How friends can enhance the wellbeing of people in early-stage dementia

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"I am daring to hope, daring to believe, in a society that no longer excludes, fears and stigmatises all of us who are living well with dementia." - Christine Bryden, PhD

(person with dementia, author and dementia advocate)

(Clarke & Wolverson, 2016, p. 9)

Abstract

Dementia prevalence is widespread globally and in Aotearoa New Zealand. It has significant economic, human, psychological and social impacts. Evidence shows-that how the person experiences dementia is largely driven through social processes, interactions, and social positioning, rather than neurogenic processes. How friends and communities treat people with dementia impacts their sense of self, quality of life and wellbeing. The objective of this study was to explore how friends can enhance the wellbeing of people in early stage dementia. Using Interpretative Phenomenological Analysis (IPA) and Appreciative Inquiry (AI) methodologies, four women living in the community with early stage dementia were interviewed in their homes to understand their lived friendship experiences, and those factors that impact their wellbeing. Data were analysed using IPA and four overarching themes were identified: 1) accept me as I am; 2) be there for me; 3) help me stay in the world; 4) show me I am worthy. Findings revealed crucial roles friends play and specific friendship behaviours that impact wellbeing. Findings showed that accepting the women's limitations and acknowledging their needs and wishes was important to counter internalised stigma, and to help them adjust to a changing conceptualisation of self. Acceptance, together with social support, enabled them to participate in activities that kept them engaged in the world. These factors contributed to their sense of self-worth, and all four factors were interrelated. This study provides insight into why these factors are significant for people in early stage dementia and how they might impact wellbeing. Based on the findings, a simple strengths-based framework and pragmatic tool is provided as a guide to having positive social interactions with people with dementia. This study adds to, and strengthens, the literature on critical wellbeing and social relationship factors for people in early stage dementia, and demonstrates the relevance and applicability of these factors within a New Zealand context. It shows people in early stage dementia have unique insights to what is important to them for their own wellbeing and highlights the critical role of friends.

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To my mother, Becky, who was the inspiration for this thesis.

Becky died from dementia in 2014 with her four adult children around her. In her last few days we camped and slept beside her in her room, reminiscent of wonderful childhood days. We lovingly held her, caressed her, reassured her and continued to reaffirm her worth as she gently slipped away. Becky remains deep in our hearts forever.

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To my children, Natasha and Stefan

If I should ever lose you from my mind,
know that you will always, *always* be deep in my heart

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Introduction

Dementia is widespread, predominantly affecting older people. With the world-wide population ageing, prevalence is rapidly increasing and dementia is now one of the greatest global challenges for health and social care (Livingston et al., 2020). The number, costs and nature of dementia make it one of New Zealand's biggest healthcare issues (Alzheimer's New Zealand, 2017b). There is an urgent need to raise awareness and understanding of dementia across all levels of society as a step towards improving the quality of life of people living with dementia (World Health Organisation, 2015). As there is currently no cure or medical treatment on the horizon, helping people to live well with dementia through psychosocial approaches, is essential. There are several arguments for this from economic, public health, social and human rights perspectives. By enabling people to live well with dementia, they are able to live in the community for longer and delay institutional care thereby preventing the health-care system becoming overwhelmed and avoiding the associated public health-care costs. Furthermore, those who are supported to live well with dementia can also continue to contribute to society through paid and voluntary work for longer. They can continue to fulfil important social roles, including familial roles, essential for their wellbeing and for those around them. People generally live for many years after the onset of dementia. With appropriate support, many can and should be enabled to continue to engage within society and enjoy a good quality of life. A key goal of New Zealand's Healthy Ageing Strategy is "to give people who are living with dementia, the best possible independence and wellbeing" (Ministry of Health, 2016), and the New Zealand Dementia Care Plan 2020-2025 has set a vision for an Aotearoa New Zealand where people living with dementia receive the support they need to live their best possible lives, with autonomy, meaning and dignity (Robertson et al., 2020)

The approach to dementia has evolved throughout the ages. Historically, dementia was viewed as a sign of 'madness' (Berrios, 2017). In some cultures, dementia was seen as a punishment for the sins committed in one's life (Cheung, Appleton, Boyd, & Cullum, 2019), and yet in others, people with dementia were accorded a higher spiritual status (Bartlett & O'Connor, 2010; Lanting et al., 2011). In the Western world in the pre 1980s, dementia was associated with senility and was largely seen as a natural outcome of ageing. This focus changed in the early 1980s when dementia was widely recognised as a biomedical condition, portrayed as a neurodegenerative disease with an inevitable trajectory of irrevocable decline . The biomedical model brought benefits, such as earlier diagnosis and access to services. It also helped others recognise that the 'problematic' behaviours witnessed were outside the control of the person. An exclusive biomedical focus, however, also had unintended negative consequences. For one, it negated the person behind the disease and relegated them to a passive victim at the mercy of a disease described as a 'death that leaves the body behind' (Bartlett & O'Connor, 2010).

In the 1990s, a more humanistic approach evolved. One of the great pioneers of this perspective was Tom Kitwood who advocated for a psychosocial approach, recognising the impact of others' treatment on the person with dementia . He argued that a person's standing and status is created and maintained by others and that people have a responsibility to maintain personhood for the person with dementia (Kitwood, 1997). In this context, it is the person, and not the disease that takes centre stage, and their needs and wishes must be respected and honoured. He asserted that the central need for people with dementia is love, and to feel respected and cared for. Surrounding needs include comfort, identity, occupation, inclusion and attachment (Kitwood, 1997). The shift from a focus on disease process to a focus on personhood and interpersonal relationships has had a significant impact on improving the quality of life for people with dementia.

More recently the focus has been extended to encompass not only personhood which is needs based, but also social citizenship which is rights based, and emphasis is placed on people with dementia being afforded the full rights of social citizenship (Bartlett & O'Connor, 2010). This allows for both active and passive modes of citizenship. Passive citizenship implies the need for people with dementia to have ready access to welfare and care needs; active citizenship implies bi-directional movement, recognising that people with dementia are impacted by their sociocultural context, and at the same time, have agency and can influence their sociocultural context (Bartlett &

O'Connor, 2010). Increasingly, people with dementia are active in shaping strategies and policies that impact them, subscribing to the principle of ‘nothing about us, without us’(Bryden, 2016; Dixon, Laing, & Valentine, 2020).

In some ways this evolution can be viewed as initially focusing on the micro level of the disease pathology, then shifting to the inter-relational meso level, and ultimately out to the societal macro level. However, rather than viewing these as discrete approaches, focus across these three ecological levels, needs to be simultaneously maintained to enable the wellbeing of people with dementia. This requires an understanding of the impacts of dementia from biomedical, psychological, social and societal perspectives. Therefore, this thesis first defines dementia using the biomedical model, broadly outlines the impacts of dementia, then focuses in on social factors and how people adjust to dementia, before providing a brief overview of broader environmental factors that contribute to wellbeing. Ultimately, however, this study provides an in-depth analysis on the role of friends (focusing on the meso level), and how they impact the wellbeing of people with dementia.

DEFINING DEMENTIA – A BIOMEDICAL MODEL

The Evolving Conceptualisation of Dementia within a Biomedical Model

Dementia is an umbrella term referring to a clinical syndrome and disease process, rather than a specific disease. It is characterised by progressive cognitive decline leading to significant social and functional impairment which adversely impacts the person's daily functioning. This conceptualisation of dementia is similar to that of Kraepelin's in the late 19th century, commonly regarded as the founder of modern psychiatry and psychopharmacology (van Praag, 2008). He proposed that the primary cause of psychiatric illness was due to biological and genetic malfunctions. Through rigorous, scientific observation and longitudinal studies of patients, Kraepelin developed a classification system for mental illness, based on *patterns* of symptoms, rather than isolated symptoms. This formed the basis for modern day classification systems such as the Diagnostic and Statistical Manual for Mental Diseases (DSM) and the International Classification of Diseases (ICD) (van Praag, 2008). Changes in conceptualisation of dementia are apparent in these evolving systems.

As the DSM is widely used globally and is the classification system used in New Zealand, where this study takes place, emphasis is given to this system. The first two editions of the DSM gave a general description of organic brain syndrome (OBS), describing it as "a mental disorder caused by diffused impairment of brain function and impaired cognitive functions"(Kane & Thomas, 2017, p. 34). It encompassed both delirium and dementia, the former being described as an acute brain syndrome, and the latter, as a chronic brain syndrome, primarily differentiating them on the basis of reversibility. It failed to recognise however, the reversibility of some types of dementia and excluded focal impairment (Kane & Thomas, 2017).

The DSM-III retained OBS, however, it was the first classification system to introduce dementia as a unitary concept, positioning it as one of ten OBS subtypes (Kane & Thomas, 2017), and it further distinguished it from delirium. It specified memory loss as a necessary criterion for diagnosis, together with impairment in multiple higher cortical functions as well as interference in daily functioning. Previous DSM versions had considered interference in daily functioning to be an indicator of severity but not a diagnostic criterion.

The DSM-IV disposed of the term OBS because there was concern that this inadvertently implied that ‘non-organic’ mental disorders did not have a biological basis (Kane & Thomas, 2017). The core characteristics for a dementia diagnosis, such as memory loss and other cognitive deficits were retained. Specifically, it stipulated memory loss *and* at least one of the following: aphasia (a communication impairment affecting the production or comprehension of language), apraxia (a motor impairment affecting the ability to perform purposeful actions), agnosia (inability to recognise objects and people), and disturbance in executive functioning, impacting planning, decision-making and problem-solving. One fundamental change, however, was the lowering of the thresh-hold for functional impairment from ‘sufficient to interfere with social or occupational functioning’ to ‘sufficient to cause limitations in complex activities’, e.g., managing finances (Kane & Thomas, 2017). This change recognised the very gradual and insidious decline caused by dementia and enabled people to be diagnosed earlier. Earlier diagnosis is important as it generally leads to more positive outcomes for people with dementia because they can proactively plan and adjust to the disease, receive early support and treatment, and in certain types of dementia, such as those caused by vitamin deficiencies or alcohol and substance use, it can be treated and reversed if caught early.

Current Conceptualisation

The DSM 5 (American Psychiatric Association, 2013) (the current classification system) introduced changes to both the nomenclature and to the diagnostic criteria, now referring to dementia as ‘major neurocognitive disorder’. This was partly to move away from the term ‘dementia’ which had perjorative and stigmatising connotations, and also to disassociate it from Alzheimer’s Disease (AD) which for many, had become synonymous with dementia, rather than being viewed as only one type of dementia

(Kane & Thomas, 2017). In practice, the term dementia is still widely used amongst clinicians and the general population. For this reason, ‘dementia’ is used interchangeably in this study. The broader framework was developed to encompass all dementing disorders across a broad age span. Critics, however, argue that this has confused the focus, because most people with dementia have wide-spread degenerative brain disease and are generally older than those with static single-deficits from traumatic brain injury or HIV (Kane & Thomas, 2017).

The DSM-5 (American Psychiatric Association, 2013) specifies the following diagnostic criteria for major neurocognitive disorder: evidence of significant cognitive decline from a previous level of performance in *one* or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition), based on concern of the individual or informant that there has been a significant decline in cognitive functioning, and as identified through assessment; *and* cognitive deficits interfere with independence in every day functioning. Thus, memory loss, which is a typical early feature of AD, but not necessarily all dementias, is no longer a requirement for diagnosis. Gaining an informant’s perspective is important as sometimes, people with dementia may not complain of cognitive decline due to anosognosia, a loss of self-awareness (Scott & Barrett, 2007).

The DSM-5 (American Psychiatric Association, 2013) also specifies the level of severity and accompanying behavioural disturbances: *mild* indicates difficulty with instrumental activities of living such as housework and managing money; *moderate* indicates difficulty with basic activities such as feeding and dressing; and *severe* indicates full dependence. Behavioural disturbance specifiers include psychotic symptoms, mood disturbance, agitation, apathy and other behavioural symptoms. The type of dementia, severity level and associated behavioural disturbances all have implications for how the person experiences dementia, and their treatment and care.

The DSM-5 (American Psychiatric Association, 2013) distinguishes between major and minor neurocognitive disorder recognising the continuum between normal cognitive functioning and dementia, with mild cognitive impairment (minor neurocognitive disorder) sitting somewhere in the middle. It is distinct from normal ageing characterised by a slight decrease in cognitive speed and memory. The key distinguishing feature between major and minor neurocognitive disorder is the impact on functionality, with mild neurocognitive disorder not interfering with one's independence in everyday activities, notwithstanding the need for greater effort and compensatory strategies. In many cases, however, a diagnosis of minor neurocognitive disorder may well be the prodromal phase of major neurocognitive disorder.

Dementia Types and Aetiology

There are over a hundred different types of dementia resulting from a variety of causes including:

- neurodegenerative diseases such as AD, Lewy body disease (DLB), frontotemporal lobar degeneration, Parkinson's disease (PD) and Huntington's disease;
- infections such as HIV, syphilis and Prions disease (e.g., Creutzfeldt-Jakob disease);
- substance/medication use (e.g., Korsakoff-Wernicke from alcohol abuse)
- vascular disease;
- traumatic brain injury (TBI);
- vitamin deficiencies (e.g., B12, thiamine, folate);
- and other medical reasons including metabolic conditions such as hypothyroidism and hypoglycaemia

(Schoenberg & Scott, 2011).

The most prevalent types of dementia are AD, vascular dementia (VaD), Lewy body (DLB) and frontotemporal, although approximately 15% of people with dementia have multiple dementias, the most common being AD and VaD.

Alzheimer's Disease

AD is by far the most prevalent type, accounting for 50-75% of all dementias (Alzheimer's Disease International, n.d.-b). It is a neurodegenerative disease that takes its name from the German psychiatrist, Alois Alzheimer who, upon performing an autopsy on a 51 year old former patient, Auguste Deter, in 1906, discovered protein plaques and tangles in her brain (Berrios, 2017). Years prior, Auguste had shown signs of significant memory and cognitive impairment which continued to deteriorate until her death.

