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Living with and caring for dementia: The effects of a novel intervention on quality of life in a case series

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Abstract

Background: Dementia is associated with several modifiable risk factors including physical activity, cognitive stimulation, and social engagement. Caregiver burden is common among dementia carers and may be reduced with educational and emotional support. In partnership with the Sphere Memory and Rehabilitation Team (SMaRT), a private cognitive health provider in the East Riding of Yorkshire, we implemented a novel 'Psychosocial Intervention for Dementia' (PID) programme. **Aims:** The primary aim of this study was to evaluate the effectiveness of the SMaRT PID, to improve quality of life (QoL) for people living with dementia and their carers, in a pragmatic case-series. A secondary aim of this study was to explore the effects of the national lockdown as a result of the Coronavirus-19 (COVID-19) pandemic on QoL. **Methods:** Six individuals (age 81.5 ± 7 years [y]) living with dementia and their carers completed the SMaRT PID, combining the physical and educational training stimuli delivered in a social setting, once weekly, over six weeks. Physical capacity, QoL, and carer burden were measured at baseline and on completion of the intervention. Semi-structured interviews explored the participants' detailed perceptions of their QoL. Additionally, six individuals living with dementia (aged 76.4 ± 5.6 y) and their spousal carers completed semi-structured telephone interviews and QoL questionnaires during the first COVID-19 lockdown between April and May 2020. Results: Two of the physical tests (Berg Balance Scale and grip strength) revealed improvements or maintenance in four participants (~66%). There were no consistent changes on any other outcome measure following participation in the SMaRT PID. Analysis of results emphasised the importance of emotional support during the period of lockdown. **Discussion:** This case-series highlights the potential value of a locally delivered, combined intervention. However, a more personalised training programme may be more beneficial to people living with dementia based on the individual variability of symptoms. Overall, emotional support appears to be paramount for maintaining QoL for people living with dementia and their carers, particularly in the face of a global pandemic.

1. Introduction

Dementia is an umbrella term encompassing various dementia subtypes including Alzheimer's disease, vascular dementia, and frontotemporal dementia. Dementia is categorised by a progressive and severe decline in cognitive functioning, specifically including reductions in complex attention, executive functioning, learning and memory, language, perceptual motor cognition, and social cognition (American Psychiatric Association, 2013). The known pathologies associated with dementia development increase with age and vary between (and within) dementia types (Power et al., 2018). Thus, without a clear knowledge of a specific cause(s), it may not be possible to develop a universal cure (Fymat, 2019).

The additional financial support associated with dementia incidence, places a considerable socioeconomic burden on individuals living with dementia, their family, and on society as a whole (Wimo et al., 2017). Recent statistical modelling (Wittenberg et al., 2019), using previously published dementia data from England (2015), explored the financial implications as a consequence of dementia at a national level. The authors estimated that the total cost of dementia care in England was approximately £23 billion, which equated to £3.6 billion of healthcare costs, £9.8 billion social care costs (of which £3.9 billion were met by local authorities and £5.9 billion by service users), and £9.5 billion of opportunity costs (loss of potential gain) of unpaid care by family and friends, respectively. Further, financial analysis identified that it would cost £46,000 per annum, per person, to ensure that adequate 'quality of life' was met and sustained. With the prevalence of dementia expected to rise alongside the ageing population, overall costs associated with dementia in England are expected to rise to £81 billion (or £59,000 per person) per annum by 2040 (Wittenberg et al., 2019).

Typically, older adults living with dementia often live independently, until they reach a point of vulnerability, at which time their family members, close friends, or general practitioner (GP), suggest a form of intervention. It has been estimated that around 540,000 people in England are currently caring for someone living with dementia (NHS Digital, 2020a), with one in every three people expected to care for a person living with dementia in their lifetime. Estimations (Government Digital Service, 2015) have suggested that approximately 50,000 people in England left work in order to care for an individual living with dementia, with a further 66,000 people significantly reducing their working hours to care for a person living with dementia (Government Digital Service, 2015). Therefore, with a rising incidence of dementia (as previously mentioned), it would be reasonable to assume these figures have since increased and will continue to do so.

Following the release of the Prime Minister's 'Challenge on Dementia 2020' (Cabinet Office, 2015), dementia was set to be a key priority for the NHS England and the Government. The paper detailed a requirement for support after diagnosis, which may consist of cognitive stimulation therapy, admiral nurses (to provide specialist support to families), and social action solutions (such as peer support and befriending services), which ultimately aim to improve quality of life for people living with dementia. The National Institute for Health and Care Excellence (NICE) suggest that in order to improve quality of life for people living with dementia, interventions may be used to promote cognition, independence, and wellbeing. These should include a range of activities that are tailored to the person's preferences, group cognitive stimulation, group reminiscence therapy, and cognitive rehabilitation or occupational therapy to support functional ability. Moreover, carers of people living with dementia should receive psychoeducation and skills training, which aim to provide them with the tools required to support the person living with dementia, while still looking after their own physical and mental health (NICE, 2018). Currently, there are no ‘gold standard’ interventions for people living with dementia and their carers.

The Alzheimer’s Society appears to be leading the way in delivering dementia-related support within the United Kingdom (UK). They provide support services for people living with dementia and their families, namely: activity groups, befriending services, information services (which provide information relating to dementia development and advice / guidance on dementia support), home care support and day services, and respite for carers. These services are available nationally and service users have reported great benefits following their interactions with the organisation (The Alzheimer's Society, 2020). However, people living with dementia and their carers may require a multiple of those services in order to gain the sufficient support required to achieve their desired level of quality of life. Therefore, a service that offers a holistic approach, combining these services may be beneficial to both people living with dementia and their carers.

In an attempt to address this gap in the service provision, some private service providers have emerged, who aim to combine physical activity, cognitive stimulation, social engagement, and support, with education, into a single service package for people affected by dementia. These service providers, specifically the Sphere Memory and Rehabilitation Team (https://sphere-rehab.co.uk; a local [East Riding of Yorkshire] multidisciplinary group of individuals, specialising in the rehabilitation of individuals with a range of neurological problems), have developed a holistic intervention, designed to be delivered in a group setting on a weekly basis, with supplementary home-based physical and cognitive tasks. Ultimately, by combining these elements, specialist service providers aim to improve quality of life in people living with dementia and reduce the level of carer burden experienced. At the time of writing, we are unaware of any local services that offer a holistic approach to improving or maintaining quality of life for people living with dementia and their carers.

1.1 Aims

In light of this, this thesis aims to evaluate and quantify the effectiveness of a bespoke, holistic intervention delivered by a specialist service provider (The Sphere Memory and Rehabilitation Team) for people living with dementia and their carers within the East Riding of Yorkshire. This study quantifies and evaluates the perceived quality of life, depression, anxiety, and physical capacity, prior to and following their single service, holistic intervention. A secondary aim was to explore the well-being of this population group as a result of social restrictions put in place by the government (commonly referred to as ‘lockdown’) in an attempt to combat the effects of a global pandemic (COVID-19).

2. Literature review

This literature review will outline the current scientific knowledge pertaining to dementia, specifically focusing on the pathophysiology, quality of life, and modifiable risk factors (i.e., physical activity levels, cognitive stimulation, and social engagement); and will critically appraise previous interventions. Further, this thesis will review the literature associated with the burden placed on those individuals caring for people living with dementia.

2.1. The Pathophysiology of Dementia

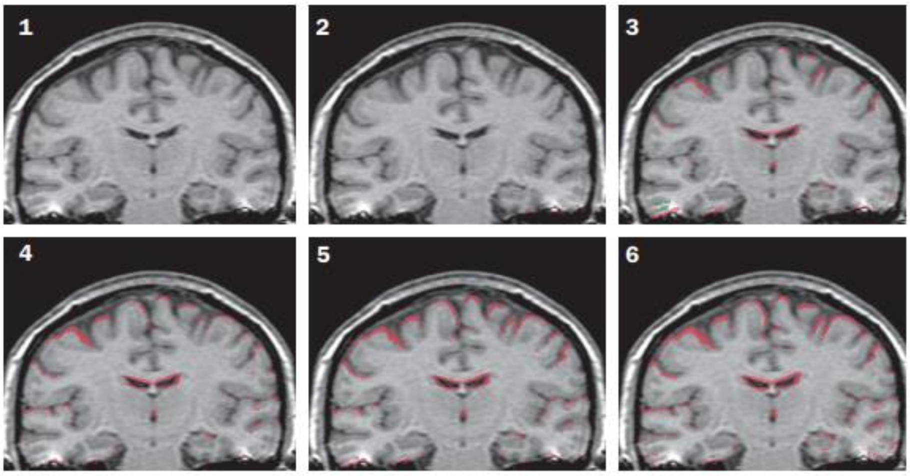
The nervous system is comprised of two cell types: neurons and glia cells (Stogsdill & Erogli, 2016). Neurons, and the communication between them, are essential for all cognitive processes. Glia cells play a supportive role and aid in the regulation of, and communication between neurons. Disruptions in cognitive functioning occur when neuronal ability or behaviour is disturbed. Neurodegeneration, defined as 'the progressive damage and/or death of neurons' is an expected process of normal ageing, which explains the apparent decline in cognitive function and memory retention in older adults (Fjell et al., 2009). Neurodegeneration associated with normal cognitive ageing does not disrupt the ability to perform activities of daily living. Despite this, it has been well documented that the prevalence of dementia is significantly associated with age, specifically in those >65 years old (Verhaeghen & Salthouse, 1997).

A variety of age related neuropathologies may contribute to the amplified neurodegeneration experienced by dementia patients (Tanskanen et al., 2017). For example, the development of Alzheimer's disease is associated with a build-up of proteins, amyloid-β, tau and α-synuclein (which may also be present in normal ageing, but to a lesser extent). The build-up of these proteins forms barriers for synaptic transmission, which hinder the communication between neurons (Compta et al., 2014; Nonaka et al., 2018), and ultimately lead to neurodegeneration and cerebral atrophy beyond that expected in relation to age and lifestyle.

Ezekiel et al. (2004) utilised magnetic resonance imaging (MRI) technology, specifically the boundary shift integral method (Freeborough & Fox, 1997), to quantify the heightened neurodegeneration in people living with dementia over a two-year period, compared to age-matched controls. Patients with Alzheimer's disease were found to display a significant reduction in brain volume (-5%), compared to controls. This evidenced the accelerated level of cerebral atrophy in those with Alzheimer's disease. Furthermore, Fox and Schott (2004) provided a visual representation of the neurodegeneration experienced by an individual during the development of Alzheimer's disease (patient X). The authors adapted the MRI data from a previous four-year longitudinal study (Rusinek et al., 2003) and the brain images were adapted to include a red overlay, which highlights the progressive rate of atrophy over time (Figure 1).

Figure 1

Neurodegeneration of the brain during the development of Alzheimer's disease

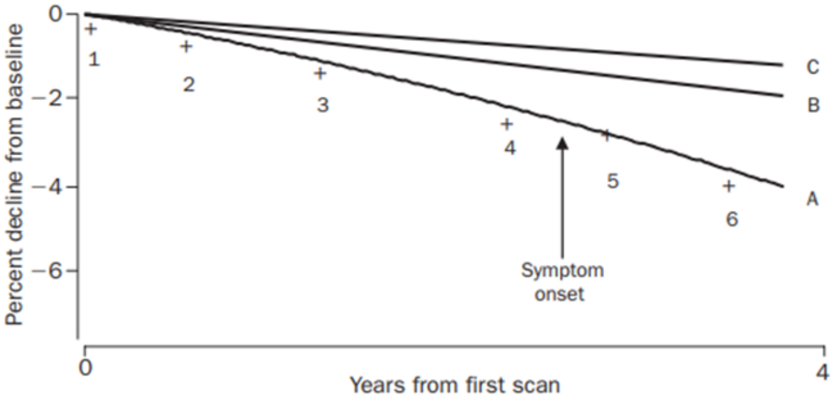


Six serially acquired T1-weighted MRI scans (adapted from Rusinek et al., 2003), positionally matched, from one individual who was asymptomatic of Alzheimer's disease at baseline, but began to display symptoms between scans 4 and 5. Scans were taken over a four-year period. Red overlay represents tissue loss compared to baseline.

In addition, Fox and Schott (2004) plotted the percentage decline of brain volume for patient X against the average rate of decline in normal and very healthy older adults (taken from Resnick et al., 2003; n = 92; Figure 2). Patient X's percentage atrophy rate was differentiable from normally ageing older adults – up to two and a half years prior to the recognition of Alzheimer's disease symptomology. Over the four-year period, the percentage decline for patient X was over twice that displayed in the normally ageing adults; thus, displaying that the development and progression of Alzheimer's disease may relate directly to a heightened level of neurodegeneration and atrophy.

Figure 2

The brain volume decline over time (y) for a patient progressing from expected cognitive performance to the development of Alzheimer's disease.



A = patient X, B = normal ageing (mean); C = very healthy older adults (mean) over the same time period. Data for B and C were taken from Resnick et al. (2003).

It is widely accepted that individual cognitive processes can be localised within the brain. Therefore, it is unsurprising that the location of atrophy/synaptic disruption determines which cognitive processes become compromised during the development and progression of dementia. For example, Di Paola et al. (2007) investigated the pattern of cortical atrophy in relation to memory performance in 18 individuals with probable Alzheimer's disease compared to age-matched healthy controls. The authors used a voxel-based morphometry technique (Ashburner & Friston, 2000), which utilises MRI technology, to analyse the area of cortical atrophy and determine whether the location of atrophy impacted performance in memory-based tests. The authors found that participants with atrophy in the entorhinal cortex were significantly less competent on the memory tasks compared to the controls (Z = 4.5), indicating an association between this brain region and memory competence. Similarly, Du et al. (2003) used MRI technology to explore differences in cortical volume between individuals with Alzheimer's disease (n = 21; age 74.5 ± 6.7) and healthy controls (n = 23; 76.5 ± 7.9). Those with Alzheimer's disease were found to have significantly greater annual percentage volume change of the entorhinal cortex (in the medial temporal lobe; left, +5.4%; right, +4.9%), which was associated with a significant moderate reduction in memory performance (r = −0.56). These findings suggest that the location of cognitive disruption, relating to memory in Alzheimer's disease may be more prominent in the left hemisphere of the entorhinal cortex, though atrophy may occur bi-laterally and in other locations.

More recently, Krueger et al. (2010) compared the rates of regional atrophy (in the frontal lobes, temporal lobes, and parietal lobes; using MRI) in groups living with Alzheimer's disease (n = 12; age 60 ± 8.3 y), frontotemporal dementia (n = 13; age 62 ± 6.2 y), or semantic dementia (n = 20; age 62.7 ± 6.3 y), and in healthy controls (n = 23; age 67.1 ± 6.9 y) over one year, respectively. The rate of atrophy in the frontal lobe in those with frontotemporal dementia was significantly higher compared to other groups (6.3% in the left hemisphere; 6.1% in the right hemisphere). Moreover, the rate of atrophy in the temporal lobes was found to be significantly higher in those with semantic dementia (5.9% on the left;

4.8% on the right) compared to the control group. These findings outline regional differences between these dementia types, which may provide evidence to support a location/lateralization of certain cognitive process (associated with these brain regions and specific associated dementia types), which if disrupted, may result in specific symptomology and behaviour.

Collectively, the literature suggests that neurodegeneration and atrophy in individuals living with dementia is greater than that experienced in normal ageing. Additionally, deterioration of specific brain regions may lead to the particular symptomology displayed in differing dementia types.

2.2. Prevalence of dementia

Data from the National Health Service (NHS) has suggested that within the UK, there are an estimated 850,000 (with or without diagnosis) people currently living with dementia, with around 80% of these (674,912) residing in England (NHS Digital, 2020b). Recent data (March, 2020), collected from over 6,500 GPs in England (estimated to cover ~99% of the population), detailed that of those registered (60,306,089), there were 470,292 diagnosed with dementia (NHS Digital). Further analysis of this data highlighted that there is an increased prevalence in women (63%) compared to men (37%), and that 454,599 people diagnosed with dementia were over the age of 65 years, equating to 96.6% of recorded dementia cases. Collectively, these data (NHS Digital, 2020b) suggest that dementia is more prevalent among women and the elderly. Moreover, when extrapolating the data at a regional level, within Yorkshire and the Humber, there were 46,339 individuals (March, 2020) diagnosed with dementia, which equated to >10% of the total recorded dementia cases in England, thus clearly highlighting the local case for concern.

Recently, Lethin et al. (2019) conducted a cross-sectional cohort study (using data from 2010 to 2013) to investigate the prevalence of dementia types in eight European countries (Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden, and the UK). Dementia diagnoses were required to be administered by health specialists (i.e., GP or a specialist physician). Data were collected in the form of interviews and questionnaires, with participants (n = 2013; age $\geq$ 65 y), documenting their dementia type (noted in their diagnosis). The descriptive data from this study revealed that Alzheimer's disease was the most common dementia type (50%), followed by vascular dementia (18%) and unspecified dementia (18%). Other dementia types, such as dementia with Lewy Bodies and frontotemporal dementia, accounted for the remaining 14% of this sample population. Similar findings were reported by Goodman et al. (2017), who investigated the prevalence of dementia types in the United States of America (using data from 2011 to 2013). Data were collected from medical centres documenting participants' (n = 21.6 million) dementia type (noted in their diagnosis). The results from this study complement those of Lethin et al. (2019), highlighting that Alzheimer's disease was the most common form of dementia (43.5%), followed by vascular dementia (14.5%), Lewy body dementia (5.4%), with frontotemporal dementia (1%), alcohol-induced dementia (0.7%), and other dementia diagnoses (0.2%). However, the authors speculated that individuals living with dementia may not have sought/received a dementia diagnosis despite its presence. If this is the case, it may be reasonable to assume that dementia prevalence reports may not give an accurate representation of the whole population and further research is required.

In light of this, Sommerlad et al. (2018) explored the accuracy of hospital dementia diagnoses (between 2008 and 2016) from the Clinical Record Interactive Search data resource (which provided pseudonymised electronic medical records from South London and Maudsley). All patients aged 65 years and older, who had been assessed for dementia, were investigated (including the Hospital Episode Statistics [HES] database, which contains clinical information regarding NHS care). The authors analysed the sensitivity and specificity of dementia diagnoses for each patient and hospital admission. Sociodemographic and clinical factors were also recorded. The results suggested that the accuracy of reporting the presence of dementia increased significantly with age (+3% per year), which may be due to mild/early-stage dementia being more difficult to diagnose. However, it may also be the case that professionals see the likelihood of dementia to be lower in younger populations and attribute symptoms to other possible causes such as depression, which shares several similarities with dementia. Depression was found to be significantly associated with a 20% reduction in the likelihood of receiving an accurate diagnosis of dementia. Moreover, individuals characterised with a marital status as either ‘single’ or ‘divorced’, were both found to be significantly less likely (-9% and -20%, respectively) to receive an accurate diagnosis of dementia than their married counterparts. This may be attributed to a marital partner having the opportunity to recognise symptomology.

Aside from marital status, Sommerlad and colleagues (2018) also investigated the accuracy of dementia reporting associated with ethnicity. Results highlighted that there were significantly lower rates of accurate reporting in ethnic minority groups, namely: Asian (-35%), Back African/Caribbean (-34%), and other ethnic groups (-54%), compared to White British individuals, respectively. The authors partly attribute this to communication difficulties, which may have been experienced by those of whom English was not their native language. Furthermore, awareness of dementia and the associated symptoms may be lower in ethnic minority groups. Mukadam et al. (2011) suggested that people in ethnic minority groups in the UK, compared to native British individuals, are more likely to attribute the symptoms associated with dementia to normal ageing. Similarly, cultural norms and expectations of a family support network in certain ethnic groups may result in individuals feeling that caring for elders with these symptoms is a family responsibility. Consequently, the findings suggest that some individuals may be less likely to report symptoms to their GP or other specialists, hindering a timely diagnosis, and the receipt of professional support. However, more research is required to confirm this.

Furthermore, the symptoms associated with dementia (i.e., memory troubles and attention difficulties) may pose as a contributor to anosognosia (impairment in the ability to recognise and understand one's illness) in those people living with dementia (Boise et al., 1999), which may delay the recognition of its presence.

In light of this, Hannesdottir and Morris (2007) investigated anosognosia in male participants with (n = 92; age 75.30 ± 6.54 y) and without (case-matched; n = 92; age 75.30 ± 6.45 y) Alzheimer's disease. Participants completed tasks, which aimed to assess anosognosia. The Objective Judgement Discrepancy (OJD; Agnew & Morris, 1998) was used to measure the individual's perceived performance on memory tests against their actual score. The Subjective Rating Discrepancy Scale (SRD; Agnew & Morris, 1998) was used to compare participants' rating of their ability to perform memory related activities with their carer/family member's estimation of the same points. Discrepancy scores were obtained by measuring the difference between responses, with results highlighting that participants living with dementia scored significantly higher in both measures compared to actual scores and carer estimations (OJD verbal +28.2 ± 4.4 points; OJD visual +6.5 ± 3.9 points; SRD global +4.3 ± 2.6 points). These findings suggest that individuals living with dementia may live in the belief that their limitations are not as severe as they may outwardly appear to others and that they overestimate their cognitive abilities as a result of being unaware of their cognitive decline. This may provide some additional explanation as to why individuals living with dementia may not seek help.

Collectively, these studies suggest that statistics pertaining to the prevalence of dementia and dementia types may underestimate and possibly also underreport the severity of the problem, especially in certain population groups (i.e., marital status).

