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AN INVESTIGATION INTO THE EFFECTS OF SPORT AND
PHYSICAL ACTIVITY ON THE WELLBEING OF PEOPLE WITH
DEMENTIA AND THOSE WHO CARE FOR THEM.

Section A: Understanding the Effects of Sport and Physical Activity on the
Psychological and Social Wellbeing of People with Dementia and their
Caregivers: A Systematic Review

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Section B: Exploring the Effects of a Golf Programme on Wellbeing for
People with Dementia, Carers and Golf Centre Staff

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Summary

The importance of community-based physical activity and sport for people with dementia (PWD) is recognised by UK healthcare policy, however, less is known about the effects of such activity on psychological and social wellbeing for this population, the importance of which has been documented. A systematic review of the existing literature is described in this manuscript, suggesting that only tentative conclusions can be derived regarding the effect of such interventions on psychological and social wellbeing, with the majority of included studies holding such outcomes as secondary to those of physical and cognitive wellbeing. Furthermore, only one study was identified which explored the effects of a sporting activity for this population.

In order to address this gap in the literature, a qualitative investigation of the effects of a six-week golf programme on the psychological and social wellbeing of PWD, carers and staff was conducted. The outcomes suggest the effects of this golf programme on both psychological and social wellbeing, with five key themes being identified: affectivity, respite, losing the dementia label, friendship/camaraderie and improving relationships. While limitations of this study are considered, the implications of these findings for social prescribing and future research are discussed.

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Section A

Understanding the Effects of Sport and Physical Activity on the Psychological and Social Wellbeing of People with Dementia and their Caregivers: A Systematic Review

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Abstract

Background: Physical activity and sport are recommended community-based activities in the UK healthcare pathway for people with dementia (PWD). While the effects of such activity on physical and cognitive wellbeing have been established, less is known about its effects on psychological and social wellbeing.

Methodology: A systematic search of all existing literature contained within the Psychinfo, Web of Science, Medline and SPORTdiscus databases was conducted in November 2018. A total of 15 studies met the inclusion criteria for this review, encompassing both quantitative and qualitative research methods. Due to the heterogeneity of the interventions and measures used in the included studies, a narrative synthesis was then conducted.

Selection criteria: Included articles contained a specific physical activity or sporting intervention for PWD (excluding mild cognitive impairment) and yielded outcomes which addressed either the psychological and/or social impact of this intervention. All reviewed articles had been peer reviewed.

Discussion: The included studies yield conflicting outcomes regarding the effects of their interventions on psychological wellbeing, though the importance of the social context of the intervention might tentatively be suggested. Only three of the studies exhibit outcomes relating to social wellbeing, limiting the conclusions which can be derived regarding this construct.

Keywords: Systematic review, dementia, physical activity, sport, wellbeing,

The dementias are a group of syndromes which are characterised by the progressive degeneration of the brain and its associated functioning (National Health Service [NHS], 2017). The effects of this degeneration often include memory loss, reduced thinking and processing speed, difficulties understanding or generating language, impaired judgement, visual and hearing impairment and reduced inhibitions (NHS, 2017), among other symptoms. Mood and behaviour may be significantly affected by dementia and carrying out activities of daily living may become difficult. Alzheimer's disease is the most prevalent form of dementia, accounting for approximately two thirds of cases (Alzheimer's Research UK, 2018). Other main types of dementia include vascular dementia (which may occur alongside Alzheimer's, resulting in a mixed dementia), dementia with Lewy Bodies and frontotemporal dementia. A number of other types of more rarely encountered dementias are also recognised, such as Huntington's disease, posterior cortical atrophy and primary progressive aphasia (Rare Dementia Support, 2018).

Although it is possible to be diagnosed with a dementia before the age of 65, age is reportedly the biggest risk factor for developing dementia (Alzheimer's Society, 2016), with a person's risk roughly doubling every 5 years beyond this age; it follows that, as life expectancy increases, so too does the prevalence of dementia.

Global and UK Context of Dementia

In the UK it is estimated that there are currently around 850,000 people living with dementia (PWD), which accounts for 1.3 percent of the population (Prince et al, 2014). The number of PWD in the UK is likely to reach one million by the year 2025 and it has become the leading cause of death in England and Wales (Public Health England, 2016). In 2017 the number of PWD globally was estimated at 50 million (World Health Organisation, 2017), with this number projected to increase to 131.5 million by 2050 (Prince et al., 2015).

Alongside this growing prevalence, the cost of dementia to the UK economy (including healthcare and supported living) is currently £26.3 billion a year (Lewis, Karlsberg-Schaffer, Sussex, O'Neill & Cockcroft, 2014), having surpassed the predictions of McCrone, Dhanasiri, Patel, Knapp and Lawton-Smith (2008), who anticipated the associated costs of care to reach £24 billion by 2026. This cost is expected to more than double to £55 billion by 2040 (Prince et al., 2014). On a global scale, the cost of dementia is predicted to rise from US\$ 818 billion as it was in 2015, to US\$ 2 trillion by 2030 (Prince et al., 2015).

Current Approaches Toward Dementia

Given the projected increase in the number of PWD globally, some have referred to dementia as an impending "epidemic" (Larson, Yaffe & Langa, 2013). In response to the severity of the estimated impact of this, dementia care and research have been highlighted as priorities by UK government policy (Department of Health, 2016). According to National Institute for Clinical Excellence guidelines (NICE, 2018) there is a recognised need for both structured clinical interventions, as well as population level interventions which might be accessed through support structures in the person's community. As suggested by NICE (2018) the current dementia pathway consists mainly of structured clinical interventions such as cognitive stimulation therapy (CST) and group reminiscence sessions. A number of studies have documented the efficacy of CST for improving cognitive function, however, these interventions appear to have little effect on mood, behaviour or the person's ability to conduct activities of daily living (Aguirre, Woods, Spector & Orrell, 2013). Furthermore, a review by Woods, O'Philbin, Farrell, Spector and Orrell (2018) suggests that reminiscence therapy has no clear effect on the mood and quality of life for PWD, while potentially increasing the anxiety of caregivers.

If the prevalence of dementia increases as anticipated, the healthcare system will see a concurrent increase in demand for its services (Robertson, Wenzel, Thompson & Charles, 2017) prompting the need for alternative avenues of care to be explored. Furthermore, NICE guidelines (2018) assert the importance of assisting PWD to maintain their independence and a level of community engagement. Suggested examples of this include offering PWD a range of leisure activities from which the person can choose, which can be tailored to individual preferences. While NHS England seek to implement some guidance around how PWD may be supported to engage in such meaningful community activities, there appears to be a lack of detail around what this might entail or how it might be achieved (NHS England, 2017a).

In line with this, the dementia 2020 challenge (Department of Health, 2016) specifically calls for communities to become "dementia friendly", which would serve to make the appropriate support available so that such activities can be made more accessible for PWD. The development of the concept of social prescribing (The King's Fund, 2017) may offer another means of increasing access to community-based interventions and support. A review by Chatterjee, Camic, Lockyer and Thomson (2017) suggests the potential for social prescribing schemes to enhance self-esteem and mental wellbeing. Research has begun to highlight the efficacy of community-based interventions; for example, Camic, Hulbert and Kimmel (2017) offered evidence for the beneficial effects of museum object handling for PWD. Current policy also points to the importance of considering the support needs of carers (NICE, 2018). However, there is a lack of research regarding the effect on the caregiver of caring for PWD (Forbes, Forbes, Blake, Thiessen & Forbes, 2015).

Sport and Physical Activity

There is currently little guidance about what specific community-based interventions might be helpful for PWD, however, Public Health England (2018) advocates for the

importance of sport and physical activity for this population. According to the World Health Organisation (2019), physical activity can be described as any bodily movement produced by energy expenditure in skeletal muscles. The physical and cognitive health benefits of physical activity have been well documented with the majority of research in this area focusing on these particular aspects of health. For example, a review by Guure, Ibrahim, Adam and Said (2017) attests to the potential for physical activity to mitigate cognitive decline. However, less is known about the effects of such activities on the psychological and social wellbeing of PWD.

Psychological and Social Wellbeing for PWD

The concept of wellbeing is difficult to define (Tyack & Camic, 2017) but refers to a more holistic view of a person's welfare, which includes both psychological and sociological factors, in addition to biological health factors (such as cognitive impairment). Indeed, evidence suggests that practitioners who work alongside PWD are sensitive to the importance of addressing such factors in addition to being sensitive to the person's rate of cognitive decline (Bowes, Dawson, Jepson & McCabe, 2013).

As documented by Orgeta, Qazi, Spector & Orrell (2015), depression and anxiety are prevalent co-morbidities in PWD, attesting to the impact that dementia can have on a person's psychological wellbeing. According to the Seung-Ho et al., (2017) up to 50 percent of PWD may experience co-morbid depression while Regan (2016) estimates the prevalence of anxiety at 5 - 21 percent, whereas the Department of Health (2013) reports that 47 percent experience depression and/or anxiety and do not feel part of their community.

Some theories highlight the importance of the social needs of PWD. For example, Sabat (2006) suggests that there are three concepts of self which are recognisable in people with dementia, one of which is particularly fragile and relates to a publically presented

persona which is reliant on one's relationships with others. Furthermore, Kitwood's psychosocial theory of personhood (1997) suggests that the personal identity and sense of self-worth of someone living with dementia are maintained through their interactions with others. Recent research appears to attest to these concepts such as Thacker's (2012) findings that social engagement may be as valuable as cognitive stimulation for people with dementia.

The Current Review

Sports and physical activity interventions have been acknowledged as beneficial avenues of care for PWD, with the physical and cognitive health benefits of such interventions having been established (Heyn, Abreu & Ottenbacher, 2004). However, less is known about the effects of such interventions on psychological and social wellbeing, which are factors that are also affected by the experience of living with a dementia. As such, this review will look specifically at the psychological and social effects of sport and physical activity on PWD and their caregivers. In line with NHS values, this review aims to further our understanding of the potential for sport and physical activity to improve the quality of life for PWD with the view to enhancing the quality of care that is offered for this population.

Methodology

In order to explore the existing evidence base a systematic review was conducted as outlined by Grant and Booth (2009). An electronic search was completed during the month of November 2018 using four databases: Psychinfo, Web of Science, Medline and SPORTdiscus. The following search terms were utilised: (Dement* OR Alzheimer* NOT Injur* NOT Damag*) AND (Sport* OR "Physical* activ*" OR Football* OR Golf* OR Walk* OR Run* OR Swim* OR Tennis OR Badminton OR Squash OR Gym* OR Basketball OR Baseball OR Bowling) AND (Wellbeing OR "Well-being" OR "Well being" OR "Quality of life" OR "Life quality" OR Depress* OR Anxi* OR Social*) AND

(Caregiver OR Carer OR Famil*). Being the most widely studied dementia subtype, Alzheimer's disease was held as its own search term. However, its prevalence as the most common form of dementia did not warrant the exclusion of the other dementia subtypes, which were also encompassed within the above search terms. Given the focus on physical and cognitive outcomes of interventions in this area of research, search terms accounting for quality of life and wellbeing were used, as psychological and social wellbeing outcomes might be broadly encompassed within such terminology. Furthermore, depression and anxiety were also used to guide the exploration of the effects of such interventions on psychological wellbeing, as these are thought to be the most prevalent co-morbid mental health difficulties experienced by PWD (Orgeta, Qazi, Spector & Orrell, 2015).

The search was not constrained by date parameters because of the relatively early stages of this area of research interest and in order to capture as many relevant papers as possible. Searches were limited to papers which appeared in peer reviewed academic journals in order to maintain the quality of the review. The titles and abstracts of the studies retrieved were examined by the author for potential relevance and eligibility for inclusion in this review. Promising papers were then read in full to further clarify their relevance, guided by the inclusion and exclusion criteria provided in table 1. The reference sections of all eligible studies were cross-checked to identify other potentially relevant studies that may have been missed. A final search was conducted using Google Scholar which returned no further potentially relevant studies. A flowchart is provided in figure 1, which illustrates the process of refining the literature for this review, in which a total of 15 studies were included.

Table 1

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
At least part of the intervention must have a specific sporting or physical activity component	Studies recruiting participants with mild cognitive impairment or acquired brain injury
Must yield outcomes which address psychological and/or social impact of the intervention on PWD	
PWD must be included in at least some part of the intervention	
Must be peer reviewed	
Studies must be published in English	

The majority of the studies (13) report quantitative methodologies while the remaining two papers document the findings of qualitative studies. The QualSysts tool (Kmet, Lee & Cook, 2004) offers two quality assessment tools (one for quantitative methodologies and one for qualitative) which were developed concurrently by the same team of analysts. In light of this, it was felt that the QualSyst tools offered some degree of consistency when evaluating the quality of this methodologically diverse cohort of studies. Both of these assessment tools demonstrate good validity and inter-rater reliability (Kmet, Lee & Cook, 2004). The tools provide a raw score out of two for a range of attributes, culminating in a summary score for each study which is presented as a percentage. The authors note that the use of raw scores is necessarily reductionist to offer a means of comparison between studies, though its inherent subjectivity may introduce bias into the review. Therefore, studies were not dismissed from this review on the grounds of their scores on the QualSyst tool. The included studies are summarised in table 2.

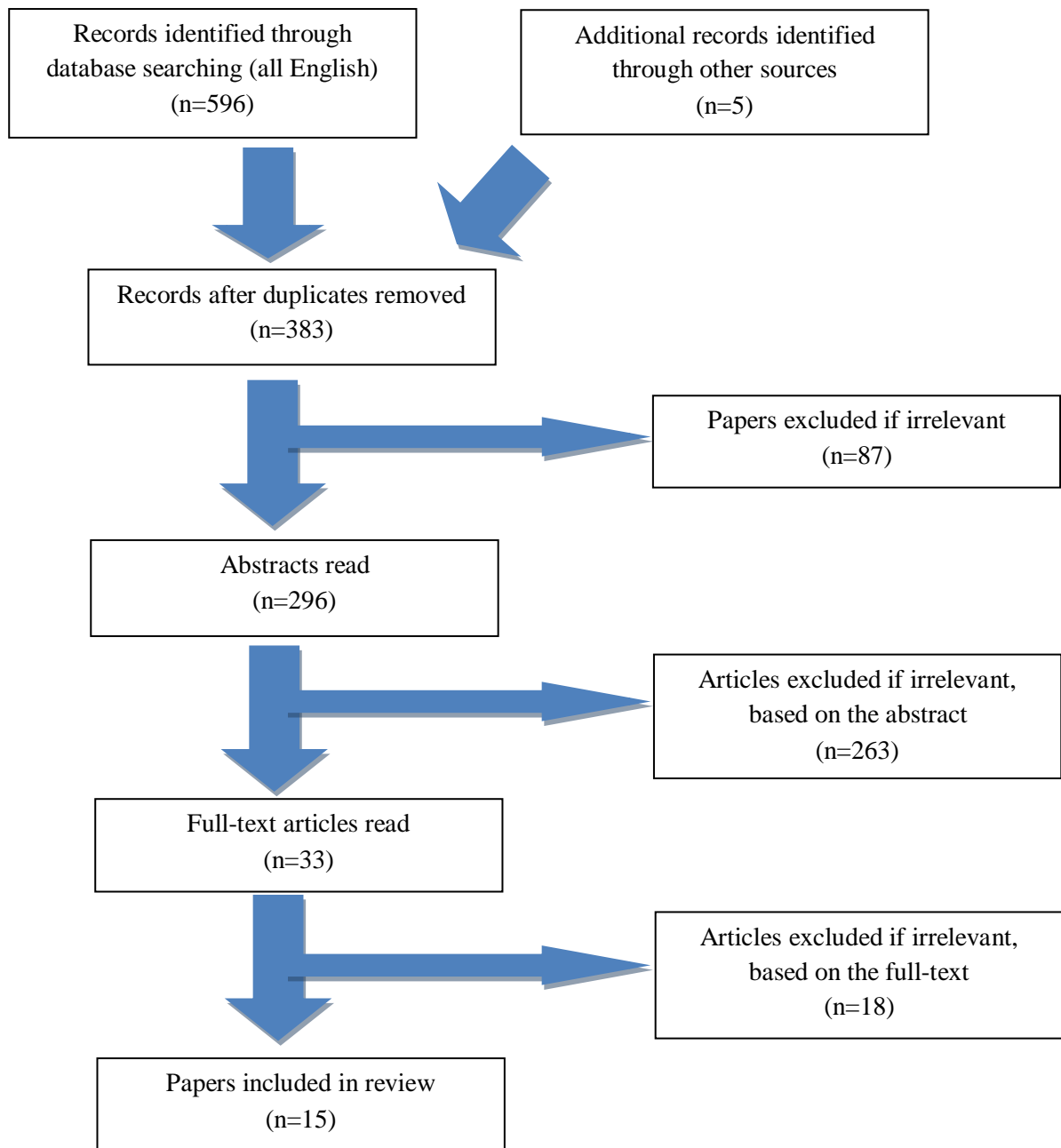


Figure 1

Flowchart depicting the process of refining studies for this review

Table 2
Summary of studies included in this review

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Carone et al., 2016 (UK)	<p>Qualitative</p> <p>PWD interviewed separately or in pairs</p> <p>Remaining participants engaged in focus group discussions</p> <p>Thematic analysis</p>	<p>Participants with early onset dementia (n=5)</p> <p>Carers (n=5)</p> <p>Coaches (n=5)</p> <p>Organisers (n=5)</p> <p>PWD were all males</p> <p>Carers were all female spouses</p> <p>Age range of PWD = 59-64</p> <p>Participants purposively recruited from the existing Nottingham County Football Club project</p>	<p>90 minute sessions, once per week</p> <p>Sessions consisted of various physical activities, such as badminton, basketball and bowls, as well as football</p> <p>Intervention already established before involvement of researchers</p>	N/A	<p>Four main themes were identified:</p> <ul style="list-style-type: none"> -Loss -Lack of resources -Enjoyment and anticipation -The "Notts County" effect 	<p>Type of thematic analysis and underlying epistemology not discussed</p> <p>All-male sample of PWD exclusively with early onset dementia - detracts from our ability to generalise findings</p> <p>No explanation of how participants were selected from the existing project</p> <p>No information given regarding structure of interviews/focus groups</p>

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
El-Kader & Al-Jiffri, 2016 (Saudi Arabia)	RCT Pre-post comparison	40 PWD (all Alzheimer's type) Male (n=29) Female (n=11) Age range = 65-75	Treadmill aerobic exercise, 3 sessions per week, for 2 months Exercise completed 1:1 with physical therapist	Lab analysis of blood tests Rosenberg Self-esteem Scale Profile of Mood States BDI Health Related Quality of Life (SF-36)	Sig. improvement in Rosenberg Self-esteem Scale scores, BDI & Profile of Mood States for exercise group No sig. changes in scores for control group Sig. difference between groups on all measures at post-test stage	No description of sampling strategy Researchers were not blind to participants' group allocation Small sample size No discussion of level of physical activity undertaken by control group

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Ferrer & Valle, 2014 (Spain)	Quasi-experimental Pre-post comparison No control group	64 PWD (all Alzheimer's type) Random sampling based on clinical records Male (n=29); Female (n=35) Average age: Male (73.55); Female (77) Various disease phases: Mild (n=19); Moderate (n=20); Severe (n=25)	Pilot exercise programme, developed following guidance from American College of Sports Medicine 1 hour, twice weekly, for 12 months Exercise type: Aerobic; resistance; cognitive re-education; psychomotor stimulation Groups of 8-10 (separated based on disease phase) PWD, facilitated by staff; caregiver not involved	Mini Mental State Exam (MMSE; cognitive capacity) Chair Stand Test (lower limb physical health) The Barthel Index (degree of autonomy) The 12-item Short Form (SF-12; health related quality of life) No specific measures regarding psychological or social wellbeing	Sig. increase in physical capacity Sig. increase in SF-12 scores (mild & moderate) Sig. physical health improvement (mild) Sig. decline in cognitive capacity (moderate & severe) Sig. increase (mild) and decrease (severe) in autonomy Effectiveness of programme diminishes as disease phase increases	Sample size too small to address difference between disease phases No control group No process evaluation (no discussion of intervention fidelity/challenges) No discussion of core component(s) of intervention SF-12 completed by caregivers; all other measures completed by researchers

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
La Rue et al., 2013 (USA)	Quasi-experimental Pre-post comparison No control group	42 PWD - does not specify types of dementia Male (n=17) Female (n=20) 94.8% were 70+ years of age Volunteer sample	90 minute sessions, once per week for 15 months Each session began with language/memory stimulation, followed by exercise Exercise consisted of strength, endurance & balance training Caregivers asked to encourage participants to complete exercises again at home. Separate social outing with volunteer once per week	GDS QOL MMSE Neuropsychological battery (CERAD) WAIS-R ABCD Battery Senior Fitness Test The Burden Interview	No change in GDS or QOL scores over time Trend towards improvement on measures of physical performance Scores from The Burden Interview are omitted	No control group Lack of rigorous statistical analysis Lots of variety in how participants exercised - no clear structure to the exercise intervention High rate of attrition is not discussed

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Lamb et al., 2018 (UK)	RCT Random allocation 2:1 in favour of exercise group Repeated measures: Data collected at baseline, 6 & 12 months Single blind	494 PWD - does not specify dementia type Male (n=301) Female (n=193) Average age = 77 Recruited from memory services across 15 English regions	First 4 months: 60-90 minutes exercise, twice weekly, plus 1 hour home exercise - Gym exercise consisted of cycling and strength (weight) training. Following 8 months: 150 minutes of weekly exercise at home; 3 motivational phone calls Gym sessions were conducted in groups of 6-8 participants	Alzheimer's Disease Assessment Scale NPI Bristol Activities of Daily Living Index EQ-5D (quality of life measure) Record of length of exercise/max weight lifted Zarit Burden Interview (for carers)	No sig. difference in NPI scores for either group No sig. difference in Zarit Burden Interview scores for carers in either group Sig. decline in cognitive impairment in both groups Physical fitness improved significantly in the exercise group	No information given regarding the activity of the control group Unclear what exercise participants undertook at home No process evaluation (no discussion of intervention fidelity/challenges)