Plaques are formed by the abnormal build-up of the protein amyloid that accumulates outside the neurons, whilst neurofibrillary tangles are formed by the protein tau which accumulates inside neurons, causing loss of neuronal connection and neuron death. This neuropathology typically begins in the medial temporal lobes, spreading to the parietal and frontal cortices, ultimately destroying most of the neocortex (Schoenberg & Scott, 2011). Autopsy confirms cortical atrophy and enlargement of ventricles. In healthy brains, glial cells such as microglia and astrocytes, rid the brain of waste and toxins, however, in those with AD, these glial cells fail to perform this protective function.

Clinical presentation, at the mild stage, is typically amnestic with impairment in memory and learning, sometimes also with deficits in executive functioning. As the disease progresses, deficits are noticeable in other domains, such as visuo-constructional, motor ability and language, while social cognition is often preserved until late stages of the disease (American Psychiatric Association, 2013). Cognitive decline is steady and gradual, and the disease follows a reasonably predictable course. Behavioural and psychological disturbances are common features. In the very early stages, depression and/or apathy are common. In later stages, psychosis, irritability, agitation, combativeness, and wandering can be observed. In the very late stage, incontinence, dysphagia (difficulty swallowing), gait disturbance, myoclonus (sudden, involuntary, jerking of muscle group) and seizures are seen (American Psychiatric Association, 2013).

Symptoms usually appear late in life, in the eighth or ninth decades. Mean life expectancy from time of diagnosis is 7-10 years, however, in the case of early onset AD (i.e., prior to age 60), life expectancy can be up to 20 years for some people. Early age onset is less common and is often due to genetic factors. Apoliproprotein E4, a protein that binds lipids (oil-soluble substances such as fat and cholesterol) and transports them in blood and cerebrospinal fluid, is associated with increased risk and earlier age onset (American Psychiatric Association, 2013). However, the greatest risk factor is age. Additional risk factors include previous TBI, and cerebrovascular dysfunction.

Vascular Dementia

VaD is the second most prevalent type, accounting for 17%-30% of all dementias (Alzheimer's Disease International, n.d.-c). VaD is attributed to vascular disease characterised by thrombosis or haemorrhage resulting in a stroke (Saddock, Sadock, & Ruiz, 2015). In a haemorrhagic stroke, a cerebral blood vessel ruptures causing bleeding in the brain; in an ischemic stroke, the blood supply to the brain is interrupted through a blockage, either from a thrombosis or embolism. The loss of blood and oxygen to the brain causes a single strategic infarct or multiple infarcts through a series of strokes which are often silent (Elkins, 2012). In vascular dementia therefore, there is cognitive deterioration following each stroke, followed by a plateau or sometimes even slight improvement as the brain attempts to create new pathways through neuroplasticity (Elkins, 2012).

Clinical presentation is heterogeneous and symptoms vary depending on which regions of the brain are affected, and the extent of the lesions. Lesions may be focal, multifocal or diffuse. With multiple infarcts, the course of decline is typically stepwise and unpredictable. Some present with an acute decline in cognition, whilst others may have gradual onset and slow progression generally due to microvascular disease leading to lesions in the white matter, basal ganglia and/or thalamus (American Psychiatric Association, 2013). Subcortical VaD is more insidious without sensory-motor manifestations, but with progressive changes in mood, personality or cognition (Tariq &

Barber, 2018). Abulia, characterised by a lack of will or initiative, emotional lability and depression are also common features. Although VaD can occur at any age, prevalence increases exponentially beyond age 65.

An interaction of biopsychosocial factors contribute to VaD. Lifestyle factors that reduce the risk of vascular disease, such as diet and exercise, therefore, also reduce the risk of VaD (Karstens et al., 2019; Tariq & Barber, 2018). Obesity, diabetes, high cholesterol levels, inactivity, smoking and hypertension are all risk factors. Life style changes can therefore provide a protective buffer. Psychosocial factors believed to also provide a protective buffer by delaying onset, or improving neurocognitive outcomes, include higher education, social engagement and mental activity (American Psychiatric Association, 2013; Tariq & Barber, 2018). According to the 2020 Lancet Commission report up to 40% of worldwide dementias could potentially be prevented or delayed by modifiable risk factors (Livingston et al., 2020)

Lewy Body Dementia

DLB is the second most common *neurodegenerative* dementia, following AD (Walker, Possin, Boeve, & Aarsland, 2015), accounting for 10%-15% of all dementias (Alzheimer's Disease International, n.d.-a). It is caused by pathological Lewy bodies, predominantly comprising abnormal deposits of the protein alpha-synuclein in the central and autonomic nervous systems (Lin & Truong, 2019). Deposits in the brainstem result in parkinsonism (a clinical syndrome characterised by tremor, bradykinesia (slow movement), rigidity and postural instability). Deposits diffused across the brainstem and cortices result in parkinsonism and cognitive symptoms (Lin & Truong, 2019). Consequently, distinguishing Parkinson's dementia (DPD) from DLB can be challenging. If dementia onset precedes or occurs within the first year of parkinsonism, then a diagnosis of DLB should be given; if dementia occurs after one year of parkinsonism, then DPD is the appropriate diagnosis (American Psychiatric Association, 2013). One current hypothesis is that in DPD, Lewy pathology begins in the brainstem and propagates upward to the cerebral cortex, and does the reverse in DLB (Lin & Truong, 2019). Some question whether PD and LBD are in fact the same underlying disease with different presentations (McKeith, 2017).

Characteristic symptoms include fluctuating cognitions with pronounced variations in attention and alertness; recurrent visual hallucinations that are well formed and detailed, REM sleep behaviour disorder (marked by abnormal dream enactment) and parkinsonism (American Psychiatric Association, 2013). Deficits on tests of attention, executive functioning and visuospatial may be prominent (Chin, Teodorczuk, & Watson, 2019; Walker et al., 2015). Despite progress in determining diagnostic criteria for DLB, the sensitivity and specificity of clinical diagnosis remains low (Wearne, Genetti, Restifo, & Harriss, 2018) and it is often misdiagnosed or undetected (Chin et al., 2019; Kane et al., 2018).

Psychosis and behavioural disturbances are common in DLB, however they are difficult to treat due to high neuroleptic sensitivity; drugs often exacerbate symptoms. Individuals with DLB frequently fall and experience syncope and momentary episodes of unexplained loss of consciousness. Compared to AD, there is generally greater impact on functionality, quality of life and care associated costs (Chin et al., 2019; McKeith, 2017). DLB usually begins earlier than AD and VaD, with onsets commonly between 50 and 70 years of age. Life expectancy from time of diagnosis is typically between 5-7 years

Frontotemporal Dementia (FTD)

FTD accounts for approximately 4% of all dementias. It is caused by degeneration of the frontal and temporal lobes without the tell-tale signs of plaques and tangles seen in AD, and is associated with serotonergic deficits (Scott & Barrett, 2007). It is characterised by the progressive development of behavioural and personality change and/or language impairment, although many people present with both (American Psychiatric Association, 2013).

Prominent features include varying degrees of apathy and blunted emotional features, or disinhibition leading to inappropriate social conduct. Individuals may lose interest in socialisation and self-care and sometimes show changes in long-standing religious and political beliefs. Other behavioural symptoms may include repetitive movements, hoarding and hyperorality. Cognitive decline is less prominent although deficits in executive functioning are present, including problems with planning, organisation and judgement. Insight is often impaired, delaying help-seeking behaviour. Memory and visuospatial skills are often preserved, particularly in the early stages. Those with the language variant experience a gradual onset of aphasia which may be semantic (difficulty understanding words), non-fluent agrammatic (difficulty in grammar and understanding complex sentences), or logopenic (difficulty in retrieving words and repeating phrases) depending on which lobes and regions of lobes are atrophied (American Psychiatric Association, 2013).

Approximately 40% have a family history of early onset neurocognitive disorder. Individuals with FTD are generally younger. Symptoms generally present in the sixth decade although onset ranges from the third to ninth decade. People tend to survive 6-11 years after symptom onset and 3-4 years after diagnosis (American Psychiatric Association, 2013).

IMPACTS OF DEMENTIA

Dementia is one of the major causes of disability and dependency among older people worldwide. It has far-reaching impacts on people with dementia, their carers, families and wider society, encompassing physical, social, psychological and economic impacts (World Health Organisation, 2015).

Prevalence

There are over 50 million people living with dementia worldwide and this is expected to triple to over 150 million by 2050 (Alzheimer's Disease International, 2018). A new person develops dementia every three seconds. Dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease (World Health Organisation, 2017). Global prevalence estimates are about 6% for those aged over 60, and 20% for those over 85 years. The number of people with dementia in New Zealand is also growing rapidly, currently at 70,000 and projected to grow to over 100,000 by 2030 and over 170,000 by 2050, representing 2.9% of the New Zealand population (Alzheimer's New Zealand, 2017a). Figures for women are 30% higher than men, partially due to their greater longevity.

Financial Impacts

The economic impact is significant, with an estimated worldwide cost of US$1 trillion in 2018, and a projection of US$2 trillion by 2030 (Alzheimer's Disease International, 2018). The cost of dementia in New Zealand was estimated to be NZ$1.7 billion in 2016, a 75% increase since 2011, and is projected to grow to approximately NZ$5 billion in today's dollars by 2050 (Alzheimer's New Zealand, 2017a).

Current dementia costs include aged care (over 50% of total costs), productivity losses from people with dementia and their carers (14.4% of total costs), deadweight losses, e.g., shifting taxes to dementia care and beneficiary costs (13.5% of total costs), hospitalisation (10% of total costs), informal care (4.1% of total costs), community care (4% of total costs), and GPs, allied health, pharmaceuticals, respite and carer support, research, mobility aids and modifications collectively accounting for just over 3% of total costs (Alzheimer's New Zealand, 2017a). These costs are unsustainable and there is a pressing need to develop more sustainable models of care. If people are supported to live better and longer at home, thereby delaying residential care, this would save NZ$22 million per month, equalling NZ$264 million per annum (Alzheimer's New Zealand, 2017a). This percentage breakdown also highlights the need for greater investment in dementia research.

Human and Social Impacts

Of far greater significance, however, are the enormous human and social impacts for the person with dementia and their loved ones. Illness can pose a threat to a person's status due to diminished control and competence, characteristics which are deeply ingrained in Western values (Hillman, Jones, Quinn, Nelis, & Clare, 2018). This is particularly salient for dementia which has been described as the 'death that leaves the body behind' or 'death in slow motion' (Kitwood, 1997; MacRae, 2007). Whilst, there is definitely a need and a move to reconstruct the portrayal of dementia in this manner, dementia does present significant loss.

In the early stages of dementia, often pre-diagnosis, there is a sense of confusion and anxiety as one struggles to make sense of their cognitive decline (Steeman, de Casterle, Godderis, & Grypdonck, 2006). Even slight changes in cognitive functioning, such as mild memory impairment and word-finding difficulties, can make complex jobs demanding and taxing (Wimo, Winblad, & Grafstrom, 1999). People want to be seen as 'normal' and often try to cover up problems and avoid situations where they might be exposed (Beard, 2004). For family members, there is confusion about subtle personality changes in the person, such as apathy, depression and paranoia. These can lead to misunderstandings between family members, impacting the quality of social interactions, family dynamics and relationships (Podgorski & King Deborah, 2009).

As the disease progresses, individuals may withdraw socially, exacerbating their symptoms and leaving them socially isolated. Many worry they will become too great a burden for family, and are fearful of being institutionalised and abandoned (Robinson, Giorgi, & Ekman, 2012). With declining functionality and independence, there is an increased need for support with daily activities, and managing these with dignity and respect is central (Prizer & Zimmerman, 2018). In the later stages of the disease, behaviour disinhibition and potential combativeness can result in further stigmatisation and social ostracisation, leading to greater isolation and loneliness (Corner, Brittain, & Bond, 2004). Loneliness is a major problem for people with dementia because they often experience loss of relationships and social contacts, and are deprived of social engagement (Biggs, Carr, & Haapala, 2019; Courtney-Pratt, Mathison, & Doherty, 2018; Moyle, Kellett, Ballantyne, & Gracia, 2011). This further exacerbates their condition, and loneliness itself has been identified as risk factor for dementia (Rafnsson, Steptoe, Orrell, D'Orsi, & Hogervorst, 2020).

These changes also put significant emotional, financial and social strains on family members and carers (Egilstrod, Ravn, & Petersen, 2018; Wimo et al., 1999). Carers are affected directly through primary stressors of providing care - experiencing role overload and/or role captivity - and through watching their loved ones decline. Confronted by loss on multiple levels (the future as they imagined it; companionship; freedom; gradual loss of the person as they knew them), carers suffer anticipatory grief (Chan, Livingston, Jones, & Sampson, 2013). They are also impacted by secondary stressors, such as role conflicts between work and caregiving, negative social reactions from others and diminishing social circles (Kimura, Maffioletti, Santos, Baptista, & Dourado, 2015; Schneider, Murray, Banerjee, & Mann, 1999). Both primary and secondary stressors contribute to feelings of depression and emotional distress (Cho, Zarit, & Chiriboga, 2009). Carers of people with dementia often experience greater stress than carers of physically frail people and are at risk of becoming physically and mentally unwell (Berwig et al., 2017). Conversely, however, it should be noted that some caregivers experience personal growth, self-affirmation and increased life satisfaction, and those with good social support in particular, as well as better socio-demographic factors and greater caregiving experience tend to fare better (Szabo, Stephens, Alpass, & Fekete, 2019).

