychological outcomes of a neuroeducation programme for people living with Mild Cognitive impairment and their families.

We would like to examine whether informing people living with MCI about their condition can help lessen anxiety, stress and depression, and also improve quality of life and cognitive function. The project involves a series of paper and pen tasks, and a 4 week power point presentation which will be conducted in or near Tallaght University hospital. All information collected will be confidential, and you can withdraw from the study at any point in time.

If you are willing to help us by participating in this study, we ask that you read the **Information Sheet** attached to this letter of invitation, and then to further read and sign a **Letter of Consent** which accompanies this information sheet. We are very grateful for your participation.

Please find my contact information below, and should you have any further questions, please don't hesitate to contact me.

Thank you

Contact details

Serena Marley

Serena.marley.2015@mumail.ie

Department of Psychology Maynooth University,

Co. Kildare, Ireland.

Appendix D Information Leaflet

Information Sheet:

An Examination of cognitive and psychological outcomes of a neuroeducation programme for individuals living with Mild Cognitive Impairment and their caregivers.

Postgraduate Researcher:

Serena Marley

Serena.marley.2015@mumail.ie

Department of Psychology Maynooth University,

Co. Kildare, Ireland.

Supervisors:

Dr. Richard Roche

Richard.Roche@mu.ie

Tel: 017086069

Dr. Sean Commins

Sean.Commins@mu.ie

Tel: 017086182

Your participation is requested in a collaborative experimental study between Tallaght Hospital and the Department of Psychology at Maynooth University. The study aims to examine the effects of a neuroeducation programme for those living with Mild Cognitive Impairment (MCI). This information sheet will give you an overview of the study.

What is the study about?

We are interested in the effect that an education programme, in particular neuroeducation programme, may have on those who are living with conditions such as MCI. We want to examine whether informing people living with MCI about their condition can help lessen anxiety and stress, and possibly improve cognitive functioning and quality of life.

What does it involve? What would I have to do?

Initially we will ask you to engage in a series of questionnaires and tests relating to memory, attention, activities of daily living and quality of life. These questionnaires/tests should take no longer than 60 minutes to complete from start to finish. These questionnaires will be posted out or emailed to you directly. A follow-up telephone call or MS Teams meeting will be made from the researcher, and she will record the answers that you give using a zoom recorder. On completion of this, you will be invited to participate in neuroeducation programme lasting up to 6 weeks, which will take one-hour per week, these sessions will take place. A link will be sent to you where you can access the material at your own leisure and the researcher will then call to discuss the material no later than five days after you receive the neuroeducation programme link. Those not taking part in the neuroeducation programme will be asked to continue their care as normal. After the neuroeducation programme, you will then be asked to retake the questionnaires that you completed at the beginning of this study.

Are there any risks to me?

There are no risks associated with this study; all the questionnaires will involve either filling in answers with pen and paper, or speaking your answers aloud. However, should you feel any discomfort, or upset during any part of this research, do not hesitate to inform the researcher who will do everything in her power to ensure that you are put at ease. If you require breaks just inform the researcher. The researcher will remain present at all times during this process. The questions that you can expect to be asked are straightforward and will similar to these: “I feel free to plan my future”. You will then be asked to rate on a scale of 0-3 how accurate this statement is. Other questions such as “Worrying thoughts go through my mind” will be asked and again you will be asked to rate how accurate this statement is for you. The neuroeducation programme will involve attending a group session and listening to a speaker for 40-45 minutes, followed by a question and answer session and an open discussion. In the unlikely event that you have any concerns about any aspect of your

performance on the questionnaires/tests, or about any aspects of the neuroeducation programme, you can contact myself, Drs. Richard Roche or Sean Commins or your consulting physician with these concerns. Contact information is at the beginning of this information leaflet.

Limits to Confidentiality;

In such instances information may be disclosed to significant others or appropriate third parties without permission being sought. Where possible a full explanation will be given to the participant regarding the necessary procedures and intended actions which may need to be taken. This occurs in one of two ways: 1. If a strong belief exists that there is a serious risk of harm or danger to either the client or another individual. This may relate to issues surrounding sexual /physical /emotional abuse; child sexual abuse; child protection issues; rape; self-harm; suicidal intent; violence or criminal activity. 2. Occasions when disclosure is required as part of a legal process or Garda investigation. In such instances information may be disclosed to significant others or appropriate third parties without permission being sought. Where possible a full explanation will be given to the client/ student regarding the necessary procedures and intended actions that may need to be taken.