2.3. Quality of life

There is no single definition, which has been universally agreed upon to describe the concept of ‘quality of life’ – due to the highly subjective nature of the term. However, the World Health Organisation (WHO) defines ‘quality of life’ as ‘an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHO, 2020).

Quality of life may be impacted upon by a wide range of predictors, including but not limited toan individual’s physical ability (Gillison et al., 2009; Kojima et al., 2016), level of independence (Chou et al., 2012), perceived social status (Pinquart & Sörensen, 2000), and cognitive capacity (Aguirre et al., 2013). As previously detailed, dementia is categorised by a progressive and severe decline in cognitive functioning. In turn, this may cause an individual living with dementia to experience a reduced sense of quality of life; mediated by a decline in attention, short- and long-term memory, reasoning, and the coordination of movement and executive function (Kemoun et al., 2010). Furthermore, the experiences of people living with dementia are highly complex and individualised (Steeman et al., 2007). Thus, it cannot be assumed that disruption to particular cognitive process(es) would result in the same feeling of loss between people.

Moreover, the specific goals, abilities, and behaviours, which are important for quality of life may vary dramatically between individuals (Farquhar, 1995; McGee et al., 1991). For example, an individual who enjoys partaking in sport may be more adversely impacted by a physical injury (resulting in the inability to participate in such physical activity) than an individual who is content with being sedentary. Collectively, this highlights the importance of perception of quality of life. Therefore, for the purpose of this thesis we will refer to the term ‘quality of life’ when addressing a person’s satisfaction with their own life.

Holst and Hallberg (2003) explored the meaning of ‘everyday life’ in individuals living with dementia (n = 11; subject characteristics not reported). The authors used open-ended questions to determine perspectives on what was important to individuals, pre- and post-diagnosis. The results from their study identified common themes, showing that individuals felt they were losing the ability to reach out to others, their sense of self-worth declined, and had begun withdrawing from activities they once enjoyed. Participants described that following the withdrawal from activities (i.e., social sewing club) they once enjoyed, they felt both positive and negative emotions. They felt relief due to a reduction in anxiety, whereas a perceived loss of friendship was also reported. This finding suggested that although individuals living with dementia may be glad to excuse themselves from certain activities, they may miss the additional benefits associated with them, namely the social contact and friendships formed within these groups.

Similarly, Steeman et al. (2007) used semi-structured interviews to allow both people living with dementia and their carers (n = 20) to talk freely about their experiences of living with the condition. Some individuals appeared to speak positively, focusing on their retained abilities rather than those abilities, which they perceived to have lost following the development of dementia. However, some individuals spoke negatively about how their dementia related decline had impacted upon aspects of their life. These findings evidenced the individual differences in the perceived experience of living with dementia.

Collectively, these studies (Holst & Hallberg, 2003; Steeman et al., 2007) highlight that people living with dementia may be keen to voice the importance of feeling valued by and connected to others, and consider it vital to their perceived quality of life. Further, these studies demonstrated that the specific goals, abilities, and behaviours, which have been found to be important for quality of life, may vary dramatically between individuals (Farquhar, 1995; McGee et al., 1991), but the ability to socialise with, and feel valued by, other people may be the most significant influencing factor for people living with dementia (Holst & Hallberg, 2003; Steeman et al., 2007). Therefore, in order to improve or maintain a satisfactory level of perceived quality of life, people living with dementia may benefit from interventions designed to enhance their opportunities to engage with others in a way that they feel valued.

2.4. Living well with dementia

Various modifiable lifestyle factors may protect against cognitive decline, the development of dementia, and its associated life limiting symptoms, such as physical activity (Arcoverde et al., 2008; Unger, Johnson, & Marks, 1997), cognitive engagement (Dustman et al., 1984), and social engagement (Williamson et al., 2009). The following sections aim to explore the literature relating to these lifestyle factors and the way in which they may protect against a reduced quality of life in people living with dementia (and cognitive impairment).

2.4.1. Physical activity and physical independence

For the purpose of this thesis, the term physical activity will refer to the movement of skeletal muscles, which ultimately increases energy expenditure above the resting metabolic rate (RMR) for an individual. Physical independence may be noticeably affected by the loss of muscle strength and mass, termed sarcopenia (Hollmann et al., 2007), which in turn may reduce one’s ability to partake in activities of daily living, impacting upon their perceived level of quality of life. Research has suggested that regular physical activity (≥ 2 times per week) may improve functional mobility (Hickey et al., 1995), balance (Howe et al., 2011), and muscular strength (Paterson & Warburton, 2010) in older adults, which may increase an individual’s ability to carry out activities of daily living independently and reduce the frequency and severity of falls (Hilliard et al., 2008).

It has been well documented that physical training can have a positive effect on physical capability. For example, Hickey and colleagues (1995) investigated the effects of a physical activity programme on functional mobility and psychological well-being in older adults. The authors in this study prescribed the ‘So Much Improvement with a Little Exercise’ (SMILE) intervention (30-min, twice per week), which combined 25 low-intensity movements developed to improve functional mobility (i.e., standing, sitting, walking, reaching, flexibility, and manual dexterity – see Hickey et al., 1992). Participants (n = 90; age 72.6 y [SD not cited]) completed a 6-week intervention, with 32 of those participants continuing the intervention for a further 12 weeks (= 18 weeks). At six weeks, participants showed significant improvements in mobility (+28%), hand activities (+11.6%), walk time (+15.5%), and number of steps (+11.4%). Participants that completed the extended intervention maintained those improvements found at six weeks. These findings, coupled with a magnitude of research (e.g., Courtney et al., 2012; Kim et al., 2012), suggest that functional mobility can be improved with a modest investment of time.

Individuals with cognitive impairment and dementia may require adapted interventions in order to experience similar improvements in physical capacity. Shaw et al. (2003) used a two-arm randomised control trial to investigate the effect of a multifactorial intervention in cognitively impaired older adults (≥65 y) with a history of falls. The intervention included a three month, supervised, home-based exercise programme (frequency of sessions not reported). Participants were randomly assigned to the intervention group (n = 130) or the control group (receiving conventional care; n = 144). No significant differences in the frequency or severity of falls between groups were found, thus suggesting an intervention of this nature may not be effective in preventing falls for this population of people. It is important to note that a higher percentage of the intervention group were community dwelling compared to the control group (34% vs 26%), which may have impacted upon the relative risk of falls. Further, non-compliance to the intervention was noted as a potential limitation to the study. The authors suggested that an extended or adapted intervention may be required for individuals with cognitive impairment and dementia.

In contrast, Toulotte and colleagues (2003) investigated the effects of a physical training programme on older adults with cognitive impairments (who had a history of falls). Participants (n = 20; age 81.4 ± 4.7 y; mass 61.5 ± 12.6 kg) were randomly assigned into either a training or control group. The training group took part in two supervised 1-hour training sessions per week for 16 weeks. In this group, exercises designed to improve muscle strength, flexibility, balance, and proprioception (i.e., walking on a variety of surfaces, hard or soft) was delivered. The control group continued their usual daily routine for the duration of the intervention. In the training group the results showed significant improvements in balance (40%), walking speed (23%), and flexibility (69%), respectively. Furthermore, during the training period, this group also reported no falls, compared to the six falls reported in the control group, which suggested that the physical improvements observed in the training group may have led to a protective factor against falls. However, the incidence of falls reportedly increased for those in the training group, each month post intervention. This indicated a need for continuous practice in order to sustain the improvements gained as a result of the intervention. These results are not consistent with those found by Shaw et al. (2003), in suggesting that a physical training programme delivered once per week, may improve physical capacity in those with cognitive impairment and dementia, but continuous physical training may be required in order to reduce the likelihood of falls on a long-term basis.

The contrast in findings of these two similar studies may outline the requirement for further research into specific physical training interventions aimed at improving physical capacity, which are adequately adapted for people with cognitive impairment and dementia. Additionally, education surrounding the importance of continued physical activity, along with the provision of tools to enable training, post intervention (such as set exercises), may enable more lasting results.

Ultimately the aim of any physical intervention is to increase physical (and/or mental) health and well-being, and thereby enhance quality of life. An extended physical training programme adapted specifically for individuals with cognitive impairment (Shaw et al., 2003) and designed for use on a long-term basis (with/without professional support; twice weekly), may provide physical benefits (i.e., reducing the number/risk of falls) for people living with dementia. Furthermore, education on the benefits of physical activity may encourage continued physical activity in this population, though further research is required.

2.4.2. Cognitive benefits of physical activity

There is a growing body of evidence to suggest that regular (≥ 3 times weekly), physical activity may positively influence cognitive performance (Colcombe & Kramer, 2003) and brain function (Burdette et al., 2010) in older adults. These cognitive affects are thought to protect against cognitive decline and the development of dementia (Laurin et al., 2001).

Early research by Dustman et al. (1984) provided evidence to support that the positive cognitive affects gained from physical activity, in the form of aerobic exercise, may be attributed to the possible increased oxygen (O_2) uptake, during aerobic exercise. The increased O_2 uptake is thought to aid cognition by promoting neurotransmitter turnover and aid metabolism. If this is the case, it would be reasonable to assume that individuals who consistently partake in aerobic exercise may be less likely to experience cognitive decline compared to those who do not.

Daniele and colleagues (2018) suggested that aerobic physical activity may improve brain function by protecting against oxidative stress, promoting the regulation of protein levels, and preventing the accumulation and mis-folding of proteins (primarily α-synuclein [α-syn], β-amyloid1-42 [Aβ] and tau), which are associated with neurodegeneration and the development of dementia (Bibl et al., 2006; Irwin et al., 2013). Moreover, Iofrida et al. (2017) investigated the presence of α-syn, Aβ and tau in the red blood cells, taken from active and sedentary individuals, following in vitro oxidative stress treatment. Twenty participants, 10 endurance athletes (age 33.6 ± 3.4 y; BMI 23.6 ± 1.9 m^2; resting heart rate [HR] 52.0 ± 3.0 $beats \cdot min^{-1}$) and 10 sedentary individuals (age 36.7 ± 3.5 y; BMI 24.8 ± 1.3 m^2; resting HR 60.1 ± 5.3 $beats \cdot min^{-1}$) were recruited for this study. Red blood cells were analysed pre- and post-oxidative stress treatment (oxidative stress treatment involved suspending red blood cells). Results showed that prior to the oxidative stress treatment the presence of both α-syn and Aβ were significantly lower in the sample taken from the endurance athlete group compared to those taken from the sedentary group. However, there was no significant difference in the tau levels. Following the oxidative stress treatment α-syn levels increased in both the endurance athlete and the sedentary groups, whereas Aβ levels increased only in the sedentary group. Data from this study provides evidence to support the early theory of

Dustman et al. (1984) who found those partaking in regular aerobic exercise may be less susceptible to the negative effects of oxidative stress, such as the accumulation of proteins, which are associated with neurodegeneration.

Several authors (e.g., Blondell et al., 2014; Guiney & Machado, 2013) have shown that various forms of physical activity may have a positive effect on synaptic functioning, neuro-plasticity, and neurogenesis, by contributing towards elevated levels of brain-derived neurotrophic factor (BDNF; a neurotroephin, which supports the growth and maintenance of neurons). This is thought to facilitate cognitive function and memory by enhancing synaptic plasticity. Although neuronal loss is thought to be permanent, synaptic dysfunction and synapse loss may be reversible (Lu et al., 2013). Therefore, providing that signs of cognitive impairment are addressed prior to neuronal loss, efforts to restore, maintain and, form new synapses may be possible. This suggests that an increase in physical activity may improve cognitive functioning in individuals with cognitive impairment. If this is the case, it may be reasonable to suggest that following a period of regular physical activity individuals may experience improvements in the ability to learn and benefit from new strategies or procedures.

Consequently, Manuela-Crispim-Nascimento et al. (2014) investigated the effects of a 16-week multimodal exercise programme (comprising exercise focused on resistance training, aerobic fitness, motor co-ordination, and balance) on BDNF and the cognitive functioning of individuals with (n = 37) and without (n = 30) mild cognitive impairment. Participants (age 67.6 ± 6.2 y; BMI 26.7 ± 4.9 m^2) were divided into either a training group or a control group, with BDNF measured pre- and post-intervention. Participants from the training group with (2.85 ± 1.9 to 3.43 ± 2.2 pg/ml) and without (2.81 ± 1.5 to 3.56 ± 1.8 pg/ml) cognitive impairments displayed a significant increase in BDNF following the intervention, with no difference found in the control group. Moreover, a significant improvement in cognitive function, assessed using the Montreal Cognitive Assessment (MCA; see Nasreddine et al., 2005), was observed in participants in the training group with mild cognitive impairment (MCA 19 ± 4 to 23 ± 3 AU). Similarly, cognitive domains were also reported to have improved significantly (executive function +20%; attention/concentration +25%) for those participants. Collectively, these findings suggest that physical activity in the form of a multimodal programme may be able to significantly increase BDNF levels in individuals with and without mild cognitive impairment, thereby supporting the theory that BDNF enhances synaptic transmission. Therefore, if individuals with mild cognitive impairment adhere to a period of physical training, they may experience improvements in cognition (mediated by increased levels of BDNF).

However, despite these potential positive outcomes for people with mild cognitive impairment, Yu et al. (2013), failed to evidence an improvement in executive function or global cognition in people living with dementia, following a moderate intensity cycling programme. Participants (n = 8; age 81.4 ± 3.6 y) were required to use a cycle ergometer, three times per week, under specialist supervision. The duration of cycling was initially set at 10 minutes, which prolonged by five minutes each session as tolerated until participants could cycle for 45 minutes, at their subjective moderate intensity as indicated on a 10-point modified Borg RPE scale (adapted from Borg, 1970). Outcome measures were recorded at baseline, and again at three and six months. Results highlighted a trend toward improvement in executive functioning from baseline to six months, though these findings were not statistically significant. Ultimately, these findings do not provide sufficient evidence to support that this form of aerobic exercise has the capacity to improve executive function. The contrast in findings between Yu et al. (2013) and Manuela-Crispim-Nascimento et al.

(2014) may indicate that exercise type or intensity may moderate the impact that physical activity has on cognitive function.

Overall, these studies (Dustman et al., 1984; Manuela-Crispim-Nascimento et al., 2014; Iofrida et al., 2017) provide evidence that various forms of regular physical activity may affect cognitive functioning positively, attributed to a change in the biological pathways. This may also delay the onset and/or progression of cognitive decline and dementia by increasing overall brain health and functioning. Furthermore, enhanced neuroplasticity following physical activity, may heighten the ability to learn and make use of new strategies and resources; for example, promote cognitive independence with the use of memory techniques. However, more research is needed to quantify the 'dose-response' relationship between exercise intensity and cognitive improvement/maintenance.

2.4.2.1. Cognitive stimulation

Intellectual and cognitive stimulation may provide a protective effect against cognitive decline and the development of dementia (La Rue, 2010; Woods et al., 2012) by promoting neurogenesis and protecting against neurodegeneration (Shors et al., 2012). Furthermore, it has been speculated that individuals living with dementia may have the capacity to learn and retain new information with the use of cognitive stimulation (Zanetti et al., 2001).

In light of the aforementioned points, Wang et al., (2002), investigated the influence of mental, physical, social, productive, and recreational activities on the development of dementia (with the use of the Mini Mental State Examination [MMSE]), in a community-based sample of participants (n = 1375 at baseline; age 81.1 ± 4.9; absent of a dementia diagnosis at baseline), spanning nine years (1987-1996). The results from this study showed that the relative risk (RR) of developing dementia was lowest in those who engaged in daily mental activity (RR = 0.54; 95% CI 0.34 to 0.87) and somewhat lower in those who engaged in some mental activity (RR = 0.81; 95% CI 0.52 to 1.26), when compared to those that did not. These findings complement those of Wilson et al. (2002) who also investigated the effect of cognitive stimulation on the development of dementia. Wilson and colleagues documented the prevalence of dementia in a population of 801 older adults who were not diagnosed with dementia at baseline. They found that frequent cognitive stimulation was associated with a 33% reduction in the development of dementia. These findings suggest that cognitive stimulation may promote healthy cognition and protect against abnormal cognitive decline.

One of the first symptoms recognised in the early stages of dementia is that of noticeably reduced memory recall (Visser et al., 1999). Despite this, some components of memory may remain somewhat preserved, namely procedural memory; a form of implicit, long-term memory, which allows the performance of tasks without conscious awareness. Zanetti et al. (2001) investigated the effects of a 3-week simulation training programme (1-hr per day, 5-days per week) on the procedural memory of individuals with Alzheimer's disease. The training programme involved 13 basic and instrumental activities of daily living (i.e., washing hands, brushing teeth, and putting objects into their correct place). Participants were randomly assigned to either a training (n = 11; age 78 ± 8.4) or control (n = 7; age 78 ± 12) group. Following the intervention, there was a significant reduction in time taken to perform the 13 activities of daily living in the training group (-79 s). However, the control group showed a non-significant increase in time taken to perform the same activities. Similarly, Farina et al. (2002) compared the effects of two training programmes on the ability to carry out activities of daily living in individuals living with mild-to-moderate Alzheimer's disease. Participants (n = 22) were split evenly and assigned randomly to either a procedural memory group (PM; age 73.2 ± 6.8 – simulations of activities of daily living [i.e., washing hands or making a cup of tea]) or non-specific cognitive training group (NSCT; age 74.5 ± 8.4 – training short-term memory [i.e., digit span recall tasks or tasks to reproduce block tapping sequences]). Results showed a significant improvement in the ability to perform activities of daily living in all participants (PM +11.1%; NSCT +9.2%). Collectively, these studies (Zanetti et al., 2001; Farina et al., 2002) evidenced that individuals at the early stages of dementia may have the capacity to retain new information when using procedural strategies. Further interrogation of the data (Farina et al., 2002) indicated that despite the significant improvements in performance, both groups showed a significant regression to pre-training levels three months following the intervention (the nurse's observation was found to regress to below baseline scoring; p = 0.01). Though, due the subjective nature of the observation scale, these results may not reflect true regression. These findings suggest that continuous training may be necessary to maintain improvements or potentially negate the effects of Alzheimer's disease, a similar conclusion to that of Shaw et al., (2003) in relation to physical capacity.

In summary, these studies (Farina et al., 2002; Wang et al., 2002; Zanetti et al., 2001), suggest that if procedural memory is still relatively intact, individuals in the early stages of dementia may have the ability to form new strategies and routines, which they can rely on when other areas of memory and cognitive function begin to fail. Further, if an individual is able to reinstate various automatic motor and/or cognitive processes, they may reduce the demands for compensatory processes. However, individuals may be required to engage in continuous training for such improvements to be sustained (Farina et al).

2.4.3. Social benefits of physical activity

Partaking in group exercise or team sports may facilitate social interaction, while promoting self-esteem and life satisfaction (Fox, 1999). This may be mediated by an increase in physical ability (and thus self-efficacy), allowing individuals to confidently take part in more social activity compared to individuals who are sedentary (Means et al., 2003). The elderly population (who are more likely to suffer from and be implicated more by falls; Fuller, 2000) may benefit socially from the positive impact of physical activity.

Means and colleagues (2003) investigated the benefits of a 6-week physical activity programme (including stretching, postural control, endurance walking, strengthening, and repetitive muscle coordination exercises) in relation to various psychosocial factors. A comparison was made between individuals who had a history of falls and those who did not (n = 66, age 72.05 ± 5.05 vs. n = 77, age 71.15 ± 0.42). Participants were instructed to self-select the frequency, resistance, and number of repetitions, which they self-selected to be at moderate intensity. The results from this study indicated a significant improvement in perceived social role (+29%), level of social activity (+17%), depression (-42%), and anxiety (-35%), as by the Arthritis Impact Measurement Scales (AIMS; Meenan et al., 1980) in those participants who had previously experienced falls. This suggests that there are benefits of self-administered strength and balance training for increased confidence and the ability to take part in social activity, mediated by improvements in physical ability, ultimately leading to an increased quality of life. The findings were consistent with previous research (Hickey et al., 1995), which also showed significant improvements in optimism (+11%), morale (+14%), and self-efficacy (+2%) following an exercise programme (SMILE; see 2.4.1 for more detail).

These findings suggest that regular physical activity may invoke positive emotions, resulting in a higher perceived quality of following the improvement to physical ability and self-efficacy. As suggested by Toulotte et al. (2003), people with cognitive impairment and dementia may have the capacity to improve physical ability with the use of physical training. Therefore, it may be assumed that, by undertaking a physical activity training programme, older adults with cognitive impairment and dementia may feel more able to partake in social activities, which may potentially lead to a higher perceived quality of life.

2.4.3.1. Social engagement

Older adults with maintained, consistent social connections and regular participation in social activities may have a decreased risk of pathological cognitive decline and developing dementia compared to those who do not (Saczynski et al., 2006). Social disengagement is thought to be a potential risk factor for cognitive decline in older adults (Williams & Kemper, 2010; Zunzunegui et al., 2003).

Zunzunegui et al. (2003) investigated the influence of social engagement on cognitive decline in older adults over a 4-year period (1993 – 1997). Participants (n = 964, community-dwelling men and women; aged >65) were required to complete a survey assessing their subjective opinion on their social life including topics related to social networks, social integration, and social engagement. Cognitive performance was measured using questionnaires assessing orientation and memory, using a scale excerpted from the Short Portable Mental Status Questionnaire (Pfeiffer, 1975), which was devised to measure cognition in elderly people with low levels of formal education. The main finding of this study indicated small but significant relationships between cognitive performance and social integration ($r = 0.21$), the number of relatives seen at least monthly ($r = 0.06$), and engagement with friends ($r = 0.16$). Overall, these findings suggest that there may be a protective effect of having an active social lifestyle on the rate of cognitive decline. The authors speculated that these findings could be a result of individuals enjoying a rich social life, being subjected to higher levels of cognitive stimulation, and having access (and support) to practise better cognitive strategies.