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Maci et al., 2012 (Italy)	RCT Pre-post comparison Single blind	14 PWD who were consecutively admitted to an inpatient ward All Alzheimer's type Male (n=6) Female (n=8) Age range = 65-87	Exercise group were collected from their homes and transported to the gym 1 hour physical activity & 1 hour cognitive stimulation every day, Monday - Friday, for 3 months Physical exercises regard: Aerobic, balance, hand-eye coordination, respiration and muscle trophism exercises	MMSE Cornell Scale for Depression in Dementia Quality of Life - Alzheimer's Disease Hamilton Anxiety rating scale Caregiver Burden Inventory (CBI) Beck Depression Inventory (BDI) Instrumental Activities of Daily Living	Sig. improvement in apathy and anxiety subscale scores on the Hamilton Anxiety Scale for exercise group Sig. improvement in Cornell Scale scores for exercise group - Sig. worsening of scores for control group Sig. Improvement in Quality of Life scores for exercise group - Sig. worsening of scores for control group For carers, sig. improvement on CBI & BDI scores for exercise group - Sig. worsening of scores for carers in control group	No explanation of the activities of the control group No comparison of scores between groups Data entered twice for analysis to account for small sample size No process evaluation (no discussion of intervention fidelity/challenges) No discussion of core component(s) of intervention Incomplete reporting of statistical analyses

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Nascimento et al., 2012 (Brazil)	Quasi-experimental, with a control group Pre-post comparison and correlation Single blind	27 community residing PWD All Alzheimer's type (mild - moderate) All female Age range = 70-86 Volunteer sample	1 hour of exercise, 3 times a week for 6 months Sessions included the following: Aerobics, flexibility, muscular resistance, motor coordination & balance exercises Other tasks include attention, recognition & praxis Each session completed as a group No information given regarding control group	MMSE Neuropsychiatric Inventory (NPI) Pfeffer Functional Activities Questionnaire	Sig. positive correlation between cognitive impairment and neuropsychiatric disorders Non-sig. correlation between performance on activities and neuropsychiatric disorders For exercise group, only total NPI and irritability subscale scores improved significantly In control group, total NPI and both delusions and agitation subscale significantly worsened	Small sample size No randomisation to conditions Unrepresentative sample All participants had been controls in another study - may enhance effects of expectation bias No process evaluation (no discussion of intervention fidelity/challenges) No discussion of core component(s) of intervention

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Padala et al., 2017 (USA)	RCT Repeated measures: Data collected at baseline, 8 & 16 weeks Crossover study	30 community residing PWD (sample size predetermined by power analysis) All Alzheimer's type (mild) Male (n=19) Female (n=11) Average age = 73	Group 1: Completed exercises on a Nintendo Wii fitness game -Exercises included yoga, strength, aerobics & balance Group 2: Walking, either indoors or outdoors Both groups exercised for 30 minutes, five times each week, for 8 weeks All exercise supervised by caregiver Participants switched groups after 8 weeks	Berg Balance Scale Activities Specific Balance Confidence (ABC) Quality of Life - Alzheimer's Disease (QOL) Falls Efficacy Scale (FES) MMSE Katz Activities of Daily Living	Sig. improvement in ABC and FES scores for Wii fit group as compared with walking group at 8 weeks - Difference no longer significant at 16 weeks, after crossover No sig. inter- or intra-group differences in QOL scores at either 8 or 16 weeks	Pilot study, intended to achieve a conservative level of statistical power Researcher and participants were not blind to group allocation Exercise intensity and fidelity was poorly monitored through a rudimentary exercise diary Only recruited participants in early stages of Alzheimer's dementia - detracts from generalisability of findings

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Rolland et al., 2007 (France)	RCT Repeated measures: Data collected at baseline, 6 & 12 months Single blind	134 PWD All Alzheimer's type (mild - severe) Male (n=34) Female (n=100) Average age = 83 Opportunity sample recruited from 5 local nursing homes	1 hour of exercise, twice a week for 12 months Exercise included: Aerobic, strength, balance & flexibility training, accompanied by music Exercise completed in groups of 2-7 participants Control group received routine medical care	Katz Index of Activities of Daily Living (ADL) Physical performance tests Mini Nutritional Assessment NPI Montgomery-Asberg Depression Rating Scale	No sig. differences between groups at any time point on NPI or Montgomery-Asberg Depression Rating Scale ADL scores declined significantly in both groups - significantly more so in controls Walking speed improvement significantly higher in exercise group	Routine medical care received by controls included some exercise through physiotherapy Between group differences present at baseline - Sig. more comorbidities in exercise group No process evaluation (no discussion of intervention fidelity/challenges)

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Steinberg et al., 2009 (USA)	<p>Randomised Controlled Trial (RCT)</p> <p>Stratified randomisation</p> <p>Repeated measures: Data collected at baseline, 6 months & 12 months</p> <p>Single blind</p>	<p>27 community residing PWD (all Alzheimer's type)</p> <p>Recruited from a local dementia programme</p> <p>Male (n=8) Female (n=19)</p> <p>Average age = 75</p>	<p>Exercise group (n=14): Daily exercise facilitated by caregiver at home, consisting of aerobic fitness, strength training & balance/flexibility exercises</p> <p>Exercise programme developed and field tested before study</p> <p>Control group (n=13) received a home safety assessment</p>	<p>Physical health: Yale Physical Activity Survey; Timed 8-foot walk; Jebsen Total Time; Chair sit to stand test</p> <p>Cognitive function: 1-hour cognitive battery; The Alzheimer's Disease Quality Related Life Scale; Neuropsychiatric Inventory; Cornell Scale for Depression in Dementia; Screen for Caregiver Burden</p>	<p>Cornell Scale for Depression scores were sig. higher in the exercise group as compared to control group (only sig. result)</p>	<p>No discussion of sampling strategy</p> <p>Just over half of participants' carers completed measure of programme compliance</p> <p>No process evaluation (no discussion of intervention fidelity/challenges)</p> <p>Small sample size</p> <p>No details given regarding the home safety assessment received by control group</p>

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Stella et al., 2011 (Brazil)	Quasi-experimental, matched pair control group Pre-post comparison Single blind	32 community residing PWD-carer dyads All Alzheimer's type (mild - moderate) Evenly split between exercise and control conditions Male (n=20) Female (n=12) Average age = 77.8 Volunteer sample	1 hour of exercise, 3 times a week for 6 months Sessions included the following: Aerobics, flexibility, strength, agility & balance exercises Control group stayed at home or performed typical activities of daily living Exercise and control groups each split into 2 subgroups of 8 participants Carers observed sessions from a distance	MMSE NPI Cornell Scale for Depression in Dementia The Burden Interview (for carers)	Sig. difference between NPI scores at 6 months (exercise group scores better than controls) Cornell Scale scores sig. lower in exercise group than control group at 6 months Sig improvement in carers' scores on The Burden Interview at 6 months for exercise group	Small sample size No randomisation to conditions No process evaluation (no discussion of intervention fidelity/challenges) No discussion of core component(s) of intervention Lack of clarity regarding activities of control group

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Taylor et al., 2017 (Australia)	Quasi-experimental Pre-post comparison Single group - no control	42 PWD - does not specify dementia type Male (n=20) Female (n=22) Average age = 83 Recruited from local dementia services in the community	Participants visited by physiotherapist 10 times across 6 months - Exercise prescribed in addition to these sessions	Battery of tests of physical health (such as reaction time & postural sway) Addenbrooke's Cognitive Examination Goldberg Anxiety Scale (GAS) Geriatric Depression Scale (GDS) Zarit Burden Interview Alzheimer's Disease Quality of Life Scale	No significant change in scores on the GDS or GAS No significant change in scores on the Zarit Burden Interview Sig. improvement in some physical domains, such as sway reduction Sig. increase in planned physical activity	Small sample size No control group Poor treatment fidelity No discussion of core component(s) of intervention Meagre description of exercise conducted throughout the study

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Teri et al., 2003 (USA)	<p>RCT</p> <p>Repeated measures: Data collected at baseline, 3, 6, 12, 18 & 24 months</p> <p>Single blind</p> <p>Designed to have 80% power</p>	<p>153 PWD (all Alzheimer's type)</p> <p>Recruited from an ongoing community based register</p> <p>Male (n=90) Female (n=63)</p> <p>Age range = 55-93</p> <p>89% Caucasian</p>	<p>Exercise group: minimum 30 minutes per day, facilitated by carer at home, consisting of aerobic, strength training, balance and flexibility exercises</p> <p>Health professionals visited participants for 12, hour-long sessions over a 3 month period</p> <p>Control group received routine medical care</p>	<p>Medical Outcome Study 36-item Short-Form</p> <p>Health Survey & Sickness Impact Profile</p> <p>Hamilton Depression Rating Scale</p> <p>Cornell Scale for Depression in Dementia</p>	<p>Sig. improvement in physical function for treatment group at 3 months - maintained at 24 months</p> <p>Sig. improvement in Cornell Scale scores for exercise group as compared to controls at 3 months - difference in scores no longer significant at 24 months</p>	<p>No process evaluation (no discussion of intervention fidelity/challenges)</p> <p>Describes how fidelity to the exercise programme was ensured, but does not measure it</p> <p>No discussion of core component(s) of intervention</p>

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Williams & Tappen, 2008 (USA)	<p>Quasi-experimental</p> <p>3 treatment groups; no control group</p> <p>Random assignment to groups</p> <p>Pre-post comparison</p> <p>Single blind</p>	<p>45 PWD (all Alzheimer's type)</p> <p>Male (n=5) Female (n=40)</p> <p>Age range = 71-101</p> <p>Opportunity sample from residents of 8 long-term care facilities</p>	<p>Participants in each group received their intervention 5 days a week, for 16 weeks</p> <p>Length of time of intervention gradually increased up to a maximum of 20 minutes</p> <p>Group 1: Strength, balance, flexibility & walking exercises</p> <p>Group 2: Walking only</p> <p>Group 3: Casual conversation, avoiding therapeutic interaction</p> <p>All interventions conducted 1:1 with researcher</p>	<p>Cornell Scale for Depression in Dementia</p> <p>Dementia Mood Assessment Scale (DMAS)</p> <p>Alzheimer's Mood Scale</p> <p>Observed Affect Scale (OAS)</p>	<p>Cohort as a whole showed sig. improvement in scores on the Cornell Scale, DMAS, OAS & Alzheimer's Mood Scale</p> <p>Only sig. difference between conversation group and exercise groups was on OAS</p>	<p>Small sample size</p> <p>Sig. differences in baseline MMSE scores and treatment intensity were noted</p> <p>No process evaluation (no discussion of intervention fidelity/challenges)</p> <p>No comparison of groups</p>

Study	Design	Participants	Intervention	Outcome measures	Findings	Limitations
Wu et al., 2015 (USA)	<p>Qualitative analysis of field notes, open-ended questions to caregivers and transcribed video recordings of exercise sessions</p> <p>Constant comparative method</p> <p>Study embedded in a pilot clinical trial (quasi-experimental, controlled crossover study)</p>	<p>11 PWD (all Alzheimer's type)</p> <p>Male (n=2) Female (n=9)</p> <p>Age range = 79-96</p> <p>Participants recruited from a day care facility</p>	<p>Group 1 (PLIE): Participants engaged body awareness sequences, followed by interactive and playful physical exercise</p> <p>Group 2: Participants engaged in the usual chair-based exercised conducted at the facility</p> <p>Both groups met for 40 minutes, 3 times a week, for 18 weeks. Participants then switched groups for a further 18 months</p>	N/A	<p>Three main themes were identified:</p> <ul style="list-style-type: none"> -Functional changes: Body awareness and movement memory -Emotional changes: Personal meaning and stories -Social changes: interpersonal relationships 	<p>Insufficient presentation of quotations to support themes</p> <p>Unclear whether data for analysis was collected during both groups, or just the PLIE group</p> <p>Potential for observer bias is mentioned but not discussed in relation to outcomes</p> <p>Open-ended questions for caregivers are not presented or explained</p>

Structure of the Synthesis

As suggested by Grant and Booth (2009), the synthesis of the studies included in this systematic review was conducted in a narrative style. A narrative synthesis has been suggested as an alternative to meta-analysis when it is inappropriate to perform the latter (Campbell, Katikireddi, Sowden, McKenzie & Thomson, 2018) due to the heterogeneity in interventions and outcome measures used across studies (Peters, 2011). As such, guidance on the process of conducting a narrative synthesis was followed (Cochrane Consumers and Communication Review Group, 2013). Studies were first grouped based on their ability to answer the individual components of the question underpinning this review (effect on psychological wellbeing of PWD; social wellbeing of PWD; caregiver wellbeing). The overall robustness of evidence considered in this review, possible sources of bias and potential recommendations are also discussed.

Synthesis

Quality Assessment

The quality of all the studies included in this review was assessed using the appropriate QualSyst tool, the outcomes of which are shown in tables 3 and 4. The studies were diverse in terms of the quality ratings they obtained, ranging from 59.1 - 92.9 percent. However, it should be noted that the study by La Rue et al. (2013) received the lowest quality score (59.1 percent) and is an outlier in this regard; this study focused predominantly on describing the physical adaptation of its intervention to suit a rural community and subsequently lacks clarity and experimental rigour across the domains of the QualSyst tool.

A common area in which the quality of the quantitative papers was consistently scored below the maximum mark related to insufficient detail provided in their results; only

five of the quantitative papers received full marks in this area. All studies which did not score maximum points failed to provide sufficient information about the results of their statistical analyses, reporting only mean scores and significance levels without a statement of variance.

Another common area of concern regarding the quality of the quantitative cohort of papers relates to sample size; only four of these studies scored full marks in this area, all of which were RCTs. These studies either incorporated a large sample (Teri et al., 2003, Rolland et al., 2007 & Lamb et al., 2018) or provided an *a priori* power calculation to provide justification for their sample size (Padala et al., 2017). The remaining studies all utilise arguably small samples, which may detract from their ability to detect significant changes in outcome scores. In addition, the power of these studies (and appropriateness of their sample sizes) is not discussed.

Table 3			
<i>QualSyst scores for qualitative studies</i>			
	Lead author	Carone	Wu
1. Question / objective sufficiently described?		2	2
2. Study design evident and appropriate?		1	2
3. Context for the study clear?		2	2
4. Connection to a theoretical framework / wider body of knowledge?		2	2
5. Sampling strategy described, relevant and justified?		1	1
6. Data collection methods clearly described and systematic?		2	2
7. Data analysis clearly described and systematic?		2	1
8. Use of verification procedure(s) to establish credibility?		2	2
9. Conclusions supported by the results?		2	2
10. Reflexivity of the account?		1	1
Total (%)		85.0	85.0

Table 4
Qualsyst scores for quantitative studies

Lead author	Ferrer	Steinberg	Teri	Nascimento	Stella	Maci	El-Kader	Rolland	Williams	Lamb	Taylor	Padala	La Rue
1. Question/objective sufficiently described?	2	2	2	2	2	2	2	2	2	2	2	2	1
2. Study design evident and appropriate?	2	2	2	2	2	2	2	2	2	2	1	2	1
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	1	2	2	2	2	1	2	2	1	1	2	0
4. Subject (and comparison group, if applicable) characteristics sufficiently described	2	1	2	2	2	2	2	2	2	2	2	2	2
5. If interventional and random allocation was possible, was it described?	N/A	2	2	0	0	2	2	2	2	2	N/A	2	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	2	2	2	1	2	0	2	2	2	N/A	0	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	0	0	0	0	0	0	0	0	0	N/A	0	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	1	2	2	2	1	1	1	2	2	1	2	2	1
9. Sample size appropriate?	1	1	2	1	1	1	1	2	1	2	1	2	1
10. Analytic methods described/justified and appropriate?	2	2	2	2	2	1	2	2	2	2	2	2	1
11. Some estimate of variance is reported for the main results?	2	2	2	0	2	2	2	2	2	2	2	2	2
12. Controlled for confounding?	1	2	2	1	2	2	2	2	2	2	1	2	1
13. Results reported in sufficient detail?	1	1	2	2	2	0	1	1	2	1	1	2	1
14. Conclusions supported by the results?	2	2	2	2	2	1	2	2	2	2	2	2	2
Total (%)	77.3	78.6	92.9	71.4	75.0	71.4	71.4	89.3	89.3	82.1	77.3	85.7	59.1

Study design. Of the quantitative studies included in this review, eight were randomised controlled trials (RCT) and five studies utilised a quasi-experimental design. Quasi-experimental designs are less experimentally rigorous than RCTs, which is reflected in the scores for item 12 of the QualSyst tool regarding control of confounds. RCTs are designed to reduce the potential impact of confounding variables through the process of randomisation, whereas quasi-experimental studies do not control for confounding variables as rigorously. While they each provided sufficient detail regarding the baseline characteristics of their sample, the quasi-experimental studies failed to statistically evaluate or comment on the potential impact of these factors on their outcomes. Three are single group designs and the QualSyst tool accounts for this by removing the three questions related to randomisation and blinding from the overall pool of questions for quasi-experimental designs (denoted by a score of "N/A" in table 4). As such, the overall scores of these single group design studies are made more directly comparable to the other, more experimentally robust studies.

Interestingly, none of the studies in which participant blinding was plausible incorporated a successful mechanism through which this was achieved. As described by Karanicolas, Farrokhyar and Bhandari (2010) participant blinding is important as a means of deterring participants from behaving in a way that may bias study outcomes.

It is important to note that 12 of the 15 studies included in this review recruited only participants with Alzheimer's disease. Although including only people with a diagnosis of Alzheimer's may help to reduce the potentially confounding effects of different dementia subtypes on study outcomes, this detracts from the ability to generalise the results to other dementia subtypes. The remaining three studies give a more ambiguous description of their participants as having a diagnosis of "dementia".

Psychological Wellbeing

Nine of the quantitative studies utilised at least one outcome measure focussing specifically on symptoms of depression, while only two studies included a specific anxiety measure. These studies were grouped in terms of the direction of effect of their outcomes.

Specific measures - positive outcomes. The oldest study reviewed (Teri et al., 2003) presents the results of an RCT. Using a large sample ($n = 153$), patient-carer dyads were randomly assigned to the intervention group or the control group which received routine medical care. The complex intervention was conducted in the participants' own homes where they were met by a health professional for 12, hour-long sessions over 3 months. During these sessions, both the PWD and their carer were introduced to new techniques including aerobic, strength, balance and flexibility exercises, though these are not specified. Carers were also given instructions about how to reduce the occurrence of challenging behaviours, which adds to the complexity of this intervention. Their analysis found a significant reduction in scores on the Cornell depression scale at three months, at which point input from the health professionals ended. At 24-month follow-up, the difference in scores on this measure were no longer significant. While the adherence of the health professionals to the training protocol was monitored and encouraged, it was expected that the PWD would engage in 30 minutes of exercise daily which was not strictly monitored; it is therefore plausible that rates of daily exercise differed between participants in the intervention group. The authors also note that the number of PWD doing more than 60 minutes of exercise per week declines over time, which suggests the importance of input from a health professional to ensure that rates of exercise (and the potential benefits of this) are maintained.

A study originating from Brazil (Stella et al., 2011) utilised a matched pair control group design in order to account for potential differences in the amount of current exercise

and psychological symptoms across participants at baseline. As a group, participants in the exercise condition completed stretching, aerobic, strength, flexibility and balance exercises for 60 minutes, three times a week for 6 months, while the matched controls received no intervention; while these exercises were not specified in any greater detail, the authors state their adherence to a previously trialled five-phase protocol for exercise with older people in Brazil. The authors document significant improvements on the Cornell depression scale over time for the exercise group and significant differences between the two groups on this measure at six months. This study also utilised the Neuropsychiatric Inventory (NPI), which showed an improvement in symptoms of agitation, depression, anxiety, apathy, disinhibition and irritability after six months for the exercise group. Unlike the majority of studies included in this review, this study holds the psychological effects of their intervention as their primary focus, rather than the intervention's effects on physical health. Incorporating a small sample ($n = 32$), effect size was not considered while the attrition rate ($n = 10$) further detracts from the power of the analysis. Moreover, participants with more severe Alzheimer's were excluded from the study, which limits our ability to generalise these findings to people in the later stages of the disease.

In an RCT conducted by Maci et al (2012), PWD were subjected to more intense physical exercise as a group for five days a week across a three-month period. This complex intervention consisted of one hour of physical activity (exercises for balance, hand-eye coordination, respiration and muscle trophism) plus one hour of cognitive stimulation (orientation, memory, language and executive function tasks). Participants were collected from their homes in the community each morning in a mini bus, facilitating a space in which generic social interaction could be encouraged. As opposed to their control group counterparts, participants in the exercise group demonstrated significant reductions in depressive symptoms and both apathy and anxiety. However, the authors note that the data

were double entered and cleaned before the analysis was conducted, without explanation of what this entailed or why this was necessary. This manipulation of the data may detract from its authenticity and the subsequent validity of the analysis.

The three studies discussed above provide support for the effectiveness of complex interventions consisting of balance, strength and aerobic exercise, both individually at the person's home and within the social context of a group setting. As noted by Greenhalgh (2014), an interpretation of the core components is required for such complex interventions so as to determine what elements should be standardised, however, no such discussion is volunteered by these studies.

The study by El-Kader & Al-Jiffri (2016) furthers our understanding of aerobic exercise in isolation. This paper utilised an RCT in which 40 people with Alzheimer's disease were randomised to either an aerobic (treadmill) exercise condition or a treatment as usual control condition. Using a comparatively simple intervention, PWD in the exercise condition met with a physiotherapist for 10-30 minutes of treadmill activity three times a week for two months. Significant improvements in self-esteem and depression scores for people in the exercise condition after two months were reported. However, outcomes regarding psychological wellbeing were regarded as secondary and a comparison of scores for these measures between groups is not offered, nor is a comparison of pre-intervention demographics between groups. As such, the homogeneity of variance between groups and the efficacy of the randomisation procedure is assumed. If accurate, the outcome of this study might suggest the particular importance of aerobic exercise for psychological wellbeing.