Psychological impacts

Whilst there are mixed reports on the degree of self-awareness in early stage dementia (Clare, Nelis, Martyr, Woods, et al., 2012), a large body of research shows that during the early stages, people have high self-awareness (Caddell & Clare, 2011; Gorska, Forsyth, & Maciver, 2018; Harman & Clare, 2006; Hillman et al., 2018; Katsuno, 2005; Low, McGrath, Swaffer, & Brodaty, 2018; Macquarrie, 2005), although both psychological and social factors have been shown to influence scores on measures of awareness (Clare, Nelis, Martyr, Roberts, et al., 2012). In some cases, denial mechanisms may be active; in other cases, how people are socially treated and positioned, impacts awareness scores. Variations in level of awareness in early stage dementia is therefore due to a complex interplay of biopsychosocial factors (Harman & Clare, 2006), however numerous studies demonstrate that some level of awareness is retained throughout the course of the disease.

This insight can be a double-edged sword, on one hand alerting people to seek medical help, but it can also cause severe psychological pain with people experiencing a range of emotions such as shame, embarrassment, humiliation, guilt, fear and sadness (Martin, Turner, Wallace, Choudhry, & Bradbury, 2013; Mok, Lai, Wong, & Wan, 2007). These emotions, particularly, shame, guilt and stigma may lead to social isolation, avoidance and exclusion (Katsuno, 2005; Phillipson, Magee, Jones, Reis, & Skaldzien, 2015). One of the greatest challenges people with dementia experience, is coming to terms with psychological, social and functional losses (Robinson et al., 2011) which are often interlinked and dynamic. Loss of intimacy with one's partner and role changes within the family relationships can shift one from a position of equal standing to one of dependence (Gorska et al., 2018), and people are acutely aware of others' patronising comments and diminishing trust in them (Mok et al., 2007). Even labelling a family member as a ‘carer’ can be viewed as disempowering leading to premature disengagement from life activities (Martin et al., 2013).

There is often a profound sense of loss as autonomy and agency diminish together with the ability to engage in meaningful productivity, or to connect with loved ones in the same way prior to the disease (Steeman et al., 2006). This can lead to feelings of incompetence and worthlessness which negatively impacts one’s self-esteem, an evaluative component of self-worth, prone to fluctuation. Self-identity, a relatively more stable concept of self, is also severely impacted as people may experience an anguishing sense that the very essence of who they are is being eroded (Beard, 2004).

DEMENTIA AS A SOCIALLY CONSTRUCTED PHENOMENON

Social Positioning of People with Dementia

How the person experiences dementia is driven only in part by the type, stage and severity of dementia as described through the biomedical model. Of far greater importance, however, is how the person is socially positioned through social interactions. Kitwood (1997) described a 'malignant social psychology' that marginalises people with dementia, objectifying them and stripping them of their personhood. Through processes of 'labelling' where a person's behaviour is misattributed to their illness rather than being seen as a reaction to how they are being treated, 'stereotyping', 'infantilising' and 'invalidating,' people with dementia are often positioned as socially inferior and addressed in a condescending manner which is disempowering (Sabat & Lee, 2012; Samuelsson, Österholm, & Olaison, 2015).

Deeply disturbing accounts of people's lived experiences of dementia describe how their voices have been silenced, even by their own carers; their thoughts, feelings and experiences invalidated; how friends have turned their backs and withdrawn social contact; how family members have stopped communicating with them; how they are no longer consulted about their own needs and wishes; how their ability to perform a function is questioned and mistrusted; and how their movements and activities are restricted (Patterson, Clarke, Wolverson, & Moniz-Cook, 2018). These negative responses and attitudes towards the person with dementia become internalised, undermining the person's confidence and leading to greater disability and a diminished sense of self (MacRae, 2011), exacerbating feelings of incompetence, frustration, depression and unworthiness (Sabat & Lee, 2012). Thus, much of the human suffering and sense of loss experienced by people with dementia is shaped, not through neurogenic processes, but rather through social interactions and how people with dementia are socially positioned.

It is important to note that 'social malignancy' is almost always unintentional. Rather, it is a complex interplay of multiple factors such as a lack of understanding of dementia by 'healthy' others including misconceptions by professionals; a paternalistic approach driven by the desire to protect someone who is seen as vulnerable; denial mechanisms to counter one's own fears or feelings of guilt; misconstruing reactions and behaviours of the person with dementia and attributing them solely to the disease, rather than seeing them in context, e.g., an expression of frustration or indignation because of how one is being treated. Although unintentional, malignant social positioning (Sabat, 2019) clearly has far reaching impacts at both the individual and societal level. At the individual level it impacts on basic human rights, dignity and quality of life. At the societal level, it impacts on policy and care models with an over-emphasis on the biomedical model including medicalisation of the person and overuse of medication for behaviour management, instead of taking a person-centred approach that recognises the needs of the individual (Sabat, 2019). It creates communities that are unwelcoming and non-inclusive which alienate and marginalise people with dementia.

Threat to Self-hood

How individuals treat people with dementia also has a significant impact on their sense of self. Identity, or self-concept, is a multidimensional construct and various models have been used to conceptualise it. Some emphasise different identities over the lifespan. Interestingly, in this model, identity studies with both healthy older people and those with dementia, both show the family role to be the strongest and the career role, the weakest (Caddell & Clare, 2013b; Cohen-Mansfield, Golander, & Arnheim, 2000). This underscores the importance of relationships.

Fitts describes different dimensions of self, encompassing physical, moral, personal, social and family (Fitts & Warren, 1996). Similarly, Neisser's (1988) five factor model comprises the ecological self (the self with respect to the physical environment determined through perceptions); interpersonal self (the self in interactions with others); extended self (the self experienced across time including past, present and anticipated future); private self (including conscious experiences, dreams, inner thoughts and feelings); and conceptual self (a culmination of the four selves, including traits, roles and autobiography). These five selves, although distinct, are interdependent so that individuals experience a unified self (Caddell & Clare, 2013c). Despite their differences, each model indicates that self-hood is not constructed in isolation, but rather in relationship with others.

Some argue that many of these conceptualisations of identity require autobiographical memories. If one cannot remember what they stand for, their significant relationships and life history, then how can they maintain their self-identity? Others question this relationship between autobiographical memory and identity and have found no clear linear relationship between decline in memory or cognitive functioning, and identity (Caddell & Clare, 2010, 2013a). Furthermore, Lesser (2006) argues that even if dementia damages awareness of identity, it can never destroy identity; past and present exist and decline and growth are both a part of identity.

According to the social constructionist view of identity, self-hood can be expressed in three ways: self-1, through the use of personal pronouns "I, me, my, mine" to relate that our beliefs, attitudes and experiences belong to 'me' as an entity; self-2, by articulating our physical and psychological attributes both present and past, and our beliefs about those attributes; self-3 comprises our multiple social personae, such as loving parent, loyal friend, with each persona having a unique set of behaviours (Sabat & Collins, 1999). Even when one no longer remembers how old they are or where they live, they still retain self-1, simply by stating "*I* don't know".

Several case studies illustrate how people with dementia actively pursue maintaining their 'self-2' by recounting their past attributes prior to their disease, such as having been an articulate presenter, or the life and soul of the party (Sabat, Fath, Moghaddam, & Harré, 1999). At the same time, they acknowledge current attributes imposed on them through dementia, such as now being inarticulate and struggling to find words. Thus, past and present attributes contribute to their self-identity. Creating opportunities for people with dementia to experience biographical continuity is therefore important to their sense of selfhood (Sabat, Johnson, Swarbrick, & Keady, 2011). Rather than confining the person to attributes of the disease that are an anathema to them, one should work collaboratively with the person to help rekindle, or at least acknowledge, the attributes that have so powerfully contributed to their selfhood .

Self-3, the social self, is particularly dependent on the interrelationship with others and is therefore more vulnerable than the other two selves (Sabat, 2002). Healthy others have the ability to nurture self-3 of the person with dementia by keeping the various social personae alive through engagement and interaction. Maintaining selfhood, therefore, requires the co-operation of others (Sabat et al., 1999). This, according to Kitwood, is one of the primary goals of caring for the person with dementia (Kitwood & Bredin, 1992).

As illustrated, selfhood is shaped by a complex interplay of how others socially position the person and how they view themselves (Patterson et al., 2018). Social malignancy, has a deleterious effect on selfhood, particularly for the person with dementia as they may not have the words or cognitive ability to relocate themselves. For example, in a social interaction two types of positioning are at play: interactive, where one person positions another, and reflexive whereby a person positions themselves. If a healthy person rejects how they have been positioned, they can, through reflexive positioning, reposition themselves in a more congruent way. However, if a person with dementia has word-finding difficulties or can’t remember important self-identifying factors, they will be locked in to how society and those around them position them (Sabat, Napolitano, & Fath, 2004). The greatest threat to selfhood, therefore, is how the person with dementia is viewed, positioned and treated by those around them through social interactions.

Maintaining Self-hood

A review of studies on the impact of dementia on self and identity demonstrates that, irrespective of the methodology, model and measure used, there is evidence for persistence of self throughout the course of dementia, although some aspects of self are diminished. This holds true for both qualitative studies deploying social constructionist approaches, interactionist perspectives of self, embodied selfhood, self-narratives, thematic analyses, as well as quantitative studies measuring autobiographical memory, role identities, self-recognition and self-knowledge (Caddell & Clare, 2010). Some studies measure single elements of self, whilst others attempt to measure self as a unitary construct. The plethora of measures is largely due to the multidimensionality of selfhood and the ambiguity of what constitutes self, and there is an argument for using a consistent framework, such as Neisser's (1998) five factor model (Caddell & Clare, 2013c). Despite this, the vast majority of studies support the maintenance of selfhood in people with dementia.

Whilst self-concept has been shown to remain intact in the early stages of dementia (Clare, Nelis, Martyr, Woods, et al., 2013), some posit that self-concept remains stable only because the revised self is not updated with new information due to failing memory. Other studies, however, highlight how people in the early stages of dementia are actively involved in preserving their identity, holding on to the image they have of themselves prior to the onset of dementia, whilst simultaneously recognising changes in themselves since the onset, and incorporating this into their evolving self-concept (Caddell & Clare, 2011). This reflects a continuum of responses to dementia ranging from self-maintenance to self-adjustment (Clare, Nelis, Martyr, Woods, et al., 2013) and affirms identity construction as a lifelong process (Beard, 2004; Charmaz, 1991). It is also important to note that whilst one may incorporate elements of chronic illness into their self-concept, it does not define the person. Ann Johnson who was diagnosed with early onset dementia at age 52 reminds us "Dementia is not an identity, it's a label … a brain disease. I have dementia, I also have a life. I still have the fundamental principles of being able to give and receive love and care" (Sabat et al., 2011, p. 285).

Many challenge the need to hold cognition in such a lofty position and stress that the body itself is an important source of selfhood (Kontos, 2004). This embodied self is similar to Neisser's (1988) ecological self and Fitts's physical self. Indeed, Cowley (2018) gives a philosophical account of a woman in the late stages of dementia, who continues to experience pleasure and explains how this too is a key part of her identity, both bodily and psychological identity. He argues further for identity shaped through intimate relationships, such as through friends, and advocates that they have an important role in holding both the person's humanity and identity. Even in the very late stages of dementia, when one may be totally dependent, and unable to recognise their own family members, selfhood persists. People continue to experience positive emotions, whether it be pleasure from music, enjoying a meal, watching a baby, hearing laughter or the sensation of being gently caressed (Radden & Fordyce, 2006). Self cannot be reduced to cognition; even as cognition declines, emotion is still present and this too is a core part of the person (Beard, 2004; Radden & Fordyce, 2006).

Evidence shows that maintaining identity in the early stages of dementia contributes to lower levels of anxiety and depression, and better quality of life (Caddell & Clare, 2012). A biomedical approach to providing care for the person with dementia is clearly limited, and only addresses a very narrow element of dementia. The need for a more holistic biopsychosocial approach is paramount to both honour the person's selfhood and minimise the psychological pain experienced. Kitwood (1997) argues that the primary goal of dementia care is to maintain personhood in the face of cognitive decline. He further asserts that personhood is not constructed independently, but rather by and through social interaction. Curating an identity 'with', 'for' and 'about' the person with dementia, thereby preserving their personhood as their memory fails, is essential (Crichton & Koch, 2007). Family and friends play a critical role in curating this self-identity, telling and retelling the story to the person, encouraging their input, recognising their feelings and acknowledging who they are (Crichton & Koch, 2007). Even in very late stage dementia, people show positive emotion and pleasure in being affirmed. "Their personhood needs to be continually replenished, their selfhood continually evoked and reassured" (Kitwood & Bredin, 1992, p. 285).

ADJUSTING TO DEMENTIA

Adjusting to dementia is an on-going process encompassing psychological, practical and social adaptations, such as resetting expectations and goals, altering the environment, modifying activities and mobilising support. A diagnosis of dementia often triggers this adjustment process, enabling the person to begin the process of psychological, social and instrumental adjustment

Diagnosis and Adjustment

A dementia diagnosis and disclosure marks a pivotal moment for the person. It can be very confronting for the person with dementia and their family, and for some it may conjure up a sense of 'spoiled identity' (Sabat, 2019). For others, however, it can provide a sense of relief to have an explanation for the changes they have been experiencing (Steeman et al., 2006). The World Alzheimer report 2011 states diagnosis is a human right and disclosure is strongly recommended (Alzheimer's Disease International, 2011; Devoy & Simpson, 2017). Many physicians, however, are often reluctant to disclose a diagnosis for several reasons, including: believing the person with dementia lacks the mental capacity and insight to comprehend; concerned the diagnosis will cause unnecessary psychological distress; fear of suicide ideation; paternalistic and nihilistic attitude of the physician; perceiving diagnosis as futile because the disease is incurable; viewing treatment benefits as limited; concerns about stigmatisation; uncertainty about the course of the disease; risk of potential misdiagnosis; and fear of ruining patient/physician relationship (Cornett & Hall, 2008; Kaduszkiewicz, Bachmann, & van den Bussche, 2008; McKinlay, Leathem, & Merrick, 2014). Indeed, when disclosure is not managed with sensitivity, it can result in premature disengagement from life, stigmatisation and loss of self-esteem and identity (Low et al., 2018).