More recently, Marioni et al. (2015) investigated the relationship between social activity, cognitive decline, and dementia risk, using data from the Paquid cohort, which provided longitudinal data of older adults with up to 20 years of follow-up. They assessed social pursuits, social network size, and degree of satisfaction with social relationships, against cognitive change over the time in 2854 older adults (mean age 77 y [SD not reported]). Results highlighted a lower prevalence of dementia in individuals reporting higher levels of social engagement (hazard ratio [HR] = 0.7). Therefore, the results complemented those of Zunzunegui et al. (2003), in suggesting that social activity may protect against the development of dementia.

Furthermore, an important consideration for older adults living with dementia is that the type of social engagement can influence the association between social engagement and cognition. This can be demonstrated in research by Ellwardt and colleagues (2013) who assessed the relationship between social engagement (determined by the frequency and quality of social support received) and cognition (i.e., MMSE). Data were collected from over 2255 participants (aged 55-85) over a 6-year period. Findings suggested that emotional support was significantly associated with a decrease in loneliness (βint = 0.35), and loneliness was found to be negatively correlated with cognition scores (βint = 0.05). Thus, it may be assumed that increased emotional support may result in increased cognition, mediated by levels of perceived loneliness. Therefore, the mere involvement of social activity may not adequately benefit individual’s cognition if the individual does not feel emotionally satisfied by such interactions.

Perceived quality of life in people living with dementia has been linked to their social engagement and perceived social independence (Stoner et al., 2018). One's sense of social independence may be influenced by the perceived sense of ability to make decisions independently, with or without support, and the ability to maintain control over their lives. Furthermore, a lack of social engagement may lead to the experience of depression (Stoner et al), with further potential adverse implications for cognition.

Similarly, loneliness may be associated with an increased risk of dementia. Sutin and colleagues (2020) investigated the effect of loneliness on the development of dementia over a ten-year period. Participants (n = 12,030, age 67.3 ± 10.5, without dementia at baseline; recruited from the ongoing Health and Retirement Study [HRS]; Sonnega et al., 2014) took part in both the Modified Telephone Interview for Cognitive Status (van den Berg et al., 2012) and the University of California, Los Angeles (UCLA) Loneliness Survey (see Hughes et al., 2004) at two-year intervals. The results highlighted that for every single point increase of loneliness, there was a 40% increased risk of developing dementia. These findings highlighted that feelings of loneliness may contribute toward the development of dementia; however, the authors speculated that the relationship may be mediated through stress biomarkers (i.e., cortisol reactivity) and that further research is required.

Moreover, loneliness is known to be strong predictor of depression in older adults (Perlman & Peplau, 1981; Singh & Misra, 2009). Depression is a common comorbidity of dementia and may be associated with an accelerated level of cognitive decline compared to those without depression (Rapp et al., 2011), which may be linked to feelings of loneliness and social disengagement. Golden et al. (2009) sought to determine the relationship between social networking, loneliness, depression, anxiety, and quality of life in older adults; levels of which were determined by the Geriatric Mental State diagnostic interview

(Copeland et al., 1976). Responses from the participants (n = 1299; > 65) indicated that 25% of the male participants and 40% of the female participants had experienced loneliness, with around 10% of all participants reporting ‘painful loneliness’. Being lonely was associated with a lower probability of being ‘very happy’ (Odds Ratio [OR] = 0.29) and a lower probability of being satisfied with life (OR = 0.34). Similarly, having a non-integrated social network was found to be associated with a lower probability of being satisfied with life (OR = 0.53). Further, loneliness and having a non-integrated social life were found to be common among individuals that reported depression; 86% of the participants who reported depression, also reported loneliness and/or a non-integrated social network. These findings highlight the association between social engagement and depression in older adults. However, this observational study cannot conclude a causal relationship and further experimental research is required.

Similarly, Singh and Misra (2009) investigated the relationship between depression and loneliness, depression and sociability, and sociability and loneliness, using specially designed questionnaires. A moderate significant relationship was found between depression and loneliness (r = 0.5), yet no significant correlations were observed between depression and sociability or sociability and loneliness. These results highlight the link between depression and loneliness, and the subjective nature of the importance of sociability. It may be the case that some individuals do not require as much social engagement as others in order to avoid loneliness and, thus depression.

The frequency and quality of social contact required for an individual to feel content differs between people (Franck et al., 2016). For example, one may require daily contact from loved ones to avoid feelings of isolation and loneliness, whereas another individual may feel content with far less frequent contact. Therefore, sociability as an individual construct may contribute little toward the occurrence of depression. However, it may be the case that a perceived reduction in sociability may impact upon feelings of loneliness. Older adults, particularly those in the early stages of dementia, often find their friendship circles begin to decrease over time (Van Tilburg, 1998). This may be due to a number of reasons including death of friends, physical inability to attend events, worsening cognitive ability to partake in activities, and stigma associated with dementia. It may be the case that as one's social circle decreases, individuals are likely to recognise this and perceive their sociability as less than adequate (in comparison to what it once was), thus eliciting feelings of loneliness and perhaps depression (Cacioppo et al., 2010).

Rapp et al. (2011) investigated the theory that comorbid depression with dementia is associated with a higher level of cognitive decline over time. Participants ($n = 313$; age 87 ± 6.7) with or without dementia and/or a history of depression, were assessed for levels of cognition using the MMSE, clinical interviews, and information from the Clinical Dementia Rating scales (Morris, 1997). The presence / absence of depression was determined by a questionnaire devised by the researchers based on the Structured Clinical Interview for DSM-5 Axis I disorders (Glasofer et al., 2015). The results from this study showed that having a history of depression alone did not significantly accelerate cognitive decline, but the presence of major depression during the study did ($\beta = -4.16$, $SE = 1.2$); therefore, suggesting that the effects of depression on cognition may not be permanent or detrimental to future cognition. Furthermore, a significant interaction of major depression and dementia was found ($\beta = -2.72$; $SE = 0.65$), highlighting the comorbidity of both dementia and depression (simultaneously). Comorbid dementia and depression may result in further cognitive decline than if one were acting alone, potentially accelerating the effect of depression on cognitive degradation in people living with dementia (or vice versa).

Admittedly, the relatively new focus on research into social engagement, in a bid to protect against cognitive decline, means that evidence is currently limited. However, the evidence that has highlighted the positive outcomes that social engagement interventions have had on older adults (Ellwardt et al., 2013; Zunzunegui et al., 2003) may strengthen the assumption that individuals at the early stages of dementia may benefit in a similar fashion. Emotional support may be an essential contributor to the benefits of social activity (Marioni et al., 2015). Therefore, interventions that target strengthening emotional support systems for people living with dementia (such as with their carers, or by enabling the formation of friendship bonds) may allow for a decreased progression of cognitive decline. However, further evidence is required to support this.

2.4.4. Caregiver burden

Care of individuals living with dementia in their own home often begins with the spouse or adult child of the person living with dementia (van der Lee et al., 2014). Emotional connections between a person living with dementia and their carer, such as the bond between marital partners or parent and child, has a great impact upon the intensity of caregiver burden experienced (Cheng, 2017). Due to the perception of changes experienced throughout the development of dementia, familial caregivers have been found to elicit feelings of pre-death grief.

Lindgren and colleagues (1999) investigated grief patterns and their relation to the losses experienced by familial caregivers of people living with dementia. Spousal caregivers (n = 22, age range 40 to 88) and adult children caregivers (n = 11, age range 44 to 70) provided responses to the Family Caregiver Background Inventory (which assessed the caregiver's perceptions of experiences and feelings prior to the onset of dementia) and the Caregiver Experience Inventory (which assessed the caregiver's current experiences and feelings). Correlations between the two surveys showed that a perceived loss of the future with the person living with dementia were significantly associated with moderate symptoms of grief (anger r = 0.43; despair r = 0.53; somatisation r = 0.39). These findings suggested that one of the most prominent concerns among caregivers of people living with dementia, may be the perceived adjustment to the future of their relationship with the person living with dementia. This gives explanation to the higher level of caregiver burden associated with familial caregivers compared to paid caregivers. In a systematic review conducted by Feast et al. (2016b), the most common and significant influence on carer burden for individuals caring for their loved ones, was the changes noted in the person living with dementia. In addition, depressive behaviours, agitation, aggression, and apathy displayed by people living with dementia have been found to be the most distressing behaviours from a carer's perspective (Feast et al., 2016a). Therefore, it would be reasonable to assume that carers who have or had a strong bond with the person prior to disease onset, may experience higher levels of carer burden than those without an emotional tie.

With this in mind, it is unsurprising that carers of family members with dementia have been found to report higher levels of care related depression (Papastavrou et al., 2007) and emotional stress (Allen et al., 2017) compared to carers of other life limiting disabilities (eg., physical disabilities), due to the perceived change in personality. Collectively, these findings highlight the requirement for support interventions aimed specifically at familial carers of people living with dementia, in order to reduce the negative consequences.

Aside from the perceived losses associated with dementia, the additional stress and depression found in caregivers of people living with dementia may be attributed, to some extent, to an apparent lack of understanding surrounding dementia pathology across the population. Glynn and colleagues (2017) investigated the knowledge among the general public (in the Republic of Ireland) with regard to dementia, its causes, and the modifiable risk factors. A representative sample of the population (age > 16; n = 1217) were required to give true / false answers to a series of dementia related facts. Participant responses were marked as either correct or incorrect based on evidence available at the time of testing. Overall, knowledge surrounding dementia among participants was low, with 26% of the participants reporting (incorrectly) that dementia is a normal part of getting old and 23% reporting that people younger than 65 years do not get dementia. Further, knowledge surrounding dementia risk factors was low, with only 24% of participants displaying knowledge about modifiable risk factors. These findings highlighted the lack of basic knowledge pertaining to dementia across this population, despite over half (52%) of the sample reporting knowing somebody who has/had dementia.

Similarly, Paton and colleagues (2004) investigated the level of understanding that familial carers (of people living with dementia in England; n = 205, mean age 63 y [SD not reported]) tended to have on the symptomology and longevity of dementia. Researchers used qualitative, semi-structured interviews, enabling carers to speak freely about their understanding and opinions (without the person of interest to the study in attendance). The results showed that most of the negative behaviours displayed by people living with dementia (≥ 84%) were not thought to be attributed to the presence of dementia, despite them being aware of the diagnosis. Moreover, 25% of carers believed that the individual living with dementia could control these undesired behaviours. Often carers attributed the observed negative behaviours to depression, frustration, and pre-morbid personality types. It has been suggested that individuals may be more inclined to sympathise with their loved ones (living with dementia), if they are more informed about how dementia affects the brain and cognition, and can therefore rationalise particular behaviours (Pinquart & Sörensen, 2006). This may reduce the level of frustration and burden experienced by the carer.

Ostwald and colleagues (1999) highlighted the potential value of a psychoeducational intervention on the reduction of and/or protection against carer burden, which otherwise may be experienced within the same time frame. More recently, Martín-Carrasco et al. (2009) further investigated the effect of a similar psychoeducational intervention on caregiver burden in Alzheimer's disease caregivers. Familial caregivers of people with Alzheimer's disease were randomly allocated into the intervention group (n = 60, age 61 ± 13.8) or the control group (n = 55, age 55 ± 13.3). The intervention consisted of eight sessions (over a four-month period), which taught strategies for confronting common problems for Alzheimer's disease patient care. Carer burden was measured using the Zarit Burden Interview (ZBI; Zarit, Reever & Bach-Peterson, 1980) method (pre- to post-intervention). The results complement those of Ostwald et al. (1999), by showing a significant reduction in burden among those in the intervention group (-8.09 AU) and increased burden in the control group (+2.08 AU). Moreover, 98% of the caregivers in the intervention group reported that the intervention was useful. These findings suggest that psychoeducational interventions may reduce (and prevent significant increase in) caregiver burden in carers, and the carer's negative reactions to behaviour displayed by people living with dementia.

Furthermore, Navidian and colleagues (2012) investigated the effects of a 4-week (120 minutes per session) psychoeducational intervention (which incorporated a group discussion element) on burden in carers of individuals living with mental disorders compared to controls (which consisted of 'routine care'). The intervention consisted of a 50-minute lecture and a question-and-answer group session, which encouraged communication between participants. The results highlighted that the caregivers in the intervention group displayed a significant reduction in burden (-27.1 points on the ZBI), from baseline to post-intervention, and a further 4-point reduction at the three-month follow-up. Moreover, these authors also found that those who participated in social engagement benefitted significantly more than those that were less socially active. However, the control group displayed an increase in burden (+3.9 points) over the same time period. These findings suggest that a psychoeducational intervention, involving group discussions may reduce caregiver burden in those caring for individuals with mental disorders, and that psychoeducational interventions with the additional element of social engagement may provide more significant reductions in burden. The authors attributed these findings to carers' knowledge and understanding of the disorder along with improvements in social interactions/support, as a result of the group intervention and the opportunity for social interactions.

These findings were further evidenced by Czaja and colleagues (2013) who investigated the effects of a psychosocial, multicomponent intervention (delivered via videophone technology over a five-month period), compared to an information only intervention, on caregiver burden in dementia carers. Caregivers were assigned to either the psychosocial intervention (n = 30, age 57 ± 15 y) or the information only group (n = 63, age 61.5 ± 11.8 y). Standardised measures of depression, caregiver burden, and social support were used. Following the intervention, 46.2% of the participants in the psychosocial intervention group showed a significant increase in positive experiences of caregiving compared to 16% of the participants in the information only group. These findings suggest that the addition of social interaction may impact on the level of benefit taken from interventions, and that social support may provide more positive results compared to information/increased knowledge alone.

Collectively, these studies indicate that psychoeducational interventions may have positive effects on caregiver burden by enhancing knowledge and understanding of dementia and dementing diseases (Pinquart & Sörensen, 2006). However, effects may be greater when coupled with social interventions (Czaja et al., 2013). Therefore, it may be reasonable to assume that an intervention, which enables carers to gain a greater understanding surrounding dementia along with the opportunity to share and converse with others, may be beneficial in reducing carer burden in carers of people living with dementia.

2.5 Living with dementia in lockdown

Toward the end of 2019, Coronavirus-19 (COVID-19 [a respiratory illness of varying severity]) was identified as a global threat. This pandemic has, and is likely to continue to affect the global population in a number of ways, namely the direct health impact of the virus, the impact of the virus on healthcare systems (i.e., the UK National Health Service), the economic consequences of the virus, and the social consequences, among others (Brown et al., 2020). Following the anticipated presence of active COVID-19 cases within the UK, and the associated health risk to the population, the UK Government announced on the 16th March 2020 that those over the age of 70 years and those with pre-existing medical conditions (who were deemed to be more likely to suffer fatal consequences of the virus) should isolate themselves for their own protection (Government Digital Service, 2020b). Shortly after the initial government announcement, a subsequent recommendation was made (Government Digital Service, 2020a), requesting those sub-groups to self-isolate for at least a 12-week period. On the 23rd March a further announcement was made instructing all British citizens to ‘stay at home unless necessary’ (Government Digital Service, 2020a). This, and subsequent periods of imposed social isolation, became widely referred to as ‘lockdown’ among citizens. For the purpose of this thesis, we refer to the lockdown period, which occurred between 23rd March and 23rd June 2020.

These government guidelines saw the closure of gyms and exercise groups, social groups, intervention groups, and many other groups or activities providing an outlet for physical activity, cognitive stimulation, and social engagement. Further, as individuals were required to ‘stay at home’, those without access to private outdoor spaces may have been unable to benefit from being outdoors other than the one-hour limit of outdoor activity per day. According to analysis of Ordnance Survey statistics, as many as one in eight (12.5%), British households do not have access to private outdoor space (including privately shared). Furthermore, despite older adults (aged ≥65) being more likely to have a private garden space, one in 12.5 (8%)were found to be living without such a space (Office for National Statistics, 2020). Therefore, with the social restrictions in place, it may be assumed that older adults and individuals with pre-existing medical conditions (including dementia), particularly those without access to private outdoor space would spend a large majority of their time indoors, with little contact with the outside world and/or other people. It is important to note that older adults who had previously enjoyed an active, social lifestyle may be disproportionally affected due to their perceived loss of social contact and the loneliness, which may accompany this loss (Brooke & Jackson, 2020).

2.5.1. Social isolation, the health-related consequences

Social isolation refers to the objective and quantifiable reflection of the absence of contact with others, and is often considered a close relative to loneliness, though the two are independent constructs (Brooke & Jackson, 2020). Humans, as a species, benefit from social relationships as they promote both mental and physical wellbeing (Cacioppo & Cacioppo, 2014). Therefore, social isolation, at any age, may result in dire consequences to both mental and physical health for individuals. Social isolation has previously been linked to cognitive decline and the development of dementia (see Chapter 2.4.5– social engagement), poorer mental (Heikkinen & Kauppinen, 2004) and physical health (Pressman et al., 2005), and increased all-cause mortality rate (Steptoe et al., 2013). This highlights the potential health and wellbeing risks associated with the government-enforced period of social isolation, particularly among those groups (age ≥ 70 or with pre-existing medical conditions), advised to isolate for an extended period of time.

Hawton et al. (2011) investigated the relationship between social isolation in older adulthood and health status. Participants (n = 393) were allocated into one of three groups (determined by the Rand Social Health Battery; Donald & Ware, 1984): 1) at risk of social isolation group (R; n = 232; age 71.5 ± 11.8), 2) socially isolated group (SI; n = 94; age 69.7 ± 12), and 3) severely socially isolated group (SSI; n = 67; age 69.8 ± 12.1). The results from this study showed significant differences in the self-reported scores of mental health, determined by the 12-item Short Form (SF-12) physical and mental health summary scales (Ware et al., 1995) between groups (-0.08 ± 0.02 AU from R to SI and -7.1 ± 1.2 AU from SI to SSI). Significant differences were also found in health-related quality of life between groups (-0.04 ± 0.03 AU from R to SI and –0.19 ± 0.14 AU from SI to SSI), as determined by the EuroQol (EQ-5D, Herdman et al., 2011). Interestingly however, when quantifying physical health, no significant changes were found. These findings suggest that social isolation may be associated with a depletion in mental health and health related quality of life.

Cornwell and Waite (2009) examined the extent to which social disconnectedness and perceived social isolation were related to physical and mental health in a larger sample of older adults (n = 2910; age 68 ± 7.8). Data were collected between 2005-2006 and were analysed in relation to self-rated physical health, self-rated mental health, social disconnectedness, and perceived isolation. The results highlighted that social disconnectedness and perceived isolation were significantly associated with moderately poorer self-rated physical health (r = -0.42 and r = - 0.43, respectively) and '*moderate*' to '*large*' associations with poor self-rated mental health (r = - 0.36 and r = - 0.8), respectively. These findings support that of Hawton et al. (2011) in suggesting that social disconnectedness and perceived isolation may be associated with a lower level of mental health. Though, in contrast to Hawton and colleagues (2011), Cornwell and Waite (2009) evidenced an association between social disconnectedness and perceived isolation with poorer physical health.

These studies (Cornwell and Waite, 2009; Hawton et al., 2011) identified the association between perceived social isolation and health status in older adults. Therefore, it may be assumed that the social restrictions imposed on older adults, to protect them from the virus in relation to the COVID-19 pandemic, may have a negatively affected their overall mental and physical health. However, due to ethical reasons experimental evidence for this is not available from previous research. Research following the implementation of social restrictions and lockdown may allow researchers to build an evidence base surrounding the health impacts of social isolation and restricted social contact in people living with dementia and their carers.

2.5.2. Infection rates and immune response

Physical health is thought to be negatively associated with social disconnectedness as an individual construct (Cornwell & Waite, 2009). This association may be a result of the health-risk behaviours displayed in less socially connected individuals (e.g., poor diet; Weyers et al., 2010). Cacioppo et al. (2002) investigated the association between social isolation and physical health, specifically in older adults. Data regarding individual's perceived level of loneliness (lonely or not lonely), health behaviours (e.g., abstaining from alcohol and smoking, controlling caffeine consumption, and exercising regularly), and salivary cortisol levels (indirect marker of stress) were analysed (n = 25; age 65 ± 1.4). The results highlighted no significant effect of loneliness on health behaviours or cortisol levels. These findings did not support the association between physical health and social isolation being mediated by health behaviours (or cortisol levels).

However, more recently, Algren et al. (2020) also investigated the association between social disconnectedness and health-risk behaviours. Data from 5113 individuals were analysed (22% of which aged ≥65) to determine social connectedness, including cohabitation status and frequency of meeting with friends. Individual's health-risk behaviours were also assessed, based on poor diet, smoking, alcohol consumption, and inadequate exercise. The results showed a significant relationship between social isolation and those health-risk behaviours (OR = 2.25, OR = 1.4, OR = 1.29 and OR = 2.1, respectively). Overall, it may be reasonable to assume that health-risk behaviours are associated with social disconnectedness, though further research into this association specifically in older adults is required.