GDPR Guidelines;

In accordance with legislation, your data will be coded, meaning your name will not be associated with any information that you give. Your name will only appear on the consent form, which will be stored separately to any data collected. On the consent form you will also be asked if the two supervisors, Drs. Richard Roche and Sean Commins can have access to this information. All results of the tasks and answered questionnaires will be stored on an encrypted computer or in a locked filing cabinet in the Department of Psychology, Maynooth University. Information will be retained until 2026 to allow for completion of a Masters project, and also for publication of any results that this project yields. Following this, all data will be destroyed by either Drs. Richard Roche or Sean Commins. If your information is needed for anything else, you will be contacted and consent will be sought again. Furthermore if you wish to make a complaint about how your data will be handled, you can log a complaint with the Data Protection Commissioner 21 Fitzwilliam Square, Dublin 2 DO2 RD28, Phone: 0761 104 800.

What happens to my test scores?

The printed data from your participation (i.e. test scores) will be strictly confidential and will be kept in a locked cabinet in the Psychology Department. Your results will be kept confidential by assigning a random number to each participant instead of your name. Aside from your name and age, no other personal data will be recorded. With the exception of the researcher(s) involved in running this study, nobody will be allowed to see or discuss any of your data. Your data will be combined with many others and reported in group form – averages etc. – only group and not individual scores will be used.

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Can I withdraw from the study?

Yes, you may withdraw from the study at any time, and your data will not be included in the study. If you are willing to help us by participating in this study, we will ask you to sign a **Letter of Consent** which accompanies this information sheet. We are very grateful for your participation.

If you suffer from **any** of the following, you may **not** be eligible to take part:

- History of drug or alcohol abuse;
- History of Traumatic Brain Injury (TBI), or Acquired Brain Injury (ABI);
- History of Psychiatric Conditions;
- Current diagnosis of anxiety and/or depression;
- Motor Function Impairments;
- Evidence of Epilepsy;
- Aphasia;

If you suffer from/have suffered from any of the above, please let us know so that we can determine if you are still eligible to take part.

Thank you

Appendix E Consent Form

Informed consent form for Student research

In agreeing to participate in the research I have an understanding of the following:

This Research is being conducted by Serena Marley as an postgraduate student of the Psychology Department within Maynooth University. The research has been approved in principle by the Ethics Committee of Maynooth University, and Tallaght Hospital. There are no ethical concerns within this study. However, it is the above named student's responsibility to follow the ethical guidelines when they are interacting with any and all participants taking part in the research including, and not limited to the handling and collection of data. If I have any concerns about my involvement within the research, I understand that I can refuse to participate at any stage. I also have the option of withdrawing my data up until the point of publication, and I can view my data at any given point during the research process

I have been given a brief description of what is involved and what the research is looking at. There is no degree of discomfort associated with my participation in this study and I am aware that all my information will be handled in the strictest confidence. I am also consenting to the researchers supervisors Drs. Richard Roche and Sean Commins to have access to my information should they require it, but all ethical and GDPR guidelines will be followed at all times. The data from all participants within this study will be complied, analysed and then submitted in a report to the Psychology Department of Maynooth

University, and will also be published in a peer reviewed journal. No participant will be identified by name at any point for the data analysis or in the final report. If at the end of my participation I have any questions or concerns, these will be addressed fully.

Signed…….. Participant

Signed…….. Researcher

Date……..

CONSENT FORM

An examination of cognitive and psychological outcomes of a neuroeducation programme, for individuals living with Mild Cognitive Impairment.