Using a different methodological approach, Williams and Tappen (2008) randomised people with Alzheimer's disease into three experimental groups; one received strength (such as knee bends and toe rises) and aerobic exercise (walking), one received aerobic exercise

alone and the third received social conversation. Although lacking a control group for comparison, this multi-group study allows the effects of different components of physical activity (woven together in other studies) to be investigated. The authors found that all three groups improved significantly in terms of their scores on the Cornell depression scale and dementia mood assessment scale, with no significant differences detected between groups. Despite randomisation of participants, baseline differences were found between groups, though these are not discussed in any further detail and could partly account for the results obtained.

In line with the findings of El-Kader and Al-Jiffri (2016), the outcomes of this study suggest that aerobic exercise has a positive effect on the psychological wellbeing of PWD, both when it is the sole component of physical activity and when coupled with strength-based exercise; the insignificant difference between these two groups might suggest that the addition of strength-based physical activity does not improve the efficacy of aerobic exercise to have a positive effect on psychological wellbeing. Interestingly, the significant improvement in scores for those who received one-to-one social conversation might suggest the importance of social interaction in facilitating psychological wellbeing. Given that all groups had to converse non-therapeutically with their interventionists to some degree, it is feasible that this may constitute an important component in the significant changes underpinning each of the three groups. Furthermore, the participants were recruited from care homes in which they may be exposed to more opportunities for social interaction than those who reside in the community, which may account for the non-significant differences between groups.

Specific measures - negative outcomes. Steinberg, Leoutsakos, Podewils & Lyketsos (2009) describe another small sample RCT study in which participants were asked to complete a daily exercise schedule at their home in the community facilitated by

caregivers. This exercise consisted of aerobic, strength, balance and flexibility exercises while the control group received a home safety assessment; the authors state that the exercise programme was field tested before the commencement of the study, though no further specific details are volunteered regarding either condition. The analysis suggests that there was a significant increase over time in symptoms of depression in the exercise group from baseline to the end point of data collection after 12 weeks. However, it must be noted that the results of this analysis are poorly described and difficult to understand. Fidelity to the exercise programme was assessed using exercise diaries completed by the caregivers, which were not returned by around half of participants, resulting in uncertainty around compliance with the exercise programme. The authors concede that the significant increase in depression scores may reflect a chance finding, given the limitations of this study. Interestingly, the intervention used in this study does not include any face time with health professionals such as physiotherapists, with all exercise being orchestrated by the person's caregiver. In light of the evidence for the potential importance of social interaction, this study might suggest that interaction with new people (that is, not solely caregivers with whom the PWD has an existing relationship) is a key ingredient to promote psychological wellbeing.

The study by Rolland et al. (2007) used a large Alzheimer's sample (n = 134) recruited from five nursing homes in the same region. Participants were randomly assigned to routine medical care from the nursing home or one hour of physical activity, twice per week for 12 months. The physical activity sessions consisted of walking for half the session to achieve moderate breathlessness, interspersed with strength exercises focusing on the lower extremities (such as squatting). The analysis showed no significant difference in depression symptoms between groups at either six or twelve months, as rated by the Montgomery-Asberg Depression Rating Scale. The authors note that routine care within all five nursing homes was very good, which suggests that all participants were receiving beneficial input

outside of the exercise sessions, the effects of which were beyond the scope of the study to detect. Given the evidence presented thus far for the potential benefits of exercise on psychological wellbeing, the outcome of this study is curious and might suggest that it is not the exercise itself that promotes psychological wellbeing, but some other factor which was present in both groups.

Interestingly, the main focus of the physical activity in this study was walking, as is the case for the study by El-Kader and Al-Jiffri (2016), though these two studies yield differing results regarding the effect of their interventions on psychological wellbeing. As Rolland et al. (2007) describe, only fairly ambulatory participants who could transfer from a chair and walk without human assistance were included in their study. This differs to the sample recruited by El-Kader and Al-Jiffri, who describe only excluding people with potential cardiac issues. It is therefore possible that the participants used by El-Kader and Al-Jiffri were less ambulatory at baseline and so engaging in a walking-based exercise programme may have a more noticeable impact on this sample, as opposed to that used by Rolland et al. (2007).

A study reported by Taylor et al. (2017) included a wider range of dementia presentations within their community-dwelling sample. Participants received ten visits from a physiotherapist over a six-month period who demonstrated strength (such as sit-to-stand and knee extensions) and balance (such as side stepping) exercises to both the PWD and their caregiver. Further exercise was also prescribed by the physiotherapist based on the person's physical ability. Caregivers completed exercise diaries which revealed that only 45 percent of prescribed exercise was undertaken. The authors reported that there were no significant changes in scores on the Geriatric Depression Scale after six months, however, baseline scores on this measure were found to be low, thus minimising the scope for these scores to change significantly. Similarly, the analysis suggests no significant change in participants'

levels of anxiety, although the authors report a reduction in participants' reported concern about falling, which is an anxiety that has been found to be more prevalent in PWD versus healthy adults (Kasai et al., 2017). Given the variance in fidelity to the prescribed exercise, it is hard to draw confident conclusions regarding the effects of the intervention.

The study by La Rue et al. (2013) utilised a sample of 42 community-dwelling individuals with unspecified dementia. Participants were supervised in performing 90 minutes of language/memory stimulation activities, followed by unspecified strength, endurance and balance exercises using a resistance band. This activity was completed once a week with a health professional, while caregivers were encouraged to guide the PWD to complete the exercises a second time each week. On a different day the PWD would be accompanied by a volunteer on a social outing, such as going for a meal or visiting the library. The authors do not report any statistical analysis but state mean scores and potential trends in the data; there appeared to be no clear change in depression scores. It should be noted that there was a large rate of attrition throughout this study ($n = 25$), the significance of which is not discussed in relation to the stated outcomes. The lack of a trend towards improved depression scale scores, despite the inclusion of a weekly social engagement, might question the notion that novel social interaction is a key aspect of interventions in terms of positively affecting the person's psychological wellbeing.

Taylor et al. (2017) and La Rue et al. (2013) both recruited participants with a diagnosis of dementia rather than Alzheimer's, specifically. It is interesting to consider whether the inclusion of participants with dementias other than that of Alzheimer's was accountable for the insignificant results that were found on measures of psychological wellbeing in these studies; those studies discussed above that document significant results all recruited a sample of people with Alzheimer's dementia. This may raise the question of

whether the beneficial effects of exercise on psychological wellbeing is more pronounced in people with Alzheimer's disease.

Generic measures. Four of the quantitative studies utilised generic measures of wellbeing (Lamb et al., 2018; Nascimento, Teixeira, Gobbi, Gobbi & Stella, 2012; Ferrer & Valle, 2014 & Padala et al., 2017), within which some questions regarding psychological wellbeing are embedded. Therefore, total scores on these measures are affected by a range of different constructs and do not solely reflect the person's psychological wellbeing.

A recent study originating in the UK (Lamb et al., 2018) documents an RCT which recruited a very large sample of people with a diagnosis of dementia. For the first four months the exercise group attended weekly gym sessions, in which they completed aerobic and strength exercises, which was substantiated by a further hour of similar exercise at home. For the subsequent eight months they completed 150 minutes of weekly exercise at home, during which time they received three motivational phone calls from the research team. The battery of outcomes used included the NPI, which touches on a number of possible tenets of psychological wellbeing, such as depression, anxiety, irritation and apathy. No significant differences in either the exercise or control groups were found on this measure. It is plausible that physical activity may have an effect on some aspects of psychological wellbeing (such as depression) but not others, which may not have been detected using a generic measure. The authors document a significant decline in cognitive function in the exercise group, which they associate with the potential effects of deoxygenation of brain cells as a result of moderate-rigorous exercise; it has been suggested that cognitive decline may be linked with depression in PWD (Geerlings et al., 2000).

Nascimento et al. (2012) also used the NPI as an outcome measure for their quasi-experimental study. Individuals in the exercise condition met as a group three times a week

for six months and completed aerobic, strength, flexibility and balance exercises, interspersed with attention and memory related tasks. Unlike the study by Lamb et al. (2018), this study found a significant improvement in total scores on this measure after the six-month period. However, their small sample had all been controls in a previous study, which might produce participant expectation bias. Furthermore, the sample consisted entirely of women in the mild-moderate stages of Alzheimer's, which detracts from our ability to generalise the results of this study to the wider population of PWD.

Using an uncontrolled quasi-experimental design, Ferrer and Valle (2014) invited people with Alzheimer's disease to exercise in groups of nine or ten. Across the space of 12 months participants completed aerobic, resistance, cognitive re-education and psychomotor stimulation exercises twice a week for one hour. They utilised the 12-item Short Form, which is a generic quality of life measure which includes a question regarding mental health. The authors report a significant improvement in self-reported life quality according to this measure, however, the total score on this measure is less representative of a person's psychological wellbeing than the NPI or more specific measures of particular constructs of psychological wellbeing, such as depression.

The quasi-experimental repeated measures study documented by Padala et al. (2017) divided participants into two groups both completing 30 minutes of home exercise five times each week for two months. One group completed fitness exercises using activities from a console-based game (Wii Fit™), including yoga, strength, aerobics and balance exercises, while the other group engaged in walking at a self-selected pace. The authors utilised the Quality of Life - Alzheimer's Disease measure, which is similar to the quality of life measure used by Ferrer and Valle (2014), and similarly they report no significant inter- or intra-group differences in this measure from pre- to post-intervention.

Qualitative findings. One of the two papers only utilising qualitative methodologies (Carone, Tischler & Denning, 2016) documents an exploration of themes regarding psychological wellbeing. This study reports the outcomes of a qualitative study in the UK which conducted interviews and focus groups with five men with early onset dementia, their wives and members of staff working alongside them. The men attended a weekly activity session at a local football club, consisting of various sporting activities including (but not limited to) football. The authors conducted a thematic analysis which identified four key themes including one relating to anticipation and enjoyment. While lacking a quantifiable measure of change in psychological wellbeing, the methodology facilitated an exploration of possible themes as evidenced by quotes from the data. This study suggests the potential importance of having a regular, enjoyable activity to look forward to each week as an important factor in promoting psychological wellbeing, adding weight to the importance of the context rather than the content of the activity. The authors also comment on the theme of emotional change as noted by the wives and staff of the participants relating to the concept of feeling "normal" again, with the sporting activity offering a means of escaping from the diagnosis of dementia for a time. Recruiting only men with early onset dementia, we cannot extrapolate the themes originating from this study to the wider population of PWD. Furthermore, this is the only study included in this review which utilised a sporting activity as its intervention, which offers physical activity in a different context to using targeted exercises, for example, to build strength.

Social Wellbeing

Only three of the 15 papers included in this review produced outcomes relating to social wellbeing. This appears to be a particular focus of the two qualitative studies, while only one quantitative study (Ferrer & Valle, 2014) included a non-specific outcome measure in which a single question about "social function" was embedded.

The study by Carone et al. (2016) also comments on the effects of the sports group on the social wellbeing of the PWD. The authors identified a theme raised by the PWD regarding the social opportunities offered by the group; they noted the importance of being able to meet people in a similar situation, experiencing a similar diagnosis, in which the person could feel accepted without needing to explain their difficulties. The authors comment on the poignancy of this in light of the PWD's perceived feelings of isolation due to a lack of support from family and friends.

The other qualitative study by Wu et al. (2015) used a constant comparative method to explore the effects of their intervention on the social interactivity between their participants with Alzheimer's disease. Utilising a small sample, participants were divided into two groups, the first of which received 40 minutes of body awareness, exhalation and interactive movement sequence exercises, as a group for eight weeks. Attendance of the group was dependent on the number of times the PWD attended the day service at which the study was based, though the authors do not comment on overall attendance rates. The second group received the usual group exercise classes which were offered at the day centre, which consisted of chair-based exercises; after eight weeks, the participants switched groups. The authors comment on the participants becoming more relaxed around other participants over time in the first group, in which the exercises often involved collaboration between participants. They suggest evidence of growing trust as participants became increasingly alert and responsive to one another during exercise which involved group participation. They state that the PWD became more creative and caring in their suggestions to one another, smiling, laughing and asking more personal questions during their interactions over time. The authors relied heavily on field notes written after the group sessions, which may be prone to recall bias. Similar to the study by Carone et al., (2016), the outcomes of this project point toward

the possible effects on social wellbeing of interacting with peers during physical activity for PWD.

Caregivers

Despite all papers referring to the importance of the role of caregivers in the daily lives of their participants, only seven studies included a measure of caregiver wellbeing.

The qualitative study by Carone et al. (2016) reports a theme around the importance of a space for the wives of the PWD to talk to one another while their partners were engaged in sporting activity. They posit that the opportunity to give and receive support from other people in a similar care-giving position, while having a break from their caring role, has important implications for the caregivers' psychological and social wellbeing.

The studies by Stella et al. (2011) and Maci et al. (2012) document interventions which are not facilitated by the carers at home. In the former study, carers were able to spectate the group from a distance, whereas in the latter study carers were left to go about their daily lives as the PWD were collected from their homes by minibus. Both studies demonstrate improvements in caregiver wellbeing as measured by outcomes on the Burden Interview (Stella et al., 2011) or the Caregiver Burden Inventory (Maci et al., 2012) as a result of their cared-for counterpart taking part in the physical activity group. Collating these outcomes might suggest the importance of a peer support network for carers in order to promote their wellbeing, however, the opportunity for some time away from the PWD might also be an important factor which underpins the procedure in all three studies.

Interestingly, the experimental procedures documented by Lamb et al. (2018) and Taylor et al. (2017) both required the carer to facilitate at least part of the PWD's physical activity at home. The carers therefore became enmeshed in the intervention and did not

receive the same break or social support which might have been offered in other studies. Both of these studies utilised the Zarit Burden Interview which discovered no significant differences between pre and post scores in either experimental or control conditions. This might provide further support for the importance of offering an opportunity for a break from the caregiving role, in order to promote the carers' wellbeing.

Unfortunately, both Steinberg et al. (2009) and La Rue et al. (2013) report the administration of a quantitative outcome of caregiver burden but do not document the outcomes of these measures. In both of these studies, the carers are also required to facilitate physical exercise at home; if the outcomes of these measures have been omitted due to null results, this would add further weight to the role of a space away from caregiving in engendering caregiver wellbeing.

Discussion

Overall, the number of papers included in this review (15) is small and furthermore, not all of these studies specifically addressed both psychological and social wellbeing outcomes for both PWD and their caregivers. Indeed, a number of papers labelled such outcomes as secondary to those relating to physical health (for example, see Rolland et al., 2007).

The majority of papers included in this review report the outcomes of complex interventions, across which there is evident heterogeneity. While some studies state that their physical activity protocol was based on previous research (e.g. Teri et al., 2003), the majority appear to be bespoke interventions designed for that particular study, with no apparent similarity across the interventions that were implemented. While the inclusion of strength, balance and flexibility exercises appears to be a clear theme between most studies, the inconsistencies (or uncertainty) regarding the specific activities utilised detracts from the reliability of the results of these studies.

The geographical breadth of the reviewed studies is also notable. This poses a question regarding the extent to which differences in results might be attributable to cultural differences, for example, regarding prevailing attitudes and responses to PWD; as evidenced by Lawrence, Murray, Samsi and Banerjee (2008), there are differences in the ideologies and approaches towards caring for PWD between people of different cultures. Furthermore, the majority (11) of studies specifically recruited people with Alzheimer's disease; the results of these studies therefore cannot be assumed to be relevant or generalisable to other subtypes of dementia. Moreover, three studies do not specify the type(s) of dementia experienced by participants; given the variability of symptoms between dementia subtypes, this lack of clarity is unhelpful and limits the confidence with which recommendations can be made from the outcomes of these studies.

Quality of Evidence

The QualSyst tool identified 14 of the 15 studies included in this review as scoring higher than 70 percent, which constitutes a relatively conservative cut-off point for the acceptable quality of an article (Kmet, Lee & Cook, 2004). While eight of the studies included in this review document the outcomes of RCTs, a number of common methodological flaws exist across all of the reviewed studies. For example, the use of small, unjustified sample sizes may detract from the power of those studies to detect significant outcomes. Furthermore, none of the studies documented a procedure which included participant blinding, which may introduce the confounding effects of expectation bias from participants.

Potential Biases in the Review Process

As Snilstveit, Oliver and Vojtkova (2012) assert, the narrative approach to synthesis undertaken in this review can be prone to bias due to its inherent degree of subjectivity, as the

narrative is guided by the information which seems most significant to the reviewer. However, guidance from the Cochrane Consumers and Communication Review Group (2013) was followed to offer clarity with regard to the process of conducting this synthesis, with the view to minimising the effects of the reviewer's own subjectivity. The approach to synthesis was pre-specified, such that studies were grouped together in terms of their ability to answer the individual components of the overarching question guiding this review, based on the measures used and outcomes discussed. This guidance was adhered to in order to prevent the findings of some studies being emphasised above others; studies were not discussed in the order of the reviewer's preference or in terms of the reviewer's judgement of their quality. This structure was adhered to throughout and was not adapted as the papers were synthesised.

Clinical Implications

In light of the relatively few studies meeting inclusion criteria for this review and the conflicting outcomes they yield regarding the effects on psychological wellbeing, caution is warranted when drawing conclusions regarding the clinical implications of this review. Furthermore, only two studies were able to offer any degree of insight regarding the effects of their intervention on social wellbeing for PWD. However, given the overall theme emerging in terms of the type of physical activity employed across these studies (strength, balance and flexibility), the lack of consistent results may suggest that a different mechanism of change affects psychological wellbeing.

While the heterogeneity of interventions makes it hard to determine what factors are most important to facilitate psychological wellbeing, the synthesis of these studies tentatively suggests the importance of the social context of the physical activity. There is preliminary evidence for the importance of social interaction which aligns with Kitwood's (1997)

psychosocial theory of personhood, which asserts the importance of interactions with others for the maintenance of the individual's sense of personal identity and self-worth. More specifically, this review suggests the importance of interactions involving people outside the person's immediate care network. This aligns with Sabat's (2006) view that the most fragile concept of the self in PWD is a publically presented persona that is contingent on the social relationships we have with others; this sense of a persona that is visible more publically suggests the importance of interactions outside of our closest (and therefore less public) relationships.

Less can be derived from the effects of these interventions on social wellbeing, however, having a regular, enjoyable activity to look forward to may be an important factor. This provides support for current healthcare policies regarding the need for PWD to be able to choose from a range of activities in line with their interests (NICE, 2018).

Although only seven of the reviewed studies addressed caregiver wellbeing, there appears to be an emerging theme in that caregiver wellbeing is positively affected when they are not responsible for orchestrating the exercise at home. This aligns with the concept of respite for carers of PWD which has been described as an opportunity for the carer to receive a break from the caregiver role while the PWD is looked after by someone else (NHS, 2019). This provides support for the importance of respite for carers, as advocated by current guidance in UK healthcare policy (NICE, 2010).

Recommendations for Future Research

Future research should address the common methodological limitations found in most studies by providing, for example, a justification of sample size and statistical power and applying participant blinding procedures to alleviate the potential for expectation bias. Furthermore, people living with forms of dementia other than Alzheimer's disease appear to

be largely excluded from the majority of studies; while Alzheimer's is the most prevalent form of dementia, it only accounts for two thirds of all instances of dementia (Alzheimer's Research UK, 2018).

It is important to note that only one of the reviewed studies explored the impact of a sport-based physical activity on the wellbeing of PWD and their carers. In light of the importance of PWD being able to choose activities in line with their own interests, it is plausible that sporting activities might offer different avenues and environments for social interaction and physical activity which may be preferable to some. Further research is needed to ascertain any differing effects of sporting endeavours over targeted physical exercise (such as strength training).

This review of the literature found only two papers utilising a qualitative methodology, which has been suggested as a means of exploring meaning and perspectives from the viewpoint of the participants (Hammarberg, Kirkman & de Lacey, 2016). Given the complexity and subjectivity of the concept of social wellbeing, such methodological approaches might be best suited to the exploration of factors affecting this aspect of wellbeing. It might be poignant to note that the only two studies included in this review which offered insight into the effects of their interventions on social wellbeing were the studies utilising such a methodology. Indeed, NHS England (2017b) testify to the importance of qualitative research for developing insight into service user experience, which might serve as a basis for directing further research enquiries going forward.