In contrast, the higher prevalence of physical illness in socially deprived individuals may be a result of a depleted immune response system. Pressman et al. (2005) investigated the relationship between social integration and loneliness in predicting immune function following individuals' first Influenza vaccination. Participants (37 men and 46 women; aged between 18 to 25 y), with no previously reported health problems, were required to report their social network size, levels of loneliness, and stress four times daily spanning a 13-day period. On day 3, participants received their Influenza vaccination. Antibody levels were assessed at baseline (day of immunization), as well as one month and four months post-immunization. Antibody production was found to be significantly associated with social network size (1-month $\Delta R^2 = 0.07$; 4-months $\Delta R^2 = 0.08$) and loneliness (1- & 4-months $\Delta R^2 = 0.04$). These findings suggest that low social engagement and higher feelings of loneliness may result in a less efficient immune response. The association between social engagement and immune response found, may also be applicable to older populations, though further research is required. If this is the case, it may be reasonable to assume that the government-advised social restrictions may have adverse effects on the immune system response in individuals who have experienced a depletion in social contact during the COVID-19 pandemic; ultimately leaving them more susceptible to the virus and other potential health depleting illnesses.

Furthermore, older adults and individuals with pre-existing medical conditions, who were advised to self-isolate prior to, and for longer periods than the younger population (other than those with pre-existing medical conditions), may be affected more severely by the lockdown period than younger generations without pre-existing conditions. It is important to recognise that the COVID-19 pandemic is ongoing; therefore, the magnitude of health implications may not be anticipated accurately.

2.5.3. The extended impact of lockdown on people living with dementia and their carers

In addition to the previously discussed implications of reduced social engagement on the mental and physical health of people living with dementia (see section 2.4.5. – Social engagement), the restrictions surrounding social contact may pose extended adverse effects on individuals living with dementia. Community-dwelling people living with dementia often rely on services, which aid their ability to live independently (i.e., care services and meal delivery services). These services are likely to have been adversely impacted on due to COVID-19 and the social restrictions put in place (Brown et al., 2020). Without the aid of these services, individuals living with dementia may be left without adequate food, medication, and personal hygiene care, thus posing a further direct threat to their overall health.

Furthermore, the social restrictions surrounding the pandemic may also impact upon the basic routines and activities, which have been found to promote physical and mental health (i.e., physical activity groups; Hickey et al., 1995; Toulotte et al., 2003). Symptomology associated with dementia, primarily memory troubles and impairment to reasoning (American Psychiatric Association, 2013), may affect how an individual comprehends the requirement for reduced contact with others (i.e., their adult children or friends) and disruption to their usual routine (Velayudhan et al., 2020; Wang et al., 2020). This may potentially lead to a heightened perceived sense of isolation and loneliness among individuals living with dementia in the threat of this pandemic. However, as this is a novel situation, to date, literature is sparse and therefore fails to provide evidence for these assumptions. Further research is required to investigate the effects of the vast changes to life in the presence of a global pandemic, on individuals living with dementia.

Additionally, social restrictions relating to the COVID-19 pandemic are likely to pose further threat to the caregivers of individuals living with dementia compared to their peers (Greenberg et al., 2020). Closure of services and facilities disrupted routines, and lack of respite for carers may contribute toward amplified levels of frustration and caregiver burden experienced (see section 2.4.7 – Carer burden). Again, it is important to note that at this current time we may only speculate and form assumptions, further research surrounding the impact of social restrictions on caregiver burden for carers of people living with dementia will be required as the situation progresses.

2.6. Summary

As detailed in this literature review, the presence of dementia may affect a variety of cognitive processes, which in turn have a negative impact upon a person's perceived quality of life and the level of carer burden experienced by their loved ones. The pathophysiology, behaviours, and perceived quality of life displayed in people living with dementia may be somewhat influenced by various modifiable risk factors such as their level of physical activity, cognitive stimulation, and social engagement (with emotional support). Interventions that combat these risk factors, if caught early enough, may allow the retention, or in some cases, retrieval of capability, which may otherwise limit quality of life in people living with dementia. Furthermore, caregiver burden, in the loved ones of people living with dementia, may be reduced by promoting knowledge and understanding surrounding the condition's pathology and providing support interventions, which foster positive coping strategies.

Additionally, the literature suggests that social isolation may be detrimental to cognition and overall health of individuals. Therefore, it is reasonable to assume that following a period of government issued social restrictions in the UK (and global) population, individuals, in particular older adults and those living with or caring for a person living with dementia, may experience a rise in mental and physical health problems.

2.7. Specific objectives and hypotheses

The main aim of this study was to investigate whether a novel 6-week intervention combining physical and cognitive training in a social setting (developed by the Sphere Memory and Rehabilitation Team's Psychosocial Intervention for Dementia - hereafter referred to as SMaRT PID) could improve the quality of life for both people living with dementia and their carers. Specifically, our primary objective was to investigate the effect of the SMaRT PID on depression, anxiety, quality of life, and ability to perform activities of daily living in people living with dementia. Secondly, we sought to quantify the impact that group intervention training would have on carer burden in those individuals caring for a person living with dementia. We hypothesised that following completion of the SMaRT PID, people living with dementia would experience lower levels of depression and anxiety and a higher perceived quality of life. Similarly, we hypothesised that carers would experience reduced levels of carer burden following the intervention.

A secondary aim of this study was to explore the effect of government induced social restrictions on older adults living with dementia and their spousal caregivers. We hypothesised that both people living with dementia and their carers would experience negative effects as a result of the lockdown and display higher levels of depression, anxiety and a lower quality of life than what would otherwise be expected.

3. Methods

This chapter describes the ethical procedures, participant characteristics, inclusion and exclusion criteria, testing protocol, psychometric properties of the outcome measures, details of the intervention schedule, and statistical analysis.

3.1. Ethical considerations

Full ethical approval was granted by the University of Hull Faculty of Health Sciences ethics committee (Ref: FHS170; Appendix A). Participants were given a Participant Information Sheet (PIS [Appendix B & C]), which outlined the study aims and objectives and included contact details of the research team, inviting them to make contact (with the researchers), if they had any further questions. Prior to testing, each couple were informed of the potential risks and benefits of the investigation.

Participants that took part in the intervention were required to provide written informed consent (Appendix D). Furthermore, all participants were free to withdraw at any time, without having to provide a reason. Participants that took part in telephone interviews were required to provide verbal consent.

Prior to enrolment, participants living with dementia were required to complete an institutional pre-exercise medical questionnaire, which included details of typical physical activity. Data obtained from this questionnaire were used to determine if participants were required to consult their GPs prior to participation in this study as a result of underling contraindications (e.g., heart problems, which may pose risk during physical activity) that may be exacerbated by this study.

3.2. Participants

3.2.1. Recruitment

Sixteen participants (8 participants living with dementia and 8 carers) were recruited by word of mouth at pre-established dementia groups within the local community, and via an advertisement on social media (Facebook), between the months of September 2019 and March 2020. All participants were recruited in pairs, each pair included one participant living with dementia and one carer.

3.2.2. Inclusion and exclusion criteria

Participants living with dementia were included if they had a diagnosis of dementia (dementia type was not specified) from their GP (length of time living with dementia did not affect participant inclusion). Individuals with physical disability, musculoskeletal injury (prior to intervention), life limiting disease or unrelated cognitive difficulties were excluded from the study. Participants living with dementia were required to be accompanied by the same carer (above the age of 18) throughout the study.

3.2.3. Participant characteristics

All participants (*n* = 16), detailed in this case series lived in the local community (Hull and East Riding of Yorkshire). Six of the participants living with dementia lived with their spousal caregiver, one lived independently receiving paid care, and one lived in a nursing home. All had been diagnosed with dementia (type not specified). Participant characteristics are summarised in Table 2. These participants were an opportunistic sample and varied according to age, gender, physical stature, condition, and cognitive status (though cognitive status was not measured). Prior to starting this study participants did not have any musculoskeletal or neuromuscular conditions that would preclude them from participating in the programme. According to the answers provided by participants on the institutional pre-exercise medical questionnaire, the notification of participation to primary care physicians was not deemed necessary across the sample. Overall, attendance was high; 5.2 ± 0.5 sessions (out of 6 sessions). Two couples dropped out of the intervention and did not complete any aspect of the post-testing. A further two couples were unable to take part in the physical tests. Therefore, questionnaire data and physical test data were analysed for six and four couples, respectively (baseline and post-intervention).

Table 2
Participant characteristics at baseline and post-intervention

	Baseline	**Post-intervention**
Pairs (*n*)	8	6
Completed QoL questionnaires (*n*)	8	6
Completed physical tests (*n*)	8	4
Age of person living with dementia (years)	79 ± 2.8	81.5 ± 7
Gender of person living with dementia (male:female)	4:4	2:4
Height (cm)	161.1 ± 10.6	157.6 ± 9.3
Mass (kg)	72.9 ± 15.6	68.3 ± 13
Relationship status (% married/widowed)	75/25	66/33
Level of lifestyle and physical activity * (% sedentary/moderately active)	37.5/62.5	50/50
Relationship to carer (% spouse/paid care)	75/25	66/33

Data reported as mean ± standard deviation (SD)
*As measured by the pre-exercise medical questionnaire (University of Hull)

3.2.4. Case description

Among those participants living with dementia that completed the intervention (*n* = 6), four were married and co-habiting with their spouse, one was widowed and living independently with care, and one was widowed and living in a nursing home. The four married participants were accompanied by their spouse to the sessions. In all cases spouses were considered to be caring for the person living with dementia. Paid carers assisted the remaining two participants.

3.3. Study Design and Procedures

This study sought to quantify the effectiveness of a combined physical and cognitive training intervention on both people living with dementia and their carers. We used an observational cohort study design. Prior to, and following the intervention, the same physical test battery was administered. This battery included tests to assess balance, muscular endurance, and hand grip strength. Participants living with dementia were also assessed for descriptive quality of life indicators, which were quantified using carefully selected depression and anxiety questionnaires. The level of caregiver strain was assessed at the same time points using a specific questionnaire.

3.3.1. Sphere Memory and Rehabilitation Team's Psychosocial Intervention for Dementia (SMaRT PID)

Participants were required to attend six sessions on consecutive weeks. Sessions were one hour in duration and took place at the same time and location (in a local community hall) each week, from the 6th November until 18th December 2019. All training groups began with a standardised warm-up that consisted of various game-based tasks designed to incorporate cognitive and physical activity (e.g., ball passing games and stacking cups).

Participants were then given information in the form of a simple presentation, led by a local clinical psychologist (linked to the SMaRT team), followed by group discussions, regarding specific behaviours common in dementia such as repetitive behaviours, reduced attention, aggression, and wandering. This was followed by the introduction of potentially helpful strategies to target difficulties common in dementia such as attentional difficulties and poor memory retention (previously utilised by the SMaRT team in their work with individuals with brain injury; for example, see Appendix G. The strategies were discussed among the group and participants were encouraged to practice utilising them in the presence of the clinical psychologist in order to instil confidence in using them. Participants were then invited to discuss any of the strategies they may have found helpful in day-to-day life. At the end of the session, participants were given a demonstration of the physical homework activities and asked to complete these activities to the best of their ability (for example see Appendix H. Participants were requested to complete the home-based activities three times, prior to the next group session. Use of strategies and how participants found the home-based physical activities were discussed in the next session.

3.3.2. Outcome measures

Outcome measures were structured in accordance with the American College of Sports Medicine (ACSM) guidelines for conducting health-related physical fitness testing (ACSM, 2018), in the order mentioned below. All outcome measures were administered at baseline and on completion of the intervention.

3.3.2.1. The Short Anxiety Screening Test (SAST; Sinoff et al., 1999)

The SAST was used to detect anxiety levels in participants living with dementia. The survey comprised of 10 questions, which required an answer of either ‘rarely or never’, ‘sometimes’, ‘often’ or ‘always’. Answers were allocated points based on the positive or negative wording of the question (1-4 or 4-1, respectively). Total number of points were calculated for each participant; as specified by the authors, a score ≥24 indicated anxiety at the clinical level. The SAST has been found to offer a high level of validity in the detection of anxiety in the elderly, and is thought to be unaffected by gender or environment of testing (sensitivity 75.4%, specificity 78.7%; Sinoff et al., 1999). Although the SAST has not been used with individuals with severe dementia, this intervention was aimed at individuals in the early stages of dementia. Therefore, this measure was deemed appropriate.

3.3.2.2. The 15-item Geriatric Depression Scale (GDS-15; Yesavage et al., 1982)

The GDS-15 was used to assess the presence of depression in the participants living with dementia. This 15-item screening test assesses depression levels in older adults. Questions require either a ‘yes’ or ‘no’ answer, and one point is allocated for each positive response. A score of 0-4 indicated that participants were normal and a score of 5-15 indicated that participants were depressed. The survey has been found to have high validity (sensitivity = 81%; specificity = 75%; Wancata et al., 2006) and reliability among people living with dementia (O'riordan et al., 1990).

3.3.2.3. The 10-item Recovering Quality of Life (ReQoL-10; Keetharuth et al., 2018)

The REQoL-10 was used to assess quality of life in the participants living with dementia. This measure comprises 10 mental health questions and one physical health question. Questions required a response between ‘none’ and ‘all of the time’. Positively worded questions score 0-4 points and negatively worded questions score 4-0 points, respectively. A score ≥25 indicated that participant’s quality of life was subjectively adequate; a change in score ≥5 points indicated a meaningful change in perceived quality of life. The survey has been found to have excellent test re-test reliability (ICC = 0.85) and construct validity (r = >0.80), and can distinguish a change in quality of life, alongside changes to mental health (Keetharuth et al., 2018).

3.3.2.4. Caregiver Strain Index (CSI; Robinson, 1983)

Carers were required to complete CSI, which is a 13-point questionnaire that measures one’s level of strain relating to care giving. The questionnaire comprises statements based around common stressors (including financial, physical, psychological, social, and personal stressors), which are typically associated with care giving. Participants were required to indicate ‘yes’ or ‘no’ to each of the statements, indicating whether they agreed or disagreed with these statements (at the time of completing the questionnaire). A higher score indicated a higher level of strain; a score ≥7 indicated strain at a clinical level. A change in score ≥2.8 indicated clinically meaningful change. Research has suggested the CSI to have a high level of reliability (α = 0.90; Thornton & Travis, 2003).

3.3.2.5. The Berg Balance Scale (BBS; Berg et al., 1992)

The BBS was used to assess static balance and fall risk in the participants living with dementia. It comprises 14 tasks designed to measure balance and functional mobility: sitting unsupported, change of position, sitting to standing, change of position, standing to sitting, transfers, standing unsupported, standing with eyes closed, standing with feet together, tandem standing, standing on one leg, turning trunk with feet fixed, retrieving objects from the floor, turning 360 degrees, stool stepping, and reaching forward. Each task was awarded a score between 0-4 points based on participant performance (see Appendix E for detailed scoring method). Scoring was achieved by the same two researchers and the median score of the two, used. Scores from each task were summed to provide a total score out of 56 points.

A score of <20 points indicates that an individual is at high risk of falls, scores between 21 and 40 points would indicate an individual is at 'medium risk' of falls, and a score >41 points would indicate that an individual is at 'low risk' of falls. A change in score ≥1.92 indicated a clinically meaningful change (for people living with dementia; Telenius et al., 2015). The BBS has been found to have an excellent test-retest reliability (ICC = 0.77; Holbein-Jenny et al., 2005). Similarly, high intrarater (ICC = 0.98) and interrater (ICC = 0.98) reliability has been found in community-dwelling older adults (Berg et al., 1992), which does not differ significantly in populations with dementia (Telenius et al., 2015). The measure has been found to have high specificity (96%) for predicting non-fallers, but low sensitivity (53%) in the prediction of falls (Bogle Thorbahn & Newton, 1996).

3.3.2.6. The 30 Second Sit to Stand Test (30s STS; Jones et al., 1999)

The 30s STS was used to assess balance, functional mobility, and strength in the participants living with dementia. Participants were required to sit with their back straight on an armless chair, with their feet shoulder width apart, their arms crossed at the wrists and held on their chest. The participants were then asked to stand and sit as many times as they could comfortably within 30 seconds. The number of times the participant managed to complete the full process of 'sit to stand' was recorded. If participants used their hands at any time, they scored zero. A change in score ≥5 repetitions indicated a clinically meaningful change. The measure has been found to have an excellent test-retest reliability (r = 0.89), interrater reliability (r = 0.95), and criterion validity (r = 0.78; Jones et al., 1999). Moreover, it has been deemed suitable to assess balance, functional mobility, and strength in people living with dementia (Telenius et al., 2015).

3.3.2.7. The Timed Up and Go Test (TUG; Podsiadlo & Richardson, 1991)

The TUG was used to assess participants' balance, mobility, walking ability, and fall risk. Participants were required to sit in a chair with their back against the chair back. On command, they were required to rise from the chair, walk three meters ([m], which had been pre-marked) at a comfortable pace, turn around, and walk back to the chair and sit down. Time was measured in seconds (s). A change in score ≥4.09 s, indicated a clinically meaningful change (Ries et al., 2009). The measure has been deemed appropriate to use on people with Alzheimer's disease (Ries et al., 2009) and may predict falls in older adults. However, the sensitivity (56%) and specificity (60%) suggest that error may be common (Bhatt et al., 2011). The test-retest reliability has been found to be adequate (ICC = 0.56) in elderly adults (Rockwood et al., 2000); however, it is important to note that individual variability is high (Ries et al., 2009).

3.3.2.8. Grip Strength Measurement (GS)

Grip strength measurement was used to assess the isometric strength of the dominant hand and forearm on the participant living with dementia. Grip strength was measured using a hand-held dynamometer (Biometrics G200, Biometrics, Newport, Wales, UK) and recorded in kg. Participants were required to stand with their arm parallel to their body and instructed to squeeze the device as hard as they could comfortably. This positioning was used due to perceived restrictions in shoulder movement among the sample population. The mean score of three trials was recorded for each participant. A change in score ≥6 kg indicated clinically meaningful change (Nitschke et al., 1999). The measure has been found to have an excellent test-retest reliability (ICC = 0.954 Left hand; 0.912 Right hand; Bohannon & Schaubert, 2005).

3.3.2.9. The Six Minute Walk Test (6MW; Butland et al., 1982)

The 6MW was used to assess functional exercise capacity. Participants were required to walk at a comfortable pace along a 30-m stretch, for six minutes, with total distance walked (m) recorded. Participants were able to take breaks if required, but the timer did not stop if they decided to do so. A change in score ≥33.47 m indicated a clinically meaningful change (Ries et al., 2009). Test-retest, interrater, and intrarater reliability have been found to be excellent (ICC = 0.982 to 0.987; 0.97 to 0.99; 0.76 to 0.90, respectively; Ries et al., 2009; Tappen et al., 1997).

3.3.2.10. Semi-structured Interview

Participants living with dementia and their carers were required to partake in a semi-structured interview as a couple. Participants were informed that interviews were audio recorded and would be later transcribed verbatim. Semi-structured interviews were conducted by the same researcher for all pairs and were conducted in a quiet, private area. The interview topic guides can be found in Appendix F.

3.3.3. Adaptions due to Coronavirus-19

As a result of the COVID-19 pandemic, the planned second group intervention (scheduled to commence in April 2020) was unable to take place. Initially, we aimed to postpone the intervention to a later date. However, it became apparent that the social restrictions were unlikely to be removed to allow sufficient time for the second group to complete the intervention within the required timeframe for a full-time Masters by Research qualification (dictated by the University of Hull's schedule for completion). Therefore, alternative methods of data collection were explored, but deemed unsuitable, due to the potential harm to participants as a result of un-trained physical activity, and the inability to provide the session content remotely (due to limited resources of participants).

Consequently, we attempted to explore the forced removal of social engagement (outside of their household) in a population of 12 people (six people living with dementia and their carers), recruited from the individuals who had already participated in the intervention and those who had been due to take part in the intervention, which was cancelled. It was therefore decided that telephone-based interviews would be used to gather data regarding the experiences that participants had had during the period of reduced social contact. This was achieved by conducting participant-led conversations in order to allow themes to emerge naturally, with some guidance from the administrator (see Appendix I - topic guide). These interviews took place between the 30th of April and the 14th of May 2020. Participants living with dementia also completed the ReQoL – 10, GDS and

SAST; carers completed the CSI. These were either completed over the phone or sent and returned via post/email, depending on participant preference.

3.3.4. Data analysis

3.3.4.1. SMaRT PID intervention

Two of the couples who completed the intervention in late autumn 2019, were unable to attend the laboratory for post-testing. Consequently, the questionnaires were posted to them and returned these via post. As the second intervention group (scheduled for spring 2020) was unable to participate, and given the small participant numbers, it was decided to analyse the study data using a case series approach. A change in score, which surpassed the minimal detectable change for each outcome measure indicated a meaningful change. All numerical data were analysed descriptively in customised Excel spreadsheets (Office 365, Microsoft, Microsoft Campus, Reading, UK), with mean ± standard deviation (SD) reported, unless otherwise stated. No formal statistical analyses were undertaken. Qualitative data from the post-intervention interviews (autumn 2019 intervention cohort), were analysed according to Braun and Clarke (2006) thematic aalysis approach (see Table 1).

Table 1

The six-stage process of thematic analysis (adapted from Braun & Clarke, 2006)

Phase	Process
Data familiarisation	Transcription of data, reading and re-reading data and noting down initial ideas
Initial code generation	Coding interesting data features systematically across the entire data set, collating data relevant to each code
Searching for themes	Collating codes into potential themes, collating all data relevant to each potential theme
Reviewing themes	Cross-checking themes in relation to the coded extracts and entire data set, generating a thematic map of the analysis
Defining and naming themes	Analysis to refine the specifics of each theme and overall story of analysis, generating clear definitions and names for each theme
Report production	Selection of compelling extract examples, final analysis of selected extracts relating back to the research question and literature

3.3.4.2. Living with dementia in lockdown

Qualitative data from the social isolation telephone interviews were also analysed according to Braun and Clarke's (2006) thematic analysis approach. Questionnaire data were analysed in relation to the pre-determined clinical cut off points, specified by the authors of those assessments.