To be completed by the **PARTICIPANT**:

I have read and understood the information leaflet.	YES	NO
I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.	YES	NO
I have received enough information about this study.	YES	NO
I understand that I am free to withdraw from the study at any time without giving a reason and this will not affect my future medical care.	YES	NO
I agree to allow the researchers use my information (personal data) as part of this study as outlined in the information leaflet.	YES	NO
I agree to allow the researchers access my medical records as part of this study *(if applicable)*	YES	NO
I agree to be contacted by researchers as part of this study *(if applicable)*	YES	NO
I consent to take part in this research study having been fully informed of the risks, benefits and purpose of the study	YES	NO
I give my explicit consent to have my data processed as part of this research study'	YES	NO
I consent to be potentially contacted again at a later date for a follow-up to this study.	YES	NO

Participant's Name (Block Capitals):	
Participant's Signature:	
Date:	

To be completed by the **RESEARCHER**:

I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could	YES	NO

understand. I have invited him/her to ask questions on any aspect of the study.		
I confirm that I have given a copy of the information leaflet and consent form to the participant.	YES	NO

Researcher's Name (Block Capitals):	
Researcher's Title & Qualifications:	
Researcher's Signature:	
Date:	

Appendix F: Trail Making Task (TMT)

Trail Making Test (TMT) Parts A & B

Instructions:

Both parts of the Trail Making Test consist of 25 circles distributed over a sheet of paper. In Part A, the circles are numbered 1 – 25, and the patient should draw lines to connect the numbers in ascending order. In Part B, the circles include both numbers (1 – 13) and letters (A – L); as in Part A, the patient draws lines to connect the circles in an ascending pattern, but with the added task of alternating between the numbers and letters (i.e., 1-A-2-B-3-C, etc.). The patient should be instructed to connect the circles as quickly as possible, without lifting the pen or pencil from the paper. Time the patient as he or she connects the "trail." If the patient makes an error, point it out immediately and allow the patient to correct it. Errors affect the patient's score only in that the correction of errors is included in the completion time for the task. It is unnecessary to continue the test if the patient has not completed both parts after five minutes have elapsed.

Step 1:	Give the patient a copy of the Trail Making Test Part A worksheet and a pen or pencil.
Step 2:	Demonstrate the test to the patient using the sample sheet (Trail Making Part A – *SAMPLE*).
Step 3:	Time the patient as he or she follows the "trail" made by the numbers on the test.
Step 4:	Record the time.
Step 5:	Repeat the procedure for Trail Making Test Part B.

Scoring:

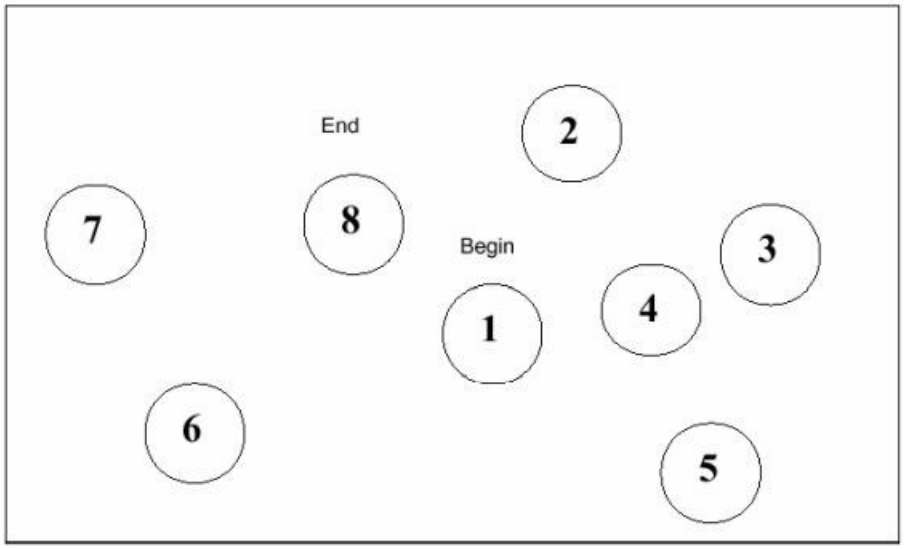
Results for both TMT A and B are reported as the number of seconds required to complete the task; therefore, higher scores reveal greater impairment.