When diagnosis and disclosure is managed with sensitivity, individualised to the person, it can be both empowering and supportive. Patients and carers generally value the truth told in a straightforward and compassionate manner that instils hope and empowerment; and they want follow-up information and the opportunity to ask questions as part of an ongoing process (Mastwyk, Ames, Ellis, Chiu, & Dow, 2014). After a dementia diagnosis, the focus should shift to re-enablement where people with dementia are supported to live well with dementia (Alzheimer's Disease International, 2018). Family physicians play a key role in how the person with dementia adjusts to a diagnosis and gains access to support networks (Cockerill et al., 2006). When managed well, and with the support of those around them, diagnosis and disclosure can be the first crucial step to supporting the person with dementia to make adaptive psychological, instrumental and social adjustments.

Psychological Adjustment

Psychological adjustment involves working through a process of loss and grief, adaptation and finally acceptance, whilst aiming to maintain one's sense of self (Bunn et al., 2012; Mok et al., 2007). The onset of dementia places enormous demands on one. Yet, as testament to the remarkable human spirit, people engage in a number of coping strategies to adjust. These largely fall into two main categories along the same continuum: self-protective and integrative strategies. Self-protective strategies involve attempting to hold on to one-self and maintaining a sense of normality, whilst integrative strategies involve confronting the challenges and threats face-on, balancing hope and despair, and eventually coming to terms with the disease (Clare, 2002; Steeman et al., 2006). Responses may be influenced by the person's understanding of dementia. For example, findings in one study showed that those who acknowledged a dementia diagnosis tended to use self-adjusting or integrative strategies, whereas those who thought their forgetfulness was a normal part of ageing, relied more on self-maintaining or self-protective strategies (Harman & Clare, 2006). Self-maintaining strategies include denial, avoidance, minimisation and normalisation of symptoms, comparing oneself to others less fortunate and reinforcing one's identity through past experiences and family (Low et al., 2018).

Another study highlights how people in the early stage of AD simultaneously engaged in a process of acknowledgement and resistance in an attempt to maintain agency (Macquarrie, 2005). Acknowledgement was expressed through thoughts and feelings about their symptoms and specific strategies to cope with these. For example, relinquishing an activity by choice, such as driving, rather than being told to, provided a greater sense of agency. Similarly, choosing to withdraw from a social activity rather than facing embarrassment by one's word-finding difficulty. Resistance was expressed through strategies to normalise or minimise symptoms, such as attributing memory lapse to old age. These responses are not static classifications of acceptance or denial, but rather dynamic responses on a continuum. They should not be attributed to neurogenic disease processes; they are one's attempt to hold on to their agentic selves when challenged by a major cognitive disorder and social processes that undermine their agency (Macquarrie, 2005).

Interviews with people in the early stages of dementia reveal five key interrelated processes that one undergoes in coming to terms with dementia: noticing the changes, reacting to them, trying to explain them, experiencing the emotional impact of the change, and attempting to adjust to the changes (Clare, 2002). Another study found similar findings, comprising five different stages: antecedents, anticipation, appearance, assimilation and finally acceptance (Hall, 2003). Antecedents included shifts in functioning, alerting the person that something was wrong, although this was often misattributed to stress, aging or other health problems. Anticipation included anticipating a diagnosis and then worrying about future losses and becoming a burden on others. Appearance involved recognising that others were aware of their declining memory and functionality; sadly, many described hurtful reactions from people. Assimilation involved assimilating the disease into their inner and outer worlds, their feelings and thoughts, and the adjustments they made to accommodate their declining memory and functionality, including how they engaged with others. When people were supportive this enabled them to reach acceptance and focus on achieving quality of life, whereas negative reactions from others had a devastating effect. Other factors that contributed to their acceptance included maintaining a sense of humour and being able to do something meaningful and altruistic.

Another study attempting to understand people's lived experience of early dementia highlights their acknowledgement of having dementia and their understanding about the disease, expressed as a realisation that 'it would only get worse'. At the same time, they engaged in strategies to maintain their sense of identity expressed as 'I want to be me' (Harman & Clare, 2006). These findings provide further evidence for simultaneous and cyclical self-adjusting and self-maintaining coping strategies. It highlights how people are actively seeking equilibrium between loss and maintenance of self (Steeman, Dierckx De Casterlé, Grypdonck, Tournoy, & Godderis, 2013). It also demonstrates that maintaining a sense of self is important to people with dementia - perhaps even more so, as they are confronted by a disease that gradually diminishes their world, and a society that appears to undermine their personhood.

Maintaining hope is also central to adjusting to dementia (Cotter, Gonzalez, Fisher, & Richards, 2018). Individuals with a higher level of hope also tend to have a greater sense of self-worth (Cotter, Gonzalez, Fisher, & Richards, 2011; Woods, 2012). Hope is a catalyst that enables people to cope and navigate significant life challenges. A conceptual analysis of hope in people with dementia revealed that hope centred around four key areas: (1) hope in the experience of loss and ongoing adjustment; (2) future orientation of hope; (3) hope and social identity and social network; and (4) hope and adaptation to daily living (Cotter, 2009). Thus, hope is framed within the context of one's reality, acknowledging the constraints of dementia. Strengthened by hope, and with support from others, people engage in practical tactics to help them cope and adjust.

Practical Adjustment Strategies

Practical adjustment may include focussing on broader issues such as planning to get one's finances and living arrangements in order, adapting the physical environment to accommodate changing abilities, taking care of advance care planning and appointing an enduring power of attorney (Cotter, Spriggs, & Razzak, 2018; Drury-Ruddlesden & de Vries, 2019; Harrison-Dening, 2013; Woodbridge et al., 2018). It also includes micro adjustments that impact on every day functioning. People demonstrate great resourcefulness in dealing with their impaired cognitive ability and functionality. To counter memory loss, people use memory aids such as keeping journals, writing ‘to do’ lists, setting alarms as reminders to take certain actions, having visible calendars, and keeping names of their children and grandchildren in a handy location. People work hard to strengthen their cognitive functioning, even as it is declining, by engaging in cross-words, maths puzzles, reading books, taking a new course, learning a new language or instrument and playing cards. This often means having to exert extra effort to retain the rules of card games such as bridge, by reading up on the rules prior to each game. Cooking, once effortless and accomplished without recipes, poses challenges and individuals may resort to using post-it notes to mark particular recipes, and write notes to themselves to remind them to turn off the stove.

Some take a more holistic approach to health, and modify their diet eating foods rich in vitamins and considered good for the brain, and vigilantly maintain their physical fitness. Others focus on pursuing work or a hobby for as long as possible and some take up new work and responsibilities, such as housework or gardening, or looking after grandchildren, seeking to make a meaningful contribution to their families (Matchar & Gwyther, 2014). They continue to make meaningful contributions to wider society in other ways, through paid or voluntary work, or by participating in research and advocating for people with dementia. Given the heterogeneity of people with dementia, the activities they choose to pursue and the contributions they make are diverse.

Social Adjustment

Social adjustment includes the repositioning of self and others, as friends, family members and carers take on new roles, and relationships are redefined. It also involves creating strategies to remain connected to the community. In early-stage dementia, people strive to remain socially connected to friends and actively pursue social activities with trusted others, whether it’s going for a walk together, or going out for a meal. They are active and agentic in managing social connections and often work hard at impression management, although it is mentally exhausting (Birt et al., 2020).

People can and do continue to enjoy fulfilling relationships. One study highlights how married couples, faced with spousal dementia, continued to nurture their relationships and both worked hard to maintain their identity of couplehood, believing strongly in partnership for life, reciprocity and forgiveness (Davies, 2011). Despite shifting roles from one of independence to dependence, they remained interdependent and were committed to working through difficulties and enjoying activities together.

People with dementia are active agents who interact with their illness and, like healthy others, seek to make a meaningful contribution (Matchar & Gwyther, 2014). They seek social connection and strive to maintain their self-identity often through what they do. Gradually, as functionality declines, the concept of being valued shifts from being valued for what one does, to being valued for who one is (Steeman et al., 2013).

LIVING WELL WITH DEMENTIA

Defining Living Well

Living well with chronic illness and disability has been defined as ‘the best achievable state of health that encompasses all dimensions of physical, mental and social wellbeing’ (Clare et al., 2014). In New Zealand, Durie’s Te Whare Tapa Whā model of wellbeing also includes spiritual wellbeing (Durie, 1985). Stephens (2017) proposes that rather than framing healthy ageing through the moralistic ‘successful’ ageing model which puts responsibility for health on the individual, thereby excluding those who are disadvantaged due to disability, chronic illness or social and structural inequalities, and also bestows a sense of ill-founded blame on individuals, the focus should shift to a ‘capability’ framework which emphasises what people are able to do and be. This conceptualisation is more inclusive and better reflects the possibility and reality of living well with dementia. It also aligns strongly with positive psychology which helps individuals and cultures better achieve what they already value (Seligman, 2019).

The experience of living well is indexed by positive evaluations of subjective wellbeing, life satisfaction and quality of life (Clare et al., 2014; Wu, Clare, & Matthews, 2021). These indices, although interrelated, comprise distinct elements. Subjective wellbeing reflects the emotional response to circumstances, including the right balance of positive and negative emotions (Diener & Chan, 2011). The PERMA model posits five basic elements of wellbeing encompassing positive emotion, engagement, relationships, meaning and accomplishment (Seligman, 2019). Life satisfaction encompasses a sense of happiness, wellbeing, purpose and meaning, personal growth, a sense of being in control of one’s life, and active social participation (St. John & Montgomery, 2010). Quality of life is subjective and contextual and relates to one’s personal goals, expectations, standards and concerns. It is affected by one’s physical health, psychological state, personal beliefs, social relationships and their environment (World Health Organisation, 1998).

As illustrated above there are multiple conceptualisations of wellbeing, making it difficult to untangle the different elements and clearly distinguish between overlapping and connected constructs. What each of these conceptualisations have in common, however, is that they all highlight the individual's subjective evaluation based on what the individual values, and they also all emphasise social factors as being pivotal. These definitions and conceptualisations of wellbeing align with Kitwood's early view of wellbeing in dementia, focusing on four global states: maintaining a sense of self-worth; maintaining agency; social confidence or feeling at ease with others and welcomed by others; and maintaining hope (Kitwood & Bredin, 1992).

A Strengths-Based Approach

Despite the indisputable losses and challenges presented by dementia, people can and do live well with dementia. Whilst some studies have indicated lower life satisfaction in older people with dementia compared to those without dementia or cognitive impairment, the size effect has been relatively small (St. John & Montgomery, 2010). Furthermore, people with dementia tend to rate their life satisfaction higher than those reported by proxy (St. John & Montgomery, 2010). Rather than accentuating a deficit narrative of people's lived experiences of dementia, narrowly viewed through the biomedical paradigm, some studies have taken a strengths-based approach (Hillman et al., 2018). Despite this, some argue that many of these studies restrict these narratives to coping and countering loss (Wolverson, Clarke, & Moniz-Cook, 2016). A meta-analysis of strengths-based studies provides an alternative view, seen through the paradigm of positive psychology (Wolverson et al., 2016). It elucidates how some people with dementia are primarily actively engaged in life and focussed on ageing well, rather than on their dementia. Additionally, instead of positioning people as actively confronting the challenges of dementia within a 'coping' discourse, this could equally be seen from a positive psychology perspective, framing people as brave, agentic and persistent in pursuit of their goals. This study also reveals how some people with dementia may transcend their condition and achieve personal growth, through gratitude and reviewing their life within its full context (Wolverson et al., 2016).

MacRae's (2007) interviews with people in early stage dementia highlight their determination to 'make the best of it' by using strategies such as humour, normalisation, present-time orientation and life review. Life review has been found to be beneficial for people with early to middle stage dementia by helping them maintain self-continuity and increasing quality of life scores (Subramaniam, Woods, & Whitaker, 2014). Focusing on the present and making the most of life is a common phenomenon for those faced with a chronic illness and impending death (Charmaz, 1991). Some interviewees expressed personal growth, stating that they now had more patience for others and a deeper appreciation for life. They accepted their diagnosis and saw dementia for what it is, an illness, not something to be embarrassed by. Contrary to the views of others, who focused largely on what people with dementia could not do, interviewees focused more on what they could do, such as reading, maintaining physical fitness, playing bridge, doing cross-words and socialising. Their self-identity was not dominated by dementia. In response to the 'who am I?' question, where people are asked to think of multiple responses, none of them referred to their dementia, but rather to their social roles and positive attributes. Some had constructed a new identity as one who helps others by participating in research and advocating for people with dementia. Critical, to their positive outlook, however, was the support of those around them, who continued to affirm their worth and selfhood.

Another study highlights how people with early stage dementia who initially struggled with a deep sense of loss and uncertainty following their diagnoses, experienced a strong sense of purpose, self-worth and agency when they joined the self-help network, Dementia Advocacy and Support Network International (DASNI) (Clare, Rowlands, & Quin, 2008). They took on important roles of supporting each other as well as educating others and advocating for people with dementia. They realised that there is life beyond a diagnosis of dementia and that they could make a worthwhile contribution in helping to affect societal change for the benefit of people with dementia in general. This realisation, together with social support and the purposeful work they were undertaking had a positive impact on their psychological wellbeing. This demonstrates how people with dementia can continue to have a fulfilling life, and highlights the importance of social support.