4. Results

4.1. Intervention

4.1.1. Quantitative outcome measures

Improvements were observed in all participant pairs following the SMaRT PID (quality of life questionnaires [Table 3]; physical measures [Table 4]). In the four pairs that completed all experimental protocols, improvements were noted in at least five (55.6%) of the nine outcome measures. In the two pairs who were unable to complete the physical outcome measures, improvements were noted in at least one (25%) of the four quality of life measures.

Table 3

Quality of Life outcome measure scores for each participant (pre- and post-intervention), including absolute change

		Recovering Quality of Life - 10			Geriatric Depression Scale			Short Anxiety Screening Test			Caregiver Strain Index (completed by the carer)		
		Score	ABS		Score	ABS		Score	ABS		Score	ABS	
P1	Pre	33	-2		**5**[c]	-3	↑	17	2		**8**[c]	**-4***	↑
	Post	31			2			19			4		
P2	Pre	37	2	↑	4	-3	↑	12	2		0	0	N/A
	Post	39			1			14			0		
P3	Pre	26	**8***	↑	**6**[c]	-5	↑	18	-5	↑	**9**[c]	**-4***	↑
	Post	34			1			13			5		
P4	Pre	38	-4		3	2		14	1		**13**[c]	**-9***	↑
	Post	34			**5**[c]			15			4		
P5	Pre	27	**9***	↑	3	1		18	-6	↑	5	2	
	Post	36			4			12			7[c]		
P6	Pre	26	**-5***		3	4		18	2		**14**[c]	**6***	
	Post	**21**[c]			**7**[c]			20			**20**[c]		

ABS = absolute change, ↑ = positive change

N/A = participant did not feel the measure was applicable and did not provide responses

[c] = scores which exceeded the clinical threshold of each test as specified by authors: Recovering Quality of Life – 10 = ≤24 AU; Geriatric Depression Scale = ≥5 AU; Short Anxiety Screening Test = ≥24 AU; Caregiver Strain Index = ≥7 AU.

* indicates clinically meaningful change exceeded: Recovering Quality of Life – 10 = 5 AU (Keetharuth et al., 2018); Caregiver Strain Index = 2.8 (Thornton & Travis, 2003)

Table 4

Physical outcome measure scores for each participant (pre- and post-intervention), including absolute change

		Berg Balance (AU)			30s STS (reps)			Timed Up and Go (s)			Grip Strength (kg)			Six Minute Walk Test (m)		
		Score	ABS		Score	ABS		Score	ABS		Score	ABS		Score	ABS	
P2	Pre	47	**5***	↑	8	1	↑	12.4	**7.3***		12.5	3	↑	300	**-70***	
	Post	52			9			19.7			15.5			230		
P3	Pre	53	0		8	4	↑	13.5	-2.6	↑	26	3.3	↑	480	-13	
	Post	53			12			10.9			29.3			467		
P5	Pre	52	1	↑	11	**-5***		12.9	-0.8	↑	8.5	**7.5***	↑	350	**146***	↑
	Post	53			6			12.1			16			496		
P6	Pre	46	1	↑	4	-4		21.6	**-8.5***	↑	17.8	**9.7***	↑	390	**222***	↑
	Post	47			0			13.1			27.5			612		

ABS = absolute change

% = percentage relative change

↑ = positive change

* = clinically meaningful change exceeded: Berg Balance Score = 1.92 AU (in people living with dementia; Telenius et al ., 2015), 30s STS = 5 reps (in older adults with osteoarthritis; Wright et al., 2011), Timed Up and Go = 4.09 s (in people with Alzheimer's dementia; Ries et al., 2009), Grip Strength = 6 kg (in healthy adults; Nitschke et al., 1999), Six Minute Walk Test = 33.47 m (in people with Alzheimer's dementia; Ries et al., 2009)

4.1.1.1. Participant 1

Participant's 1 (P1) GDS-15 scores indicated depression at a clinical level prior to the intervention. However, post-intervention their score decreased to below the clinical cut-off. Their carer (P1C) displayed a meaningful decrease in CSI score, which indicated strain at a clinical level before, but not after intervention. However, these positive results were accompanied by an increase in SAST score and a reduction in ReQoL-10 score. These scores did not exceed the clinical threshold and were, therefore, not considered meaningful. Prior to the post-intervention assessment, P1 experienced an injury (suspected broken rib), which prevented them from partaking in the physical outcome tests.

4.1.1.2. Participant 2

Participant 2 (P2) showed improvements on the BBS, which exceeded the clinically meaningful detectable change. However, these positive changes were accompanied by clinically meaningful declines in the 6MW and TUG (which exceeded the clinically meaningful detectable change). Participant's 2 change in scores in these three outcome measures were not consistent with all other participants (see Figures 3 to 5). Their carer (P2C) scored zero on the CSI at both time points. As P2C was not emotionally related to P2, they felt as though the statements did not apply to them.

Figure 3

Individual differences in changes to Berg Balance Scores, highlighting P2's disparity to the group

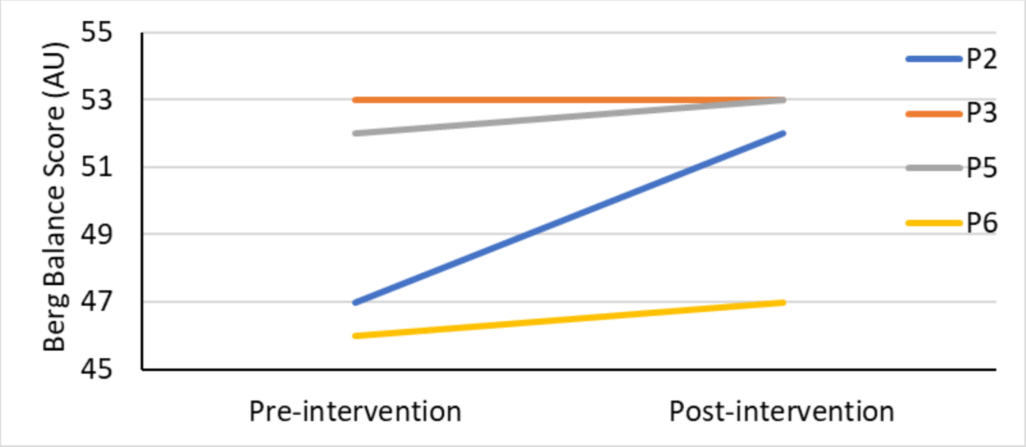


Figure 4

Individual differences in changes to Timed Up and Go scores, highlighting P2's disparity to the group.

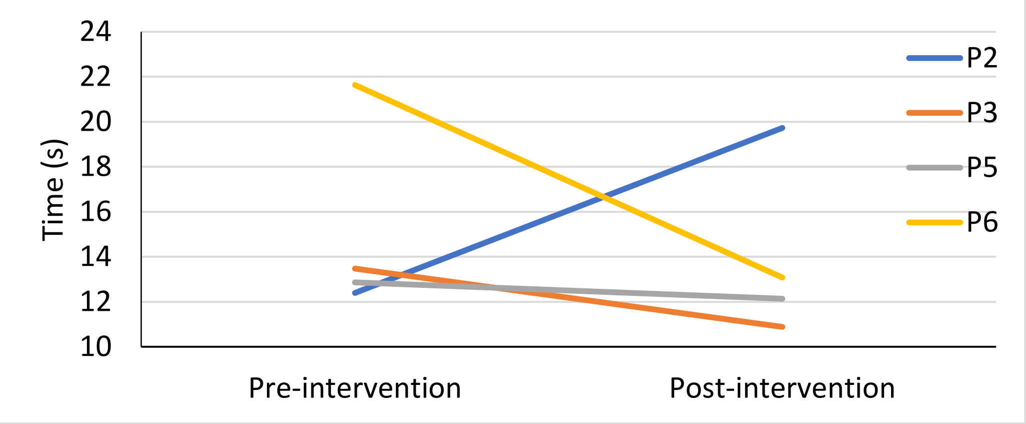
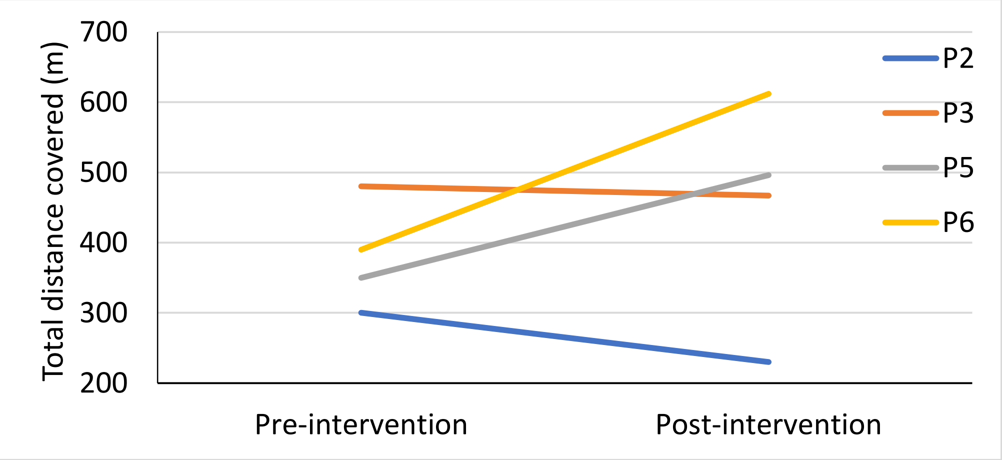


Figure 5

Individual differences in changes to the Six Minute Walk Test, highlighting P2's disparity to the group.



4.1.1.3. Participant 3

Participant 3 (P3) displayed improvements in three of the five physical outcome measures, maintained their score in the BB, and declined in the 6MW. However, these changes were not clinically meaningful, yet a clinically meaningful improvement in ReQoL-10 was found. Furthermore, at baseline, the GDS score indicated depression at a clinical level, yet their score post-intervention indicated no presence of depression. Their carer (P3C) showed meaningful improvements in CSI score. These positive findings were corroborated by the qualitative feedback from P3 and P3C.

4.1.1.4. Participant 4

Participant 4 (P4) became unwell prior to the post-intervention assessment and was unable to complete the physical outcome measures. They were assessed on the QoL measures remotely, but displayed less favourable scores than in their baseline responses, with an increase in GDS score, which was higher than the clinical threshold post-intervention versus baseline. Despite this, their carer (P4C) displayed a meaningful improvement in their CSI score and on multiple occasions spoke about the positive impacts the intervention had had on their daily lives.

4.1.1.5. Participant 5

Participant 5 (P5) displayed meaningful improvements in GS, 6MW, and ReQoL-10. However, a meaningful decrease in the number of 30s STS repetitions was found post-intervention compared to their baseline score. Their carer (P5C) displayed an increase in CSI, which indicated that they were above the clinical threshold post-intervention, but not at baseline. However, during discussions and final interview, P5C voiced their positive opinions on the intervention and the benefits that both P5 and P5C had experienced as a result, which contradicted the increase in CSI score.

4.1.1.6. Participant 6

Participant 6 (P6) displayed a positive meaningful change in TUG, GS, and 6MW tests. However, this participant opted out of one of the physical outcome measures (30s STS) at the post-intervention assessment for reasons unknown. Post-intervention scores of the ReQoL-10 and GDS indicated a decline in quality of life, with a clinical level of depression, which was not present at baseline. Similarly, their carer (P6C) showed a meaningful negative change in the CSI from baseline to post-intervention, which indicated the presence of greater strain post-intervention compared to their baseline scores.

4.1.2. Qualitative outcome measures

4.1.2.1. Baseline

Thematic analysis was completed for interviews with the participants living with dementia and the carers, with both parties present. Eight pairs completed the baseline interview. Thematic analysis of pre-intervention transcripts highlighted five main themes: verbal communication, anosognosia, perception of personality changes, carer strain, and understanding dementia (Table 5).

Table 5

The main themes and sub-themes identified during thematic analysis of baseline interviews for people living with dementia and their carers

Main theme	**Sub-theme (if applicable)**
Verbal communication	N/A
Anosognosia	Cognitive unawareness Behavioural unawareness
Perception of changes	Memory Apathy and motivation
Carer strain	Loss and grief Frustration Lack of ‘me time’
Understanding dementia	Carer understanding Stigma

Verbal Communication

Among the participants living with dementia, most provided little contribution during interviews, often relying on their carer to respond to questions on their behalf. During the interview, one carer acknowledged that they were solely contributing to the interview. In reply, the person living with dementia voiced that they were happy with this and would contribute to the conversation if required.

> “I will tell you if I disagree with you” (P6; their only verbal contribution to the interview).

On this occasion it was not made clear why the person living with dementia did not want to contribute verbally to the interview. However, the person living with dementia responded to their carer’s comment in a way that suggested they agreed.

At times when participants living with dementia contributed verbally during the interviews, some deviated off topic. They randomly began speaking in depth about past events and memories. The researchers listened, but attempted to steer the conversation back toward relevant subject. These comments were not included in the analysis.

Anosognosia

Cognitive unawareness

During the interviews, when asked about their experience of living with dementia, participants living with dementia varied in their responses, some appeared to be unaware of their limitations relating to dementia or underestimated them. Cognitive unawareness appeared to be present in P1 and P2 (the two participants living with dementia accompanied by paid carers). They made comments, which suggested that they did not feel limited by dementia. One participant joked about dementia, seemingly unaware of their diagnosis.

> "No, I'm alright, fit as a fiddle… Well yeah, I aren't far off [having dementia, jokingly]. I feel exactly the same as I've always felt. I'm quite happy with my life and my outstanding… I haven't had any problems." (P2)

Similarly, another participant made comments suggesting that their life had not changed following the onset of dementia. Though in this case, they were aware that they experienced memory troubles.

> "I've felt like this all my life really, nothing's changed… I never really think about it [dementia and memory loss], I can't bring to mind how it affects me." (P1)

It was clear that the paid carers were aware of additional dementia related limitations, but entertained the person's living with dementia perspective on their own experience. For example, they smiled sympathetically while the person living with dementia was speaking about their lack of negative symptoms, but in order to convey to the researcher that the person living with dementia may be unaware of their own issues, one carer commented:

> "I think she forgets that she forgets… she realises she has a bad memory, but she forgets the conversation we've had about it." (P1C)

Participants living with dementia accompanied by their spouse appeared to have more awareness of their dementia diagnosis and limitations in comparison to those attending with a paid carer. They displayed signs that they doubted their ability to maintain conversation with the researcher and for giving accurate descriptions of their experience. During the conversation, the people living with dementia regularly looked to their carer for approval and asked for confirmation that they were correct.

> “I go to a keep fit class, don’t I?” (P4)

> “I used to be energetic, didn’t I?” (P5)

> “…and we go to that place, don’t we?” (P7)

Moreover, the continuous requirement for approval from the caregiver in the married pairs was apparent among multiple participants. This highlighted an awareness of the level of dependence the participants living with dementia had on their spousal carers. The approval seeking may have also indicated some discomfort when answering questions in the fear of articulating their own limitations. Some participants living with dementia however, did refer specifically to their memory troubles and change in daily activities, which displayed their awareness; though it was unclear if they were aware of the full extent of their limitations.

> “oh, just in this last year, erm, remembering things I suppose, I think remembering (looking to spouse for confirmation). It’s irritating.” (P4)

> “well, erm, I can’t remember things. I can [remember things] from years back but not from this week or last week.” (P7)

Other than P2, the participants living with dementia that completed the interview before the intervention, appeared to be aware of a variety of lifestyle changes they had experienced, though it was unclear whether they attributed these changes to the limitations brought upon by dementia or other factors (i.e., old age or mobility troubles).

> “We go singing four times a month, but I used to be in a choir, but I stopped going. I like singing and playing the piano.” (P1)

> “Erm, ha-ha, I do a lot of running (looking at spouse for confirmation), well I used to” (P3), “we do walk now” (P3C), “it’s fantastic” (P3).

> “I can’t be bothered mostly. And it is mostly boredom. If I had something to do other than watch the television.” (P4)

> “I used to be really energetic.” (P5)

One participant living with dementia, despite awareness of the diagnosis received from their GP, appeared to be in denial about the severity of their symptoms. Their carer described their awareness of dementia related limitations. However, the participant living with dementia did not make any reference to their own decline, instead they suggested that they did not agree with the severity of their symptoms, attributing them to the normal ageing process.

> “I can’t accept it; I can’t accept it at all. I just can’t accept it love. I don’t want to get old… I tell my grandchildren to never get old” (P5)

In contrast, another participant specifically spoke about their awareness of dementia progression and appeared worried about the progressive nature and uncertainty of living with dementia. They made a comment referring to the other participants in the group, indicating that they were aware that their own limitations may continue to increase and considered the impact it may have on their spouse.

> “It does worry me, like these people like myself, and I worry about how (P7C) is coping. And I don’t want to hurt her.” (P7)

Behavioural unawareness

During the interviews, carers referenced some behavioural changes, which had occurred in the participants living with dementia, following the onset of their condition. These varied between individuals, although one carer spoke about the changes in their person’s living with dementia mannerisms, indicating that they now behaved differently compared to before the onset of dementia. The carer reported the display of repetitive behaviours and that the person living with dementia would show anger and/or frustration by using negative language directed at the carer.

> “Just his mannerisms and the way he was. He kept saying things over and over again and just the things he was doing… Obviously he says some nasty things and it gets you, you know? He doesn’t realise he’s saying it.” (P7C)

Perception of changes

This theme was consistent across all carers; both paid carers had known the people living with dementia prior to diagnosis and commented on the impact of dementia on them as a person. The theme comprises of two further sub themes: memory, and apathy and motivation, respectively.

Memory

Carers each spoke about the participant’s living with dementia decline in memory. The memory problems discussed were mainly related to a decline in short-term memory, while long-term memory appeared to remain intact for all participants.

> “She realises that she had a poor memory, but she forgets the conversations we’ve had about it… she can remember everything before her husband died.” (P1C)

> “(P4) is good [with memories] from years ago, but [they forget] what’s happening this hour/this day.” (P4C)

> “We know she has a memory problem. I asked her to bring something three times and she forgot three times.” (P5C)

Despite memory problems being mentioned by all participants during the baseline interview, only one carer spoke about strategies already in place to aid the person living with dementia to remember and complete daily tasks.

> “I’ve bought a clock, so she can see the date/day/time… we have a diary out now all of the time… she’s kept diaries all her life so if we want to know what happened one day we can look. I know when things started changing.” (P4C)

Apathy and motivation

Multiple carers reported a decrease in motivation, which led to a change in behaviour in the participants living with dementia as a result of its onset. They believed that a decreased motivation led the person living with dementia to be less active and involved in tasks, which they had previously enjoyed.

> “She was very active, and it’s stopped. She will get in my car, but she used to go everywhere by herself. She used to love gardening; she could get lost in the garden. She used to swim every week, but it’s all gone… it’s all changed now, she’s not active enough… we’re trying to get her motivated.” (P4C)

> “She used to like to cook and now she can’t stay stood at the stove for too long. Your [talking to the person living with dementia] mind is telling you, you haven’t done any house work today, but it used to be a daily ritual… she’s lacking in motivation.” (P5C)

> “I’d like to think he could be more motivated, if I left him, he would stay in bed all day.” (P6C)

In order to understand the apparent behaviour changes, one carer attributed their partner’s lack of motivation to “not knowing what they (the person living with dementia) want" as a result of dementia pathology. The carer appeared to believe that, although the person living with dementia showed signs that they were not enjoying certain activities, they thought that if they continued to partake, they would enjoy the activities as they had before dementia onset.

> "And then one week he (P6's friend) said (P6) he didn't want to go any more, but I said he had dementia he doesn't know if he wants to go or not, you have to keep taking him and he will eventually like it." (P6C)

Similarly, fatigue was reported as a possible cause of a reduction in motivation and behaviour change among the participants living with dementia. A lack of energy was thought to alter behaviours as the person living with dementia required more breaks and rest time, which interfered with what had previously been their daily routine.

> "She gets tired quickly, she rests quite a lot during the day. She will put her feet up at about 10am and then after the evening meal at about 6ish…" (P5C)

> "She can sleep for England." (P4C)

Carer strain

Carers reported some of the difficulties they had experienced while caring for the person living with dementia; this theme emerged from the spousal carers. They spoke about how the changes associated with dementia had impacted on their own life. This theme is comprised of a further three sub-themes: loss and grief, frustration, and lack of 'me time', respectively.

Loss and grief

One spousal caregiver spoke about their perception of changes in the person living with dementia impacting on their own current and future life. They referred to the deterioration, which had already occurred in the person living with dementia, and how they worry about their own future following the progression of dementia in their spouse.

> "He's vanishing… I don't want to live without him." (P6C)

It was clear from interviews that the concern regarding the changes was common among all spousal carers.

Frustration

Spousal carers spoke about the frustrations they experienced while caring for the person living with dementia and the changes in their spouse's abilities. The presence of dementia was a consistent cause of frustration among carers, often due to the inability of the people living with dementia to carry out daily tasks and chores (i.e., cooking, cleaning, and gardening). This appeared to add strain to carers, due to increased individual workload and carrying out tasks, which they may previously have relied on their spouse for, on top of their caring requirements.

> "He doesn't do the gardening anymore, so I have to do it, or I have to pay someone to do it… I'm ashamed of my house because I don't have time to do anything because I do everything for (P6)." (P6C)

One carer acknowledged their frustration toward the person living with dementia and spoke about discussing this with their GP. It appeared that although this was something they were working on, they still struggled to keep their frustrations at bay.