	Average	Deficient	Rule of Thumb
Trail A	29 seconds	> 78 seconds	Most in 90 seconds
Trail B	75 seconds	> 273 seconds	Most in 3 minutes

Sources:

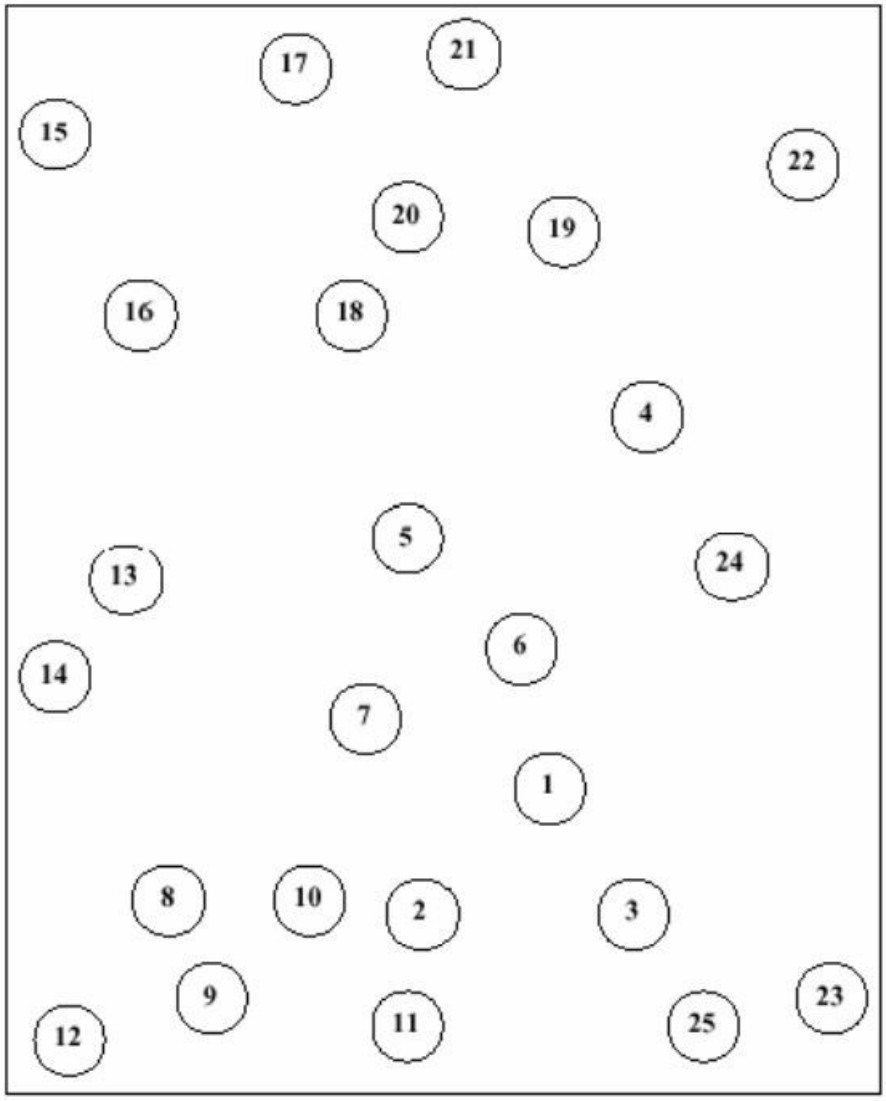
- Corrigan JD, Hinkeldey MS. Relationships between parts A and B of the Trail Making Test. *J Clin Psychol*. 1987;43(4):402–409.
- Gaudino EA, Geisler MW, Squires NK. Construct validity in the Trail Making Test: what makes Part B harder? *J Clin Exp Neuropsychol*. 1995;17(4):529-535.
- Lezak MD, Howieson DB, Loring DW. *Neuropsychological Assessment*. 4th ed. New York: Oxford University Press; 2004.
- Reitan RM. Validity of the Trail Making test as an indicator of organic brain damage. *Percept Mot Skills*. 1958;8:271-276.