References

- Aguirre, E., Woods, R. T., Spector, A., & Orrell, M. (2013). Cognitive stimulation therapy for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing Research Reviews, 12*, 253-62. doi: 10.1016/j.arr.2012.07.001
- Alzheimer's Research UK. (2018). *Alzheimer's disease*. Retrieved from <https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/about/>
- Alzheimer's Society. (2016). *Risk factors for dementia*. Retrieved from https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf
- Bowes, A., Dawson, A., Jepson, R., & McCabe, L. (2013). Physical activity for people with dementia: A scoping study. *BMC Geriatrics, 13*(129). Retrieved from <https://doi.org/10.1186/1471-2318-13-129>
- Camic, P. M., Hulbert, S., & Kimmel, J. (2017). Museum object handling: A health-promoting community-based activity for dementia care. *Journal of Health Psychology*. Advanced online publication. doi: 10.1177/1359105316685899
- Campbell, M., Katikireddi, S. V., Sowden, A., McKenzie, J. E., & Thomson, H. (2018). Improving conduct and reporting of narrative synthesis of quantitative data (ICONS-Quant): Protocol for a mixed methods study to develop a reporting guideline. *BMJ Open, 2018*(8). Retrieved from <https://bmjopen.bmj.com/content/8/2/e020064.info>

- Carone, L., Tischler, V., & Dening, T. (2016). Football and dementia: a qualitative investigation of a community based sports group for men with early onset dementia. *Dementia, 15*, 1358-1376. doi: 10.1177/1471301214560239
- Chatterjee, H. J., Camic, P. M., Lockyer, B., & Thomson, L. J. M. (2017). Non-clinical community interventions: A systematised review of social prescribing schemes. *Arts and Health, 10*. 1-27. doi: 10.1080/17533015.2017.1334002
- Cochrane Consumers and Communication Review Group. (2013). *Cochrane Consumers and Communication Review Group: Data synthesis and analysis*. Retrieved from <http://cccr.org.cochrane.org/sites/cccr.org.cochrane.org/files/public/uploads/Analysis.pdf>
- Department of Health. (2013). *Dementia: A state of the nation report on dementia care and support in England*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf
- Department of Health. (2016). *Prime minister's challenge on dementia 2020: Implementation plan*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
- El-Kader, S. M. A., & Al-Jiffri, O. H. (2016). Aerobic exercise improves quality of life, psychological well-being and systemic inflammation in subjects with Alzheimer's disease. *African Health Sciences, 16*, 1045-1055. doi: <http://dx.doi.org/10.4314/ahs.v16i4.22>
- Ferrer, B-C. S., & Valle, A. D. (2014). A rehabilitation program for Alzheimer's disease. *Journal of Nursing Research, 22*, 192-199. doi: 10.1097/jnr.0000000000000046

- Forbes, D., Forbes, S. C., Blake, C. M., Thiessen, E. J., & Forbes, S. (2015). Exercise programs for people with dementia. *The Cochrane Database of Systematic Reviews*, 2015(4), 1-130. doi: 10.1002/14651858.CD006489.pub4
- Geerlings, M. I., Bouter, L. M., Schoevers, R., Beekman, A. T. F., Jonker, C., Deeg, D. J. H., ... Schmand, B. (2000). Depression and risk of cognitive decline in Alzheimer's disease: Results of two prospective community-based studies in The Netherlands. *The British Journal of Psychiatry*, 176, 568-575. doi: 10.1192/bjp.176.6.56
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*, 26, 91-108. doi: 10.1111/j.1471-1842.2009.00848.x.
- Greenhalgh, T. (2014). *How to read a paper: The basics of evidence-based medicine* (5th ed.). Oxford, UK: BMJ Books
- Guure, C. B., Ibrahim, N. A., Adam, M. B., & Said, S. M. (2017). Impact of physical activity on cognitive decline, dementia, and its subtypes: Meta-analysis of prospective studies. *BioMed Research International*, 2017. Retrieved from <https://doi.org/10.1155/2017/9016924>
- Hammarberg, K., Kirkman, M., & de Lacey, S. (2016). Qualitative research methods: When to use them and how to judge them. *Human Reproduction*, 31, 498-501. Retrieved from <https://doi.org/10.1093/humrep/dev334>
- Heyn, P., Abreu, B. C., & Ottenbacher, K. J. (2004). The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 85, 1694-1704. doi: <https://doi.org/10.1016/j.apmr.2004.03.019>

- Karanicolas, P. J., Farrokhyar, F., & Bhandari, M. (2010). Blinding: Who, what, when, why, how? *Canadian Journal of Surgery*, *53*, 345-348. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947122/>
- Kasai, M., Meguro, K., Ozawa, H., Kumai, K., Imaizumi, H., Minegishi, H., ... Itoi, E. (2017). Fear of falling and cognitive impairments in elderly people with hip fractures. *Dementia and Geriatric Cognitive Disorders Extra*, *15*, 386-394. doi: 10.1159/000480497
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press
- Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Alberta, Canada: Alberta Heritage Foundation for Medical Research. Retrieved from <https://www.ihe.ca/publications/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields>
- La Rue, A., Felten, K., Duschene, K., MacFarlane, D., Price, S., Zimmerman, S., & Hafez, S. (2013). Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities. *Seminars in Speech and Language*, *34*, 170-184. doi: 10.1055/s-0033-1358370
- Lamb, S. E., Sheehan, B., Atherton, N., Nichols, V., Collins, H., Mistry, D., ... Lall, R. (2018). Dementia and physical activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: Randomised controlled trial. *BMJ*, *2018*(361). Retrieved from <https://www.bmj.com/content/361/bmj.k1675>

- Larson, E. B., Yaffe, K., & Langa, K. M. (2013). New insights into the dementia epidemic. *The New England Journal of Medicine*, *369*, 2275-2277. doi: 10.1056/NEJMp1311405
- Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of black Caribbean, south Asian and white British carers of people with dementia in the UK. *British Journal of Psychiatry*, *193*, 240-246. doi: 10.1192/bjp.bp.107.045187
- Lewis, F., Karlsberg-Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *The trajectory of dementia in the UK - making a difference*. Retrieved from <https://www.ohe.org/publications/trajectory-dementia-uk-making-difference#>
- Maci, T., Le Pira, F., Quattrocchi, G., Di Nuovo, S., Perciavalle, V., & Zappia, M. (2012). Physical and cognitive stimulation in Alzheimer's disease. The GAIA project: A pilot study. *American Journal of Alzheimer's Disease & Other Dementias*, *27*, 107-113. doi: 10.1177/1533317512440493
- McCrone, P., Dhanasiri, S., Patel, A., Knapp, M., & Lawton-Smith, S. (2008). *Paying the price: The cost of mental health care in England to 2026*. Retrieved from https://www.kingsfund.org.uk/sites/default/files/Paying-the-Price-the-cost-of-mental-health-care-England-2026-McCrone-Dhanasiri-Patel-Knapp-Lawton-Smith-Kings-Fund-May-2008_0.pdf
- Nascimento, C. M. C., Teixeira, C. V. L., Gobbi, L. T. B., Gobbi, S., & Stella, F. (2012). A controlled clinical trial on the effects of exercise on neuropsychiatric disorders and instrumental activities in women with Alzheimer's disease. *Revista Brasileira de Fisioterapia*, *16*, 197-204. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/22499405>

National Health Service. (2017). *Dementia guide*. Retrieved from

<https://www.nhs.uk/conditions/dementia/about/>

National Health Service. (2019). *Carers' breaks and respite care*. Retrieved from

<https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/>

National Institute for Health and Care Excellence [NICE]. (2018). *Dementia: assessment, management and support for people living with dementia and their carers*. Retrieved from

<https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#interventions-to-promote-cognition-independence-and-wellbeing>

National Institute for Health and Care Excellence [NICE]. (2010). *Dementia: Support in health and social care*. Retrieved from

<https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-10-Respite-services-for-carers#quality-statement-10>

NHS England. (2017a). *Implementation guide and resource pack for dementia care*.

Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf>

NHS England. (2017b). *Building greater research insight through qualitative research*.

Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2017/04/bitesize-guide-qualitative-research.pdf>

Orgeta, V., Qazi, A., Spector, A., & Orrell, M. (2015). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment: Systematic review

and meta-analysis. *The British Journal of Psychiatry*, 207, 293-298. doi:
10.1192/bjp.bp.114.148130

Padala, K. P., Padala, P. R., Lensing, S. Y., Dennis, R. A., Bopp, M. M., Robertson, P. K., & Sullivan, D. H. (2017). Home-based exercise program improves balance and fear of falling in community-dwelling older adults with mild Alzheimer's disease: A pilot study. *Journal of Alzheimer's Disease*, 59, 565-574. doi: 10.3233/JAD-170120

Peters, J. (2011). *Is a meta-analysis right for me?* [PowerPoint slides]. Retrieved from https://medicine.exeter.ac.uk/media/universityofexeter/medicalschoollresearch/pentag/2011-04-05_Peters_Is_a_meta-analysis_right_for_me.pdf

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., ... Salimkumar, D. (2014). *Dementia UK: Update second edition*. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf

Prince, M., Wimo, A., Guerchet, M., Ali, G-C., Wu, Y-T., & Prina, M. (2015). *World Alzheimer's report 2015: The global impact of dementia*. Retrieved from <http://www.worldalzreport2015.org/downloads/world-alzheimer-report-2015.pdf>

Public Health England. (2016). *Data analysis report: Dying with dementia*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733065/Dying_with_dementia_data_analysis_report.pdf

Public Health England. (2018). *Dementia: Applying all our health*. Retrieved from <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

- Rare Dementia Support. (2018). *Rare dementias*. Retrieved from <http://www.raredementiasupport.org/>
- Regan, M. (2016). *The interface between dementia and mental health: An evidence review*. Retrieved from <https://www.mentalhealth.org.uk/sites/default/files/Dementia%20paper.pdf>
- Robertson, R., Wenzel, L., Thompson, J., & Charles, A. (2017). *Understanding NHS financial pressures. How are they affecting patient care?*. Retrieved from https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Understanding%20NHS%20financial%20pressures%20-%20full%20report.pdf
- Rolland, Y., Pillard, F., Klapouszczak, A., Reynish, E., Thomas, D., Andrieu, S., ... Vellas, B. (2007). Exercise program for nursing home residents with Alzheimer's disease: A 1-year randomized, controlled trial. *Journal of the American Geriatrics Society*, 55, 158-165. doi: 10.1111/j.1532-5414.2007.01035.x
- Sabat, S. R. (2006). Mind, meaning and personhood in dementia: The effects of positioning. In J. C. Hughes, S. J. Louw, and S. R. Sabat (Eds.) *Dementia: Mind, meaning and person* (pp. 287-302). Oxford: Oxford University Press
- Seung-Ho, R., Han-Yong, J., Kang, J. L., Seok, W. M., Dong, W. L., Narei, H., ... Chang, U. L. (2017). Incidence and course of depression in patients with Alzheimer's disease. *Psychiatry Investigation*, 14, 271-280. doi: 10.4306/pi.2017.14.3.271
- Snilstveit, B., Oliver, S., & Vojtkova, M. (2012). Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. *Journal of Development Effectiveness*, 4, 409-429. doi: 10.1080/19439342.2012.710641

- Steinberg, M., Leoutsakos, J-M. S., Podewils, L. J., & Lyketsos, C. G. (2009). Evaluation of a home-based exercise program in the treatment of Alzheimer's disease: The maximizing independence in dementia (MIND) study. *International Journal of Geriatric Psychiatry, 24*, 680-685. doi: 10.1002/gps.2175
- Stella, F., Canonici, A. P., Gobbi, S., Santos-Galduroz, R. F., Cação, J. deC., & Gobbi, L. T. B. (2011). Attenuation of neuropsychiatric symptoms and caregiver burden in Alzheimer's disease by motor intervention: A controlled trial. *Clinics (Sao Paulo), 66*, 1353-1360. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/21915483>
- Taylor, M. E., Lord, S. R., Brodaty, H., Kurrle, S. E., Hamilton, S., Ramsay, E., ... Close, J. C. T. (2017). A home-based, carer-enhanced exercise program improves balance and falls efficacy in community-dwelling older people with dementia. *International Psychogeriatrics, 29*, 81-91. doi: 10.1017/S1041610216001629
- Teri, L., Gibbons, L. E., McCurry, S. M., Logsdon, R. G., Buchner, D. M., Barlow, W. E., ... Larson, E. B. (2003). Exercise plus behavioural management in patients with Alzheimer's disease: A randomized controlled trial. *JAMA, 290*, 2015-2022. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/14559955>
- Thacker, S. P. (2012). *Social engagement may be as important as cognitive stimulation therapy in dementia*. Retrieved from <https://www.bmj.com/content/bmj/344/bmj.e1607.full.pdf>
- The King's Fund. (2017). *What is social prescribing?* Retrieved from <https://www.kingsfund.org.uk/publications/social-prescribing>

- Tyack, C., & Camic, P. M. (2017). Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review. *International Psychogeriatrics*, 29, 1261-1280. doi: 10.1017/S1041610217000667
- Williams, C. L., & Tappen, R. M. (2008). Exercise training for depressed older adults with Alzheimer's. *Aging and Mental Health*, 12, 72-80. doi: 10.1080/13607860701529932
- Woods, B., O'Philbin, L., Farrell, E. M., Spector, A. E., & Orrell, M. (2018). Reminiscence therapy for dementia. *The Cochrane Database of Systematic Reviews*, 2018(3). 1-130. doi: 10.1002/14651858.CD001120.pub3
- World Health Organization. (2017). *Dementia*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>
- World Health Organization. (2019). Global strategy on diet, physical activity and health. Retrieved from <https://www.who.int/dietphysicalactivity/pa/en/>
- Wu, E., Barnes, D. E., Ackerman, S. L., Lee, J., Chesney, M., & Mehling, W. E. (2015). Preventing loss of independence through exercise (PLIE): Qualitative analysis of a clinical trial in older adults with dementia. *Aging and Mental Health*, 19, 353-62. doi: 10.1080/13607863.2014.935290

Section B

Exploring the Effects of a Golf Programme on Wellbeing for People with Dementia, Carers and Golf Centre Staff

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Abstract

Introduction: The growing prevalence of dementia is a global concern. The care pathway within the UK healthcare system advocates for the importance of engagement with community-based activities for people with dementia (PWD), including sport. Although the importance of psychological and social wellbeing for PWD has been established, there is a paucity of evidence regarding the effects of sport and physical activity on these constructs.

Method: The study design was a qualitative enquiry, utilising multiple avenues of data collection. PWD and carers participated in a six-week golf programme, facilitated by golf centre staff. Overall, ten PWD, five carers and three staff provided data for the study, which was subjected to thematic analysis.

Results: The analysis culminated in the establishment of five central themes: affectivity, respite, losing the "dementia" label, friendship/camaraderie and improving relationships. Underlying subthemes were identified, while potential links between themes were highlighted.

Discussion: This study adds to the evidence base for the role of golf (and sport more generally) in enhancing the psychological and social wellbeing of PWD, carers and staff. This concurs with existing policy which asserts the importance of engaging with community-based physical activity for this population. Potential mechanisms for these effects, limitations and implications are discussed.

Key words: Dementia, golf, sport, wellbeing, thematic analysis

Dementia describes an array of neurodegenerative syndromes characterised by the progressive loss of cognitive functions which often include memory, processing speed, executive function, vision, hearing and our ability to comprehend and utilise language (National Health Service, 2017). There is currently no known cure for dementia and with age being the biggest risk factor associated with its development (Alzheimer's Society, 2016), increasing life expectancy is inevitably mirrored by an increase in the number of people living with dementia (PWD). As such, Dementia has become the leading cause of death in England and Wales (Public Health England, 2016).

Current Approaches to Dementia Care

In order to address what some have described as an impending epidemic (Larson, Yaffe & Langa, 2013), advances in dementia care and research have been marked as priorities by UK government policy (Department of Health, 2016). The most recent guidance published by the National Institute for Clinical Excellence (NICE, 2018) advocates for population level interventions accessed within the person's local community in addition to more structured clinical interventions such as cognitive stimulation therapy. Indeed, research has begun to illustrate the potential of community-based interventions, for example, museum object handling has been shown to have beneficial effects for PWD (e.g. Camic, Hulbert & Kimmel, 2017). Another avenue of population level interventions that may be beneficial to PWD relates to sport and physical activity, which is advocated by Public Health England (2018). The cognitive and physical health benefits of such activity for PWD has been well documented; for example, evidence suggests the potential for physical activity to mitigate cognitive decline (Guure, Ibrahim, Adam & Said, 2017).

There is also consideration of the systemic impact of dementia on those who care for PWD with current policy highlighting the importance of addressing the needs of carers

(NICE, 2018). As the severity of dementia increases so too does the necessary input from carers (such as friends, family and staff), carrying challenges to wellbeing and the potential for development of mental ill-health for those who provide care (Brodaty, Green & Koschera, 2003).

Psychological and Social Wellbeing for PWD

While important, a person's overall wellbeing is contingent on more than their physical health alone with some theories highlighting the significance of psychological and social wellbeing for PWD. Psychological wellbeing has been described as the difference between one's positive and negative feelings, such that more positive (and less negative) emotions result in greater wellbeing (Bratt, Stenström & Rennemark, 2016). The prevalence of co-morbid depression and anxiety for PWD (Orgeta, Qazi, Spector & Orrell, 2015) have been documented, illustrating the potential effects of the condition on psychological wellbeing. Furthermore, the effects of dementia on self-esteem - defined as the emotional evaluation of our self-worth (Hewitt, 2009) - as a result of one's perceived loss of ability has also been identified (Alzheimer's society, 2019).

Social wellbeing describes our appraisal of our relationships with others, including feeling like an accepted, integrated and contributing member of society (Keyes, 1998). Kitwood's (1997) psychosocial theory of personhood suggests that the personal identity and self-worth of PWD are maintained through their interactions with others. Moreover, Sabat's (2006) three concepts of self, the most fragile of which is a publically presented persona that is contingent on one's social relationships with others, highlights the social needs of this population.

Current Evidence for Sport and Physical Activity in Dementia Care

Compared to the physical health benefits, less is known about the potential effects of sport and physical activity on the psychological wellbeing of those affected by dementia; few studies include measures of psychological wellbeing as these are largely regarded as secondary to those of physical health outcomes (e.g. Rolland et al., 2007). This may reflect a current research focus that prioritises the identification of the physical health and cognitive benefits of physical activity for PWD. While some studies demonstrate a significant and beneficial effect of physical activity on specific measures of depression and anxiety (Stella et al., 2011; Maci et al., 2012), other studies report insignificant changes on measures of these constructs (Rolland et al., 2007; Taylor et al., 2017). Further studies incorporate generic measures of wellbeing which contain single items addressing depression or anxiety but again such studies have yielded both significant (Ferrer & Valle, 2014) and insignificant (Padala et al., 2017) results. Although most of these studies utilised similar types of physical activity (aerobic, strength, balance and flexibility exercises), the heterogeneity of these interventions lessens our ability to determine what aspects of the intervention might impact on psychological wellbeing.

Even less evidence exists regarding the effect of such interventions on social wellbeing. To date, only two qualitative studies have endeavoured to comment on the sociological implications of their interventions for PWD (Carone, Tischler & Dening, 2016; Wu et al., 2014). However, both of these studies suggest a positive impact of physical activity in this regard, such as feeling supported and accepted, and becoming increasingly alert and responsive to others over time.

A small number of studies document the psychological and social effects of such interventions on the carers. In those studies where carers were able to spectate the PWD

doing the activity (Stella et al., 2011) or were otherwise not involved with the facilitation of the intervention (Maci, et al., 2012), significant reductions in caregiver burden were reported. In contrast, studies in which the interventions were at least in part facilitated by the carer at home (Lamb et al., 2018; Taylor et al., 2017) tended to yield insignificant changes. This might tentatively suggest that being removed from the delivery of wellbeing interventions is a key mechanism in facilitating the mitigation of carer burden.

While the available evidence in this area is limited, there is some initial support for the potential of physical activity to have a beneficial impact on the psychological and social wellbeing of both PWD and their caregivers. Interestingly, there only appears to be one study which investigates the effects of playing sport for PWD (Carone et al., 2016) while other studies incorporate a preconceived exercise routine, resulting in sporting activities being largely overlooked.

The potential of golf. Golf is arguably a unique sport in terms of the multifaceted array of potential sources of stimulation that it offers, including both cognitive and social stimulation. Stenner, Mosewich & Buckley (2016) presented the views of golfers who suggest that golf helps to keep the mind active, as well as offering them membership to a stable community of peers, a place of support and a means of relieving stress. To date, research concerning the effects of golf has concentrated on the physical impact of playing golf. For example, the Walker Research Group (2011) comment on the number of health and fitness benefits it yields across age groups. It is therefore reasonable to assume that golf can offer physical health gains for people with dementia, the benefits of which are well documented (Guure, Ibrahim, Adam & Said, 2017).

In contrast, very little is known about the psychological and social wellbeing effects of playing golf (Murray et al., 2017), though Carless and Douglas (2004) have found some

tentative evidence for the beneficial effects of playing golf for people with severe mental illness. It would therefore be valuable to investigate the potential for golf to provide psychological and social benefits within a population level setting for people with dementias and carers.

NHS Values

The present study was conducted as part of an NHS funded doctoral programme, as reflected by its grounding in a number of NHS values. Incorporating the views of PWD, carers and staff aligns with respecting and valuing the perspectives of every person involved in the care pathway. It also encourages a more inclusive approach to health care in terms of asserting the importance of overcoming ageist beliefs and practices.

Research Question

The following overarching research question was used to guide the present study: what are the psychological and social benefits of a six-week golf programme for PWD, their carers and golf centre staff? Two sub-questions were contained within this: what are the most important components of the programme for PWD and their carers?; What does playing golf mean for this population? For example, is it taking part in the sport of golf, socialising or learning/maintaining a skill?

Method

Design

The study design was a qualitative enquiry, utilising multiple avenues of data collection and thematic analysis (TA). Qualitative research is often used to explore the complexities of human experience owing to its high level of flexibility (Carone et al., 2016). Clarke and Braun (2018) recognise that TA is a method which varies in terms of analytical

procedure and guiding philosophy; this study utilised a “coding reliability” approach (p. 108) which uses a structured approach to coding to encourage the reliability and accuracy of this process. Underpinned by epistemological empiricism (Hossain, 2014), this study emphasises the role of experience (both the participants' and the researcher's) in deriving knowledge of the effects of a six-week golf programme on psychological and social wellbeing.

A variety of data collection techniques were employed including audio recorded interviews, focus group discussions and video data. This multifaceted approach to data collection allowed for the triangulation of data in order to maintain qualitative validity. Audio recorded data were subjected to an inductive thematic analysis, which has been identified as a means of exploring themes which might help to provide a focus for further research (Guest, Namey & Mitchell, 2013). This qualitative methodology helps identify shared meanings and experiences (Braun & Clarke, 2006) and to understand what is common in the way a topic is talked about (Braun & Clarke, 2012).

Participants

A total of 12 PWD (10 males) expressed an interest in taking part in the study (mean age = 72, SD = 9.38), only three of whom had played golf previously. All participants reported a familiarity with the sport and an understanding of the basic premise of how it is played, having known someone that has played golf or having seen it played on television. All participants were able to stand for prolonged periods of time as required for golf play; one individual fatigued more quickly as a result of tremors related to Parkinson's disease and needed to sit down briefly on some occasions. Involvement in this study was not contingent on the person having a specific dementia diagnosis or any previous experience of golf and no participants were excluded. A brief mini mental state exam (B-MMSE; Folstein, Folstein, White & Messer, 2010; appendix 1) was conducted in order to provide context regarding

dementia severity. Table 5 provides a description of participant demographics. Two PWD were unable to attend their final group session, resulting in ten PWD contributing data for this study.