> "It's hard to deal with the frustration, our own GP suggested it's something I need to try to master." (P5C)

The difficulty in dealing with these frustrations was also mentioned by other carers, one of whom felt like the frustrations were too much.

> “There are times I don’t think I can cope.” (P6C)

This carer had noted that they had discussed their frustrations with their GP. During one of the sessions this carer also had a personal conversation with the clinical psychologist delivering the session, which was not recorded.

Lack of ‘me time’

Spousal carers felt as though their time was spent mainly caring for their spouse rather than enjoying their own lives. Due to the uncertainty and fear around the people living with dementia’s limitations, carers appeared apprehensive to leave the people living with dementia alone for long periods of time. This resulted in a lack of personal time, which contributed to their stress and frustration.

> “I need time to relax for myself, at the moment I can leave him but only for an hour at the most... I do one thing a week without you [directed toward P3].” (P3C)

> “I get a carer in from the care people once a month, and I get time off to go and see some friends for a few hours.” (P6C)

For most pairs (other than the two participants with paid carers), carers were not accessing regular help, but voiced their desire in looking for extra support.

> “I’d like to get some information about where I can get some help. We don’t have family close by.” (P3C)

This highlighted a requirement for information about available support and services to be distributed to carers of people living with dementia, particularly for those living away from family support networks.

Understanding dementia

Carers spoke about the people living with dementia and made a reference to their understanding of dementia, in general. This theme comprises two further sub-themes; carer understanding and outside stigma.

Carer understanding

The two paid carers had prior experience of working with people living with dementia and had received training. The remaining six carers did not appear to have received much information from their GPs about dementia, its causes, suggested coping strategies, and/or available help. Carers reported an awareness of a decline in memory, motivation, and sociability of the people living with dementia, but appeared to not know much other than their own lived experiences.

> "It's hard, I don't expect people to understand because I don't understand. I don't know how he got it [dementia], he's never had a heart attack or anything like that… I couldn't believe it had happened to us." (P6C)

Furthermore, it was clear that carers wanted to gain some insight into how dementia affects the people living with it.

> "it [the intervention] might give us a better understanding of people who are going through this." (P2C)

Stigma

Only one carer referred to people outside of the family. They spoke about the participant living with dementia's friendship group and how it had changed since their diagnosis. They interpreted this as their friends deserting them as a result of them developing dementia.

> "All his friends had deserted him that's what terrified me. But people have shunned us, but one or two neighbours look out for us." (P6C)

4.1.2.2. Post-intervention

Post-intervention interviews took place one week following the final intervention session. All 12 participants that completed the intervention took part in the post-intervention interviews and expressed their enjoyment and self-reported positive outcomes as a result of the intervention. Due to minimal input from the people living with dementia in these interviews, post-intervention analysis was mainly from a carer's perspective. Thematic analysis of post-intervention interviews highlighted two main themes: intervention elements and constructive feedback (Table 6).

Table 6

The main themes and sub-themes identified during thematic analysis of post-intervention interviews for people living with dementia and their carers

Main theme	Sub-theme
Intervention elements	Physical activities Cognitive stimulation Social engagement Carer burden Enjoyment
Constructive feedback	N/A

Intervention elements

Carers and people living with dementia appeared to enjoy and benefit from the intervention sessions. The theme is comprised of five further sub-themes: physical activity, cognitive stimulation, social engagement, carer burden, and enjoyment.

Physical activity

The physical activity element of the intervention received some positive and some negative feedback. Some participants enjoyed the physical activities, they spoke about the enjoyable aspect for both the people living with dementia and the carer.

> "He enjoyed many of the exercises especially the walking." (P6C)

> "We enjoyed the physical tests – quite unexpected." (P5C)

> "The exercises were good, I enjoyed doing them with her." (P2C)

In contrast, some participants did not enjoy the physical activity and carers reported the person living with dementia refusing to complete them despite their apparent ability to.

> "He did not like all the exercises, some he would not do – in his youth he did a lot of running and other sport." (P6C)

> "She completed the exercises without trouble, when she wanted to." (P2C)

One carer spoke about how they performed the physical activities together with the person living with dementia.

> "It was good to get her active again. We practised the exercises at different times through the day and saw some improvements. We realise we need to keep doing more, 'use it or lose it', turn the TV off and get active. I realise it for myself too." (P4C)

In contrast, some carers did not feel the physical exercise were beneficial to the participants living with dementia due to their perceived existing high level of physical ability, and therefore, did not complete all of the physical activities set.

> "We did not find the physical tasks at home useful. Fortunately, he is still physically fit, but I have kept the notes for future reference." (P3C)

> "She is very physically able anyway." (P2C)

Cognitive stimulation

Carers felt that the participants living with dementia benefitted from stimulation, which the intervention provided in the form of interaction with others and the requirement for attention and use of cognitive processes during tasks set. They enjoyed seeing the people living with dementia engaging in activities and discussions and spoke about the positive impact gained from the cognitive stimulation. One pair in particular, appeared to benefit from the use of cognitive strategies, which were taught during the intervention.

> "We are going back to doing things step-by-step, it takes longer but I don't feel like I have to do everything." (P3C)

The carer began to re-train the participant living with dementia to do simple tasks by doing them step-by-step and practising repeatedly at home, as detailed during the intervention sessions. Furthermore, the carer noted that following the intervention the person living with dementia was making progress at remembering/re-learning their spousal carer's name, which appeared to be a very positive moment for them both.

> "We have been practising [P3] remembering my name, today I asked him what my name is, and he got it right (both smiling excitedly). He usually says our daughter's name." (P3C)

They utilised 'errorless learning' (Wilson et al., 1994), a process in which the person living with dementia is prompted immediately after an error to guarantee success, the prompting then fades following more correct responses, which was one of the strategies taught during the intervention.

Social engagement

When analysing the group dynamics of the intervention sessions, social and motivational elements to the tasks appeared to contribute to additional cognitive stimulation. One carer spoke about this in comparison to the stimulation available in the home.

> “P4 felt motivated and interested, the stimulation and encouragement were good. The motivation was greater at the group sessions than at home where is it easy to get stuck in front of the TV all day.” (P4C)

Further, the participants also enjoyed and appeared to gain from the social element in the sense of being around other people in a similar situation to themselves.

> “We enjoyed the interaction with like-minded people.” (P5C)

> “(P6) was in company… we see very few people, so it was good to expand our number of acquaintances.” (P6C)

Carer burden

During post-intervention interviews, carers spoke about the positive impact of the educational aspects of the intervention in helping them to gain some understanding into what their partner was going through, along with some explanation surrounding some behaviours common in dementia.

> “It was really interesting to learn about what happens to the brain, it helped me understand more… It was really good for raising awareness and understanding.” (P2C)

> “(the intervention) educated me more about the condition.” (P4C)

> “It was beneficial trying to understand the workings of the brain and its various components. I liked seeing the brain and that different areas are responsible for different behaviours/changes.” (P5C)

Seemingly, due to an increased understanding of dementia, carers appeared to be less frustrated with the behaviours displayed by the person living with dementia (eg., reduced motivation). They acknowledged the need to be more patient, allowing the person living with dementia time to process information.

> "Before, I wasn't handling it very well, I was irritated and in denial I think." (P4C)

> "The carer needs a lot of patience." (P3C)

The understanding that caring for a person living with dementia requires patience was consistently discussed during post-intervention interviews. It appeared that carers felt more confident voicing this need for patience following the intervention, which may be a result of group discussions, which confirmed that frustration was common among carers. It was suggested that sessions aimed specifically on support and advice for carers, without the person living with dementia present, would be beneficial.

> "I would like a more detailed guidance for the carer, particularly to handle patience." (P5C)

One carer was initially frustrated with the person living with dementia repetitively asking what the time was or what the date was. At one of the later sessions, the carer spoke excitedly about buying a 'dementia clock' (as recommended by another carer during the group sessions), which stated the time, day, and date – noting how they would tell the person living with dementia to look at the clock if they asked the time/date. Even though the person living with dementia still asked, the carer appeared much less frustrated as they could help the person living with dementia to help themselves. Similarly, another carer reported a reduction in frustration following the use of strategies, which involved completing tasks step-by-step. This enabled the person living with dementia to be more independent (than they had been previously) during some tasks.

> "I have realised he is capable of doing more for himself. I have taken on board the strategies… He struggles with some tasks. We have gone back to making cups of tea and other simple but helpful tasks. Even small improvements are encouraging." (P3C)

Enjoyment

This theme appeared to be consistent across participants. Both the carers and the people living with dementia enjoyed the activities during the sessions and spoke about the fun they had during the sessions.

> "We enjoyed the weekly session, it was fun and friendly, we still play balloon tennis!" (P3C)

> "We recommend attending the group sessions. They have various activities, stimulation and social involvement. We really enjoyed this and recommend it." (P4C)

> "We weren't really sure what to expect. We enjoyed it all." (P5C)

> "He enjoyed many of the exercises, especially the walking." (P6C)

The enjoyment of the sessions may have contributed toward the high attendance rate.

Constructive feedback

Participants mentioned that a carer-only group, focussing on strategies for patience, with the opportunity to speak with other carers, may benefit them and help to ease some aspects of caregiver burden.

> "I would like a more detailed guidance for the carer, particularly to handle patience, frustration and life changes." (P4C)

This was also mentioned during group discussions, at which point all carers appeared interested in the possibility of a carers' group.

Another interesting point that was made related to the delivery of group sessions was that some participants were hard of hearing and found it difficult, on occasion, to follow the group discussions. Along with this, people living with dementia may have found it difficult to keep sustained attention and/or remember aspects of the presentations and discussions following the sessions.

> "He listens so very hard, but he forgets almost as soon as something is said to him. He is deaf and will not wear his hearing aid." (P6C)

> "She didn't join in with the discussions, I think maybe she couldn't hear it that well. She doesn't wear her hearing aid." (P2C)

4.2. Living with dementia in lockdown

In total, six pairs (three of which had taken part in the intervention; see participant characteristics in Table 7) took part in the semi-structured telephone interviews and the quality-of-life questionnaires (conducted in April/May 2020; data from six pairs are reported in Table 8). All pairs consisted of one person living with dementia and their familial caregiver (five spousal, with one adult child of the person living with dementia). All pairs were living together at the time of interview.

Table 7

Participant characteristics for lockdown interviews

	Social isolation period
Pairs (*n*)	6
Age of person living with dementia (years)	76.4 ± 5.6*
Gender of person living with dementia (male:female)	2:4
Gender of carer (male:female)	4:2

Data are reported as mean ± standard deviation (SD)

*One participant did not provide information regarding their age

4.2.1. Quantitative outcome measures

Mean scores for REQOL-10, GDS, and CSI found that participants living with dementia (and their carer, where relevant), on average, did not surpass the specified cut off points to indicate cause for concern for those outcome measures. However, participant scores on the SAST indicated that, on average, the participants living with dementia were within the clinical range for anxiety (See Table 8).

Table 8

Scores for quality-of-life outcome measures for participants during lockdown

	Recovering Quality of Life - 10	Geriatric Depression Scale	Short Anxiety Screening Test	Caregiver Strain Index
Score	25.1 ± 7.2	5.5 ± 3.8	18.8 ± 2.2	8.5 ± 1.9

Data are reported as mean ± standard deviation (SD).

Clinical threshold of each test as specified by authors; Recovering Quality of Life – 10 = ≤24 AU; Geriatric Depression Scale = ≥5 AU; Short Anxiety Screening Test = ≥24 AU; Caregiver Strain Index = ≥7 AU

4.2.2. Qualitative outcome measures

Consistent with the previous interviews (above), carers mainly contributed to interviews and four of the participants living with dementia did not contribute to the telephone interviews at all. Thematic analysis (according to Braun & Clark, 2006; Table 3) of telephone interviews, highlighted four main themes; social engagement, lockdown activities, mood and coping, and breaking guidelines (Table 9).

Table 9
The main themes and sub-themes identified during thematic analysis of telephone interviews conducted during lockdown

Main theme	Sub theme
Social engagement	Phone/video call technology
Lockdown activities	Gardening
Mood and coping	Impact of lockdown on the person living with dementia Confusion Fatigue Carer burden
Breaking guidelines	N/A

Social engagement

Participant's reactions to the restrictions differed between individuals; some participants adopted a positive outlook and attempted to "make the most of it".

> "We just don't go anywhere, but we get a lot of attention from the children." (P4C)

> "We speak to our children on the phone regularly, we see our neighbours, they're our friends which is nice. We live on a corner so when we play table tennis on the drive we can see people walking past and talk to them so we aren't without contact." (P2C)

> "We have lots of friends and our children check up on us." (P5C)

Conversely, other participants spoke about having some contact with others, but in a way, which suggested dissatisfaction.

> "We don't see people, although we have friends and family spread about. They ring regularly but it's not the same as being able to say 'I'm coming to see you' and I'm finding that very hard. It's difficult, very difficult. Sometimes we see the

> neighbours in their gardens, but you’re still talking from a distance, it’s not a normal conversation you have.” (P3C)

> “We have friends, but we can only speak to them on the phone or videocall and it’s not the same. I go hours when I don’t get much conversation from him. I knew it was going to be hard.” (P6C)

It was apparent that the participants that appeared to be more positive about the situation spoke about their adult children making efforts to check in on them.

Phone/video call technology

One carer noted that the person living with dementia did not enjoy socialising via telephone, which they attributed to their language processing speed.

> “But he can’t talk to people on the phone, only face-to-face, because he knows he can take his time and answer. He’s better talking to someone [in person] rather than on the phone.” (P6C)

On the telephone, individuals are unable to see if the person they are speaking with hears and/or understands the message, which may result in disjointed conversation(s). Whereas, in person, visual clues may prompt the recipient to allow more time for information processing. The use of video call technology has the potential to enable individuals to see each other while conversing remotely; however, this requires the availability of the internet and the knowledge of how to use such technologies. Of the participants in the study, all but one pair had access to the internet; though, during interviews it was clear that prior to the period of social isolation participants had not used video calling. The charity groups (e.g., The Alzheimer’s Society) had been in touch with the participants in order to try to arrange a way of continuing their group sessions remotely.

However, at the time of our interviews this had not been put in place, but participants appeared to be excited at the thought of joining the sessions again.

> “Well the organiser of the singing group (Singing for the Brain), rang me to see if we have a computer, because they are going to do it that way… She loves singing.” P3C

Lockdown activities

Participants, in particular those that had taken part in the SMaRT intervention, appeared to be aware of the benefits of keeping active and spoke about a variety of activities, which they had taken part in during the period of social isolation. This theme comprises of one sub-theme: gardening.

Gardening

Spending time in the garden was a common activity among participants. Most mentioned spending time in their garden as a regular activity throughout the lockdown period. For some participants, this involved gardening and taking care of their garden, and for others this involved enjoying their garden when the weather was nice enough to sit outside.

> “The best thing we’ve got is that we can go out in the garden, so when the weather is nice that’s great, but when it’s not it’s quite difficult because you’re not supposed to go out or go very far.” P3C

> “We have a nice garden and a nice lawn, so we sit in the sun. We potter about going in the greenhouse and that. We need to keep active.” (P4C)

However, in contrast to the majority of participants, one spoke about how the person living with dementia was no longer interested in spending time gardening.

> "We were in the garden this morning, we did some gardening. Well I did. He isn't too keen on it now, there's not much he is keen on now." (P6C)

Mood and coping

Within the sample of participants, most carers reported that they were coping with the lockdown well and keeping in good spirits. This theme comprises four further sub-themes: views of the person living with dementia, confusion, fatigue, and carer burden.

Impact of lockdown on the person living with dementia

Only one person living with dementia spoke about their view on the social restrictions. They made comments, surrounding their struggle with life during the period of social isolation and that they could not enjoy life without socialising and visiting different places rather than staying at home.

> "I will be dead, I'm not doing well. Oh no we're definitely at the end of life, well there's nothing to do or nowhere to go." P3

It is unclear if these views were influenced by the presence of dementia.

Confusion

As expected, the memory disruptions experienced by individuals living with dementia appeared to contribute to additional confusion and dismay regarding the imposed social restrictions. One person living with dementia spoke about how their friends no longer came to see them, expressing their inability to comprehend the reason why they were unable to socialise with other people.

> "A lot of my friends are lost, their attitude is 'ugh'. This morning for the whole morning there's only three people (that walked by the house)." P3

Following this comment, P3's carer went on to explain that P3 would look out of the window to see if people were walking past the house and rush out to talk to them, regardless of if they knew them or not. The acceleration of cognitive decline in individuals living with dementia may have resulted in additional experiences of confusion surrounding the lockdown, which was acknowledged by numerous carers.

> "It's your whole life put on hold. For people living with dementia, it's a part of their life that they'll never recover from. It must be really, really trying for people living with dementia because they're confused anyway." (P3C)

> "She might just get up and want to go out. She doesn't always get why she can't go out. We were just told to stop going out with no warning." (P4C)

Fatigue

Another common theme, which became apparent during telephone interviews was the daytime sleepiness experienced by the people living with dementia.

> "She gets tired a lot, she's resting right now." (P5C)

One carer spoke about the person living with dementia's daytime sleepiness as though it had only become a factor during the social isolation period.

> "He's just going to bed now, he sleeps a lot at the moment." (P6C)

Carer burden

Carers reported some difficulties, which had been faced as a result of the person living with dementia's condition rather than the worries associated directly with COVID-19. They reported the additional strains placed on them during this period due to the person living with dementia's inability to carry out particular tasks unsupervised.

> "He's happy. But there's still that I can't trust him to do much, he wants to be with me all the time. So, it's hard to set things up that we can both do. So, it's hard, but I would say that we're doing fine. We do alright, we do fine really. In lots of ways

> really. But nobody knows how hard it is, because I manage him and what he does. Which is good, I want to really." (P2C)

> "I do, I definitely do feel quite constrained with what I have to do." (P3C)

> "We're better than we have been. We've really been struggling. I get cross with him… He's a bit down as-well, but I think he just reflects my moods." (P6C)

Breaking guidelines

Multiple carers spoke about how they had partaken in activities, which broke the government guidelines on social isolation. One carer mentioned going 'out' at the beginning of the advised social isolation period, and that their adult children 'told them off'.

> "Well, we're stuck with this. I just had my 83rd birthday but I had a cake but couldn't have a party. It's shocking. I went out a little bit at first but got told off by the kids." (P4C)

It appears there were two reasons among the participants, which resulted in them breaking the guidelines. The first was the lack of social contact and needing to spend time with other people for both the carer and the person living with dementia.

> "One of our neighbours came into the house and we sat at the other end of the room, that has been nice. Some of our friends won't come. We have one neighbour who will sit outside." (P3C)

The second reason participants gave for wanting to break guidelines was in order to escape the confinement of their own home.

> "We aren't supposed to be out in the car, but we have been getting in the car and going for a drive around the country roads, which is ok." (P3C)

“We aren’t supposed to be going out, but I can’t bare these four walls any longer. So, we drove somewhere and went for a little walk and came home again. That perked me up… We went out, but we were careful, if we saw someone coming we crossed over the road. We went out at half past eight one night and didn’t see a soul. I need it and I’m sure he does too.” (P6C)

5. Discussion

The primary aim of this thesis was to explore and quantify the efficacy of a novel, six-week physical and psychological intervention (Sphere Memory and Rehabilitation Team's Psychosocial Intervention for Dementia [SMaRT PID]), designed to improve quality of life for people living with dementia and their carers, utilising both quantitative and qualitative research methods. A descriptive analysis of the data pre- and post-intervention found that all participant pairs experienced an improvement in one or more of the outcome measures. Additionally, we sought to analyse the effect of the group intervention on carer strain in caregivers of people living with dementia. Throughout these sessions and at post-intervention interviews, carers spoke positively about how the SMaRT PID enhanced their quality of life, as a result of their attendance. However, this was not reflected in the Caregiver Strain Index scores. A secondary aim was to investigate the impact of the COVID-19 related social restrictions on individuals living with dementia and their familial caregivers. Participants appeared resilient to the potential reduction in quality of life during lockdown, and this was attributed largely to their increased emotional support from family members.

In relation to interventions designed specifically for people living with dementia, it is important to note that due to the progressive nature of dementia pathology (American Psychiatric Association, 2013), a slight decline in, or maintenance of capability, may not signify a lack of effect from the intervention, but rather a protective factor against decline. Furthermore, due to the pragmatic nature of this case series, it is important to note that participants' life experiences, outside of the intervention, may have also influenced their perceived quality of life. Therefore, the changes in outcome measures for participants may be reflective of circumstances, experiences and thoughts unrelated to the SMaRT PID.

5.1. Perceived quality of life following the SMaRT PID

The SMaRT PID was delivered in a social group setting with the intention of improving quality of life for people living with dementia and their carers. The intervention combined a physical training programme with the teaching of cognitive strategies, in which social engagement was actively encouraged. As discussed previously, physical activity (Hickey et al., 1995; Means et al., 2005), cognitive stimulation (Zanetti et al., 2001; Wang et al., 2002), and social engagement (Golden et al., 2009; Singh & Misra, 2009), may contribute in protecting against a declining quality of life in individuals with cognitive impairment and dementia. Furthermore, psychoeducational interventions may protect against carer burden for caregivers (Ostwald et al., 1999; Martín-Carrasco et al., 2009).