Trail Making Test Part A – *SAMPLE*

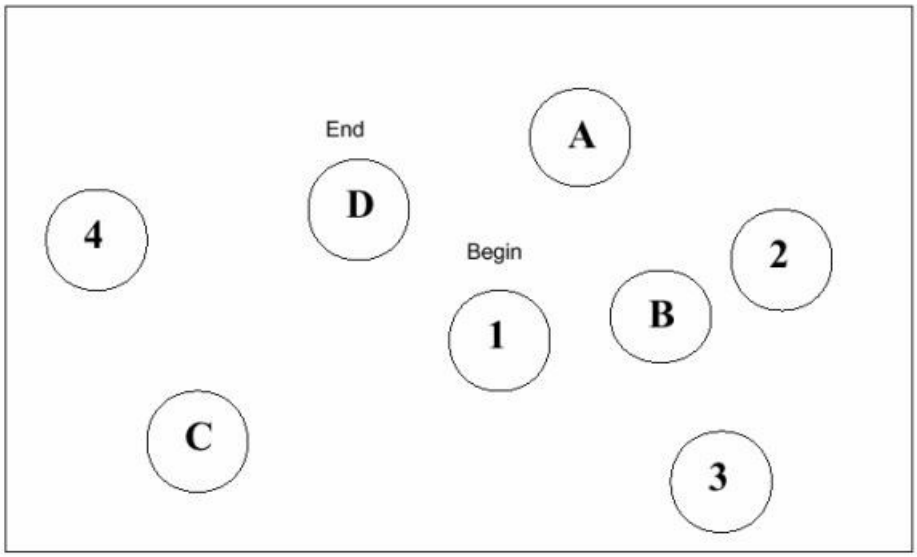


Trail Making Test Part A

Patient's Name: _____ Date: _____

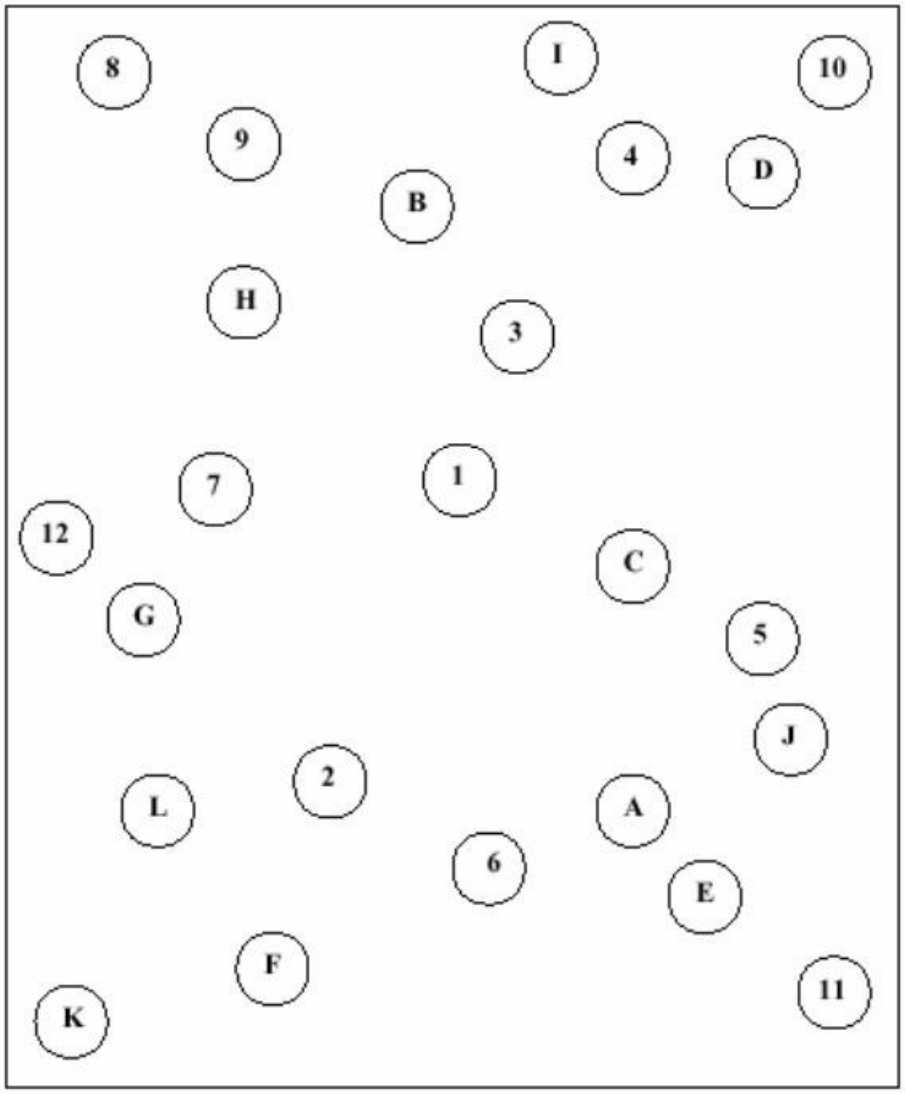