Participant	Dementia	Gender	Age	B-MMSE
1	Early onset	Female	58	15
2	Alzheimer's	Male	84	8
3	Alzheimer's	Male	90	5
4	Lewy Body	Male	65	9
5	Parkinson's	Male	72	8
6	Early onset	Male	62	16
7	Early onset	Female	64	14
8	Alzheimer's	Male	69	13
9	Lewy Body	Male	70	12
10	Lewy Body	Male	74	8
11	Alzheimer's	Male	77	3
12	Alzheimer's	Male	79	6

Five carers were invited to take part in the study, all of whom gave their consent to partake. Finally, three members of staff from the host golf club were recruited due to their involvement with the facilitation and orchestration of the golf programme.

The proposal for this study was reviewed favourably by the ethics panel at the Salomons Institute for Applied Psychology (appendix 2).

Procedure

This study was based at a single golf club in the South East of England, at which all meetings with participants took place. A timeline of research events and the production and analysis of data is provided in table 6.

Time	Period of study	Research event	Data produced	
↓	Before programme	Group facilitators identified Consent obtained from staff Staff attended training Initial meetings with researcher for PWD and carers Consent obtained from PWD and carers B-MMSE completed		
	During programme (repeats for each golf group)	Golf group begins		Video data Audio data Audio data
		Final (sixth) session	Session attended and video recorded by researcher Focus group attended by PWD and carers at end of session	
		Carer interviews conducted		
		<i>Three golf groups were run consecutively</i>		
	After programme (all three groups completed)	Staff focus group		Video data transformed to audio data
Analysis	All audio data transcribed Transcribed data used to develop and refine codebook and themes Inter-rater reliability assessed			

The PWD and carer dyad. PWD and their carers were recruited via local dementia action alliances and Admiral Nurses. Those expressing an interest in the study were sent information forms (appendices 3 & 4) regarding the project before being invited for an initial meeting with the primary researcher, at which time the B-MMSE was completed. This meeting also presented an opportunity for participants to ask questions. Following this the PWD was asked to give their informed consent to take part. At this stage, carers accompanying the PWD were also asked if they would meet with the researcher at the end of the study and informed consent was obtained.

Each PWD and carer dyad was then invited to attend the next available group; three groups were conducted in total with the groups limited to between three and five PWD per group so as to maximise the amount of support given to each individual by staff. Each group

consisted of six weekly sessions lasting approximately three hours and tailored to the needs of the PWD within each group. Each session began and ended with a 45-minute refreshment break in which PWD, carers and staff engaged in conversation (not necessarily about golf), allowing 90 minutes for golf play. The golf play began with putting in the first session, continuing to chipping and longer iron shots as each group programme progressed, all conducted at the venue's outdoor putting green and driving range facilities. Each session was facilitated by the same two staff members who engaged participants in exercises to teach and practise the different skills involved in hitting each club (putter, wedge and long irons) with the exception of the driver; a more nuanced technique is required for the driver which distinguishes it from the other clubs and so it was omitted. At the end of the final session, participants were taken onto the course to play the first hole, simulating friendly match-play conditions. Due to bad weather, the golf play in the fourth session of one group was replaced with videos of golf and extended refreshment breaks. All PWD and three carers participated in playing golf, while two carers opted to spectate.

The primary researcher joined the final session of each group, which was conducted as usual with the researcher taking part in the golf play alongside participants. Joining in with the groups' activities was considered to be less distracting to participants than having the researcher present as an observer. This session was video recorded using a 360-degree Fly™ camera (360-Fly, 2017; appendix 5). The final session was selected to allow the group time to form, minimising the level of intrusion into participants' experience that was inherent in the introduction of the researcher and camera equipment. The 360-Fly™ camera was chosen due to its small size (similar to a tennis ball) and mounted on the researcher's golf trolley so as to be inconspicuous. Following the golf play in the final session the researcher joined the refreshment break and engaged PWD and carers in an audio recorded focus group (45 minutes; see appendix 6) where the experiences of the golf programme for PWD was the

main focus of conversation. Carers were contacted via telephone for a 20-minute semi-structured interview two weeks after their group concluded (see appendix 7) to ascertain their experience of the programme, which was also audio recorded.

While initial written consent was obtained from all participants, it is recognised that the capacity to give consent might fluctuate for those with dementia (Beuscher & Grando, 2009). In order to address this, guidance regarding the method of process consent (Dewing, 2008) was followed by reconfirming the person's interest and consent to continue with the project at the start of the final session.

Staff. The two group facilitators were identified with support from the club manager based on their coaching ability and experience of working with groups; one facilitator was an accredited golf coach. An information sheet was given (appendix 8) and the study and their prospective involvement were discussed before all three gave their informed consent. Staff then received training from the founder of the "Golf in Society" initiative, which is an existing dementia friendly golf programme based elsewhere in the UK. This training was designed to give staff the requisite skills and awareness for working alongside PWD. The two facilitators accompanied the group during the golf play for each session of all three groups, while the club manager was present during at least one refreshment break for each session; each facilitator missed one session due to illness, which did not result in disruption to the schedule of the programmes.

Video data from the final session of each group were divided into four-minute segments capturing participants before, during and after different activities within a continuous viewing period. The video data were used to inform an audio recorded focus group discussion with staff (2.5 hours; appendix 9); dividing the video into segments offered this meeting greater structure in which a segment was viewed and discussed before moving to

the next. Three segments from each golf group were selected, representing a good range of activities and participants, which was confirmed by research supervisors prior to the focus group. Garcez, Duarte & Eisenberg (2011) warn of the loss of key information that comes from the process of transforming video to audio data by verbally describing gesture, gaze and expressions, detracting from the richness of the data. The purpose of this focus group was to transform the data by discussing it, thus maintaining its detail. This was followed by a 20-minute focus group discussion which sought to address any feelings and experiences from the staff that had not yet been explored.

Quality assurance. Throughout this study the primary researcher kept a reflective journal (appendix 10) and met with his supervisors to discuss responses to the data, such as the choice of video segments, in order to remain mindful of their inherent biases. For example, acknowledging that the researcher had been a keen golfer for three years at the beginning of this study helped the researcher and supervisors to remain sensitive to a range of experiences (both positive and negative) of golf to emerge.

In order to assess inter-rater reliability, one transcript with highlighted coded segments was examined by an independent research colleague in terms of the themes represented by these codes. The outcome of this suggests strong reliability (Cohen's kappa = 0.96; Hruschka et al., 2004).

Results

An inductive thematic analysis focusing on semantic themes across all audio recorded data was conducted in order to answer the research question "What, if any, are the psychological and social benefits of a six-week golf programme for PWD, their carers and golf centre staff?". This type of analysis focuses explicitly on the surface meaning of what participants have said (Braun & Clarke, 2006), allowing subsequent interpretation of those themes with

the view to theorising the broader meaning and implications of patterns identified within the data (Patton, 1990).

Analysis followed Braun and Clarke's (2006) suggested guidance. Firstly, all audio recorded interviews and focus group discussions were transcribed by the primary researcher, in order to familiarise themselves with the data. Codes were then developed to isolate interesting features of the data set in line with the research question. An initial codebook was developed using the first three coded transcripts from which potential themes were identified (Boyatzis, 1998). Codes arising in subsequent transcripts were then considered alongside these potential themes, allowing codes to either support an existing theme or to suggest other themes. Themes were then reviewed in relation to the coded extracts to determine their appropriateness as descriptors of the experiences contained within the data set. A thematic map of the analysis was devised identifying the interplay between potential themes, assisting in the gradual refinement and naming of these themes (Figure 2). Themes were then considered in terms of who they relate to (PWD, carers or staff) and which of these participants contributed data in support of each theme (Table 7). All names appearing herein are pseudonyms.

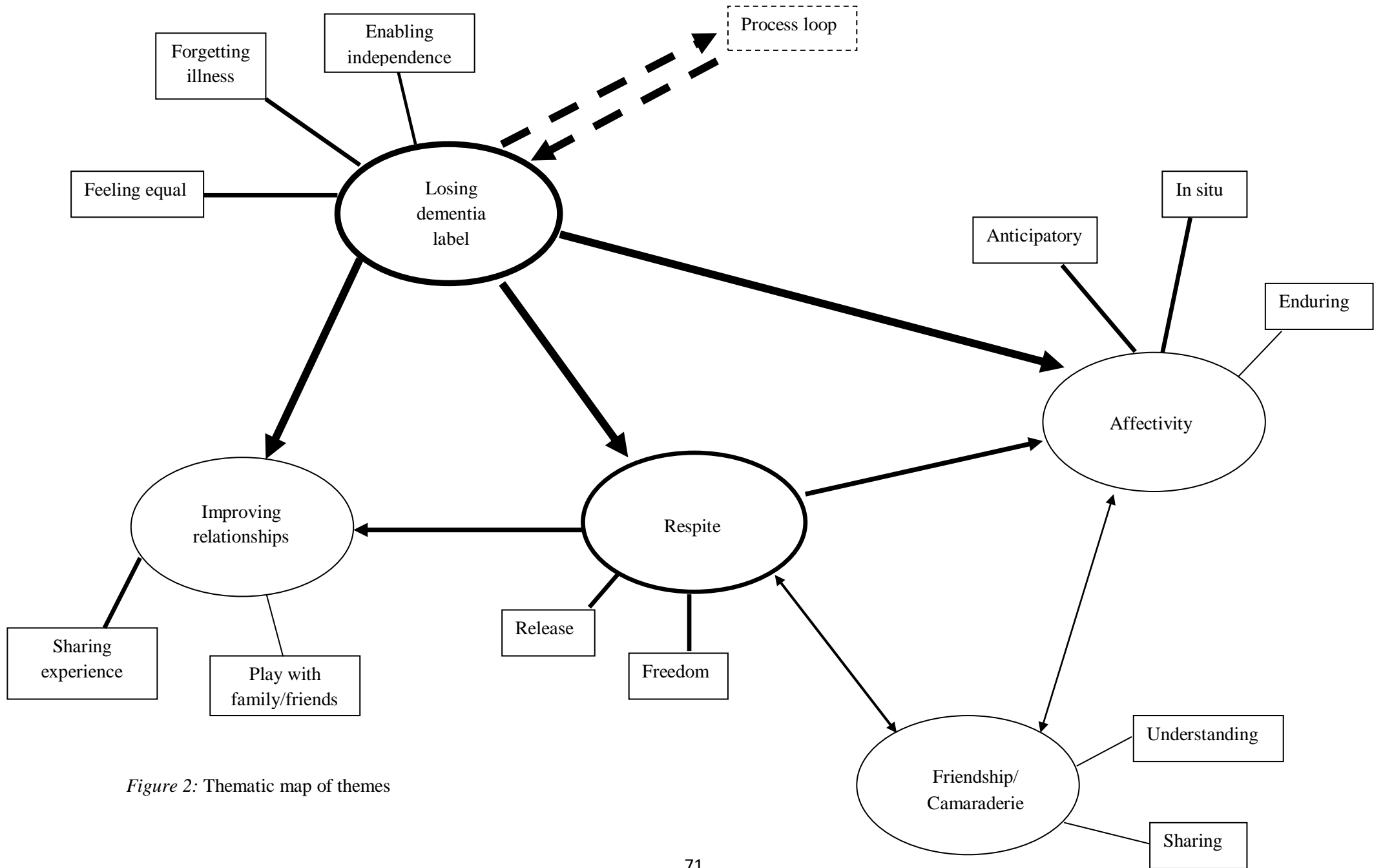


Figure 2: Thematic map of themes

Table 7				
<i>Summary of identified themes</i>				
Theme	Subtheme	Relates to:	Stated by:	Supporting quotes
Affectivity	In situ	PWD/Carers/Staff	PWD/Carers/Staff	<p>P5: "I think it's also good fun and I'd play every day of the week if I could"</p> <p>C4 "They (PWD) enjoy it and so do we"</p> <p>S2: "The biggest one for me was just rewarding. Umm, just in the sense of being able to teach them and just seeing them learn new skills - that was rewarding"</p>
	Anticipatory	PWD/Carers	PWD/Carers	<p>P1: "This has given me personal 'Oh yeah, I'm going to golf'. I'm all excited and I get home, I phone my sons... On my calendar in big letters is 'Golf, golf, golf, golf, golf'"</p> <p>P6: "Wednesday kind of starts on Monday, when you're seeing what it is you're going to be doing this week and we get all excited about that we're coming to do this"</p> <p>C1: "... I was really excited about it, coz I thought, it's not the mundane things that, like, every other thing was go and sit in a meeting... Nothing was active"</p>
	Enduring	PWD/Carers/Staff	PWD/Carers/Staff	<p>P1: "That gives me so much confidence and respect and that's why I respect Dan coz he's got time and like, yeah we hit the ball, sometimes we miss it half a dozen times, you don't see him going *sighs*"</p> <p>C5: "I think it helps their speech skills, their cognitive skills... Umm, lifts their confidence, raises their self-esteem."</p> <p>S1: "Developments show that you're not too old... That's quite inspiring isn't it, to yourself, to keep doors open and don't say no to stuff"</p>
Respite	Release	PWD/Carers	PWD/Carers/Staff	<p>P1: "There must be something, coz you do the little ones and you're like "nrrrr", I just wanna go "RRRAAAEE!"; C2: "Let it all out"; P1: Exactly, that's how I feel, you can do that"</p> <p>C4: "Took the pressure off a little bit, yeah"</p> <p>S2: "It's something so different to all the dementia groups that she goes to and it's actually such so much of a release for her"</p>

Theme	Subtheme	Relates to	Said by	Evidence from data
Respite	Freedom	Carers	Carers, Staff	<p>C3: "We knew that the people we cared for were in safe hands... So we could go off and have the freedom to play a few holes"</p> <p>C1: "It was nice, I didn't have to... I knew, on that one day a week, for them few hours, I had a break and I didn't have to... I wasn't worrying about her"</p> <p>S2: "Not having to worry, not having to focus, and they actually have that time almost to themselves to actually just, like, reset themselves"</p>
Losing dementia label	Forgetting illness	PWD/Carers/Staff	PWD/Carers/Staff	<p>P1: "You're being a normal person and it does help you. It makes you forget about, that you have something wrong with you"</p> <p>C3: "Coz I would think, like, for you and others, it makes you feel like, for a little while, you've got nothing wrong with you" - P3: "That's right, yeah, yeah"</p> <p>S1: "He said at one stage, when you're out there doing it, you forget you're ill, for a while you forget you're ill, which is quite a thing to say isn't it"</p>
	Feeling equal	PWD/Carers/Staff	PWD/Carers/Staff	<p>P6: "I kept thinking all the time, you know, I'm watching these other people and I know several times... I thought 'well these are people without dementia and they're crap compared with us"</p> <p>C3: "Because everybody's equal. There's no, somebody's got dementia and somebody hasn't. We're just, we're all equal, we're all rubbish"</p> <p>S2: "That clip right there completely sums up what we were saying earlier in the sense that somebody just starting golf is exactly the same as teaching... Possibly even needing more help than teaching anyone with dementia"</p>
	Enabling independence	PWD/Staff	Staff	<p>S3: "Holding on to independence. Still very much capable of doing her own thing - getting in a buggy, driving it, never having driven one before"</p> <p>S3: "That's why it's key sometimes for the carers to be in here and sit and have a coffee and chat, and they (PWD) be outside. Because then they can actually do things for themselves"</p> <p>S2: "I guess that's what part of this has done as well, is umm, for certain individuals and certain carers it's shown them that actually they are capable of doing stuff by themselves"</p>

Theme	Subtheme	Relates to	Said by	Evidence from data
Friendship/ Camaraderie	Understanding	PWD/Carers	PWD/Carers	<p>C1: "I think I was panicking about that, but there I didn't feel like I needed to apologise for her because they understood that's just how it affected her"</p> <p>C3: "It's really helpful because we can identify with each other with lots of things that you go 'oh yeah, I know that - we have that exactly', or 'oh gosh, tell me about it!'"</p> <p>P1: "Yeah exactly, coz people get you (here)"</p>
	Sharing	Carers	Carers	<p>C4: "It's just being with the same sort of people and banding ideas about and saying, finding out that they're having to do the same things as we are"</p> <p>C3: "It's been sort of a... Comparing notes as it were, as to how to cope in your situation and how the person you're caring for copes"</p> <p>C1: "It was just nice to be able to sit there and have someone to talk to and know that that is normal, or, maybe try this, give you ideas and tasks to try and help you"</p>
Improving relationships	Sharing experience	PWD/Carers	Carers	<p>C5: "It was an activity they could do together that was, that made them laugh and smile and be happy, umm, and then they had happy memories of being together, so that made a big difference... That is a very positive thing"</p> <p>C3: "So it's quite nice to spend that time together where I'm not having to do, umm, sort out his diary, look at his finances, make phone calls, send emails, you know... Arrange his life"</p>
	Play with friends/family	PWD	PWD/Carers	<p>P8: "I've got family who play golf and before, no I would never. I'd get invited but, I've never gone. I wouldn't mind actually going."</p> <p>C2: "They normally organise a tournament 3 times a year, with my son-in-laws and friends, so you could join" - P10: "Oh yes, I could"</p> <p>C5: "So it's not just about people with dementia, or people with long term conditions, it's about the whole family, so it's about bringing everybody together"</p>
Key: PWD = P1-10 ; Carers = C1-5 ; Staff = S1-3				

Theme I: Affectivity

This theme speaks to the expressions of affect within the data as a result of the person's participation in the golf programme. Three subthemes helped describe the different types of affectivity that were expressed: *in situ*, *anticipatory* and *enduring*.

In situ relates to the short-term and transient affect that was expressed during golf play, which was experienced by all three groups of participants. Regarding the PWD and carers, this describes feelings of being enthused by playing golf (P9: "Oh it's absolutely amazing, brilliant") and gaining a sense of enjoyment (C3: "at the end of the sessions they've all said they've enjoyed it, and not showing signs of frustration"). This latter quote reflects the overall lack of any expressed frustration, although one PWD did comment on their initial frustration (P4: "Taking half a dozen strokes to get the ball going and then it only goes ten feet, I find that very frustrating"). Given the author's personal experience of feeling frustrated while playing golf, this was somewhat surprising. Feelings of enjoyment were expressed by carers as well as PWD (C4: "They [PWD] enjoy it and so do we"), while the staff facilitating the group reflected on feeling rewarded by the experience (S2: " Being able to teach them and just seeing them learn new skills - that was rewarding").

There was also a sense of feeling excited about upcoming golf sessions, which contributed to the subtheme of *anticipatory* affectivity. This was shared by both PWD and carers who expressed the view that the golf sessions were more active and enjoyable (and therefore something to look forward to) than other dementia-focused activities, such as "mundane" support groups.

The final subtheme relates to a more *enduring* affectivity; rather than the person's transient feelings, this subtheme pertains to the effects of golf on more enduring affective experiences, which occurred in all three groups of participants. For PWD, this related to

feeling more confident and a boost to self-esteem and morale (C3: "Whether it's consciously a huge boost to your morale, subconsciously it must be doing something for you... here you are at 90 learning something new"). For carers, there was the sense that the positive affectivity continued beyond the end of each session (C4: "I feel a lot more light-hearted when I come home from it"), while staff spoke of a sense of feeling inspired by the PWD who conveyed the message that "you're not too old" and playing golf is possible despite the challenges of living with dementia.

The theme of affectivity may link with the themes of respite, losing the dementia label and friendship/camaraderie. It is reasonable to assume that gaining respite is likely to provide some relief from more unpleasant affective states (such as feeling irritated) which the person might arrive with at the golf session. Furthermore, being able to lose the label of dementia for a time alongside a felt sense of camaraderie is likely to catalyse those feelings of enjoyment and excitement for the next session.

Theme II: Respite

The theme of respite describes the opportunity for relief from difficult and uncomfortable emotions, as well as an opportunity for carers to have a break from their role as caregiver. As such, this theme has two subthemes: *release* and *freedom*.

Release relates to the sensation of being able to vent or express uncomfortable feelings, which was relevant for both PWD and carers. Regarding the PWD, there was a sense of being able to relieve frustration (C2: "I still think that is a form of release... on the, you know the... frustration"), which may align with the lack of frustration at golf that was expressed. Some PWD described how it was especially enjoyable for them to hit the ball hard (P2: "Not these little ones, you know, I dunno, I just feel more... when I hit it hard"), which may underpin the experience of being able to relieve frustration. For carers, there was also a

sense of being able to vent some kind of unpleasant or unwanted feelings and experiences (C1: "Just sitting there and being able to talk to them [carers] and being able to vent to them, and them vent to you, it was nice"); unlike the release from frustration that is more explicitly commented on for PWD, what exactly the carers are able to vent is less explicitly described in the data and is therefore open to interpretation. Although they did not experience their own sense of release, this subtheme was also evidenced by the staff.

The subtheme of *freedom* relates only to the carers and describes a sense of being able to achieve either emotional or physical distance from their cared for counterpart. Examples from the data suggest that the golf sessions might have engendered a sense of freedom from the burden of worrying about the person they care for or feeling able to leave the PWD to take part in the group without the carer feeling they needed to be present. This may be underpinned by the carer perceiving the group as a safe environment (C1: " I didn't feel on edge, like, leaving her there... I felt like that was her safe haven"). This subtheme was also addressed by staff, who commented on the group as a means of allowing carers some freedom from focusing their attention on the PWD, allowing them time to "reset".

The theme of respite is connected with all themes, as indicated by the bold black lines. While it is plausible that respite will make the experience of positive affect more likely, it may also act as a means of improving the relationship between the PWD and the carer; respite has been suggested as a means of managing caregiver burden, the effects of which include relationship strain (Cheng, 2017). Furthermore, it is possible that the experiences of friendship/camaraderie and respite are entwined; feeling a "bond" with others may engender trust and confidence, allowing both carers and PWD to feel more comfortable releasing their frustrations to friends and peers, rather than acquaintances.

Theme III: Losing the Dementia Label

Another theme regards the experience of being able to temporarily shed the label of dementia as a result of playing golf. Not only does this apply directly to the PWD, it may also have an impact on the way carers and staff think about and interact with them. This theme has three subthemes: *forgetting illness*, *feeling equal* and *enabling independence*.