Dementia Friendly Communities

There is increasingly a focus on creating dementia friendly communities where people with dementia can continue to live with dignity within their community, free from stigmatisation and isolation, and with access to good support services. Key pathways include public awareness and accurate education about dementia, normalising dementia, connectedness within the community, and infrastructures that enable people to actively engage in their community with easy access to support services (Courtney-Pratt et al., 2018).

The movement towards dementia friendly communities supports a growing recognition that people living with dementia have the right to dignity, respect, autonomy, independence and an active voice within their communities. Currently, at least 19 countries have a national dementia policy or plan: Australia, Belgium, Costa Rica, Cuba, Denmark, Finland, France, Ireland, Israel, Italy, Japan, Luxembourg, Mexico, Netherlands, Norway, Republic of Korea, Switzerland, United Kingdom of Great Britain and Northern Ireland, and the United States of America. Priorities specified within the policy and plan include raising awareness, early diagnosis, good quality continuing care and services, caregiver support, workforce training, prevention and research (World Health Organisation, 2015). In New Zealand, the New Zealand Framework for Dementia Care emphasises similar focus areas and it advocates for care and support services that meet the unique needs of individuals’ cultural, social, family and whānau, spiritual, occupational and economic needs (Ministry of Health, 2013) .

Japan is recognised as being the country where dementia friendly communities began (Williamson, 2016). Other countries, such as, the Netherlands and Italy have taken a leading role in setting up dementia-friendly neighbourhoods (Ricci, 2019). The Four Cornerstones Model provides a framework for creating a dementia friendly community by focussing on place, people, networks and resources. Places such as restaurants, banks and leisure centres are easily accessible and welcoming for people with dementia. People are aware of dementia, non-judging, empathetic and supportive, and networks for and led by people with dementia are valued. Additionally health and social care resources are readily available (Crampton & Eley, 2013). Rather than imposing a one-size fits all model, community stakeholders should be proactively engaged and involved in discussions about how to create inclusive and supportive communities that cater to the needs of people with dementia, and harness personal, relational and contextual strengths specific to the community (Courtney-Pratt et al., 2018).

Key barriers to creating dementia-friendly communities, however, are the perpetuating societal narratives that create and maintain stigma. The media can support by portraying people through a personhood lens, focussing on the person rather than the disease (Cullum, Simpson, & Gounder, 2020). People need accurate and balanced information so that they can recognise dementia for what it is, as opposed to how dementia has historically been portrayed. People need to speak about it openly and engage with people with dementia. It is through contact and engagement, and positive social and educational campaigns that dementia can be accurately represented, destigmatised and normalised, as has been done for other chronic illnesses, such as cancer (Courtney-Pratt et al., 2018).

Social Support

It has long been established that physical care alone is insufficient for one's wellbeing, and that social contact is crucial (Bowlby, 2005) Irrespective of the stage of dementia, people are social beings who derive benefit from warm social relationships (Sabat & Lee, 2012).   A Swedish study of people diagnosed with early stage dementia reported that they continued to attend a support group, not because of the information that was shared, but because of the social interaction and friendships (Kjallman Alm, Hellzen, & Norbergh, 2014).   Peer support creates positive emotional and social impacts through identification with others, commonality of experiences, and support reciprocity (Keyes et al., 2016). Furthermore, social interaction has been shown to delay cognitive decline (Hikichi, Kondo, Takeda, & Kawachi, 2017). Social support, especially informal support from caring family and friends is crucial for quality of life in people with dementia. It helps build resilience enabling individuals to cope better with everyday challenges of dementia (Matchar & Gwyther, 2014). Social support and participation in activities has a positive impact on people with dementia, and life satisfaction is higher in those with good social networks and social support (Clare et al., 2014). Studies show a clear correlation between the quality of relationship with significant others, and quality of life in early-stage dementia (Clare, Nelis, Martyr, Markova, et al., 2013).

Social engagement with familiar others, such as friends and family, helps counter loneliness which is a significant issue for people with dementia. Loneliness both exacerbates, and is a precursor to cognitive decline. Weiss (1974) proposes two distinct forms of loneliness: social isolation, when there is an absence of friends and family; and emotional isolation when an individual lacks an emotional attachment to another person (Moyle et al., 2011). Studies show that social support and being married can lead to increased life satisfaction in people with dementia (Ataollahi Eshkoor, Hamid, Nudin, & Mun, 2014). Family and friends can play a significant role in easing both social and emotional isolation. An Australian study highlighted that people with dementia don’t want to simply be taken to a day centre with unfamiliar people, where the environment may be noisy and not conducive to conversing; instead, they would rather spend quality time with familiar people who bring comfort (Moyle et al., 2011).

Positive social interactions and supportive relationships reduce the negative impacts of dementia and can counter stereotyping, stigmatisation and marginalisation of others. Generally, people with early stage dementia are aware of their impairment and want to continue living their normal lives (Langdona, Eaglea, & Warner, 2007). Studies show that strong social support enables people with dementia to live safely and remain actively engaged in their community for longer (Wiersma & Denton, 2016). Caring friends and family can help people with dementia to stay engaged and active, living meaningful lives and maintaining their identity, by treating them with respect and dignity, involving them in social activities, and encouraging and enabling them to perform chores and feel useful and valued (MacRae, 2011).

Even in moderate and late stages of dementia, people actively engage in social interactions whether through language or embodied self-expression (Medeiros, Saunders, & Sabat, 2012; Sabat & Lee, 2012). In one study, people expressed their appreciation for their long-time friends, seeing them as people they could trust and confide in. They felt these friends valued and respected them for who they were, not for what they could remember (Medeiros et al., 2012). Friends demonstrated commitment and loyalty not only to the person, but also to their relationship which they valued (Harris, 2013). They continued to see the person for who they were, not a diagnosis. Likewise, those with dementia spoke about the importance of reciprocity and mutual benefits of their friendship . Others expressed sorrow at losing their friends when they most needed them, simply because their friends were uncomfortable being around them and did not know how to react (Harris, 2013). How people engage with their friends with dementia has a profound impact on how people experience dementia.

SUMMARY AND KEY INSIGHTS

The prevalence of dementia is widespread and, given our aging population, it is rapidly increasing both globally and within New Zealand, with more people being diagnosed earlier. Virtually everyone will be affected by dementia in some form whether directly, or indirectly through family members and friends. Dementia has significant, far-reaching human, social and economic impacts for the individual, their carers, family, friends and wider society. The type of dementia, age of the person, comorbidity, and psychosocial factors impact people's lifespan, however, many people continue to live for several years within the community before going into residential care. The evidence shows that how the person experiences dementia is largely driven through social processes, interactions, and social positioning, rather than through neurogenic processes. How communities and friends treat people with dementia, therefore, has a significant impact on the person's sense of self, their quality of life and wellbeing.

People with dementia, especially in the early stages of dementia, generally have a high level of awareness, and studies show that some level of awareness is retained throughout the course of the disease. Given this awareness, and confronted with cognitive decline, changing roles and relationships, people with dementia often experience extreme feelings of loss, uncertainty, fear and grief. At a time when they most need support from family and friends, their social network and support dwindles, leaving them isolated, alone and often stigmatised . This impacts their self-esteem and self-identity, undermining their confidence and accelerating their social and cognitive decline, resulting in greater disability, premature disengagement, early dependence, depressed mood and a significantly diminished quality of life.

Much of this psychological suffering and premature disengagement can be ameliorated by caring friends who continue to invest in the relationship and honour their friendship. However, many friends withdraw, either because they believe the person lacks awareness, or because they don't know how to respond to the cognitive decline, or because they find it too painful to see their friends struggling, or can't cope with the fact that they may no longer be recognised. These are issues for the cognitively intact friends to grapple with, not the person with dementia. The person with dementia should not be forsaken because of others' discomfort. On the contrary, the person with dementia is actively trying to come to terms with their illness and adjust to the impacts on their daily functioning, their relationships and sense of self. They need their friends more than ever to stand by them, comfort them during times of distress, help them to remain actively engaged in life and the community, remind them of treasured moments and loved ones, reaffirm their worth and life, their contributions past, present and future, nurture their self-esteem and support them to maintain their self-identity.

While there has been much focus on supporting carers and family to cope with looking after a person with dementia, it is only latterly that the focus has turned to supporting the person with dementia to live well, and there is an increasing focus on creating dementia friendly communities. However, whilst there is a general consensus that people with dementia need to be treated humanely, with dignity, and be afforded every opportunity to enjoy quality of life, there is a lack of awareness amongst lay people, on how to achieve this. Lay people, such as friends, are ill-equipped, and don't know how to support their friends who have dementia, even if they have a strong desire to do so. Education, information and guidance has largely been targeted at family and caregivers, and professionals in residential care, not friends. This represents a gap in the literature, with far less research and understanding of the role of friends in supporting people with dementia.

Additionally, whilst recent studies increasingly attempt to give voice to people with dementia, the focus is generally limited to understanding their lived experiences. There is an opportunity to take this a step further, by tapping into people's own wisdom and insights as to how they would prefer to be supported by their friends. Whilst researchers generally acknowledge that the person with dementia is an expert on their lived experience, many researchers tend to position themselves, and not the person with dementia, as the expert in identifying and developing possible solutions for those with dementia. Notwithstanding the expertise and role of professionals, there is an opportunity and need to conduct research in a way that gives greater voice to people in the early stages of dementia, honouring their wishes, insights and expertise and enabling them to be more agentic, taking an active role in providing guidance as to how friends can enhance their wellbeing.

The intent of this study is to engage with people in the early stages of dementia to understand from them how friends can best support them in their wellbeing. The focus is on wellbeing, as opposed to a narrow focus on support within a deficit model. Themes may provide a useful framework or blueprint for friendship interactions with people in the early stages of dementia. It is hoped that this will serve as a pragmatic guide for all of us in the community, thereby enabling people to live well with dementia. The specific question being explored is: how can friends enhance the wellbeing of people in early-stage dementia?

METHODOLOGY

The methodologies used in this study were Interpretative Phenomenological Analysis (IPA) and Appreciative Inquiry (AI). Methodologies can be combined and flexed provided a clear and coherent epistemology is maintained throughout the research (Carter & Little, 2007).

Interpretive Phenomenological Analysis (IPA)

IPA is underpinned by phenomenology and hermeneutic epistemologies. Phenomenology is concerned with people's subjective lived experiences, and hermeneutics is concerned with how people interpret and make sense of their experiences (Smith & Eatough, 2012). The ontological assumption underpinning both phenomenology and hermeneutics is that there are multiple realities, as opposed to 'one reality' or one universal truth. Realities are constructed by people engaging in the world and these cannot be separated into a Cartesian dualism of mind and body. Epistemologically therefore, how people come to know and understand their world is through experiencing it, and constructing meaning from it and about it. This framework acknowledges the interactive role of researcher and participant in constructing meaning (Laverty, 2003).

IPA is aligned to Heidegger's interpretive approach of phenomena. From a hermeneutics perspective, Heidegger asserts that as people are already in the world, living it and experiencing it, the starting point for understanding human behaviour is the pre-reflective 'ready-to-hand' mode, when people are actively engaged in an activity (Packer, 1985). However, to interpret the deeper meaning of this activity, one needs to push this understanding into the 'unready-to-hand' mode when the individual involved in the activity becomes more aware of the significance of the different elements of the activity, usually because it has been thwarted in some way (Packer, 1985). This can be orchestrated by getting the individual to reflect on the different elements of a particular phenomenon. In the current study, participants were asked to reflect on pleasurable moments with a friend and how this made them feel.

In IPA it is not sufficient to merely describe – hermeneutics requires one to interpret and make sense of the phenomena being explored and views understanding and meaning as contextual, cyclical and incomplete. The researcher engages in the 'double hermeneutic' attempting to make sense of the participant's own sense-making (Smith, 2011a). This requires the researcher to examine the different elements of the participant's experience both discretely and holistically, moving backwards and forwards between the whole and its parts, to interpret the deeper meaning. The researcher needs to be simultaneously immersed in the participant's experience, attempting to stand in the shoes of the participant, whilst also maintaining a critical view and probing further to uncover deeper, hidden meaning (Smith & Eatough, 2012).

Clearly, this is constrained by participants' abilities to articulate their thoughts and experiences. One might therefore question the suitability of this approach for people with cognitive impairment, such as dementia. However, the participants in this study were all at the early stage of dementia and were able to describe their experiences and articulate their thoughts. In fact, several studies have used IPA in research with people with dementia (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Clare, Rowlands, & Quin, 2008; Harman & Clare, 2006; Smith, 2011a). Furthermore, all people have limits in describing their experiences and expressing their thoughts. These limitations do not invalidate their description or interpretation of their experience. Additionally, language alone cannot truly do justice to describing and explaining phenomena. For example, does language fully capture the physical and emotional experience of being in love? Whilst hermeneutics is textual, it considers text as broader than language, encompassing art, music, body expression including silence. Finally, interpretation is also constrained by the researcher's own bounded knowledge, viewpoint and skills in analysing, reflecting, interpreting and illuminating insights. Hermeneutics allows for this, recognising that we are all bound by our sociohistorical context.

Whilst our sociohistorical context constrains our perspectival horizons (Laverty, 2003) we can broaden our perspectival horizons and expand our thinking by being open to others' perspectives, and achieving what Gadamer terms a 'fusion of horizons' between past and present thinking (Gadamer, 1975; Martin & Sugarman, 2001). In the current study, this fusion of horizons is apparent in the way participants' accounts altered the researcher's pre-conceptions of people with dementia. Unexpectedly, the researcher found no obvious tell-tale signs that any of the people in this study had dementia. Approaches, such as IPA therefore, have the ability to be transformational for both researcher and participant (Giddings & Grant, 2002).

IPA is idiographic, focusing on in-depth analysis at the individual level, so sample sizes are small, sometimes involving just a single case (Smith, 2011a). Where multiple individuals are involved, they are generally homogenous, and IPA attends first to each individual before seeking to find convergence and divergence across individuals. Lived experience is the fundamental unit of analysis . IPA focuses on a relational chain between embodied experience, discussion about the experience, the participant's sense-making of the experience and their emotional response to it (Smith, 2011a).