Participants' perception of their quality of life varied between individuals as expected. Moreover, the differences between baseline scores and post-intervention scores on the quality of life questionnaires were not consistent across the sample of participants living with dementia. One participant (P3) displayed an improvement in all quality of life measures, including an increase in REQoL-10 score (above the MDC), a reduction in GDS score, which indicated the presence of depression to a clinical level at baseline and not post-intervention, and a reduction in SAST score. However, P4 and P6 displayed the opposite, with a reduction in REQoL-10 score (above the MDC for P6); an increase in GDS score, which indicated the presence of depression to the clinical level post-intervention, which was not present at baseline; and a slight increase in SAST score. All other participants displayed both positive and negative changes to the outcome measures post-intervention, compared to their baseline results. These findings support early suggestions, which indicated the individual differences between people regarding the specific needs to sustain an adequate quality of life (Farquhar, 1995; McGee et al., 1991); therefore, highlighting the requirement for a more individualised training programme and strategy set, in order to focus on specific factors considered important to the person living with dementia.

It is important to acknowledge that carers aided the participants living with dementia in completing the quality-of-life questionnaires, by reading and differentiating the questions, discussing answers, and marking the response. Thus, carers may have influenced the responses to these outcome measures. Carers have been found to view the quality of life of people living with dementia as being lower than the individual rates their own quality of life (Conde-Sala et al., 2009). Therefore, the results from the quality-of-life outcome measures used may not display a true representative on the subjective experience of the participants living with dementia. Conversely, it is important to note that individuals living with dementia may be unaware to some extent of their own symptoms and behaviours (Starkstein et al., 1996), whereas their caregivers may have the ability to provide insight into their experiences; particularly, spousal caregivers that can compare the current behaviour(s) to how they were prior to dementia onset. Therefore, the information gained from the quality-of-life questionnaires and from carers during interviews, may hold value even when comments were not supported by the participants living with dementia. However, this must be interpreted with caution and should not be analysed as the view of the person living with dementia, as their actual experience may not be the same as the subjective view of their carer.

Physical capacity

All participants displayed an increase in grip strength and an increase or maintenance of Berg Balance Scale score following the SMaRT PID compared to their score at baseline. This was consistent with earlier research (Toulotte et al., 2003; Hilliard et al., 2008), which found significant improvements in balance following a physical training programme and concomitantly improved quality of life by reducing the likelihood of falls in older adults, with cognitive impairment. No other outcome measure, in the present study, saw consistent improvements or maintenance across the sample.

Although there is evidence to suggest that a six-week training programme (eg., the SMaRT PID) may be sufficient to elicit positive effects on physical capacity and overall quality of life (Hickey et al., 1995), some authors (Toulotte et al., 2003; Lam et al., 2018) have suggested that the duration of a physical intervention involving people living with dementia may be more beneficial to their quality of life if the duration is more than 8 weeks. Furthermore, the required duration may also vary dependent on the intended outcome. For example, some authors (Lam et al., 2018) have suggested that training programmes may improve balance, and walking endurance after only an 8-week programme; yet, it may take up to 12 weeks to show an improvement in mobility. Therefore, the potential benefits from the 6-week SMaRT PID may have been more consistent if delivered over a longer period of time.

The SMaRT PID was delivered once weekly, with the intention that participants would complete the physical training set a further three times at home (within the seven-day period), before the next session. However, it is important to note some participants in our study did not complete all of the ‘homework’ training exercises required, as reported by multiple carers. For example, one carer reported; “He did not like all the exercises, some he would not do …” and another participant would only complete the homework “when she wanted to”. Enjoyment of physical activity differs among people regardless of cognitive impairments (Mullen et al., 2011) and is thought to be a predictor of participation and outcome of physical activity (Buckworth et al., 2007). During the weekly SMaRT PID group sessions, all participants completed the physical tasks that were set, and appeared happy to do so. However, only one participant pair reported completing all ‘homework’ tasks; therefore, it may be the case that participants found the physical activity more enjoyable during the group sessions and were less motivated to take part at home.

Another possible explanation for this compliance in group, compared to the non-compliance at home, may be a result of social facilitation (Allport, 1924). Social facilitation theory is thought to have stemmed from early research by Triplett (1898) who identified a superiority in outcome when working on a familiar task in the presence of others, compared to working alone. In a meta-analysis, Burke and colleagues (2006) compiled evidence, which ultimately suggested the superiority of training in group settings over training alone. It may be the case that in the group setting in the present study, participants’ performance was influenced by being in the presence of others (who were also attempting the same task), which then diminished when they were set the same task to complete alone in their home, with only the presence of their carer. This theory is supported by previous research (Kahn et al., 2002), which suggested that the presence of social support may enhance overall engagement in physical activity. Therefore, it may be the case that the SMaRT PID may produce more consistent improvements by offering additional group training sessions, rather than setting homework tasks, which individuals may be less likely to engage in.

Prior to the intervention, participants ranged from leading a sedentary lifestyle to leading a moderately active lifestyle, as indicated on the self-reported PAR Q. Therefore, their individual lifestyle may alter how they viewed the physical activities set, mediated by their perceived sense of ability and possible ongoing health issues such as arthritis, which was noted by multiple participants. The lack of consistency among participants in their completion of ‘homework’ tasks, may be attributed to the standardised training programme. The physical activities set for participants were not individualised to focus on personal targets, which may have caused disinterest (Fasola & Mataric, 2012), or inadvertently disadvantaged some participants. It has been suggested (Jancey et al., 2009) that older adults may be less inclined to partake in certain forms of physical activity due to discomfort (i.e., aches and pains) and awareness of reduced abilities (in comparison to their younger years), thus highlighting their reduced capacity for involvement. Therefore, by incorporating the individual circumstances and ability of participants into the training program, participants may have felt more comfortable and confident to attempt these tasks at home, away from the group, which may have provided additional confidence.

Effective physical training programmes have the capacity to improve multiple aspects of quality of life, including physical competence (i.e., balance and strength). In this study, the scores obtained from the physical outcome measures at baseline highlighted that participants in the study were not considered to be at risk of falls at the time of admission to the intervention, with all participants scoring above 38 in the Berg Balance test (scores ≤38 indicative that individuals living with dementia are at risk of falls; Telenius et al., 2015). Therefore, it may be the case that participants did not feel physically vulnerable and thus, did not consider the physical aspect of the intervention to be of importance to their personal needs and/or goals. This was confirmed during analysis of baseline interviews, with participants reporting their interest in the intervention was more focused on strategies geared toward reducing memory troubles and improving motivation.

Often the positive results from training programmes are not found to be long lasting following a period of time ‘off program’, therefore physical activity should be continuous in order to sustain improvements (Toulotte et al., 2003). Participants in the SMART-PID, who did not complete the required physical activity throughout the duration of the intervention, may be unlikely to practice the physical activity set continuously in the long-term without the support from the group (Kahn et al., 2002). Therefore, any improvements gained from the supervised sessions would be unlikely to be sustained. It may be beneficial, following the SMaRT PID, for participants to be encouraged, by the group leaders, to join or partake in local groups to allow for continued group based physical activity.

Cognition

Aside from improving physical capacity, physical activity (in particular aerobic activity) can also significantly improve brain function (Dustman et al., 1984) and morale (Hickey at el., 1995). It has been suggested that older adults may not be aware of the potential cognitive benefits associated with physical activity (Franco et al., 2015), which may help to explain why participants displayed a lack of motivation to complete the physical tasks when not in the presence of the group. An example of this was observed during the post intervention interview, with one participant stating, "we did not find the physical tasks useful, fortunately [P3] is still physically fit". This highlighted a lack of awareness, among participants, surrounding the benefits of physical activity, which extends further than physical capacity.

Our findings were consistent with previous research (Jette et al., 1998), which suggested a requirement for older adults to have knowledge of the health benefits of physical activity in order to ensure adequate adherence to training programmes. We suggest that more education on the potential benefits of physical activity for cognition may be important during the initial intervention session of the SMaRT PID, in order to promote compliance to the set tasks.

As indicated in the baseline interviews, memory troubles was one of the leading worries reported by participants. Following participation in the SMaRT PID, some carers reported noticeable improvements in some areas of the persons' living with dementia memory. For example, one person living with dementia (P3) managed to remember their spouses' name, which was a clear victory for them. Similarly, P2's carer noted that they had started to remember where they were going when travelling to the SMaRT PID sessions. These achievements following participation in the SMaRT PID were in line with previous research which suggested that people at the early stages of dementia may have the capacity to retain new information when using procedural strategies. (Zanetti et al., 2001; Farina et al., 2002).

Our findings may support the potential cognitive benefits of the SMart PID. However, outcome measures were selected to assess perceived quality of life rather than cognition, thus, we are unable to provide clear evidence of this.

Social engagement

During the group sessions, it was apparent that participants living with dementia were less involved in the group discussions than their carers. Cognitive and behavioural changes, associated living with dementia progression (such as apathy and agitation), may contribute toward a declining desire or ability to engage in social activity (Hackett et al., 2019; Singleton et al., 2017), thus resulting in the participants living with dementia being uninvolved in the group discussions. This may have inhibited the potential social benefits for the participants living with dementia, providing some explanation regarding the inconsistent results found in the quality-of-life questionnaires, and the failure to support previous findings in similar interventions.

Caregiver strain

The SMaRT PID offered the caregivers of participants living with dementia the opportunity to learn more about dementia pathology, and the behaviours associated living with dementia development. Additionally, the intervention sessions were designed to be delivered in a group setting and participants were actively encouraged to converse with others and contribute to group discussions, especially surrounding the experience of caring for a person living with dementia.

Caregivers scores on the CSI suggested that at baseline four of the five carers who completed the measure (one carer did not feel the measure was relevant as a paid carer), lay within the clinical range for caregiver strain. At post-intervention testing, three of those carers' scores reduced to fall below the clinical cut-off. However, two carers displayed an increase in their score; one of which was above the clinical threshold at baseline, and the other was above the clinical threshold at post-intervention testing, but not at baseline. Both of the individuals showing an indication of increased carer burden following the intervention had experienced adverse events outside of, and unrelated to the intervention, which may have impacted on their level of burden.

For those carers displaying a reduction in caregiver strain, they appeared to attribute the change to some of the teachings delivered during the SMaRT PID sessions; for example, one carer reported "It [the SMaRT PID] has helped me appreciate everything that she is going through… I'm used to being someone who doesn't suffer fools. Now I know I need to mellow it". Multiple participants had similar responses and spoke about how their patience with the person living with dementia had improved following the intervention. It may be the case, that prior to their participation in the SMaRT PID, those carers may have believed that the person living with dementia had been displaying behaviours to factors other than the presence of dementia. For example, multiple carers spoke about the requirement to be more patient with the person living with dementia, following the clinician led group discussion around the fatigue associated with dementia. At baseline, carers attributed the person living with dementia behaviours to being 'lazy' or displaying a lack of motivation.

Previous research (Paton et al. 2004) has suggested that a large proportion of familial caregivers do not attribute dementia-related behaviours to dementia pathology. Therefore, by enabling greater understanding surrounding the cause and effect of various behaviours associated with dementia, the psychoeducational element of the intervention may have contributed to a reduction in caregiver strain among carers.

This finding/observation was consistent with previous research (Salfi et al., 2005), which suggested that the more informed caregivers were, the more likely they were to seek support and partake in activities, which may reduce their burden. By allowing carers to be more aware of the limitations that people living with dementia may have and the possible explanations behind them, carers may be more able to attribute behaviours to triggers and/or causes and seek appropriate strategies to aid them. For example, one carer was initially frustrated with the person living with dementia repetitively asking what the time was or what the date was. Following one of the group discussions one carer spoke excitedly about buying a 'dementia clock', recommended by another carer in the group, which stated the time, day, and date. They spoke about how they would tell the person living with dementia to look at the clock if they asked the time/date. Even though the person living with dementia still asked, the carer appeared much less frustrated as the person living with dementia was able to use the tool. Similarly, another carer reported a reduction in frustration following the use of strategies, which involved completing tasks step-by-step. This enabled the person living with dementia to be more independent (than they had been previously), during some tasks.

This reduction in frustration as a result of seeing small, but positive changes to daily life, may be a result of feelings of hope that participants may have felt following the successful use of new strategies. Hope has been found to positively influence mental and physical strength and enhance carers' ability to find the positives of a situation (Duggleby et al., 2009). Furthermore, research (Czaja et al., 2013) has shown an enhanced positive outcome for carers by improving their knowledge pertaining to available support and their use of strategies surrounding common dementia related behaviour. During the SMaRT PID intervention sessions, participants were given plenty of opportunities to discuss strategies with other participants, and share advice surrounding the available support within the local area.

In the present study, carers reported the desire to obtain more information on the local services and support available. One carer commented "The sit in service [the carers form of respite] is only available every three weeks. I'd like to get some information about where I can get some help. We don't have family – and I need the time to relax for myself". Moreover, carers discussed the positive influence of the advice given to them by others within the group; for example, the use of the 'dementia clock'. This was consistent with previous findings, which suggested that familial caregivers generally require additional information, education, and support (than what is readily available to them) when faced with the dementia diagnosis of a loved one (Peterson et al., 2016). Despite participants attending other social groups, in which they have the opportunity to converse with people in similar situations, it was apparent that they may not have previously spoken to others in a bid to seek advice. Therefore, the SMaRT PID opened up new opportunities to some, by highlighting that there may be additional support and services that have been accessed previously by others, which were openly discussed in the group setting.

5.2. Living with dementia in lockdown

The presence of a global pandemic, along with the strategies in place to protect those at risk while reducing the spread of the virus, is likely to have had and continue to have numerous negative effects on the population as a whole. We hypothesised that following a period of social disengagement during the lockdown period, participants living with dementia would experience a lower perceived quality of life and increased depression and anxiety, and that their carers would experience higher levels of carer burden. It is important to note that data were collected only from the initial lockdown period between March and June 2020, and that findings may have differed if interviews had taken place in subsequent lockdown periods.

All participants that took part in interviews were recruited from pre-existing organised groups for people living with dementia. Therefore, it is known that prior to the government advised period of social isolation (nationally), all participants had been active within their local community and had regular contact with other people. As anticipated, the period of social isolation altered life for both the participants living with dementia and their carers, as they were unable to socialise with others or attend activity groups in line with their usual routines. Participants differed in their responses when discussing the social restrictions. This may be unsurprising due to the individual differences in the frequency and quality of social contact required to feel satisfied (Singh & Misra, 2009). Since our hypotheses were formed, research by Luchetti et al. (2020) has provided evidence to suggest that older adults may be more resilient to the social restrictions compared to younger generations. The authors reported that older adults may have experienced a higher level of support (i.e., more frequent telephone calls by loved ones and additional support to access food and shopping necessities from family or friends), as a result of the pandemic related restrictions, thus reducing the perception of loneliness and burden, which had been hypothesised. In our study, it was apparent that the participants who appeared to be more positive about the situation, spoke about their adult children making extra efforts to check in on them despite the reduced professional support and availability of group support as a result of the COVID-19 pandemic. Life satisfaction in older adults is influenced more positively by familial support compared to support from peer groups (Yeung & Fung, 2007). Therefore, it may be unsurprising that those participants who felt they received support from their adult children were more satisfied with their level of contact than the participants that did not receive support from their children or other family members.

Furthermore, participants spoke about the activities they were taking part in, in order to keep active during lockdown. Gardening was the most commonly mentioned activity for participants during this time, which is unsurprising as it is thought to be one of the most popular leisure activities among older adults (Patterson & Chang, 1999), providing an element of physical activity and a sense of achievement (Scott et al., 2015). However, while time in the garden was spoken about as being an enjoyable activity for participants, it is important to note that during the time of interviews, the weather in the local area was pleasant and sunny, the sunniest April on record to date (Press Office, 2020). Weather conditions are an influencing factor on the outdoor activity of older adults (Aspvik et al., 2018). It may be assumed that had interviews taken place at a time when the weather was more inclement, participants may have been less likely to benefit from spending long periods of time enjoying their garden space and fresh air.

As expected, some level of confusion among the individuals living with dementia was reported; however, it is unclear if this confusion related to the pandemic specifically, or the symptomology of dementia, in general. Similarly, carers also reported frustrations with regard to caring for the person living with dementia, though it was unclear if this was a result of the imposed social restrictions.

5.3. Limitations

The development of the COVID-19 pandemic resulted in multiple, substantial limitations for the study. Firstly, the second cohort of participants (due to start in April 2020) was unable to take part in the intervention due to the group design, which required social interaction – not permitted at the time. This ultimately reduced the sample size of the study, which compromised our ability to determine whether the intervention was actually effective at enhancing quality of life and physical outcomes. For this reason, we adopted a case series approach. The use of a case series poses the ability to explore in-depth observations. However, as this approach was not the initial intention of the study, data that may have allowed further conclusions to be drawn, may have been missed (e.g., the heterogeneity of participants, and asking more specific questions about lifestyle and participants' individual experiences).

An additional consideration is that, due to the adoption of a case series approach, an additional emphasis was put on the analysis of interviews with participants. As this was not initially intended to pose such a large contribution to our findings, interviews were not as in-depth as they would otherwise have been, and additional researchers were not allocated to validate the transcribed interview transcripts and analysis. Analysis of interview transcripts were therefore conducted by a single researcher, which may have skewed the findings as a result of the subjective nature of thematic analysis, and the researcher's previous individual experiences, views, and opinions.

Furthermore, ethnicity and medication use were not reported as potential confounding variables, this limited our ability to identify the impact these may have had on outcomes.

5.4. Recommendations for future research

This pilot study provided evidence of individual differences in response to the participation in a novel intervention (SMaRT PID). Participants had different physical, mental, and social backgrounds, and also had different motivations for taking part in the study. We recommend that future research into the delivery of such an intervention to group of individuals with more similarities in their abilities and motivations would be beneficial. This would allow for group discussion focus to be more relevant to all participants.

Secondly, participants reported that they did not complete some home-based tasks because they perceived them as too easy or too challenging, despite being offered easier and harder options. Therefore, we suggest research analysing the potential benefit of interventions, which provide a more personalised training programme, focusing on individual targets.

Similarly, we suggest research into the potential benefit of more frequent guided group sessions (i.e., two per week as opposed to one), which may provide more consistent effects among participants living with dementia, as found in previous interventions of a similar nature (Toulotte et al., 2003), whilst also incorporating a progressive overload.

This was SMaRT team’s first implementation of a psychosocial intervention aimed to improve quality of life for people living with dementia. The present trial was an exploratory study, which aimed to investigate the SMaRT PID programme and its potential benefits to quality of life for people living with dementia and their carers. We recommend that future research makes use of a randomised control trial to compare outcome measures following participation to people living with dementia undergoing ‘normal’ care routines.

5.5. Practical implications

The primary aim of this thesis was to assess the potential quality of life benefits of the SMaRT PID for people living with dementia and their carers. Our recommendations follow:

- The SMaRT PID should be adapted to be more personalised and focus on the individual needs of the people living with dementia within the group.
- There is a requirement for group sessions to be more frequent than once weekly, in order for people living with dementia to consistently benefit from the physical training aspect of the SMaRT PID.
- The SMaRT PID should be extended past the current six-week delivery, in order for people living with dementia to benefit from the physical training programme.
- Familial carers of people living with dementia should be offered psychoeducation in order to improve their understanding of dementia, what they might expect following a diagnosis, and where to access support.
- Support groups for familial carers should be recommended at the point of diagnosis.
- Familial carers for people living with dementia require additional support from other family members and friends in order to maintain an adequate quality of life.

6. Conclusion

Following participation in the SMaRT PID, all participant pairs experienced improvements in one or more of the outcome measures and expressed their enjoyment in taking part. However, the effect of the intervention on the individual outcome measures was not consistent across participants. These inconsistencies may be explained by the heterogeneous nature of the group and the different motivations for partaking in the intervention.

The individual experiences during the COVID-19 fuelled lockdown varied between participants. Although frustrations were evident among the participants, they appeared to be resilient to the social restrictions and gained great comfort in the support of their family and friends, particularly for the carers. The participants living with dementia experienced confusion surrounding the situation, but it was unclear if this could be explained by dementia symptomology in general or if it was worsened by the social restrictions as hypothesised.

In conclusion, this study highlighted that people living with dementia and their carers may benefit from a six-week intervention, which incorporates physical activity, social engagement, and educational elements. However, we suggest that a more individualised approach to the training programme along with an increase in the number of weekly group sessions may be required, in order to produce more consistent outcomes. Ultimately, the study highlighted the importance of social and emotional support for people living with dementia and their carers, in day-to-day life, and during novel circumstances such as the national lockdown.

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Appendices

Appendix A) Ethical Approval

UNIVERSITY OF HULL

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PRIVATE AND CONFIDENTIAL
Sarah Parkinson
Faculty of Health Sciences
University of Hull
Via email

18th September 2019

Dear Sarah

REF FHS170 - Holistic Rehabilitation for People in Early Stages of Dementia and Their Families

Thank you for submitting your ethics application to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

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Appendix B) Participant Information Sheet 1

Sphere Memory and Rehabilitation Team

UNIVERSITY OF HULL

Holistic Rehabilitation for People in early stages of dementia and their families

Participant Information Sheet 2019– Client Version 1.0

Dr. J. Bray, Prof. N. Vanicek, Miss. S. Parkinson – University of Hull
Dr. K. Dawson, Dr. C. West, Dr. C. Bolton, Mr. T Pattle – Sphere Memory and Rehabilitation Team

Sphere Memory and Rehabilitation Team and the University of Hull would like to invite you to take part in a research study which aims to assess the effectiveness of a 6-week dementia intervention programme. In order to help you make an informed decision please read the following information. If you have any further questions please feel free to contact one our research team (contact information above).