Forgetting illness relates to the experience of the diagnosis of dementia withdrawing from conscious awareness as a result of playing golf, which was commented on by the PWD, carers and staff alike. Some participants described their thoughts regarding golf giving them a purpose (P1: " It gives you a purpose, that's what I think, that's what I've got out from it.") and something to focus on (C3: "It seems to take their minds off of the dementia itself. Umm, it seems to give them a focus on something else, umm, something to aim for"), which may help to understand the mechanism through which the PWD were able to forget about the label. For carers, there was a sense of their cared for counterpart becoming the person that they were before dementia (C1: "It was clear that I had my mum back, watching her [play golf]"). This subtheme also relates to staff experiences of coaching and facilitating the groups, with the presence of dementia fading away from being their central focus (S2: "it's not like I'm coaching someone with dementia, I'm just coaching someone").

The subtheme of *feeling equal* describes the sense of golf being a "leveller", in that playing golf helped to level the hierarchical imbalance between PWD and those without dementia. This was described by all three groups of stakeholders which might suggest that experiencing all parties as being equal was a shared sensation, which in turn may have served to reinforce this perception of equality for all involved. The examples provided from the data may illustrate that golf is a sport that is not easily learned, regardless of cognitive or physical impairment; the fact that both carers and PWD were "all rubbish" might undermine

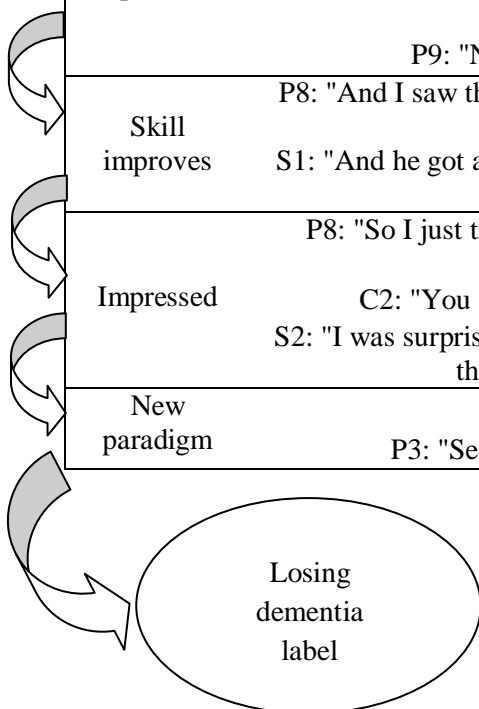
expectations that dementia would prevent participants from being able to learn how to play as well as people without dementia (P7: "Whose gonna teach a person with dementia? Umm, my reflexes are much slower now and, dunno, maybe keep asking questions coz I've forgotten and all this sort of thing").

Unlike the other two subthemes, *enabling independence* was addressed only by staff and relates to their perception of how giving too much support to the PWD detracts from their experience and sense of personal agency. Considering the potential for carers to be overly supportive, one staff member remarked that "They're (carers) constantly doing stuff for them rather than letting them (PWD) do it for themselves", which was not always felt to be necessary (S1: "Five seconds longer and he would have done it [for himself]"). Staff also commented on their approach to coaching which allowed the PWD to make mistakes and engendered a sense of personal agency (S2: "Allowing room for those mistakes, not jumping in and giving orders... Giving back that sense of, I guess, independence, doing it for themselves"). Interestingly, this approach may have helped staff feel a greater sense of understanding of the participants' character which may have enhanced the relationship between staff and the PWD. For example, regarding the "cricket style" way that one PWD held the golf club, "You knew part of who he was just from the way he held the golf club, umm, and that kind of then opened up other avenues of conversation". Being able to recognise the personalities of the PWD in such a way may have facilitated the mechanism of losing the dementia label for staff members.

A process loop also appeared to be in evidence, which may help to understand the mechanism through which the PWD were able to lose their diagnostic label through golf play. As described, there was a sense of dementia meaning that one is no longer able to acquire skills to the extent that someone without dementia may be able to, while social norms might dictate that PWD need to be extensively supported, detracting from their sense of

independence and personal agency. In line with this, PWD spoke of their arguably low expectations of their ability to learn to play golf before starting the programme. However, as the group progressed and their golfing ability improved their earlier expectations were challenged. This may have led to a heightened awareness of, and a sense of being "impressed" by, the progress that was attained. As such, the previous paradigm of being less capable due to dementia was revised and replaced by a sense of being capable and efficacious. This new paradigm may have helped PWD feel detached from the dementia label as a result of their experience of not conforming to the dominant narrative of dementia as rendering a person less able to learn and remember new skills. This mechanism is described alongside supporting quotes from the data, in table 8.

Table 8	
<i>Process loop for theme of "losing dementia label"</i>	
Process loop stage	Supporting quotes
Expectation	P7: "Whose gonna teach a person with dementia? Umm, my reflexes are much slower now and, dunno, maybe keep asking question coz I've forgotten and all this sort of thing" P9: "Not so easy to remember the different things, you know"
Skill improves	P8: "And I saw that Curtis did improve, you know, he did improve, like I believe we all did really" S1: "And he got amazing at it, so to do with picking things up... he was acquiring the skill and it was amazing to see"
Impressed	P8: "So I just tried that and that's how I'm sure... Coz I was amazed with myself really" C2: "You know, I was quite impressed on watching the others as well" S2: "I was surprised at the amount that they can remember when it's just a skill based thing and once it's something that the body's repeating"
New paradigm	P6: "We are so very, very capable" P3: "Several things... An ability to achieve more than I expected"



While losing the dementia label is arguably linked to the theme of affectivity it also links with the themes of respite and improving relationships. As a result of experiencing agency (establishing a new paradigm), PWD may gain some respite from the stigma and narratives which are carried by the label of dementia. Furthermore, without this label being as ostensible, carers may not feel as though they need to be continually involved in giving support, facilitating their ability to have some *freedom* for themselves and attain their own respite. Moreover, the experience of *feeling equal* may facilitate an improved relationship between the PWD and their carer as it allows a more mutual relationship to be rediscovered, even if only for a limited time such as when playing golf. The way staff interact with the PWD may also be affected by the reduced poignancy of the label, such as regarding the decision to give the responsibility of driving the golf buggy to participants (S2: " I know a few of them were particularly wanting to jump in the buggy and have a go... It was just part of giving them the whole experience of what golf is").

Theme IV: Friendship/camaraderie

This theme describes the experience of developing a "bond" and a sense of unity with other members of the golf group, and relates to both the PWD and carers but not staff. There are two subthemes encompassed within this theme: *understanding* and *sharing*.

Understanding relates to the experience of being in the company of people who can directly relate to one's own experiences, either regarding living with dementia or caring for a PWD. More specifically, this describes the validating experience of being able to relate to one another's experiences and feeling comfortable and safe amongst fellow golfers, which may subsequently lead to a reduction in trepidatory anxiety. For example, describing her provisional "panic", one carer expressed her relief at feeling like other group members were able to understand how her mother's dementia affected her use of language (C1: "I didn't feel

like I needed to apologise for her because they understood that's just how it affected her"). As such, this suggests a possible link between this theme and that of affectivity.

Perhaps as a result of feeling understood, *sharing* relates to carers expressing the benefits of being able to share ideas with other experienced carers, which may enhance their ability to cope with particular difficulties. Interviews with carers appear to suggest they found it helpful being in the company of others who have experienced similar difficulties and were therefore able to share coping strategies, thus benefiting from the lived experience of others.

Theme V: Improving Relationships

This theme describes the potential effects of the golf programme on improving the relationships between PWD and those around them, including carers and staff present at the programme, as well as friends and family members outside of the programme. This theme houses two subthemes: *sharing experience* and *playing with family/friends*.

Sharing experience describes the effect of both the PWD and their carer being present at the programme, such that an enjoyable experience could be shared that left both parties with fond memories and/or emotions from that time that they had spent together. This *shared experience* may also have catalysed conversations at a later time, adding a mutual point of interest to the interpersonal relationship (C2: "I mean we obviously had something to talk about when we got back"). Furthermore, evidence from the data suggests that sharing time together which is not related to the carer helping the PWD to manage aspects of their lives with which they may now need support (such as their schedule and finances) may be a somewhat novel and welcome way of spending time together. As such, carers are offered a break from the responsibility of having to "arrange his life" due to the effects of dementia, which may reinforce the experience of losing touch with the dementia label.

The subtheme regarding *playing with family/friends* describes how some PWD felt more able and inclined to join family or friends in their golfing sessions at the end of the programme. As such, the golf programme may have facilitated other avenues for *shared experience*, as the PWD feels empowered to engage in golfing activities with friends/family outside of the programme, which may help to improve these relationships.

Discussion

Psychological Wellbeing

The present study suggests the potential role of a six-week golf programme in promoting experiences of positive affect in PWD, carers and staff. Moreover, the analysis suggests that this might act on a number of temporal levels with positive affective states being experienced during the golf play, in anticipation of golf and after the person has left the session. Self-esteem is described in this study as an *enduring* construct as it has been characterised as a relatively stable trait as compared to more transient affective states such as excitement (Orth, 2017). However, it was beyond the scope of this study to ascertain the longitudinal effects of the golf programme. Participating in the golf play was described extensively as an enjoyable experience, suggestive of the experience of positive affect as a result of the programme for both PWD and carers, while staff commented on feeling rewarded and inspired by their involvement.

The sense of being able to achieve more than expected may have been a key process in allowing the PWD to lose the dementia label for a time, subsequently influencing self-esteem. One mechanism which might explain this concerns the person's perceived independence; while the importance of maintaining one's own agency is highlighted in UK government policy (NICE, 2018), there is an expectation that independence decreases as dementia progresses (McLaughlin et al., 2010). The potential for the programme to enable

independence was a subtheme advocated in particular by staff, which may have facilitated the experience of personal efficacy, achievement and self-esteem for PWD.

Given the author's personal experience of frustration during golf play, the lack of expressed frustration was particularly surprising. While playing golf may be a frustrating experience for some, this raises the question as to why this was not the experience of these participants. One explanation is that living with dementia can be a distressing and frustrating experience for both PWD and carers (NHS, 2018), which may mean that participants attended the group with pre-existing frustrations. Instead of adding to these, the process of striking the ball (particularly hitting it hard and far) may have offered a cathartic means of *release*, alleviating pre-existing frustrations. This might suggest the potential for golf to assist in the mitigation of unfavourable affective states, as well as promoting those that are more favourable.

Additionally, there was a sense of respite which was achieved by the carers as a result of their involvement with the golf programme. While respite alone may not be enough to reduce feelings of depression in carers (Lundervold & Lewin, 1987), it has been suggested that respite may have a positive effect on caregiver burden and mental health (Mason et al., 2007). Respite may have been achieved due to the responsibility of care being passed to staff facilitators, but it is also plausible that sharing an experience with the PWD that is not related to "arranging his life" may have offered further respite for both parties from their usual relational dynamics, as was noted in art gallery programmes for PWD and carers (Camic, Tischler & Pearman, 2014).

While studies have found contradictory evidence regarding the effects of sport and physical activity on psychological wellbeing for PWD this continues to be an area of study that is largely under-developed, with the majority of studies placing secondary importance on

the effects of such activity on this construct. The present study provides support for the usefulness of a six-week golf programme in facilitating positive affective experiences, enhancing the psychological wellbeing of all participants involved as defined by Bratt et al. (2016). This is in line with studies by Stella et al. (2011) and Maci et al. (2012) regarding the effects of physical activity.

Social Wellbeing

Regarding social wellbeing, camaraderie between group members was an identified theme in this study, aligning with previous research which suggests the role of physical activity (Wu et al., 2014) and football (Carone et al., 2016) in facilitating experiences of acceptance and support. The data also suggest the role of the programme in improving relationships between PWD and carers through shared experience. Also expressed was the prospect of feeling able to play golf with family/friends outside of the programme, which might facilitate the improvement of the relationships of the PWD more broadly.

Golf has been described as a game which promotes positive social interactions through its core values (Play Golf America, 2014). Indeed, the time in between shots coupled with the opportunity for refreshment breaks facilitates a space in which social interactions can occur. This was also the case in the present study with participants suggesting the sense of camaraderie amongst peers which they experienced during the golf programme. In particular, being accompanied by a group of fellow golfers with whom one feels comfortable and understood provided a sense of relief and an opportunity to relinquish the need to explain or justify the behaviours of the PWD. Furthermore, being in such company provided the opportunity for sharing experiences and coping strategies between group members, developing a "bond" and a supportive community of peers.

The study also suggests the potential of the golf programme to help improve the PWD-carer relationship. While not unique to golf, participants commented on being able to spend time together that did not carry the connotations of "arranging" the life of the PWD. As such, playing golf provided a space where the label of dementia could recede from the conscious awareness of PWD, carers and staff alike, facilitating relationships in which all parties felt more equal. This may have been particularly poignant for PWD and carers for whom this may have offered an opportunity for positive reminiscence, the beneficial effects of which have been documented (Cotellie, Manenti and Zanetti, 2012).

Sabat (2006) describes the most fragile view of oneself as the person's publically presented persona which is reliant on the cooperation of others in a social context (Hampson & Morris, 2016). While PWD expressed being "impressed" with their achievements, Sabat's theory suggests the importance of carers and staff being concordant in this experience (as suggested by the analysis), moving away from a view of the PWD as incapable and thus cooperating in constructing a valued social identity (Sabat, Napolitano & Fath, 2004). The process loop mechanism, which suggests a shift towards a new social paradigm in which PWD are perceived to be more capable than originally expected, might encourage greater parity in social roles, supported by the theme which suggests a sense of feeling equal. As such, the golf programme might have a helpful effect on the most fragile aspect of self for PWD, moving away from a publically presented persona of needing to be cared for to one in which relationships between equals (rather than carer and cared for) could be experienced. This may have facilitated the theme which suggests that PWD and their carers were able to share in the experience of playing golf, without the overt sense of the PWD needing to be cared for.

Furthermore, Kitwood's (1997) theory of personhood asserts that the wellbeing of PWD is underpinned by the person's social interactions and not neurological changes,

suggesting the importance of the themes relating to feeling equal, developing friendships and improving relationships. Additionally, the new paradigm of personal efficacy and capability for PWD, coupled with the experience of temporarily losing the dementia label, might have a beneficial effect on the person's perceived self-worth which is an important aspect of personhood (Kitwood, 1997).

Morhardt and Spira (2013) describe the centrality of relationships in living well with dementia. Indeed, relational theories of dementia assert the importance of aligning care with the practices of mutuality and the sharing of power (Dupuis et al., 2015). In the present study the sense of *feeling equal* suggests the experience of achieving mutuality in relationships during the golf programme and the rebalancing of the hierarchical distribution of power inherent in caring for PWD (Behuniak, 2010). As such, it is feasible that the PWD will feel more valued and accepted, facilitating greater social wellbeing (Keyes, 1998).

Limitations

As noted by Braun and Clarke (2006) thematic analysis is not a passive process; themes do not reside in the data waiting to be found but are actively constructed by the researcher. As such, the themes documented in this study are based on the interests and perspectives of the author, such that another person analysing the data might arrive at a different set of themes. However, the assessment of inter-rater reliability suggests a strong level of coding validity. Maintaining a reflective journal has also encouraged an awareness of the impact of personal experiences and interests on the process of analysis. As a result, although no negative instances of themes were identified, the author was able to remain sensitive to the presence of unfavourable study outcomes, thus minimising the likelihood of the outcomes being affected by biases to which we are unaware.

Moreover, the video segments which were shown to and discussed with staff were selected by the primary researcher. Although these choices were discussed with supervisors, the video segments were only able to offer a brief representation of each recorded group. However, during discussion with the staff it appeared as though these segments acted as an *aide memoire*, triggering observations and reflections from sessions outside that of the viewed segments, resulting in a broader discussion. This was an unorthodox approach to the analysis of video data in response to the criticisms of Garcez, Duarte & Eisenberg (2011) who warn of the potential for key information to be lost when video data are converted to audio data through the traditional method of describing what is seen and heard. While the resulting focus group discussion helped maintain the richness of the video data, it should be noted that the golf centre staff had been invested in the facilitation and orchestration of the programme, which may have introduced the potential for bias in their observations. However, with the exception of the subtheme relating to *enabling independence*, concordant supporting quotes for themes were also obtained from non-staff participants which adds to the validity of the data obtained from staff through triangulation.

Finally, the use of a volunteer sample in this study might subject the outcomes to voluntary response bias; this study's participants are likely to include only people with a motive for attending the golf group, such as being interested in golf or being hopeful for the prospect of obtaining positive benefits. However, NICE guidelines (2018) assert the importance of PWD being able to choose which activities they engage with, akin to the sampling method used in the present study. As such, this method may be particularly apt given its alignment with current approaches to dementia care.

Practice Implications

The present study provides encouragement that participating in a community-based golf group has benefits for PWD and carers. This may have positive implications for social prescribing, which has been defined as a means of allowing professionals to refer people to a range of non-clinical services within a person's community (The King's Fund, 2017). Furthermore, the present study recruited participants with four dementia diagnoses, suggesting that golf activity might be appropriate across different types of dementias.

Moreover, the recruitment of different participants within the realm of dementia care (PWD, carers and staff) allowed the differential effects of the golf programme on each type of participant to be investigated. Living well with dementia is a systemic enterprise (Nesta, 2019), affecting the wellbeing and experiences of the PWD as well as those around them. Discussing their perception of dementia awareness across golf clubs more broadly, one member of staff remarked on their experience of golf clubs as being "horrendous in what they actually offer people" owing to a lack of a "concept of illness". In order for social prescribing to prevail, the gatekeepers of such community-based activities need an incentive to provide a service for PWD and their carers. The present study has highlighted mutual benefits of a golf programme, which may in turn provide further support for social prescribing (Thomson, Chatterjee & Camic, 2015), a process recently made part of NHS strategy (NHS England, 2019). In addition to prescribing such activities, clinical psychologists within the community might work with golf clubs or with wider organisations such as the Golf Club Managers' Association to advance the availability of dementia friendly golf programmes.

Future Research

To date, only one other study has explored the effect of a specific sporting intervention (football) on PWD and their carers (Carone et al., 2016). It is interesting to

consider why this might remain a largely unexplored area given the attention received by other forms of physical exercise with this population. The perceived reduction in one's ability as a result of dementia (as suggested by the process loop) may preclude participation in sport, as people no longer feel able to (or are deemed unable to) engage with the complexities of the skills and regulations requisite in sporting activities. It is also unclear how welcoming different sporting groups are to PWD. Future qualitative enquiry might seek to investigate this further by exploring the views of PWD, carers and staff regarding sporting activity for this population.

This study provides an initial exploration of the psychological and social effects of a golf programme for PWD, the outcomes of which warrant further investigation. The majority of participants expressed a desire to continue with the golf play beyond six-weeks though it was beyond the scope of this study to investigate the impact of longer-term involvement with the golf programme. Future research may seek to explore the effects of long-term involvement with this golf programme by extending its duration, which would allow for an investigation of the longitudinal effects of engagement with the programme. Additionally, future research might employ a quasi-experimental design to delineate the effects of the golf play from the social stimulation offered by the refreshment break on measures specific to aspects of psychological and social wellbeing.

Conclusion

The present study offers preliminary evidence for the benefits of a six-week golf programme on the psychological and social wellbeing of people with dementias, carers and golf centre staff. Five key themes were identified: affectivity, respite, temporarily losing the dementia label, friendship/camaraderie and improving relationships. The data suggest the experience of positive affective states as a result of attending the programme including enjoyment and

excitement, while the experience of not being defined by dementia may underpin increases in the self-esteem of PWD. The identified themes also suggest the role of golf programmes in fostering the development of relationships with peers with whom one feels understood and able to share experience. Furthermore, through the opportunity of a shared experience in which all parties feel equal, existing relationships between PWD, their carers and wider family/friends may be improved. Potential mechanisms for these effects, as well as limitations and implications of this study are also discussed.