IPA enables an 'engagement' approach to research (Anstiss, Hopner, van Ommen, & Yen, 2018), involving rebalancing power between researcher and participants, jointly constructing knowledge and working together towards social change that benefits people. It provides a means of giving voice to those whose voices might not otherwise be heard, such as those with dementia. This was a key reason for selecting this methodology for this study. Other reasons included IPA's focus on small sample sizes and its rich in-depth analysis at the idiographic level, rather than superficial breadth; and its explicit recognition that the researcher cannot be a neutral bystander, but rather an active agent who influences and interacts with participants, and actively engages in interpreting participants' own sense-making. This aligns with the researcher's own values of people being experts in their own lives, the need and right for marginalised people to be heard and agentic, and recognising the constraints and influences of one's own biases and perspective.

Appreciative Inquiry (AI)

AI is a methodology that searches for the best in people, their organisations and the world around them (Cooperrider & Whitney, 2005). It has been used extensively in organisational development, as an affirmative approach to change, focusing on what is good about organisations rather than taking a traditional deficit, problem-focus. Like IPA it too can be transformative. Ontologically and epistemologically it aligns well with IPA as it too is underpinned by social constructionist assumptions and it is grounded in real experiences. It differs however, in that it is based on positive psychology principles, aligned to Maslow's humanism (Cooperrider & Whitney, 2005; Seligman, 2019).

There are five fundamental principles of AI. The constructionist principle which states that we are constantly involved in understanding and making sense of the people and world around us, and that this is generative and never complete. We make sense of our world through discourse and what we focus on becomes our reality. The second principle is the simultaneity principle which posits that inquiry and change occur simultaneously. There is no such thing as a neutral question; the very question we choose to ask influences others and sows the seeds for change. The poetic principle asserts that our stories are constantly being co-authored. Like a poem, our life stories are ongoing sources of learning and inspiration, always open to interpretation. Applying this principle means that we can choose to focus on any topic, and that topic should be focused on the world we want to create together. The anticipatory principle asserts that images of the future guide current behaviours. Finally, the positive principle asserts that creating momentum for change requires positive affect and social bonding. Conversations and experiences embedded in positivity build possibilities, relationships, commitment and collaborative action. According to Cooperrider and Whitney (2005), familiarity with these principles enables one to adapt AI to unique and challenging circumstances. Whilst this methodology has been used extensively within organisations, they attest to its application with individuals too, and AI has been used in previous studies with people with dementia and their carers (Barnes, 2010; Page, Rowett, &

Davies-Abbott, 2017; Seebohm, Barnes, Yasmeen, Langridge, & Moreton-Prichard, 2010).

Generally, when applying AI methodology, researchers engage in a 4-D cycle of ‘discovery’, ‘dream’, ‘design’ and ‘destiny’ which can take many forms of expression (Cooperrider & Whitney, 2005). The discovery phase typically starts with the appreciative interview, where the question focuses on some positive experience and uses this experience as the basis for what might be in the dream phase. In this study, AI has been adapted to focus on these first two elements of the 4-D cycle. This methodology was specifically selected so that participants could focus on what is good about friendship interactions as opposed to focussing on what they might have lost through dementia. This was an important consideration of the ethical risk assessment and in applying the principles of beneficence and non-maleficence. Furthermore, learning and positive change can come from exploring positive contributing factors, and building on these. The last two phases of the 4-D cycle (design & destiny) are beyond the scope of this study. It is hoped that this study will contribute to a more fulfilling future for people with dementia through positive interactions with friends.

METHOD

Given the vulnerability of the population being studied, a comprehensive risk assessment and mitigation plan was developed (refer Appendix 1) and a number of subject matter experts were consulted to determine how best to conduct the research in a way that would both honour and protect participants. This included consulting with Alzheimer's New Zealand, Dementia New Zealand and Dementia Auckland, Massey University, University of Auckland and others in New Zealand who work with people with dementia or who have conducted research with people with dementia.

This study was approved by the Massey University Human Ethics Committee, Southern B, Application SOB 20/16. Several ethical considerations were taken into account which helped inform the choice of methodology and approach taken in this study. IPA was selected as means of understanding people's lived experience from their own perspective, giving voice to people with dementia and honouring their insights and expertise. AI, a strengths-based methodology which focuses on positive experiences and future possibilities was selected as one way to mitigate for potential distress participants might otherwise have experienced through the interview process. Semi-structured interview was the method used to gain access to peoples' lived experiences and to ascertain what 'the ideal' could look like in terms of friendship interactions.

Recruitment Procedures and Participants

Eligible participants were identified as English-speaking individuals with a diagnosis of early stage dementia who resided in the Auckland area and who wished to participate in this study. Potential participants were identified through Dementia Auckland who made contact with them or their carers directly through an email invitation to participate in the study (refer Appendices 2 & 3). This communication, which had been prepared by the researcher also included a comprehensive, user-friendly information sheet (refer Appendix 4). Those who received the email invitation from Dementia Auckland and who were interested in participating in the study reached out directly to the researcher by telephone or email. In all cases, the researcher followed up with both email and telephone conversation. Telephone conversations provided an opportunity to begin building rapport even prior to meeting participants, and emails provided written details as a confirmation and reminder. The researcher reassured participants that a follow-up reminder on the day of the interview would be sent. These personalised reminders were important and appreciated by the participants given their memory challenges as a result of dementia.

In accordance with IPA, participant numbers were kept low to allow for in-depth idiographic analysis. Although IPA can be applied to a single case study, it is preferable to have multiple participants to allow for analysis at both the individual level, and across individuals. Whilst it was hoped to have at least 8 participants in this study, this became a challenge due to COVID-19 restrictions which initially delayed the research and then later interrupted it when it was underway. Consideration was given to alternative ways of conducting interviews other than in person e.g., by zoom or telephone, however, this was deemed unsuitable for the target population and also not conducive to establishing sufficient rapport and trust for people to feel comfortable to share their experiences. Ultimately, four people participated in this study, all being women in their 70s who lived in the Auckland region.

Ethical Considerations

Confidentiality & Informed Consent

Although participants had contacted the researcher to indicate their interest in participating in the study, they were also asked in person to confirm their consent using questions from the Older Adults Capacity to Consent Research (OACCR) scale (refer Appendix 5). This scale has been used in previous research in New Zealand with people with dementia (Smith, Lamb-Yorski, Thompson, & Grootveld, 2019). Critical questions included “what is the purpose of this research?” and “if you don’t want to, do you have to take part in this research?”. This extra step was felt necessary to ensure people did not feel coerced and to ensure they knew what they were consenting to. All participants were clear on the purpose of the research, willingly chose to participate and knew they could opt out at any point. Their rights, which were made explicit in the information sheet previously sent to them through Dementia Auckland, were restated prior to commencing the interview and a hardcopy version was left with them, which included the researcher's and supervisor's contact details.

Whilst the information sheet also made explicit that the interviews would be audio recorded with participant permission, this was further confirmed at the time of the interview, and participants were reminded that they could ask for the audio recording to be turned off at any time. To protect their identify, participants were assured that their names would not be used in final transcripts and documentation. As such, pseudonyms have been used and distinguishing characteristics removed.

Power Differentials

Conducting the interviews in participants' homes would have significantly reduced any perceived imbalance of power between researcher and participant. Additionally in IPA, both researcher and participant work in partnership and the researcher emphasised this and made explicit that participants were the experts - they had the experience and knowledge - and the researcher's role was to learn. All four participants were keen to contribute to research and make a positive difference for people with dementia, and they chose, not only to receive a summary of the findings, but also to reconvene with the researcher to discuss the findings when the study was complete. This also suggests that the participants had a level of comfort with the researcher.

Support

Participants were given the option of having a support person with them at the interview. One person had her husband with her. He sat beside her and for the most part did not participate in the interview, unless she specifically sought input from him. Another participant's husband sat in an adjacent room to begin with. Occasionally, the participant would call out and confer with her husband or engage in light banter, however, as the interview progressed he moved to another part of the house to get on with his day. The two participants who lived alone were interviewed on their own. As a precaution, allowance had also been made to contact a caseworker in case a participant needed additional support, however, none of the participants required this. The researcher also remained vigilant throughout the interview for any signs of distress and had developed a plan of action in advance, to be deployed if needed. This included tactics such as checking in with the participant, offering to stop and take a break, canvassing what support they needed including utilising their support person (refer Appendix 1).

Acknowledging Researcher Limitations

Prior to commencing the research, the researcher reflected on her own professional limitations and boundaries, recognising the importance of remaining within her professional scope. Hence, having access to a caseworker with the right skills should participants have needed was important. Additionally, the researcher exercised caution when participants sought her opinion or advice. The researcher also recognised the limitations of her predominantly Western world-view and sought to learn more about Māori *tikanga*. She also proactively identified cultural advisors who could guide her in interviewing participants, communicating with *whānau* and upholding *tikanga* practices, if any participant identified as Māori. Whilst none of the participants in this study were Māori, the researcher nevertheless upheld the principles of *Te Tiriti* by working in partnership with participants to identify what was important to them and acknowledged them as the experts; ensuring participants' voices were heard and their perspectives honoured; and protecting their rights.

The researcher also critically reflected on her own biases, some which she was well aware of, and others which emerged through critical reflection. For example, having lost her mother to dementia, she felt strong empathy for the participants in the study. This may have been heightened as all participants were women. This meant she had to consciously maintain boundaries and hold her role as researcher, and not try and fill a void in participants' lives by offering companionship. By purposefully reflecting on the ways in which she was both an insider and outsider (although predominantly outsider) in conducting this research, the researcher was able to build empathy, maintain curiosity and remain open to learning (Hellawell, 2006).

Maintaining a reflexive journal and engaging in critical reflection helped the researcher challenge faulty assumptions and confront biases that she had not previously been aware of. For example, initially thinking that one participant may perceive greater loss than another because of the high profile profession she had to relinquish. Acknowledging and then challenging this assumption proved helpful. Consequently, to acknowledge and/or counteract her biases, after each interaction with a participant, whether it was via email, telephone or immediately after the interview, the researcher captured her initial reflections in a journal. Additionally, for each participant, at the conclusion of each interview she asked herself "who was this person / what were they like before dementia?", "what have they lost?" and "what strengths do they bring?".

The Interview

To ease burden on participants, face-to-face interviews were conducted in participants' homes at a time that suited them. Participants were given the option of holding the interviews in their home or other preferred location such as public library, local community centre or at Massey University Albany campus. All participants chose to be interviewed in their homes. An hour was allowed for each interview. This gave sufficient time for introductions between researcher and participant, and where applicable, their spouse; and sufficient time to engage in light-hearted conversations with both to build rapport before getting into the interview.

In accordance with IPA and AI, interview questions focused on a specific phenomenological experience with friends, the important elements of that experience from their perspective, and how it made them feel. From an AI perspective, the questions focused on specific positive experiences including what ideal might look like. For example, questions such as “Tell me about a time recently when you were with a friend, and really enjoyed that time?” and “If one of your close friends, someone you cared about deeply, developed dementia, what would you do to support their wellbeing?”.

An early interview guide was developed, primarily as a means of providing some structure to the interview and to give some fore-thought to potential questions to be explored (refer Appendix 6). The interview was specifically structured to minimise risk of distress, and whilst the final interview questions were modified and further refined in the interview sheet (refer Appendix 7), the overall structure was maintained. This included establishing rapport, setting expectations, informed consent, clarifying their rights, focusing on positive lived friendship experiences and their own wellbeing, and acknowledging their contribution. The interview guide also included tips for conducting interviews with people in the early stages of dementia (refer Appendix 6) and the interviewer adhered to these. For example, sitting close enough where the participant could easily see the interviewer’s mouth and eyes, offering encouragement, and providing reminders to what had been said prior by summarising and reflecting back. These tips were created based on existing guidelines and research (Alzheimer’s Organisation, n.d.; Bryden, 2005; Nazarko, 2015; University of Queensland Dementia Care, 2012) as well as through personal reflection and adherence to ethical principles outlined by the New Zealand Psychologists Board: 1) Respect for the dignity of persons and peoples; 2) Responsible caring; 3) Integrity of relationships; 4) Social justice and responsibility to society (New Zealand Psychologist’s Board, 2012).

Analysis

In accordance with IPA, audio recordings of interviews were transcribed verbatim. This enabled the researcher to re-familiarise herself with the data and also adopt a more critical stance, paying particular attention not only to content, but also to tone, hesitation and sighs, which conveyed, to some extent, the emotions experienced by participants, and reminded the researcher of the nuances of each interviewee. Each audio was replayed multiple times to check the accuracy of each transcription, and to enable the researcher to move back and forth between the whole and its parts, an important element of conducting IPA. Through this process some themes and insights stood out, however, the researcher deliberately slowed this process down by summarising the content of each statement made by the participant in the left hand margin, whilst also capturing key quotes and concepts that seemed pertinent to these summary descriptions. This was to minimise the impact of the researcher's own biases and the risk of missing important themes.

Once this was complete, the researcher re-read the summary descriptions and identified emerging themes in the right hand margin. These themes were checked against the actual participants' accounts to ensure relevancy. These themes were then clustered together into superordinate themes, initially by capturing individual themes on post-it notes and then manually grouping them together (refer Appendix 8). These themes were then structured in a way that could facilitate telling the idiosyncratic story of each individual participant (refer Appendices 8 – 11). This meant that a lot of contextual data that did not directly answer the research question was also themed and captured. This was an important step to help understand each person within their context and take on both the empathic and critical roles of the researcher required in IPA. The analysis of these contextual factors was important in interpreting the findings specific to the research question.