Trail Making Test Part B – *SAMPLE*

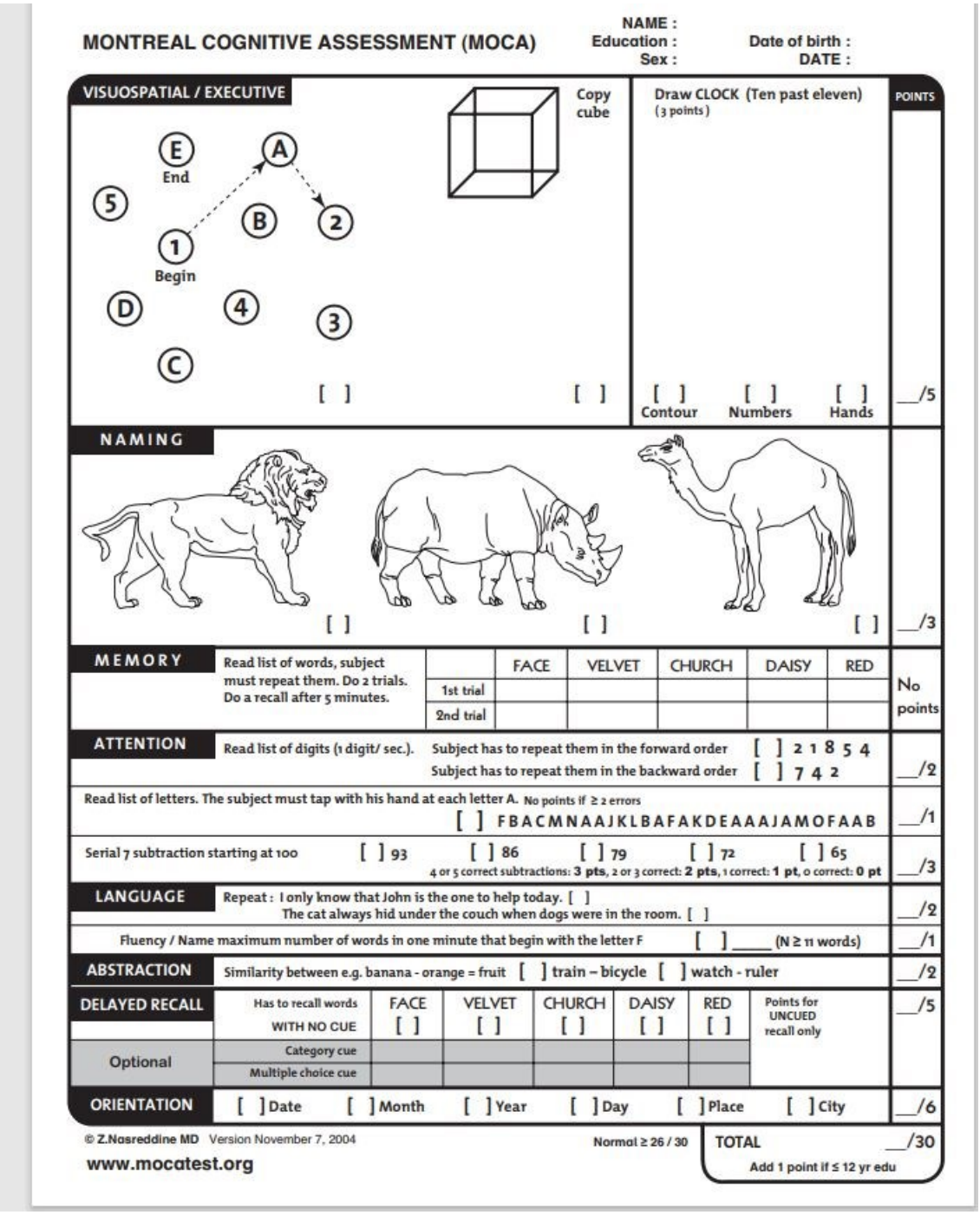


Trail Making Test Part B

Patient's Name: _____ Date: _____



Appendix G: Montreal of Cognitive Assessment (MoCA)



MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education :
Sex :
Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE — POINTS

Copy cube [ ]

Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands — __/5

NAMING [ ] [ ] [ ] — __/3

MEMORY Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

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
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B — __/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 — __/5

	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
		[ ]	[ ]	[ ]	[ ]	[ ]	
Optional	Category cue						
	Multiple choice cue						

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City — __/6

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www.mocatest.org

Normal ≥ 26 / 30

TOTAL __/30
Add 1 point if ≤ 12 yr edu

Appendix H: Cognitive Failure Questionnaire (CFQ)

The Cognitive Failures Questionnaire (Broadbent, Cooper, FitzGerald & Parkes, 1982)

The following questions are about minor mistakes which everyone makes from time to time, but some of which happen more often than others. We want to know how often these things have happened to your in the past 6 months. Please circle the appropriate number.

		Very often	Quite often	Occasion-ally	Very rarely	Never
1.	Do you read something and find you haven't been thinking about it and must read it again?	4	3	2	1	0
2.	Do you find you forget why you went from one part of the house to the other?	4	3	2	1	0
3.	Do you fail to notice signposts on the road?	4	3	2	1	0
4.	Do you find you confuse right and left when giving directions?	4	3	2	1	0
5.	Do you bump into people?	4	3	2	1	0
6.	Do you find you forget whether you've turned off a light or a fire or locked the door?	4	3	2	1	0
7.	Do you fail to listen to people's names when you are meeting them?	4	3	2	1	0
8.	Do you say something and realize afterwards that it might be taken as insulting?	4	3	2	1	0
9.	Do you fail to hear people speaking to you when you are doing something else?	4	3	2	1	0
10.	Do you lose your temper and regret it?	4	3	2	1	0
11.	Do you leave important letters unanswered for days?	4	3	2	1	0
12.	Do you find you forget which way to turn on a road you know well but rarely use?	4	3	2	1	0
13.	Do you fail to see what you want in a supermarket (although it's there)?	4	3	2	1	0
14.	Do you find yourself suddenly wondering whether you've used a word correctly?	4	3	2	1	0

		Very often	Quite often	Occasion-ally	Very rarely	Never
15.	Do you have trouble making up your mind?	4	3	2	1	0
16.	Do you find you forget appointments?	4	3	2	1	0
17.	Do you forget where you put something like a newspaper or a book?	4	3	2	1	0
18.	Do you find you accidentally throw away the thing you want and keep what you meant to throw away – as in the example of throwing away the matchbox and putting the used match in your pocket?	4	3	2	1	0
19.	Do you daydream when you ought to be listening to something?	4	3	2	1	0
20.	Do you find you forget people's names?	4	3	2	1	0
21.	Do you start doing one thing at home and get distracted into doing something else (unintentionally)?	4	3	2	1	0
22.	Do you find you can't quite remember something although it's "on the tip of your tongue"?	4	3	2	1	0
23.	Do you find you forget what you came to the shops to buy?	4	3	2	1	0
24.	Do you drop things?	4	3	2	1	0
25.	Do you find you can't think of anything to say?	4	3	2	1	0

References

Broadbent, D.E., Cooper, P.F., FitzGerald, P., & Parkes, K.R. (1982). The Cognitive Failures Questionnaire (CFQ) and its correlates. *British Journal of Clinical Psychology*, *21*, 1-16.

Appendix I: Hospital Anxiety Depression Scale (HADS)

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) _____ Anxiety (A) _____
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Appendix J: Community Integration Questionnaire (CIQ)