References

- 360-Fly. (2017). *The cameras that miss nothing and change everything*. Retrieved from <https://www.360fly.com/shop/cameras>
- Alzheimer's Society. (2016). *Risk factors for dementia*. Retrieved from https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf
- Alzheimer's Society. (2019). *The psychological and emotional impact of dementia*. Retrieved from <https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia-psychological-emotional-impact>
- Behuniak, S. M., (2010). Toward a political model of dementia: Power as compassionate care. *Journal of Aging Studies, 24*, 231-240. doi: <https://doi.org/10.1016/j.jaging.2010.05.003>
- Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing, 2*, 6-11. doi: 10.3928/19404921-20090101-04
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. California, CA: SAGE Publications
- Bratt, A. S., Stenström, U., & Rennemark, M. (2016). Effects on life satisfaction of older adults after child and spouse bereavement. *Aging and Mental Health, 21*, 602-608. Retrieved from <https://www.tandfonline.com/doi/full/10.1080/13607863.2015.1135874>

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. doi: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57-71). Washington, DC: American Psychological Association
- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*, 657-664. doi: 10.1034/j.1600-0579.2003.00210.x
- Camic, P. M., Hulbert, S., & Kimmel, J. (2017). Museum object handling: A health-promoting community-based activity for dementia care. *Journal of Health Psychology*. Advanced online publication. doi: 10.1177/1359105316685899
- Camic, P. M., Tischler, V. & Pearman, C. (2014). Viewing and making art together: An eight-week gallery-based intervention for people with dementia and their caregivers. *Aging & Mental Health, 18*, 161-168. Retrieved from <http://dx.doi.org/10.1080/13607863.2013.818101>
- Carless, D., & Douglas, K. (2004). A golf programme for people with severe and enduring mental health problems. *Journal of Public Mental Health, 3*, 26-39. doi: 10.1108/17465729200400026
- Carone, L., Tischler, V., & Dening, T. (2016). Football and dementia: a qualitative investigation of a community based sports group for men with early onset dementia. *Dementia, 15*, 1358-1376. doi: 10.1177/1471301214560239

- Cheng, S-T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, 19(64). Retrieved from <https://link.springer.com/content/pdf/10.1007%2Fs11920-017-0818-2.pdf>
- Clarke, V., & Braun, V. (2018). Using thematic analysis in counselling and psychotherapy research: A critical reflection. *Counselling and Psychotherapy Research*, 18, 107-110. doi: 10.1002/capr.12165
- Cotelli, M., Manenti, R., & Zanetti, O. (2012). Reminiscence therapy in dementia: A review. *Maturitas*, 72, 203-205. doi: 10.1016/j.maturitas.2012.04.008
- Department of Health. (2016). *Prime minister's challenge on dementia 2020. Implementation plan*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*, 4, 59-64. doi: 10.1177/174701610800400205
- Dupuis, S. L., McAiney, C., Brown, S., Carson, J., de Witt, L., Fortune, D., ... Wiedenfeld, K. (2015). *Aligning dementia care practices with relational theory: Examples from the partnerships in dementia care (PIDC) alliance*. Retrieved from https://uwaterloo.ca/partnerships-in-dementia-care/sites/ca.partnerships-in-dementia-care/files/uploads/files/adi_2015_poster_fact_sheet.pdf
- Ferrer, B-C. S., & Valle, A. D. (2014). A rehabilitation program for Alzheimer's disease. *Journal of Nursing Research*, 22, 192-199. doi: 10.1097/jnr.0000000000000046

- Folstein, M. F., Folstein, S. E., White, T., & Messer, M. A. (2010). *Mini-mental state examination, 2nd edition*TM. Retrieved from <https://www.parinc.com/Products/Pkey/238>
- Garcez, A., Duarte, R., & Eisenberg, Z. (2011). Production and analysis of video recordings in qualitative research. *Educacao e Pesquisa*, 37, 249-261. Retrieved from http://www.scielo.br/pdf/ep/v37n2/en_v37n2a03.pdf
- Guest, G., Namey, E. E., & Mitchell, M. L. (2013). *Collecting qualitative data: A field manual for applied research*. California, CA: SAGE Publications
- Guure, C. B., Ibrahim, N. A., Adam, M. B., & Said, S. M. (2017). Impact of physical activity on cognitive decline, dementia, and its subtypes: Meta-analysis of prospective studies. *BioMed Research International*, 2017. Retrieved from <https://doi.org/10.1155/2017/9016924>
- Hampson, C., & Morris, K. (2016). Dementia: Sustaining self in the face of cognitive decline. *Geriatrics*, 2016(1). Retrieved from <https://www.mdpi.com/2308-3417/1/4/25>
- Hewitt, J. P. (2009). The social construction of self-esteem. In S. J. Lopez & C. R. Snyder (Eds.), *The oxford handbook of positive psychology* (2nd ed., pp. 217-224). Oxford, UK: Oxford University Press
- Hossain, A. F. M. (2014). A critical analysis of empiricism. *Open Journal of Philosophy*, 4, 225-230. doi: 10.4236/ojpp.2014.43030
- Hruschka, D. J., Schwartz, D., St. John, D. C., Picone-Decaro, E., Jenkins, R. A., & Carey, J. W. (2004). Reliability in coding open-ended data: Lessons learned from HIV behavioural research. *Field Methods*, 16, 307-331. doi: 10.1177/1525822X04266540

- Keyes, C. L. M. (1998). Social well-being. *Social Psychology Quarterly*, *61*, 121-140. doi: 10.2307/2787065
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press
- Lamb, S. E., Sheehan, B., Atherton, N., Nichols, V., Collins, H., Mistry, D., ... Lall, R. (2018). Dementia and physical activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: Randomised controlled trial. *BMJ*, *2018*(361). Retrieved from <https://www.bmj.com/content/361/bmj.k1675>
- Larson, E. B., Yaffe, K., & Langa, K. M. (2013). New insights into the dementia epidemic. *The New England Journal of Medicine*, *369*, 2275-2277. doi: 10.1056/NEJMp1311405
- Lundervold, D., & Lewin, L. M. (1987). Effects of in-home respite care on caregivers of family members with Alzheimer's disease. *Journal of Clinical & Experimental Gerontology*, *9*, 201-214. Retrieved from <https://psycnet.apa.org/record/1988-11728-001>
- Maci, T., Le Pira, F., Quattrocchi, G., Di Nuovo, S., Perciavalle, V., & Zappia, M. (2012). Physical and cognitive stimulation in Alzheimer's disease. The GAIA project: A pilot study. *American Journal of Alzheimer's Disease & Other Dementias*, *27*, 107-113. doi: 10.1177/1533317512440493
- Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., ... Glendinning, C. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older

- people and their carers. *Health Technology Assessment*, 11(15). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK62246/>
- McLaughlin, T., Feldman, H., Fillit, H., Sano, M., Schmitt, F., Aisen, P., ...Stern, Y. (2010). Dependence as a unifying construct in defining Alzheimer's disease severity. *Alzheimers Dementia*, 2010(6). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3884683/>
- Morhardt, D. J., & Spira, M. (2013). From person-centered care to relational centered care. *Generations*, 37, 37-44. Retrieved from https://www.researchgate.net/publication/287720075_From_Person-Centered_Care_to_Relational-Centered_Care
- Murray, A. D., Daines, L., Archibald, D., Hawkes, R. A., Schiphorst, C., Kelly, P., ... Mutrie, N. (2017). The relationship between golf and health: A scoping review. *British Journal of Sports Medicine*, 51, 12-19. doi: 10.1136/bjsports-2016-096625
- National Health Service. (2017). *Dementia guide: About dementia*. Retrieved from <https://www.nhs.uk/conditions/dementia/about/>
- National Health Service. (2018). *Dementia guide: Coping with dementia behaviour changes*. Retrieved from <https://www.nhs.uk/conditions/dementia/behaviour/>
- National Institute for Health and Care Excellence. (2018). *Dementia: assessment, management and support for people living with dementia and their carers*. Retrieved from <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#interventions-to-promote-cognition-independence-and-wellbeing>

- Nesta. (2019). *Living well with dementia: Power, autonomy and independence*. Retrieved from <https://www.nesta.org.uk/blog/living-well-dementia-power-autonomy-and-independence/>
- NHS England. (2019). *Social prescribing and community-based support: Summary guide*. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2019/01/social-prescribing-community-based-support-summary-guide.pdf>
- Orgeta, V., Qazi, A., Spector, A., & Orrell, M. (2015). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment: Systematic review and meta-analysis. *The British Journal of Psychiatry*, 207, 293-298. doi: 10.1192/bjp.bp.114.148130
- Orth, U. (2017). The lifespan development of self-esteem. In J. Specht (Eds.), *Personality development across the lifespan* (pp. 181-195). London: Academic Press
- Padala, K. P., Padala, P. R., Lensing, S. Y., Dennis, R. A., Bopp, M. M., Robertson, P. K., & Sullivan, D. H. (2017). Home-based exercise program improves balance and fear of falling in community-dwelling older adults with mild Alzheimer's disease: A pilot study. *Journal of Alzheimer's Disease*, 59, 565-574. doi: 10.3233/JAD-170120
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). California, CA: SAGE Publications
- Play Golf America. (2014). *Golf is the new social network*. Retrieved from <https://www.pga.com/play-golf-america/youth-golf/golf-social-network>
- Public Health England. (2016). *Data analysis report: Dying with dementia*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733065/Dying_with_dementia_data_analysis_report.pdf

- Public Health England. (2018). *Dementia: Applying all our health*. Retrieved from <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>
- Rolland, Y., Pillard, F., Klapouszczak, A., Reynish, E., Thomas, D., Andrieu, S., ... Vellas, B. (2007). Exercise program for nursing home residents with Alzheimer's disease: A 1-year randomized, controlled trial. *Journal of the American Geriatrics Society*, 55, 158-165. doi: 10.1111/j.1532-5414.2007.01035.x
- Sabat, S. R. (2006). Mind, meaning and personhood in dementia: The effects of positioning. In J. C. Hughes, S. J. Louw, and S. R. Sabat (Eds.) *Dementia: Mind, meaning and person* (pp. 287-302). Oxford: Oxford University Press
- Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 19, 177-185. Retrieved from <https://journals.sagepub.com/doi/pdf/10.1177/153331750401900311>
- Stella, F., Canonici, A. P., Gobbi, S., Santos-Galduroz, R. F., Cação, J. deC., & Gobbi, L. T. B. (2011). Attenuation of neuropsychiatric symptoms and caregiver burden in Alzheimer's disease by motor intervention: A controlled trial. *Clinics (Sao Paulo)*, 66, 1353-1360. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/21915483>
- Stenner, B. J., Mosewich, A. D., & Buckley, J. D. (2016). An exploratory investigation into the reasons why older people play golf. *Qualitative Research in Sport, Exercise and Health*, 8, 257-272. doi: 10.1080/2159676X.2016.1148773
- Taylor, M. E., Lord, S. R., Brodaty, H., Kurrle, S. E., Hamilton, S., Ramsay, E., ... Close, J. C. T. (2017). A home-based, carer-enhanced exercise program improves balance and

falls efficacy in community-dwelling older people with dementia. *International Psychogeriatrics*, 29, 81-91. doi: 10.1017/S1041610216001629

The King's Fund. (2017). *What is social prescribing?* Retrieved from <https://www.kingsfund.org.uk/publications/social-prescribing>

Thomson, L.J., Camic, P.M., & Chatterjee, H.J. (2015). *Social prescribing: A review of UK and non-UK community referral schemes*. London: University College London

Walker Research Group. (2011). *The health & wellness benefits of golf participation and involvement*. Retrieved from <http://walkerresearchgroup.net/wp-content/uploads/2013/03/Phase-II-Report-Practical-Recommendations.pdf>

Wu, E., Barnes, D. E., Ackerman, S. L., Lee, J., Chesney, M., & Mehling, W. E. (2015). Preventing loss of independence through exercise (PLIE): Qualitative analysis of a clinical trial in older adults with dementia. *Aging and Mental Health*, 19, 353-62. doi: 10.1080/13607863.2014.935290

Section C: Appendices of Supporting Material

Appendix 1: Brief Mini Mental State Exam questionnaire

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Appendix 2: Ethical approval from Salomons ethics panel

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Appendix 3: Information sheet for people with dementia

Information for participants

Information about the research

Study title

Understanding the psychological and social impact of playing golf for people living with dementia, their caregivers and staff.

- Hello. My name is Nathan Hill and I am a trainee clinical psychologist at Canterbury Christ Church University.
- I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

- This study aims to better understand the role that golf can play in enhancing peoples' wellbeing.

Why have I been invited?

- Because you have shown an interest in playing golf at the Cobtree Manor Park Golf Club.

Do I have to take part?

- Taking part in this study is entirely voluntary.
- You are free to withdraw at any time, without giving a reason.
- Choosing not to take part will not affect your involvement with the staff and services at Cobtree Manor Park Golf Course.

What will happen to me if I take part?

- If you agree to take part, you will attend the six-week golf programme at Cobtree Manor Park Golf Club, as usual.

A short interview:

- You will be invited to meet with me for a short interview (around 20 minutes) before you start the programme.
- You can choose where we meet for this (for example, at your home or at the golf course)
- We will complete a questionnaire regarding your experience of having memory problems.
- I will also ask what, if anything, has drawn you to the game of golf.
- This meeting will be audio recorded so that I can listen back to it later in the study.

During your golf sessions

- I will accompany your group for two of the six sessions, which I will video record.
- I will not be interfering with the session in any way, but instead I would like to play some golf with you.
- We might talk informally about your experience of the golf as we play, as long as I'm not getting in the way of anyone playing golf.
- I may take some notes away with me to remind myself of the session later in the study.

At the end of the programme

- After your final session I would like to meet with the whole group for a discussion over tea, which will last between 30 and 60 minutes.
- This will be an opportunity for us to discuss your thoughts and experiences about playing golf.

- I will audio record this conversation so I can listen back to the discussion later in the study.
- The data that you provide will be treated in strict confidence.

What will I be asked to do?

- At both the interview and the group meeting, there will be a few questions or discussion points which I would like us to address.
- I will only ever ask you to contribute information that you are happy to share; there will be no trick questions.
- During the golfing sessions, I will ask about how you are and how your golf is going, but only when you are not playing a shot.

What are the possible disadvantages and risks of taking part?

- While I believe it is unlikely, there is always the possibility that some of the topics that arise in discussion may be uncomfortable for you.
- You are not obliged to give more information than you are comfortable to share.

What are the possible benefits of taking part?

- The information from this study will help improve our understanding of how golf might impact on the wellbeing of people living with memory problems.
- This may help health care professionals recommend appropriate activities to facilitate their wellbeing.
- It may also provide some suggestions or motivation for other programmes which might be beneficial.

Will information from or about me from taking part in the study be kept confidential?

- Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

- You have the right to withdraw from this study at any time, without giving a reason.
- You also have the right to request that any information you have provided us is removed from the study and destroyed; any video recordings which you feature in will be altered to hide your identity, such as by blurring facial features.
- Withdrawing from the study will not affect your involvement with the golf programme or with the staff and services at Cobtree Manor Park Golf Course.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns.

- Please leave a message for me on the 24-hour voicemail phone line at 01227 927 070.
- Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.

If you are still dissatisfied, or wish to complain formally to the university, you can do this by contacting Professor Margie Callanan, Ethics Panel chair, Salomons Centre for Applied Psychology, Canterbury Christchurch University

- margie.callanan@canterbury.ac.uk
- Tel: 03330 117 094.

Will information from or about me from taking part in the study be kept confidential?

- All information which is collected from or about you during the course of the research will be kept strictly confidential.
- All recordings will be uploaded onto a secure, password-protected laptop, and all of the files will be password protected as well.

- The recording will only be listened to by the lead researcher (Nathan Hill) and his two supervisors, Professor Paul Camic (research director at Salomons Centre for Applied Psychology) and Dr Sonia Fihosy (clinical psychologist at Mytime Active), for the purpose of data analysis.
- The video data will be viewed by staff members at Cobtree Manor Park Golf Course who you have already met during your golf programme. The staff will view the video because it would be valuable to know their thoughts and observations, having worked closely alongside you for the duration of the programme.
- All recordings will be transcribed. Your name and any identifiable information will not be transcribed, to preserve your anonymity; for example, a pseudonym (fake name) will be used instead of your real name.
- At the end of the study, all transcripts will be stored in a secure location at the university for 5 years, after which they will be destroyed.
- In the unlikely event that either you or someone else may be at risk of harm, it may be necessary for this confidentiality to be broken. However, this would be discussed with you first.

What will happen to the results of the research study?

- The results of this study will become part of my doctoral dissertation.
- They will also be submitted to an academic journal.
- A report of our findings will also be presented to the Cobtree Manor Park Golf Course, who will be able to pass this information on to you, at your request.
- I would also be happy to discuss the results of the study with you personally, should you wish.

- When the final report is written, it will be necessary to provide quotes from the data to support our findings. Only anonymised quotes will be used for this purpose. You have the right to check the accuracy of the data before the results are published.

Who has reviewed the study?

- This study has been reviewed and given favourable opinion by the Salomons Ethics Panel (Salomons Centre for Applied Psychology, Canterbury Christ Church University).

What if I want to know more?

If you would like to discuss the study further, or you have any questions about the study, please don't hesitate to contact me on the 24-hour voicemail phone line at 03330 117 070.

- **Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.**

Please do talk to others about the study if you wish.

Information for caregivers/friends/family members

Information about the research

Study title

Understanding the psychological and social impact of playing golf for people living with dementia, their caregivers and staff.

Hello. My name is Nathan Hill and I am a trainee clinical psychologist at Canterbury Christ Church University in Tunbridge Wells. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

1. What is the purpose of the study?

More research is needed to help understand the role that recreational and social activities can play in helping people to stay healthy and active.

Golf is a sport played by many people, but little is known about the psychological and social benefits this may have. This study aims to better understand the role that golf can play in enhancing the wellbeing of people.

2. Why have I been invited?

As a caregiver, friend or family member of someone living with memory problems who has agreed to take part in the golf programme, we would like to know about your thoughts and experience of their participation in the programme.

3. Do I have to take part?

Taking part in this study is entirely voluntary. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

4. What will I be asked to do?

If you agree to take part, you will be free to participate in the golf sessions as well, if you wish - this is optional. I will also be accompanying the group for one session, which I will video record.

At the end of the golf programme, I would like to meet with you for a brief interview, which I anticipate will last around 30 minutes. This meeting will be audio recorded so that I can listen back to it later.

The audio and video data that you provide will be treated in strict confidence.

5. What are the possible disadvantages and risks of taking part?

While I think it is unlikely, there is always the possibility that some of the topics that arise in discussion may be uncomfortable for you. However, you are not obliged to give more information than you are comfortable to share.

6. What are the possible benefits of taking part?

The information from this study will help improve our understanding as to what aspects of playing golf are most beneficial for people living with memory problems and those who might support them. This may lead to implications for 'social prescribing' (the recommendation, by a health care professional, for an individual to participate in a particular community based activity) and may offer some suggestions or motivation for other community programmes.

7. Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in section 10.

8. What will happen if I don't want to carry on with the study?

You have the right to withdraw from this study at any time, without giving a reason. If you withdraw from the study, we would like to use the information collected up to your withdrawal. However, you also have the right to request that this information be removed

from the study and destroyed; any video recordings which you feature in will be altered to hide your identity, such as by blurring facial features.

Choosing to withdraw from the study will not affect your involvement with the golf programme, or your relationship with the staff and services at Cobtree Manor Park Golf Course.

9. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. In this case, please leave a message for me on the 24-hour voicemail phone line at 03330 117 070. Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.

If you are still dissatisfied, or wish to complain formally to the university, you can do this by contacting Professor Margie Callanan – Ethics Panel chair, Salomons Centre for Applied Psychology, Canterbury Christchurch University – margie.callanan@canterbury.ac.uk, tel: 03330 117 094.

10. Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential.

All audio recordings will be collected using a Dictaphone, and the audio files uploaded onto a secure, password-protected laptop. All audio files will be password-protected as well. The recordings will only be listened to by the lead researcher (Nathan Hill) and his two supervisors, Professor Paul Camic (research director at Salomons Centre for Applied Psychology) and Dr Sonia Fihosy (clinical psychologist at Mytime Active), for the purpose of data analysis.

Video will be recorded using a special camera which only allows access via a password-encrypted computer. This video data will be viewed initially by the lead researcher and his supervisors, and later, by staff at Cobtree Manor Park Golf Course who have been involved

in the running of the golf programme; only people involved in the golf programme and this research will see the footage.

Video and audio recordings will be transcribed. Your name and any identifiable information will not be transcribed, to preserve your anonymity; for example, a pseudonym (fake name) will be used instead of your real name.

At the end of the study, all audio and video transcripts will be stored in a secure location at the university for 5 years, after which they will be destroyed.

In the unlikely event that either you or someone else may be at risk of harm, it may be necessary for this confidentiality to be broken. However, this would be discussed with you first.

11. What will happen to the results of the research study?

The results of this study will become part of my doctoral dissertation. They will also be submitted to an academic journal. A report of our findings will also be presented to the Cobtree Manor Park Golf Course. I would also be happy to discuss the results of the study with you personally, should you wish.

When the final report is written, it will be necessary to provide quotes from the data to support our findings. Only anonymised quotes will be used for this purpose. You have the right to check the accuracy of the data before the results are published.

12. Who is organising and funding the research?

This research is funded and organised as part of the Doctorate in Clinical Psychology at the Salomons Centre for Applied Psychology, Canterbury Christ Church University, Tunbridge Wells campus.

13. Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Salomons Ethics Panel at the Salomons Centre for Applied Psychology, Canterbury Christ Church University.

14. What if I want to know more?

If you would like to discuss the study further, or you have any questions about the study, please don't hesitate to contact me on the 24-hour voicemail phone line at 03330 117 070. Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.

Please do talk to others about the study if you wish.

Appendix 5: 360-Fly camera

*This has been removed from the electronic copy. The image can be obtained from
<https://www.360fly.com/shop/cameras.html>*

Appendix 6: Focus group schedule (people with dementia)

Participant focus group (after their sixth and final session) - semi-structured

- "What was it like to play golf?"
- "How does playing golf make you feel?"
 - "What was it about the golf that made you feel that way?"
- "How are you treated by other golfers at the golf club?"
 - "How is this different or the same with other situations and activities?"
 - "What is it like for you to be around other golfers?"
- "What was it like to play with the same people each week?"
- "How is golf different to, or the same as, other situations and activities?"
- "What, if anything, has the golf programme allowed you to achieve?"
- "What is it like to be out on the course?"
- "What challenges, if any, did you face while playing golf?"
- "How do you feel about continuing to play golf?"
 - "What support, if any, do you think you would need to facilitate this?"

Appendix 7: Carer interview schedule

Interview with carer/friend/family member

- “What is your opinion of golf for people with memory difficulties?”
- “What made you decide to (not) take part in the golf sessions?”
- “What was it like for you for your friend/family member to take part in the group?”
- “How did you feel when you heard about the golf group?”
- “Now that the group has been completed, how did the actual experience compare?”
 - “Is this any different to - or the same as - other activities?”
 - "What impact, if any, did the golf group have on you?"
 - “What was it like to meet with/be around other people who support someone with memory difficulties?”
 - "What would you like to see happen going forward?"
 - “What, if any, were the challenges that you faced?”
 - “How did you overcome these challenges?”

Information for centre staff

Information about the research

Study title

Understanding the psychological and social impact of playing golf for people living with dementia, their caregivers and staff.

Hello. My name is Nathan Hill and I am a trainee clinical psychologist at Canterbury Christ Church University in Tunbridge Wells. I would like to invite you to take part in a research study that could be important in providing support to people living with dementia. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

1. What is the purpose of the study?

More research is needed to help understand the role that recreational and social activities can play in helping people to stay healthy and active.

Golf is a sport played by many people, but little is known about the psychological and social benefits this may have. This study aims to better understand the role that golf can play in enhancing the wellbeing of people.

2. Why have I been invited?

As a member of staff who will be working with the participants in the golf programme, your first hand experience will add to the strength and depth of the study.

3. Do I have to take part?

Taking part in this study is entirely voluntary. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

4. What will I be asked to do?

If you agree to take part, you will play your part in running the golf programme. At the end of each session, you will need to briefly jot down some 'field notes' (anything that you

remember from the session), such as how the participants interacted with each other or something salient they might have said.