The purpose of this study

The Alzheimer's Society have identified that in the UK approximately 850,000 people are living with a diagnosis of dementia. It is estimated that this number may rise to over two million by 2051. In efforts with the University of Hull, Sphere Memory and Rehabilitation have devised a 6 week intervention programme for individuals at the early stages of dementia. This programme aims to enhance quality of life by combining cognitive rehabilitation and exercise prescription, whilst providing carer support. Included in the programme are strategies which aim to reduce slips, trips and falls and increase overall independence of individuals living with dementia.

You have been invited to take part because you:

- Have displayed early signs of dementia.
- Have no other mental health diagnoses.
- Have a close family member or friend who is willing to support you throughout the 6 week programme.
- Are able to partake in light exercise.
- Are available for eight consecutive weeks to complete the programme.

What will your participation involve?

- You will take part in one session per week with our rehabilitation team. This will take place in a convenient place for yourself, such as a local community centre.
- On the first and last session we will take some measurements (such as heart rate and blood pressure), and ask you to complete questionnaire (which aim to assess your mood and quality of life).
- Each week our team will explain to you your tasks for the following week. You will have the opportunity to practice these.
- Your support person (family member/friend/carer) will be present throughout so that you can both familiarise with tasks.
- You will be required to complete ‘homework’ tasks in your own time when you are with your support person.
- You will be required to wear a wrist sensor (i.e., FitBit), which will measure your heart rate, physical activity and sleep cycle throughout the 8 week period.

If you decide to take part:

- Your personal information will remain confidential.
- You will have the right to withdraw at any time.

What happens next?

If you agree to take part in this study, we will ask you to complete an informed consent form. By completing this consent form you are acknowledging that you understand the information given to you and that you agree to take part in the study. Once completing the consent form you will still have the right to withdraw at any time.

We will then inform both yourself and your support person the date that the programme will take place.

Thank you

Appendix C) Participant Information Sheet 2

Sphere Memory and
Rehabilitation Team

UNIVERSITY
OF HULL

Holistic Rehabilitation for People in early stages of dementia and their families

Participant Information Sheet – Carer Version 1.0

Dr. J. Bray, Prof. N. Vanicek, Miss. S. Parkinson – University of Hull
Dr. K. Dawson, Dr. C. West, Dr. C. Bolton, Mr. T Pattle – Sphere Memory and Rehabilitation Team

Sphere Memory and Rehabilitation Team and the University of Hull would like to invite you to take part in a research study, which aims to assess the effectiveness of a 6 week dementia intervention programme. In order to help you make an informed decision please read the following information. If you have any further questions please feel free to contact one our research team (contact information above).

The purpose of this study

The Alzheimer's Society have identified that in the UK approximately 850,000 people are living with a diagnosis of dementia. It is estimated that this number may rise to over two million by 2051. In efforts with the University of Hull, Sphere Memory and Rehabilitation have devised a 6 week intervention programme for individuals at the early stages of dementia. This programme aims to enhance quality of life by combining cognitive rehabilitation and exercise prescription, whilst providing carer support. Included in the programme are strategies which aim to reduce slips, trips and falls and increase overall independence of individuals living with dementia.

You have been invited to take part because you:

- Care for someone who have displayed early signs of dementia.
- Are willing to support the person you care for throughout the 6 week programme.
- Are able to support the person you care for to partake in light exercise.
- Are available for eight consecutive weeks to complete the programme.

What will your participation involve?

- You will support the person you care for to take part in one session per week with our rehabilitation team. This will take place in a convenient place for yourself and the person you care for, such as a local community centre.
- On the first and last session we will ask you to complete a questionnaire (which aim to assess the stress associated with caring for a person living with dementia).
- Each week our team will introduce tasks for the person you care for, we will explain to you the requirements in case they need a reminder. We can also provide written instruction if required.
- You will be required to support the person you care for to complete these tasks.
- You will be required to fill out a daily record of the wrist sensor activity worn the person you care for.

If you decide to take part:

- Your personal information will remain confidential.
- You will have the right to withdraw at any time.

What happens next?

If you agree to take part in this study we will ask you to complete an informed consent form. By completing the consent form you are acknowledging that you understand the information given to you and that you agree to take part in the study. Once completing the consent form you will still have the right to withdraw at any time.

We will then inform both yourself and the person you care for the date and the location the sessions will take place.

Thank you

Appendix D) Participant Consent

Sphere Memory and Rehabilitation Team

UNIVERSITY OF HULL

PARTICIPANT CONSENT FORM 2019 – Version 1.0

Title: Holistic Rehabilitation for People in early stages of dementia and their families

If you wish to take part in this study, **please place your initials in each of the boxes below, sign and date this form.**

Please initial box

1. I confirm that I have read and understand the information sheet **version XX** dated **XX/XX/XX** for the above study and have had the opportunity to ask any questions about the study and any questions have been answered to my satisfaction. Initials
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected. Initials
3. I agree to the University of Hull and Sphere Memory and Rehabilitation Team holding copies of my consent form, other study related documents and my contact details to allow them to send me questionnaires and to assist with study data collection. Initials
4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. Initials
5. In the event that I lose the ability to consent during the study, I understand that I will be withdrawn from the study but that data already collected with consent would be retained and used in the study. No further data would be collected. Initials
6. I am willing to receive telephone calls, emails or texts about the study in relation to study appointments, activity monitor provision and data collection. Initials
7. I understand that I can withdraw from the study at any time without prejudice. Initials
8. I agree to take part in the Holistic Rehabilitation for People in early stages of dementia and their families study. Initials

In addition to the above questions please initial the following boxes if you agree with the following statements. Your participation in this research study will not be affected if you do not agree with these *optional* statements:

9. I am willing to be contacted with a view to being interviewed about my experience of taking part in the study and agree to members of the research team having access to my contact details and interview data (*you may or may not be contacted*). Initials
10. If I take part in an interview, I am willing for it to be audio recorded and I understand that anonymised written quotations from the interview may be used in publications and presentations. Initials
11. I give permission for the researchers to publish anonymised direct quotations for the purpose of research dissemination. Initials

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Appendix E) Berg Balance Scale Scoring Instructions

Berg Balance Scale (with instructions)

SITTING TO STANDING
INSTRUCTIONS: Please stand up. Try not to use your hand for support.
( ) 4 able to stand without using hands and stabilize independently
( ) 3 able to stand independently using hands
( ) 2 able to stand using hands after several tries
( ) 1 needs minimal aid to stand or stabilize
( ) 0 needs moderate or maximal assist to stand

STANDING UNSUPPORTED
INSTRUCTIONS: Please stand for two minutes without holding on.
( ) 4 able to stand safely for 2 minutes
( ) 3 able to stand 2 minutes with supervision
( ) 2 able to stand 30 seconds unsupported
( ) 1 needs several tries to stand 30 seconds unsupported
( ) 0 unable to stand 30 seconds unsupported
If a subject is able to stand 2 minutes unsupported, score full points for sitting unsupported. Proceed to item #4.

SITTING WITH BACK UNSUPPORTED BUT FEET SUPPORTED ON FLOOR OR ON A STOOL
INSTRUCTIONS: Please sit with arms folded for 2 minutes.
( ) 4 able to sit safely and securely for 2 minutes
( ) 3 able to sit 2 minutes under supervision
( ) 2 able to able to sit 30 seconds
( ) 1 able to sit 10 seconds
( ) 0 unable to sit without support 10 seconds

STANDING TO SITTING
INSTRUCTIONS: Please sit down.
( ) 4 sits safely with minimal use of hands
( ) 3 controls descent by using hands
( ) 2 uses back of legs against chair to control descent
( ) 1 sits independently but has uncontrolled descent
( ) 0 needs assist to sit

TRANSFERS
INSTRUCTIONS: Arrange chair(s) for pivot transfer. Ask subject to transfer one way toward a seat with armrests
and one way toward a seat without armrests. You may use two chairs (one with and one without armrests) or a bed
and a chair.
( ) 4 able to transfer safely with minor use of hands
( ) 3 able to transfer safely definite need of hands
( ) 2 able to transfer with verbal cuing and/or supervision
( ) 1 needs one person to assist
( ) 0 needs two people to assist or supervise to be safe
STANDING UNSUPPORTED WITH EYES CLOSED
INSTRUCTIONS: Please close your eyes and stand still for 10 seconds.

( ) 4 able to stand 10 seconds safely
( ) 3 able to stand 10 seconds with supervision
( ) 2 able to stand 3 seconds
( ) 1 unable to keep eyes closed 3 seconds but stays safely
( ) 0 needs help to keep from falling

STANDING UNSUPPORTED WITH FEET TOGETHER
INSTRUCTIONS: Place your feet together and stand without holding on.
( ) 4 able to place feet together independently and stand 1 minute safely
( ) 3 able to place feet together independently and stand 1 minute with supervision
( ) 2 able to place feet together independently but unable to hold for 30 seconds
( ) 1 needs help to attain position but able to stand 15 seconds feet together
( ) 0 needs help to attain position and unable to hold for 15 seconds

REACHING FORWARD WITH OUTSTRETCHED ARM WHILE STANDING
INSTRUCTIONS: Lift arm to 90 degrees. Stretch out your fingers and reach forward as far as you can. (Examiner places a ruler at the end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. The recorded measure is the distance forward that the fingers reach while the subject is in the most forward lean position. When possible, ask subject to use both arms when reaching to avoid rotation of the trunk.)
( ) 4 can reach forward confidently 25 cm (10 inches)
( ) 3 can reach forward 12 cm (5 inches)
( ) 2 can reach forward 5 cm (2 inches)
( ) 1 reaches forward but needs supervision
( ) 0 loses balance while trying/requires external support

PICK UP OBJECT FROM THE FLOOR FROM A STANDING POSITION
INSTRUCTIONS: Pick up the shoe/slipper, which is place in front of your feet.
( ) 4 able to pick up slipper safely and easily
( ) 3 able to pick up slipper but needs supervision
( ) 2 unable to pick up but reaches 2-5 cm(1-2 inches) from slipper and keeps balance independently
( ) 1 unable to pick up and needs supervision while trying
( ) 0 unable to try/needs assist to keep from losing balance or falling

TURNING TO LOOK BEHIND OVER LEFT AND RIGHT SHOULDERS WHILE STANDING
INSTRUCTIONS: Turn to look directly behind you over toward the left shoulder. Repeat to the right. Examiner may pick an object to look at directly behind the subject to encourage a better twist turn.
( ) 4 looks behind from both sides and weight shifts well
( ) 3 looks behind one side only other side shows less weight shift
( ) 2 turns sideways only but maintains balance
( ) 1 needs supervision when turning
( ) 0 needs assist to keep from losing balance or falling

TURN 360 DEGREES
INSTRUCTIONS: Turn completely around in a full circle. Pause. Then turn a full circle in the other direction.
( ) 4 able to turn 360 degrees safely in 4 seconds or less

( ) 3 able to turn 360 degrees safely one side only 4 seconds or less
( ) 2 able to turn 360 degrees safely but slowly
( ) 1 needs close supervision or verbal cuing
( ) 0 needs assistance while turning

PLACE ALTERNATE FOOT ON STEP OR STOOL WHILE STANDING UNSUPPORTED

INSTRUCTIONS: Place each foot alternately on the step/stool. Continue until each foot has touch the step/stool four times.

( ) 4 able to stand independently and safely and complete 8 steps in 20 seconds
( ) 3 able to stand independently and complete 8 steps in > 20 seconds
( ) 2 able to complete 4 steps without aid with supervision
( ) 1 able to complete > 2 steps needs minimal assist
( ) 0 needs assistance to keep from falling/unable to try

STANDING UNSUPPORTED ONE FOOT IN FRONT

INSTRUCTIONS: (DEMONSTRATE TO SUBJECT) Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot. (To score 3 points, the length of the step should exceed the length of the other foot and the width of the stance should approximate the subject’s normal stride width.)

( ) 4 able to place foot tandem independently and hold 30 seconds
( ) 3 able to place foot ahead independently and hold 30 seconds
( ) 2 able to take small step independently and hold 30 seconds
( ) 1 needs help to step but can hold 15 seconds
( ) 0 loses balance while stepping or standing

STANDING ON ONE LEG

INSTRUCTIONS: Stand on one leg as long as you can without holding on.

( ) 4 able to lift leg independently and hold > 10 seconds
( ) 3 able to lift leg independently and hold 5-10 seconds
( ) 2 able to lift leg independently and hold ≥ 3 seconds
( ) 1 tries to lift leg unable to hold 3 seconds but remains standing independently.
( ) 0 unable to try of needs assist to prevent fall
( ) TOTAL SCORE (Maximum = 56)

Appendix F) Topic guides for semi-structured interviews pre and post-intervention

In the pre-intervention interview, the researcher asked:

‘What is the relationship between participants?’,

‘Can you tell me about your experience with dementia, and anything in particular that you have struggled with?’,

‘Do you currently take part in any other social or activity groups, and if so what do you find particularly helpful about them?’,

‘Is there anything in particular which you would hope to gain from this programme?’,

‘Do you have anything else you would like to add?’

Participants were given the opportunity to talk freely about anything they felt relevant.

In the post-intervention interview the researcher asked:

‘Did you enjoy attending the weekly sessions?’,

‘What was the most beneficial aspect of the sessions for the person living with dementia?’,

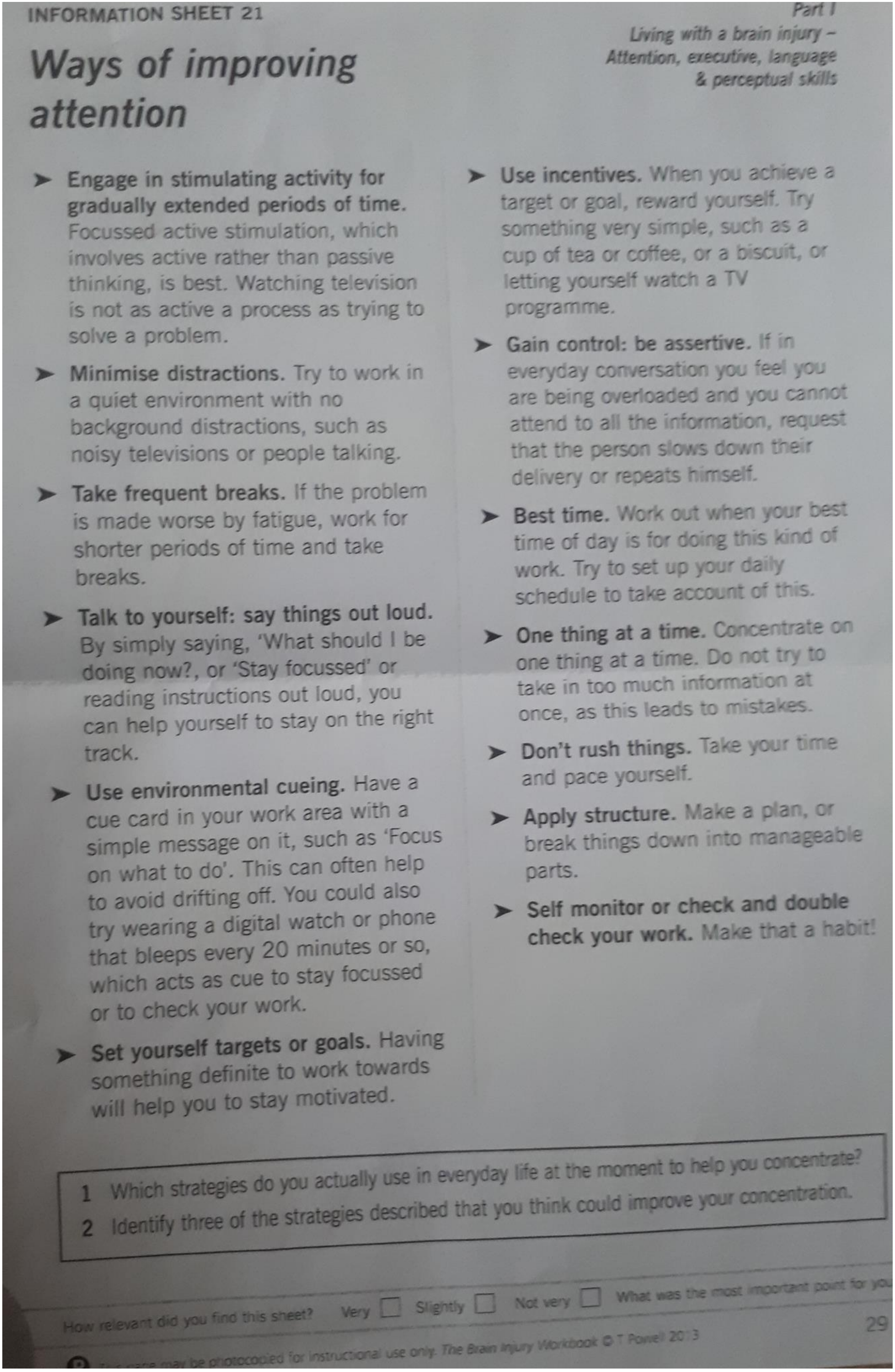
‘What was the most beneficial aspect of the sessions for the carer?’,

‘Were there any aspects which you did not find useful? (if so please state)’,

‘Do you have any suggestions on further information/experiences which may be beneficial to someone in your position?’

Participants were given the opportunity to talk freely about anything they felt relevant.

Appendix G) Strategy Example



INFORMATION SHEET 21

Part I
Living with a brain injury –
Attention, executive, language
& perceptual skills

Ways of improving attention

- **Engage in stimulating activity for gradually extended periods of time.** Focussed active stimulation, which involves active rather than passive thinking, is best. Watching television is not as active a process as trying to solve a problem.
- **Minimise distractions.** Try to work in a quiet environment with no background distractions, such as noisy televisions or people talking.
- **Take frequent breaks.** If the problem is made worse by fatigue, work for shorter periods of time and take breaks.
- **Talk to yourself: say things out loud.** By simply saying, 'What should I be doing now?, or 'Stay focussed' or reading instructions out loud, you can help yourself to stay on the right track.
- **Use environmental cueing.** Have a cue card in your work area with a simple message on it, such as 'Focus on what to do'. This can often help to avoid drifting off. You could also try wearing a digital watch or phone that bleeps every 20 minutes or so, which acts as cue to stay focussed or to check your work.
- **Set yourself targets or goals.** Having something definite to work towards will help you to stay motivated.
- **Use incentives.** When you achieve a target or goal, reward yourself. Try something very simple, such as a cup of tea or coffee, or a biscuit, or letting yourself watch a TV programme.
- **Gain control: be assertive.** If in everyday conversation you feel you are being overloaded and you cannot attend to all the information, request that the person slows down their delivery or repeats himself.
- **Best time.** Work out when your best time of day is for doing this kind of work. Try to set up your daily schedule to take account of this.
- **One thing at a time.** Concentrate on one thing at a time. Do not try to take in too much information at once, as this leads to mistakes.
- **Don't rush things.** Take your time and pace yourself.
- **Apply structure.** Make a plan, or break things down into manageable parts.
- **Self monitor or check and double check your work.** Make that a habit!

1 Which strategies do you actually use in everyday life at the moment to help you concentrate?
2 Identify three of the strategies described that you think could improve your concentration.

How relevant did you find this sheet? Very ☐ Slightly ☐ Not very ☐ What was the most important point for you

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Appendix H) Take-home Sheet Example

Top tips for this week

- Dementia affects different brain functions
- Different types of dementia affect the brain differently and therefore have different consequences
- Some people might struggle more with memory, other people might struggle to find words and so on
- You are the experts on you, so you will know what difficulties affect you most on a day to day basis

- This course will equip you with strategies to help you, like wearing glasses to help you to see better

Week 1 – Physical tasks at home

Complete these tasks 3 times within the next week

TASK 1
Step ups (at the bottom of the stairs)
Alternate feet

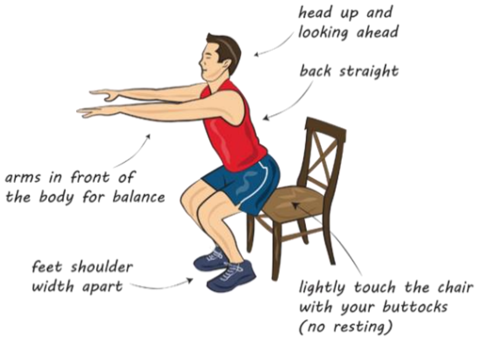
- 1 minute
- Repeat twice – rest in between
- Count out loud
- Maintain a good posture – back straight, head up

Easier	Harder
Touch the step with your foot Use the handrail for support	Step up fully and back down No support needed

TASK 2
Squats with chair and partner for support

1 minute
Stand up fully straight in between
Repeat twice

Count out loud



Easier	**Harder**
- Sit down fully each time - Hold your partners hands for support - Hold the chair for support - Go as far as you can – even if your bottom doesn't touch the chair	

Safety points

- your partner must be present to help you – standing to the side or slightly behind
- rest in between tasks and rest during the task if you need to
- have a chair nearby in case you need to sit down

Appendix I) Topic guide for social isolation telephone interviews

Topic guide for social isolation telephone interviews

Participants were given the opportunity to talk freely about anything they felt relevant.

Topics of interest encouraged by the researcher:

Participant experience of living with dementia for both the person living with dementia and their carer, in general and during the period of social isolation.

How, in general, participants were coping with the social restrictions (including access to essential supplies).

How the person living with dementia was coping with understanding and complying to the new measures, and without their usual routines.

How the carer was coping without access to respite.

The type of activities that participants were taking part in during the social isolation period.