Community Integration Questionnaire

Name:_____ Date:_____

Home Integration	Answer (circle one)	Score
1. Who usually does shopping for groceries or other necessities in your household?	Yourself alone (2) Yourself and someone else (1) Someone else (0)	
2. Who usually prepares meals in your household?	Yourself alone (2) Yourself and someone else (1) Someone else (0)	
3. In your home who usually does normal everyday housework?	Yourself alone (2) Yourself and someone else (1) Someone else (0)	
4. Who usually cares for the children in your home?	Yourself alone (2) Yourself and someone else (1) Someone else (0) Not applicable (score is the average of 1,2,3 and 5)	
5. Who usually plans social arrangements such as get-togethers with family and friends?	Yourself alone (2) Yourself and someone else (1) Someone else (0)	
Home Integration Total Score	Add the above scores together	
Social Integration		
6. Who usually looks after your personal finances such as banking or paying bills?	Yourself alone (2) Yourself and someone else (1) Someone else (0)	
Can you tell me approximately how many times a month you now usually participate in the following activities outside your home?		
7. Shopping	5 or more (2) 1 – 4 times (1) Never (0)	
8. Leisure activities such as movies, sports, restaurants	5 or more (2) 1 – 4 times (1) Never (0)	
9. Visiting friends or relatives	5 or more (2) 1 – 4 times (1) Never (0)	

10. When you participate in leisure activities do you usually do this alone or with other?	mostly alone (0) mostly with friends who have head injuries (1) mostly with family members (1) mostly with friends who do not have head injuries (2) with a combination of family and friends (2)	
11. Do you have a best friend with whom you confide?	Yes (2) No (0)	
Social Integration Total Score	Add the above scores together	
Integration into Productive Activities		
12. How often do you travel outside the home?	almost every day (2) almost every week (1) seldom/never (less than once per week) (0)	
13. Please choose the answer below that best corresponds to your current (during the past month) work situation: *Please see scoring for this item on next page*	Full-time employment (>20 hours/week) Part Time Employment (≤ 20 hours/week) Not working, but actively looking for work Not working, not looking for work Not applicable, retired due to age Volunteer job in the community	
14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation *Please see scoring for this item on next page*	Full-time Part-time Not attending school or training program	
15. In the past month, how often did you engage in volunteer activities? *Please see scoring for this item on next page*	5 or more 1 – 4 times Never	
Total Score		

Appendix K: Satisfaction with Life Scale (SWLS)

Scale:

Instructions: Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

____ In most ways my life is close to my ideal.

____ The conditions of my life are excellent.

____ I am satisfied with my life.

____ So far I have gotten the important things I want in life.

____ If I could live my life over, I would change almost nothing.

Scoring:

Though scoring should be kept continuous (sum up scores on each item), here are some cut-offs to be used as benchmarks.

- 31 - 35 Extremely satisfied
- 26 - 30 Satisfied
- 21 - 25 Slightly satisfied
- 20 Neutral
- 15 - 19 Slightly dissatisfied
- 10 - 14 Dissatisfied
- 5 - 9 Extremely dissatisfied

Appendix L: Control Autonomy Self-Realization and Pleasure (CASP-19)

CASP-19

Participant Number _____

Age _____

M/F _____

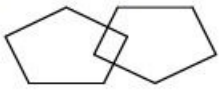
Item no	Sub-domain item no		Often	Sometimes	Not often	Never
1	C1	My age prevents me from doing the things I would like to	0	1	2	3
2	C2	I feel that what happens to me is out of my control	0	1	2	3
3	C3	I feel free to plan for the future	3	2	1	0
4	C4	I feel left out of things	0	1	2	3
5	A1	I can do the things that I want to do	3	2	1	0
6	A2	Family responsibilities prevent me from doing what I want to do	0	1	2	3
7	A3	I feel that I can please myself what I do	3	2	1	0
8	A4	My health stops me from doing things I want to do	0	1	2	3
9	A5	Shortage of money stops me from doing the things I want to do	0	1	2	3
10	P1	I look forward to each day	3	2	1	0
11	P2	I feel that my life has meaning	3	2	1	0
12	P3	I enjoy the things that I do	3	2	1	0
13	P4	I enjoy being in the company of others	3	2	1	0
14	P5	On balance, I look back on my life with a sense of happiness	3	2	1	0
15	SR1	I feel full of energy these days	3	2	1	0
16	SR2	I choose to do things that I have never done before	3	2	1	0
17	SR3	I feel satisfied with the way my life has turned out	3	2	1	0
18	SR4	I feel that life is full of opportunities	3	2	1	0
19	SR5	I feel that the future looks good for me	3	2	1	0

Appendix M: Mini Mental State Exam (MMSE)

Mini-Mental State Examination (MMSE)

Patient's Name: _____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

Interpretation of the MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8th grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

Source:

- Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975;12:189-198.