I will also be accompanying the group for two sessions, which I will video record. At the end of the study, I would like to meet with you and your colleagues to watch and discuss some of the footage. I anticipate this meeting will last between 60 and 90 minutes. This meeting will be audio recorded so that I can listen back to it later.

The audio and video data that you provide will be treated in strict confidence.

5. What are the possible disadvantages and risks of taking part?

Writing down field notes and participating in the group meeting will take up some of your contracted time at work. This may need to be discussed with your manager.

6. What are the possible benefits of taking part?

The information from this study will help improve our understanding as to what aspects of playing golf are most beneficial for people living with memory problems. This may lead to implications for 'social prescribing' (the recommendation, by a GP, for an individual to participate in a particular community based activity) and may offer some suggestions or motivation for other community programmes.

7. Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in section 10.

8. What will happen if I don't want to carry on with the study?

You have the right to withdraw from this study at any time, without giving a reason. If you withdraw from the study, we would like to use the information collected up to your withdrawal. However, you also have the right to request that this information be removed from the study and destroyed; any video recordings which you feature in will be altered to hide your identity, such as by blurring facial features.

Choosing to withdraw from the study will not affect your involvement with the golf programme, or your relationship with the staff and services at Cobtree Manor Park Golf Course.

9. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. In this case, please leave a message for me on the 24-hour voicemail phone line at 03330 117 070. Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.

If you are still dissatisfied, or wish to complain formally to the university, you can do this by contacting Professor Margie Callanan – Ethics Panel chair, Salomons Centre for Applied Psychology, Canterbury Christchurch University – margie.callanan@canterbury.ac.uk, tel: 03330 117 094.

10. Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential.

All audio recordings will be collected using a Dictaphone, and the audio files uploaded onto a secure, password-protected laptop. All audio files will be password-protected as well. The recordings will only be listened to by the lead researcher (Nathan Hill) and his two supervisors, Professor Paul Camic (research director at Salomons Centre for Applied Psychology) and Dr Sonia Fihosy (clinical psychologist at Mytime Active), for the purpose of data analysis.

Video will be recorded using a special camera which only allows access via a password-encrypted computer. This video data will be viewed initially by the lead researcher and his supervisors, and later, by yourself and your colleagues at Cobtree Manor Park Golf Course who have been involved in the running of the golf programme; only people involved in the golf programme and this research will see the footage. We are asking you to review the footage with us as your first-hand experience of working alongside the participants will be bring extra depth and strength to the study.

Video and audio recordings will be transcribed. Your name and any identifiable information will not be transcribed, to preserve your anonymity; for example, a pseudonym (fake name) will be used instead of your real name.

At the end of the study, all audio and video transcripts will be stored in a secure location at the university for 5 years, after which they will be destroyed.

In the unlikely event that either you or someone else may be at risk of harm, it may be necessary for this confidentiality to be broken. However, this would be discussed with you first.

11. What will happen to the results of the research study?

The results of this study will become part of my doctoral dissertation. They will also be submitted to an academic journal. A report of our findings will also be presented to the Cobtree Manor Park Golf Course. I would also be happy to discuss the results of the study with you personally, should you wish.

When the final report is written, it will be necessary to provide quotes from the data to support our findings. Only anonymised quotes will be used for this purpose. You have the right to check the accuracy of the data before the results are published.

12. Who is organising and funding the research?

This research is funded and organised as part of the Doctorate in Clinical Psychology at the Salomons Centre for Applied Psychology, Canterbury Christ Church University, Tunbridge Wells campus.

13. Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Salomons Ethics Panel at the Salomons Centre for Applied Psychology, Canterbury Christ Church University.

14. What if I want to know more?

If you would like to discuss the study further, or you have any questions about the study, please don't hesitate to contact me on the 24-hour voicemail phone line at 03330 117 070. Please say that the message is for me [Nathan Hill] and leave a contact number so that I can get back to you.

Please do talk to others about the study if you wish.

Appendix 9: Focus group schedule (staff)

Staff focus group -- following initial analysis of the footage by the researchers - semi-structured

Part 1) Reviewing video segments

Having just watched a clip: "Regarding the participants..."

- "...What observations did you have?"
- "...Was there anything that really struck you?"
- "...What did you notice about the way they interacted with others?"
- "...When we (the researchers) first looked at the video, we noticed bit of a theme here. Did you notice anything in particular in this video?"

Part 2) Their experience of working with the group

- "What was it like to facilitate the group?"
- "How did you feel helping the group play golf?"
- "What is your opinion of golf for people with memory difficulties?"
- "What, if any, were the challenges that you faced?"
- "How did you overcome these challenges?"
- "What would you like to see happen going forward?"

Appendix 10: Typed extracts from reflective journal

- Reviewing the video data for the first time, I'm wondering what it is that makes for a "beneficial" social interaction? I've noticed that I seem to place importance on social interactions which involve all parties actively participating in conversation. Is a social interaction any less important to an individual if they are not talking, but perhaps just listening?

- Update: Today I reviewed the video data with the staff, who expressed a different perspective on the intricacies of social interaction. Bearing in mind they have spent far longer with each participant than I have, as they have been present for every single golf session, not just one per group. The staff were unanimous in asserting the importance of listening and just being able to hear and "take in" information from other people. Interestingly Dave stated that, while Owen did not appear to speak in the clip (nor was he a particularly talkative individual), he would comment on things that had been talked about in earlier conversations that he was a part of, or on things that he had observed, such as Morris' ability to play despite pronounced Parkinson's tremors. Maybe the amount a person engages in conversation is not a useful measure of their level of social engagement; perhaps this is my own value and not one that should be universally applied?

- As I'm coding the data, I am struck by the lack of frustration that is being expressed. Speaking with PWD before starting the golf programme, I recall some expectations that may be unpleasant, such as fear of embarrassment and indeed frustration. Does this mean that the participants did not experience the frustration that some of them might have been anticipating?

Thinking about my own experience of playing golf, especially during the learning phase, I was incredibly frustrated at times; not only does your ability to hit the ball well seem to fluctuate without rhyme or reason, unlike with team sports, you only have yourself to blame for bad shots. How come the participants are not expressing frustration akin to my own experience of playing golf?

- Update: Re-visiting the focus group discussions in which participants discuss hitting the ball hard and far puts me in mind of the idea of catharsis. For me, playing golf is about

the precision of hitting good, accurate shots and the subsequent result of obtaining a good score on a hole. What if that isn't what playing golf is about for these participants? Perhaps reducing their handicap is not something they may ever hope to achieve (as one participant mentions in their focus group) and so hitting the ball hard and far becomes their goal - their source of enjoyment and achievement for that session. I've also been down to the driving range at times when I've been annoyed and frustrated, and it is quite cathartic when you hit the sweet spot and the ball goes flying! Could their golf play be cathartic to the extent that pre-existing frustrations can be expressed (on the ball) and relieved, rather than created through golf play?

- Update: I was playing golf today and I managed to hit a tree branch - the single, solitary tree branch that I probably couldn't hit again if I played the same shot 50 more times. My ball dropped straight down like a stone. This would normally be incredibly frustrating, especially as it would have been a great shot - such bad luck! But I looked to the heavens and laughed - quite funny when you think about it! Why was I not more frustrated as I thought I would have been? Given all the stress of writing the MRP, the end result of how many shots it would take me on that hole seemed trivial - it was a good shot which was met with some bad luck, but I was still out in the sunshine feeling free (for a change) from the pressures of my academic workload. Maybe this is similar to the experience of the PWD?

- Thinking about the themes that are beginning to develop in my mind, respite (particularly the subtheme of *freedom*) and losing the dementia label feel particularly poignant for me. Reflecting on why this might be the case, I find myself considering the impact of my own personal experience of dementia within my family. My Nan currently lives with moderate - severe Alzheimer's and my mother is her primary caregiver. While my Nan lives in a care home, my perception is that my Mum has experienced significant burden and guilt regarding my Nan's care, visiting her often on a daily basis. As such, my Mum's need for respite is palpable - I wonder to what extent this might underpin the poignancy (for me) of the theme around losing or detaching oneself from the dementia label. This also suggests the prospect of being able to get my Nan back - something I would do anything to achieve.

**All names have been changed to protect confidentiality*

Appendix 11: Consent form (people with dementia and carers)

(Version 1)

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Understanding the psychological and social impact of playing golf for people living with dementia, their caregivers and staff.

Name of Researcher: Nathan Hill

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that relevant sections of the data collected during the study may be looked at by the lead researcher (Nathan Hill) and his supervisors (Professor Paul Camic and Dr Sonia Fihosy), and that video clips may be seen by staff members at the golf club.

4. I understand that this study will involve the use of both audio and video-recording.

5. I agree that anonymous quotes from these recordings may be used in my doctoral dissertation and in published reports of the study findings.

6. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix 12: Consent form (staff)

(Version 2)

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Understanding the psychological and social impact of playing golf for people living with dementia, their caregivers and staff.

Name of Researcher: Nathan Hill

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that relevant sections of the data collected during the study may be looked at by the lead researcher (Nathan Hill) and his supervisors (Professor Paul Camic and Dr Sonia Fihosy), and that video clips may be seen by staff members (including myself) at the golf club.

4. I understand that this study will involve the use of both audio and video-recording.

5. I agree that anonymous quotes from these recordings may be used in my doctoral dissertation and in published reports of the study findings.

6. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix 13: List of codes from final codebook

Code	Description	Example
Excitement	Expressions of excitement	"She'd be so excited"
Chat	Being able to talk to others	"Yeah, you know, just sitting there chatting"
Laugh/joke	Being able to laugh/joke	"We all just sat there and laughed and joked around a cup of coffee"
Hitting ball hard	Liking hitting the ball hard	"I just feel more, when I hit it hard"
Good feelings	Positive affect (e.g. Enjoyment)	"It's something you could enjoy"
Relaxing	Expressions of feeling relaxed	"'Oh I can have a breather', I can relax a bit"
Strengthening	Feeling strengthened	"It gives you a bit of power, strength to carry on"
Confidence	Expressions of confidence	"Lifts their confidence"
Morale	Expressions of boosted morale	"Whether it's consciously a huge boost to your morale, subconsciously it must be doing something for you"
Purpose	Having a sense of purpose	"It's lovely to have purposeful, fixed activity"
Good for mental health	Comments regarding the effect on mental health	"I've got mental health and it was good for me as well"
Self-esteem	Expressions of boosted self-esteem	"Raises their self-esteem"
Reward	Gaining a sense of reward	"You get even more of a reward from it"
Learning new skill	Comments regarding learning something new	"Learning a new skill in the same way he's always learned new skills"
Inspiring	Feeling inspired/motivated	"I enjoyed seeing the evidence of that, that's quite inspiring isn't it, to yourself"
Environment	Comments regarding the environment	"Out there with nature and it's gonna be beautiful"
Something different	Comments regarding the difference between golf and other activities	"It was something different every week"
Forgetting illness	Forgetting about dementia	"Just being outdoors and you forget about everything"
Concentration	Something to concentrate on	"It gives them something to concentrate on"
Feel like old self	Returning to the person before the dementia	"It was clear that I had my mum back, watching her"

Improvement	Comments regarding the level of improvement	"And you showed incredible improvement"
Competition	Comments regarding competing	"It enables a safe outlet for competitiveness"
Everyone's equal	Comments regarding equality	"We're al equal, we're al rubbish"
Exceeding expectation	Learned more than expected	"... Expect of the effects of dementia, they have gone above and beyond that"
Dementia means I can't	Statements regarding dementia as a barrier to learning	"If you constantly sit there and drum into someone 'you're ill, you're ill, you're ill', it makes them think that they're not capable of doing anything"
Amazed/impressed	Feelings of surprise relating to learning	"I was quite impressed on watching the others as well"
Release	Purging of unfavourable emotions	"Talking to them and being able to vent to them and them vent to you"
Break	Statements regarding having a break from the norm (e.g. Stepping back from carer role)	"It was a bit of alone, like, a bit of a break for me"
Feel safe	Expressions of feeling safe	"I felt like that was her safe haven"
Understanding	Expressions of feeling understood	"I didn't feel like I needed to apologise for her because they understood"
Sharing experience	Comments regarding doing the activity together	"It's quite nice to spend that time together where I'm not having to... Arrange his life"
Good to talk	Positive statements regarding talking to others	"It was just nice to be able to sit there and have someone to talk to"
Friendship	Comments regarding the development friendships	"We all made a friendship together"
Sociable	Comments regarding the social nature of golf	"It's more of a social thing"
Can play with family/friends	Comments regarding playing with others outside the programme	"I've got family who play golf... I wouldn't mind actually going [with them]"
Talk to family about golf	Statements regarding conversations with family about golf	"I'm all excited and I get home, I phone my sons"

Focus	Having something on which to concentration/focus/strive	"It was focussing his mind obviously"
PWD can do this	Comments regarding PWD being able	"We are so very, very capable"
Freedom	Use of the word "freedom"	"I benefit from that so I do hve freedom"
Sharing problems	Comments regarding talking to others about difficulties	"It was nice for her to be able to... Air everything"
Support	Comments regarding giving/receiving support	"Try and help each other out with things"
Sharing knowledge	Comments regarding the exchange of knowledge	"Maybe try this, give you ideas and tasks to try and help you"
Reassurance	Experiences of feeling reassured	"It was nice to just have that and people say to you 'no, you are doing the right thing'"
Identifying with others	Expressions of feeling able to connect with others	"It was nice for her to be able to speak to someone that was in the same position as her"
Talking about golf	Comments regarding talking about golf to others	"We had something to talk about when we got back"
Playing outside of group	Comments regarding golf play outside of the group	"We meet up once a week with _____ and _____, and play"
Improving relationship	Expressions of positive impacts on relationships	"It's about the whole family, so it's about bringing everybody together"
Happy memories	Comments regarding building happy memories	"They had happy memories of being together"
Independence	Comments regarding enabling independence and autonomy	"But it gives them that bit of independence"
Giving the opportunity	Comments regarding giving PWD a new experience	"Just about giving them an opportunity to go out there and try something they've never done before"
Empowering	Comments regarding empowerment	"It gives you a bit of power, strength to carry on"
Hard for carers to step back	Expressions of carers helping too much or struggling to let go	"When it's a carer and they jump in... We have to make mistakes in order to learn"

Recooperate	Comments regarding reoperation/rejuvenation	"It just gives them that moment to just calm right down again"
Normality	Treated like and able to act "like normal"	"They talked about just normal things rather than sitting there talking about their illness"
What PWD wanted	Comments regarding PWD expressing/doing what they want to do	"A few of them were particularly wanting to jump in the buggy and have a go at least"
Illness not the focus	Comments regarding dementia not being at the forefront	"Their illness wasn't the centre of everything"
Feel comfortable	Expressions of feeling comfortable amongst others	"There I felt comfortable"
Could talk to anyone	Feeling able to talk	"That person is able to talk to any of us"
Miscellaneous	Comments not related to the research question	"He's got about 6 bikes down in our shed"

Appendix 14: Table of theme development

Start				End			
Good feelings	Enjoyment Fun Excitement	Affective change	Enjoyment Looking forward Self-esteem	Affective change	Enjoyment Looking forward Self-esteem	Affectivity	In situ Anticipatory Enduring
Freedom/break		Respite	Space to do own thing Able to vent	Respite	Morale Break from PWD Space to do own thing	Respite	Release Freedom
Forgetting about illness	Focus Normality		Having a purpose/focus		Forgetting about diagnosis		Forgetting illness
Building a support network	Building friendships	Forgetting about illness	Achievement Reconnecting with identity Normality	Losing dementia label	Feeling equal Reconnecting with identity Achievement (process loop)	Losing dementia label	Feeling equal Enabling independence Process loop
	Relating to others	Building support network/friendship	Sharing experience Reassurance		Sharing Reassurance Feeling understood	Friendship/camaraderie	Understanding Sharing
	Sharing coping skills Support Advice		Sharing coping skills		Space to vent	Improving relationships	Sharing experience Play with family/friends
				Improving PWD-carer relationship	Sharing an experience		

Appendix 15: Coded transcript

This has been removed from the electronic copy

Appendix 16: End of study notification letter and summary for ethics panel

Letter has been removed from the electronic copy

Summary of research

Background

The growing prevalence of dementia is a global concern. The care pathway within the UK healthcare system advocates for the importance of engagement with community-based activities for people with dementia (PWD), including sport. Although the importance of psychological and social wellbeing for PWD has been established, there is a paucity of evidence regarding the effects of sport and physical activity on these constructs.

Method

The study design was a qualitative enquiry, utilising multiple avenues of data collection. PWD and carers participated in a six-week golf programme, facilitated by golf centre staff. Overall, ten PWD, five carers and three staff provided data for the study, which was subjected to an inductive thematic analysis.

Results

The analysis resulted in the establishment of five key themes with related subthemes, as follows:

Theme I: Affectivity.

This theme speaks to the expressions of affect within the data as a result of the person's participation in the programme. This theme applied to PWD, carers and staff alike, and contained three subthemes (*in situ*, *anticipatory* and *enduring*), illustrating the temporal differences of the affect being expressed.

Theme II: Respite.

This theme describes the opportunity for relief from difficult and uncomfortable emotions, as well as an opportunity for carers to have a break from their role as caregiver. As such, this theme has two subthemes: *Release* and *Freedom*. This theme applies to both PWD and carers.

Theme III: Losing dementia label.

Another theme regards the experience of being able to shed the label of dementia as a result of playing golf. This applies directly to the PWD and may also affect their relationships with carers and staff. There are three associated subthemes: *Forgetting illness*, *feeling equal*

and *enabling independence*. A process loop was also identified which explains an underlying mechanism for this theme as suggested by the data; the improvement of their skills beyond the expectations of all involved resulted in feeling impressed with the performance of PWD, undermining the socially accepted paradigm that dementia prevents the learning of new skills.

Theme IV: Camaraderie.

This theme describes the experience of developing a sense of unity with other members of the golf group, and relates to both the PWD and carers but not staff. There are two subthemes encompassed within this theme: *Understanding* and *sharing*.

Theme V: Improving relationships.

This theme represents the effect of the golf programme on improving the relationships between PWD and those around them, including carers and staff present at the programme, as well as friends and family members outside of the programme. This theme houses two subthemes: *Sharing experience* and *playing with family/friends*.

Discussion

The results of the analysis suggest that involvement in the golf programme provides benefits for the psychological and social wellbeing of PWD, carers and staff members alike. While potential limitations of the study are discussed, the outcomes provide support for current policy that asserts the importance of population level activity for PWD, which might have implications for social prescribing. Potential avenues for future research are also considered.

Exploring the Effects on Psychological and Social Wellbeing of a Six-Week Golf Programme for People with Dementia, Carers and Golf Centre Staff

Background

The growing prevalence of dementia is a global concern. The care pathway within the UK healthcare system advocates for the importance of engagement with community-based activities for people with dementia (PWD), including sport. The importance of such activities for peoples' physical and cognitive wellbeing is well documented, although less is known about the effects of sport and physical activity on the psychological and social wellbeing of PWD.

Method

This study explored the views of PWD, carers and golf centre staff following their participation in a six-week golf programme. Audio and video data were collected through interviews and group discussions, which were subjected to a thematic analysis. This type of analysis looks for themes and patterns that might be present in the way a particular topic is talked about - in this case, peoples' experience of the golf programme. Overall, ten PWD, five carers and three staff provided data for the study.

Results

Five key themes were identified. Subthemes were also found for each main theme, which are written in *italics*.

Theme I: Affectivity.

This theme describes the effects of the golf programme on the feelings of all participants involved. For example, PWD and carers described feelings of enjoyment and excitement while staff spoke of a sense of reward. Three subthemes were found: *In situ* (feelings experienced during the golf groups), *anticipatory* (positive feelings of looking forward to the next group) and *enduring* (effects on self-esteem and morale).

Theme II: Respite.

This theme describes the opportunity for relief from difficult and uncomfortable emotions, as well as an opportunity for carers to have a break from their role as caregiver. As such, people described a sense of *release* from unpleasant feelings such as frustration (such as through hitting the ball really hard), as well as having some *freedom* to do the things they want to do and enjoy.

Theme III: Losing dementia label.

Another theme relates to the experience of being able to temporarily detach from the label of dementia as a result of the programme. The subthemes of *forgetting illness* and *feeling equal* might help to explain the ways in which people were able to detach from the label for a time, as people described forgetting about worries/problems and feeling as though everyone was on a level playing field. A sense of *enabling independence* was also noted, which describes how people were given space to do things for themselves (such as driving a golf buggy) or to assert their own preferences. Another interesting feature was that people often seemed "impressed" or "amazed" with the ability of PWD to learn or reconnect with the skills needed to play golf; this seemed to helpfully undermine the expectation that dementia prevents us from learning and retaining information, which allowed space for a sense of achievement and capability to be experienced.

Theme IV: Camaraderie.

This theme describes the experience of developing a sense of unity with other members of the golf group. The two subthemes encompassed within this theme are *understanding* (which relates to feeling safe and understood around people who have had similar experiences) and *sharing* (which describes the experience of being able to share knowledge and experience in order to help and support one another).

Theme V: Improving relationships.

This theme represents the effect of the golf programme on improving the relationships between PWD and those around them, including friends and family members outside of the group as well as those people involved in the group. This theme houses two subthemes: *Sharing experience*, which describe being able to share an enjoyable activity together, and *playing with family/friends*, which relates to participants feeling more inclined to play golf with friends and family outside of the group as a result of the programme.

Discussion

The results of the analysis suggest that involvement in the golf programme provides benefits for the psychological and social wellbeing of PWD, carers and staff members alike. There are some inherent limitations to the method used for this study, which mean that we should be cautious about drawing firm conclusions from these outcomes. However, the findings offer support for the importance of engagement in sport for the psychological and social wellbeing of PWD and carers, which staff may also benefit from in this regard. This may have implications for social prescribing, while offering ideas and incentives for future research in this area.

Acknowledgements

I would like to take this opportunity to express my gratitude to everyone who participated in and helped to orchestrate this study. I wish you all the very best for your future health and happiness.

Chosen journal: Dementia

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