The researcher then reviewed the themes and content focussing specifically on the research question "how can friends enhance the wellbeing of people in early stage dementia?"and themed these again for each individual. This process was repeated for all four participants. The researcher then analysed themes and content across participants looking for convergence and divergence. According to Smith (2011a), for a sample size of four participants, convergent themes reported on should be evidenced across at least three participants. This guideline seems contradictory to the in-depth idiographic analysis of IPA, where every individual's lived experience is informative and important. Smith does however, concede that a single salient quote illustrating a lone theme from a single participant can be significant and illuminating (Chamberlain, 2011; Smith, 2011b). In this analysis, rather than falling victim to methodolatry (Chamberlain, 2000), the researcher has attempted to find a balance between meeting IPA quality standards (Smith, 2011a) and honouring the voices of all participants who generously contributed to this research.

FINDINGS: CONTEXTUAL FACTORS

Before presenting the findings of the key research question, outlined below are the contextual findings uncovered through this research. It is intended to provide a glimpse into the lives of these women both before and since dementia, gain a sense of some of the challenges they encounter as well as their remarkable insights and strengths. This contextual understanding is important as it lays the foundation for more fully comprehending the specific findings on how friends can enhance the wellbeing of these women in particular, and potentially for people with dementia in general. It encompasses six over-arching themes: a life lived well; coming to terms with dementia; a sense of vulnerability; people can be hurtful; feeling down; holding on to self. They are deliberately presented in this order as in some ways, they depict the women's journeys. After portraying these contextual factors, a more in-depth analysis on how friends can enhance the wellbeing of these women is presented.

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A life lived well

All four participants were women in their 70s living in the community. Each one described a full life with vast and rich experiences, and they seemed to have an overall sense of satisfaction with how they had lived their lives, despite past hardships. This sense of satisfaction was largely driven by their connection with family and friends, and their professional achievements as exemplified by the following quotes from each participant.

> *It's not the country that makes your life great – it's your friends and family that you're close to. I had the best time of my life there.* [Tanya]

> *He's a silly old bugger but he's a rock. He frustrates the hell out of me sometimes and I frustrate the hell out of him sometimes probably…. um, but we've been married for [X number] years or so, so you know, there's a solid partnership there.* [Debra]

> *Bless them [colleagues], they are getting, they are getting a collection of my [work]together ... which is wonderful!* [Margarite]

> *I was a [professional role]. I used to be really good at that ....* [Suzie]

All four women showed strength and resilience, each having adjusted to different losses and challenges, such as marriage break-ups, financial hardship, miscarriage and loss of loved ones. However, they were at the age and stage of life where they could reflect on these as part of the "ups and downs of life" without detracting from their overall sense of a life lived well.

> *Oh yes, I had a brilliant life there. I loved every minute of it. Ah I mean, there were some tough times but they were mostly financial.* [Tanya]

> *Well we've had lots of ups and downs ... [friend] was very supportive ... so we've always supported each other.* [Debra]

Coming to terms with dementia

For these women, coming to terms with dementia involved accepting they had dementia (generally through diagnosis), recognising their limitations, developing compensatory strategies and reframing how they saw dementia. These are illustrated below.

All four women had been diagnosed with dementia within the last 2 – 3 years. One woman diagnosed herself before her diagnosis was confirmed, and another sensed a gradual decline. Two women expressed shock and anger at the initial diagnosis. The extracts below also highlight how each person experienced this in a unique way.

> *Yes, and I actually was quite aware that it was … that I had dementia before I actually went to the doctor… It was getting really bad. It wasn't so much forgetting things. Mine was disorientation. I would … I could go out of my flat and not know where I was. I wouldn't recognize anything around me where I'd lived for yonks … .and I used to get lost. I'd ring people up cry … I'd ring my daughter up crying ...* [Tanya].

> *It's been slow … you know it's been a gradual thing.* [Suzie].

> *Um, he sent me to see this psychiatrist who he approved of, a sort of colleague or something, I think. It was a great mistake. And um he did various tests on me and afterwards he told me that I had dementia which of course never crossed my mind in a million years. Um, I practically passed out. Um, and so I never went near him again.* [Margarite].

> *I've come to terms with it a bit more. Um, it was a bit of a shock. I was a bit pissed off (whispers) ... And when I told the doctor – I wasn't going to tell the doctor – but then I thought 'don't be stupid, you've got to because that's dangerous'.* [Debra]

All of the women were well aware of the limitations imposed on them by dementia and had developed compensating strategies such as writing things down to jog their memory, avoiding situations they found too challenging or stressful, not venturing far from home on their own, and relinquishing activities, like driving. In many cases, they were able to rationalise these adjustments.

> *So, I accepted it though It peeved me off, but I accepted it and tried not to be too anxious, because God forbid if I run into a car with kiddies or an old person or something, you know. And I shouldn't be driving anyway so I rationalised it and stopped driving.* [Debra]

> *And um, and actually I concentrate and prefer to be at home and looking online or doing the scripture readings on my own because I …., particularly now, I can take things in much better than if I'm at church, because when it's being read to me, I don't …. it's too much information and it clutters my brain. And then I stop thinking about …. I just can't understand anything. But when I'm at home if I don't understand, I google or go over it until I can understand.* [Tanya]

The excerpt below highlights how this woman, whilst acknowledging her limitation, also reframes it in a way that is perhaps easier for her to accept as she focuses her inability to read only on those things that are not of interest to her.

> *Well, I … well I belong to a book club …. And even though I'm not …. I used to read everything but now I'm only able to read things which are really interesting. If it's not I can't - I just can't carry on.* [Suzie]

The same woman chooses to avoid situations which she finds challenging and stressful. She appears to value competence and therefore avoids situations where her competence may feel threatened.

> *I just take it as it comes. Um, yes there's nothing that really, that I can think that really worries me unless it's somewhere that I go that there's quite um uh ... conversation which is um, how can I put it …. About things which a) I don't know a lot about and b) I would have before clicked on which I probably would find difficult to do now. So, I'd probably avoid that sort of communication, I guess.* [Suzie]

The example below, however, illustrates how one acknowledges and accepts the limitations imposed by dementia, and also adapts well to compensatory strategies.

> *Because that's the worst thing about Alzheimer's is how much you do forget … and you know, how much you do have to note down. But you do get used to, you know noting things down.* [Suzie]

Coming to terms with dementia was also helped by reframing and redirecting attention. For some of the women, this involved focusing on what they were thankful for and acknowledging that things could be worse.

> *I feel very blessed to be here ... Now I have a lot to be grateful for and look forward to. [Tanya]*

> *I'm very lucky and there are other ladies from the parish, who I know fairly well but not that well – they're a bit older than me. But they always said, um "let me know when you're back to [wellness activity] and I'll come and pick you up afterwards and we'll go and have a cup of tea" … So, I consider myself very lucky in lots of ways, that I've got that*. [Debra]

> *And in some ways, I thought, well at least it's not cancer like poor [name] had, having to deal with terrible pain.* [Debra]

> *I mean, for me having dementia is far better than having some really crippling disease. There are lots of things which are worse I think you know, as far as enjoyable life loss.* [Suzie]

Another woman found it helpful to focus on "doing something with dementia", thereby taking control and doing something which she considered worthy. As she could no longer do the work she had done formerly, being able to contribute to research may have also given her a sense of purpose and achievement.

> *I like to feel that I can do something with dementia. If I can contribute to some kind of research ... then that's taking it in my hands and saying, "I'll tell you what we're going to do with you*." [Margarite]

The excerpt below demonstrates how reframing how one thinks about dementia has helped this woman to not only come to terms with dementia, but it has also made her determined to make the most of every day.

> *Dementia is different but it's not something to fear ... I'd be very happy not to have it, but I have got it and um it's something that I'm just prepared to go along with and do as much as I can to um, I guess make every day count*. [Suzie]

A sense of vulnerability

As people age, they become more aware of their gradually diminishing abilities such as sensory loss, decreased physical stamina and decline in cognitive processing speed. This can lead to an increased sense of vulnerability which may seem foreign to former healthy, youthful selves. Those who have partners and friends at a similar age and stage can take comfort from one another as they confront their aging together. For people with dementia however, their sense of vulnerability can be quite sudden, more extreme, experienced in isolation without the opportunity to make sense of the change through shared experience with their peers. All four women expressed insecurities and vulnerabilities ranging from physical frailties, mental and social difficulties, disorientation, panic and fear resulting in greater dependence on others.

> *But then I got frail which I've been for 2 years now – nobody knows what it is. It's the … the thought is that it's a kind of, um, my brain angry with, so to speak, with the fact that I have dementia, is trying to make me ill.* [Margarite]

> *And I had no idea how I got there. It wasn't very far but I didn't know where I was. And I thought "calm down, calm down, just hang on a minute, hang on a minute".* [Debra]

> *And I mean I used to catch the same bus to church like four times a week and I'd be on the bus and I wouldn't recognise any … where I was going.   It was terrifying.* [Tanya]

> *I used to be frightened of the dark as a child um and I've never liked being on my own at night so … but I like it less now ... just the security of someone else being in the same house ... someone to help. Yes, and being able to … to know that there's someone else there* [Suzie]

> *I often think of if we were to go travelling again, it would be different you know, because I would be worried about getting lost if I went off on my own or something like that ... I'm not sure I'd want to go to some of the places we went before ... I would be a bit scared about losing my way or losing [Husband].* [Suzie]

Two women also expressed a sense of psychological vulnerability leading to gradual social withdrawal, one alluding to feelings of embarrassment and humiliation, and another a loss in confidence in her social abilities.

> *People don't like to be pushy, you know they don't like to, so to speak, force one to say "No, I'm sorry I can't come out to lunch. It's not a practical thing I can manage anymore". Umm, because they think, you know, with some justification, it's a bit embarrassing, rather humiliating thing to have to say, and that kind of thing.* [Margarite]

> *It didn't matter to me before, but I'd rather small numbers now. And I'm not so sure that I would feel so happy in a great big crowd of people that I only knew a few of. I probably wouldn't. Something I haven't done for a while*. [Suzie]

People can be hurtful

With increased vulnerability comes greater dependence on others. How people treat those with dementia therefore has a significant impact on how people adjust to, and cope with dementia, and their overall sense of wellbeing. Sadly, all four women cited examples of people's actions that had caused them distress in some way. One woman expressed hurt at being treated as if she was "la-la in la-la land".

> *Because I think, a lot of people think that if you have dementia, you're already la-la in la-la land; they don't understand ... I've heard of some friends, some people with dementia who've been um, treated I guess as if they're second ... No, treated as if they're a little bit sort of dotty. And I think that's, that's that's horrible. It's very, very … it's unnecessary and I think it's very hurtful.* [Suzie]

> *You know sometimes, um when with people you're not quite sure what to say or you forget something, some people, you see them go a little bit like that [gestures rolling eyes].* [Suzie]

Two women gave examples of friends who had deserted them at a time of great need.

> *So, I rang up this oldest and dearest friend of mine to say could she do it for me and she said 'No'. I was a bit surprised. Umm, and then she chatted for a bit and hung up on me. Um, I thought that was a bit funny. But I really didn't take it seriously, but I tried ringing her up again and um, not to ask her to do it again, but just for a chat, and she um, had a reason for cutting me off fairly quickly. And after a bit of time, I realised she dropped me cold. She didn't want me around her neck. I was flabbergasted! I'd known her for 40, 50 years ... So, I mean a lot of them [friends], basically, they just drop you.* [Margarite]

> *You can't, you know … If you're a true friend, you wouldn't just ring every few months or not bother.* [Tanya]

Hurt can also be inflicted in more subtle ways which are perhaps less obvious to people, but felt by the women, nevertheless. For example, two women spoke of being misunderstood, feeling their reality was being invalidated by people who seemed to deny their dementia.

> *They say "You look great. No, you can't have dementia". You can understand people saying that, but it's bloody stupid. Who's going to say they have dementia when they haven't? ... A couple of times I've got really close to feel like going ... "would I say I've got dementia, if I didn't for god's sake?"* [Debra]

> *I would rather they accept that I have Alzheimer's and we can talk about it, rather than them pretending that I don't have it.* [Suzie]

One woman spoke of being excluded and not being given the opportunity to express her own wishes, and having decisions made for her without consulting her.

> *Yeah, I guess there would be things which they [friends] have .... would perhaps see as now being over my head. They would perhaps say 'I'll just leave Suzie out of this one". ......I would rather decide and say, "I'm probably not up to that, but I really, really appreciate you asking me".* [Suzie]

Feeling down

Faced with coming to terms with dementia, and being confronted by diminishing capabilities, feelings of insecurity, loss of autonomy, shifting relationships and decreasing social circles, the women experienced deep feelings of depression. The excerpt below depicts the sense of hopelessness felt by one woman, and it also highlights her inner conflict, on one hand wishing to die and at the same time wanting to live as implied by her not wanting to think about it.

> *I don’t really have a ... I mean ask me that [what’s important to her wellbeing] and I just want to cry. Um, I think I’ll be dead within a year. I hope to God I am. Um, but I don’t like to think about it.* [Margarite]

For this woman, sadness was also brought about through a sense of loneliness and lack of purpose. Her expression “find yourself retired and demented” also suggests a lack of control.

> *I think, you know, move to a new place, or just, so to speak find yourself retired and demented and … so you don’t have a place to go anymore.* [Margarite]

One woman described her ongoing battle with depression whilst tentatively acknowledging and hoping that she was through the worst of it.

> *I kept getting sick and I was really struggling with … um ... er ... mental health. I would get very depressed at times ... and I wasn’t dealing terribly well with things there and I was quite down, but I’m pretty … normal now, I suppose.* [Debra]

Another woman felt depressed and also ashamed of how she was feeling about the lost vision she had for her life.

> *I was so depressed, and I really did … I shamefully admitted to my daughter once, that I just feel like I’m sitting around here waiting to die, and that’s not how I wanted to live the rest of my life or pictured it, you know*. [Tanya]

The same woman feared and grieved not only for what she would lose and how she might suffer, but also how hard it would be for her children to see her suffering. Thus, she carried the burden for herself and for those she loved.

> *And I’ve been praying to God, seriously praying, please let me die, take me home before I get to that stage ... and I would hate to think that my son and daughter*

> *would suffer seeing me suffer like that, seeing me like that ... watching me change so drastically that I might not even recognise them one day.* [Tanya]

For some, loss and sadness also centred around the realisation that one was no longer as competent as they used to be.

> *But I think, I think for me, I think, the sadness is that I used to be um, really on top of things.* [Suzie]

> *You know I, uh … It's taken me a long time to get my head around the whole bloody thing, um, and the fact that um, it's … getting worse, little by little*. [Debra]

Holding on to self

Despite their challenges and feelings of sadness and despair, these women displayed tremendous resilience and had remarkable insight. Each one had a good understanding of what was personally important to them for their own wellbeing, and they seemed to hold on to their sense of self, acknowledging both current and past roles, affirming their strengths and focusing on those things that were important to maintaining their sense of wellbeing.

All women referred to their multiple roles, past and current, encompassing professional, familial and social roles. Professional roles were seen as far more than simply careers. For example, Tanya who had given up a professional role early on in her career decades previously, often referred to herself by that role and clearly considered it a key part of her current identity. Similarly, Margarite saw her past career as fundamental to who she is, not just what she did.

For some, key activities played a significant role in defining them. For example, one woman who had to relinquish driving described it as a core part of her since she was

16, an important adult responsibility she had to take on to support her parents. This may explain her strong reaction of anger when told she could no longer drive.

> *The first thing, the doctor did, was cognitive exercises and then said I can't drive. I was so angry. I've driven since I was 16. It was a part of me – and it was quite a big part of me right from the beginning. My father was sick ... So, I, you know it was me who was at home with Mum, so you know I had to drive, as soon as I was 16*. [Debra]

The women also held on to their unique personalities and their very essence of self.

> *And I think, I think to a certain extent, how you've always been is … is …, if things change you know with Alzheimer's, what is there sort of remains there as far as your personality goes*. [Suzie]

> *I'm still Margarite.* [Margarite]

Holding on to self also included affirming one's strengths. These encompassed specific qualities and attributes, as well as capabilities. These self-affirmations may have also played an important role in managing self-esteem.

> *Well, I'm a pretty rounded sort of person in lots of ways and I am very aware of what other people have had to deal with .... I don't want to make anybody else's life difficult, for a start and I'm a very sort of pragmatic, down-to-earth person too.* [Debra]

> *You know I did all that myself. I was quite chuffed, actually ...... I'm very organised.* [Tanya]

> *I can still do quite a lot of emails* [Suzie]

> *Um yes, we talk a fair amount of shop which I've always thought was a pleasant thing to do. Well unless one gets to the stage when one is just too long out of it, but I'm certainly not that*. [Margarite]

Another way the women attempted to hold on to themselves was by trying to do more of those things that contributed to their wellbeing. All four women had good insight into what was important for them. Two highlighted the positive effects of exercise, two highlighted the joy of being out in nature, one stressed the importance of intellectual stimulation and two the thrill of exploring new places around them. However, for all women, the most resounding factor was positive human interaction.

> *The most important, important thing I think personally benefit people with dementia is … is a lively interaction with others, whether they be friends, family or … You know, fun people, doing fun stuff*. [Tanya]

This woman describes how these people interactions are not only fun and pleasurable, but they actually bring her to life.

> *You see the time I spend with them is always quality time. We always have a great time. And I just love, love them coming over, love seeing them ... because they are the ones that really bring me most to life ... through the love and the care and the laughs*. [Tanya]

For this woman, people interactions also provide her with comfort and signal to her that she is cared for.

> *Um, I'd like them to arrange with me or allow me to arrange with them conversations on the telephone which are very comforting. I don't know how I would have got through the lockdown, I must say, in total solitude without those telephone conversations. Um, and just thereby know that they care and are thinking of me.* [Margarite]

The extract below highlights not only the enjoyment of interacting with friends, but also how the mere anticipation of it provides hope and optimism.

> *I enjoy people and enjoy interacting and I really enjoy it when friends come around. I've got some friends coming around next week ... and you know, that's something to look forward to.* [Suzie]

Whilst positive interaction with others provides enjoyment, companionship and comfort, all of which are vital, it also plays a critical role in keeping one "in the world".

> *But just as I've got older and this has, this has come upon me, it is more important for me to get hold of ... for me to be in the world. I've really realised that it's important for my health, my mental health and physical health to be in the world. At least get out two or three times a week ... I need people, whereas [husband] doesn't particularly, but I need to interact, you know what I mean? ... You know, I'm that sort of a person. I need to be out and amongst things.* [Debra]

Armed with this insight, during the course of the interview, this same woman came to the realisation that she should proactively ask a couple of her close friends to connect in with her when she herself withdraws and is unable to reach out during a depressive episode. This illustrates how she actively pursues those things that are important to hold on to herself and her wellbeing.

Contextual Factors – Summary

As illustrated through these women's accounts, dementia can and does impact indiscriminately. These women all had full, active and productive lives when they were struck with dementia. Some experienced quite sudden and unexpected changes, others more gradual cognitive decline. Coming to terms with dementia has been a difficult journey for these women, however, they have all accepted it. Although hard and confronting, a diagnosis of dementia has, no doubt, facilitated this acceptance.

They are well aware of their limitations and they have been creative and agentic in developing strategies to help counteract these. They also realise, however, that quality of life will deteriorate as the disease progresses. Every day they face challenges that make it difficult for them to do the simple things they have always enjoyed, such as reading, hikes and trips away, or those things which have given them a sense of purpose and achievement, such as going to church and work. They have had to relinquish activities they can no longer manage, activities which gave them freedom and independence such as driving, going to the shops alone or venturing out for a walk by themselves. They watch their independence and sense of autonomy slowly being eroded. They feel vulnerable and insecure and increasingly need to depend more on others. The very people they depend on however, can sometimes cause them deep hurt, leaving them feeling abandoned, lonely, undermined, excluded and invalidated. They worry about the future and what will become of them. They often face these fears alone.

Despite all this, they show remarkable strength and resilience actively holding on to their sense of self, acknowledging who they are, the different roles they cherish which have also shaped them. They continue to focus on all the things they can do. They have keen insight into what is important to keep them engaged in the world, feel alive, valued and cherished. It is you and I – family, friends, community citizens making a difference through positive human interactions.

“He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata”
What is the most important thing in the world? It is people, it is people, it is people.

(Māori Proverb)

FINDINGS: HOW FRIENDS CAN ENHANCE THE WELLBEING OF PEOPLE IN EARLY-STAGE DEMENTIA

An analysis of the interviews from this study reveal four superordinate themes which elucidate how friends can enhance the wellbeing of people in early-stage dementia: 1) accept me as I am; 2) be there for me; 3) help me stay in the world; 4) show me I'm worthy. The titles of these themes are purposefully presented in the first person to accentuate the needs, voices and perspectives of the women who participated in this study. To explicate each theme, each one is presented individually, although they are all interconnected as depicted in Figure 1 below.

Figure 1: Positive contributing factors to wellbeing for people in early-stage dementia

Accept me as I am

Acceptance was a strong theme expressed by each of these women. Friends who were able to accept the women as they were, enabled the women to feel understood, acknowledged and valued. Acceptance included others having a realistic understanding of what dementia is and what it isn't, understanding and accepting changes and limitations brought about because of the disease, respecting the women's wishes, and demonstrating empathy and patience.

> *Um, really just treating me as a friend, understanding where my difficulties are, um, accepting it, understanding it, not ever sort of sniffing about it, or talking about it with someone else. You know, I guess it's just acceptance is really important.* [Suzie]

> *Um, probably more general understanding of what it's about. Because I think, a lot of people think that if you have dementia, you're already la-la in la-la land – they don't understand ... And I think that if someone has dementia and they don't belong to a group, or have got family that don't understand, I think that would be awful.* [Suzie]

> *If I get a bit confused and uptight, he will understand what I'm trying to say and why I'm doing that ... And that's a big thing*. [Debra]

Acceptance from others enabled the women to 'be themselves' and gave them a sense of being acknowledged for who they are. Simple gestures, such as eliciting the women's views, shows an understanding and acceptance of the women's needs, and it also signals to them that their views are valued.

> *Because that's the wonderful thing, friends can make such a huge difference just by accepting and not, not being … letting you be yourself and asking you "would that be alright?" and "how do you feel about that?" and that sort of thing.* [Debra]

> *I guess it's, it's just really having good friends who just take me as I am.* [Suzie]

There was a recognition that friends need to be patient with them. They were well aware that being forgetful, repeating oneself or not being able to manage certain things on their own could be "tiresome" for others. However, having friends accept these limitations and show patience and kindness is very important to them. In the extract below, Margarite suggests that patience is possible through love, like the unconditional love and understanding that one gives to a child. However, her comment "in one way you treat them like a child but in another way you don't" implies that it is important to not infantilise one. She indicates that when friends treat one with patience and understanding as shown through statements such as "no it doesn't matter", and actions to 'move it on', this helps minimise any negative feelings one may have about one's self as implied through her comment "we know we're being stupid most of the time". Thus, patience and understanding can counter negative feelings about one's self and help build self-esteem.

> *Um, I suspect it is sometimes very tiresome, listening to the same things again and again and again, or what have you. Or hearing someone again tell you that they haven't managed to do so and so ... So, It does need patience, I think. Um, and it's … If one can do it, and I think, I think love can do it. Um, in one way you treat them like a child but in another way you don't. You treat them like a child in that um, you don't get cross with them or impatient when for the 20th time they tell you that they haven't done so and so, or haven't tended to the mess again or whatever, I'm terribly sorry. You must always say "No, no it doesn't matter. What about dah-dah-dah" and just, just move it on. Um, because we know we're being stupid most of the time. It's all too obvious to us.* [Margarite]

This is further highlighted in the extracts below which show how understanding and acceptance prevent or minimise feelings of shame or embarrassment.

> *Um, just to accept that um sometimes I'm not going to …. yeah, remember or I'm going to repeat something maybe. But it's really not a problem because they know me so well now that I don't … I never feel embarrassed ... [they] accept me... It makes a big difference because you don't feel silly if you can't think of something. You don't feel silly if you can't remember something* [Suzie]

> *Yes, they're really accepting. Um, There's no discrimination. There's no feeling that um if I haven't got into the book and I haven't read it, I don't feel bad about it. It doesn't worry them ...* [Suzie]

Being understood and accepted by friends is also comforting. This is aided by shared history and familiarity, suggesting that long-standing friends have a particularly important role to play in supporting the wellbeing of their friends with dementia.

> *You know old friends are like a comfortable shoe, in lots of ways, isn't it? You don't have to explain yourself. You just are ... I think it's the not having to explain yourself. About why you are a bit ratty, or why you're a bit uptight, or why you're ratty about something. It's that they just know you so well – they accept you as you are for that day. And she probably thought 'oh she was a bit off today' as you do sometimes but the kindness was there ... Yeah, and the understanding.* [Debra]

> *Oh, just straight forwardly, my oldest, dearest friend. Talk about anything, talk about everything – always, you know as it is with really old friends ... Um, and you know, over a period of 50 years, by gosh, it's just as ... it's as nice as breathing you might say.* [Margarite]

Acceptance from others, provides the women with a sense of normality as illustrated through Tanya's comment and Suzie's description below.

> *I just feel like one of the crowd*. [Tanya]

In the following extract Suzie implies how she wishes to be treated 'as normal – like herself' as she describes how her friend treated her husband who also had dementia. She comments that she was good 'to him' and also 'for him', indicating the positive effect this had on his wellbeing. By stating how her friend spent a lot of time visiting her husband "as you would do" suggests how Suzie expects to be treated if she were in a similar predicament. Her comment highlighting how her friend missed her husband also suggests his worthiness, and perhaps alludes to Suzie's own worthiness and her need to be valued.

> *I remember her with her husband before I had dementia. And um, she was just so good for, to him and for him ... I think just treated him as if he was … as if he was normal, just him. Yes, yes. I mean they still laughed together and joked together. When he went into the dementia unit, she spent a lot of time visiting him, as you would do. But missed him as well.* [Suzie]

Acceptance was viewed as being reciprocal and a fundamental and universal need. Two women in particular, described this, acknowledging that no one is perfect, and that we all need to accept each other's imperfections and support one another. The examples below highlight this reciprocity and also emphasise the value that these women place on acceptance.

> *So, she has her issues too, in a way, so you know, she will often bring [name] with her. and I'll say, "Oh hi [name], how are you doing?", that sort of thing. And you know not everybody accepts [name] as [name] ... she's um, different* [Debra]

> *And everybody, every single person, none of us, none of us were perfect otherwise we wouldn't need to go to church to become better people, but every single one of us are broken in some way, and that broken bit is the other thing that the other person would try heal.* [Tanya]

Tanya's description of "that broken bit" conveys a strong visual of something being irrevocably damaged which others "try heal" but can never completely mend. Nevertheless, it conveys a sense of relief and comfort through others' efforts to heal and support.

Be there for me

All four women highlighted their hope and need for friends to 'be there for them' and to 'stick with them'. They wanted someone who they could "reliably count on" to support them both instrumentally and emotionally. As their independence had decreased significantly, they very much appreciated and depended on support from friends, whether it be a home-cooked meal, help with supermarket shopping, a ride to church or their book-club, a walking companion, or someone to accompany them to a medical appointment. Comments such as “I used to be in control ... it’s taken me a long time to get my head around the whole bloody thing ...” illuminate the difficult journey of gradually letting go and becoming more dependent. The following excerpts illustrate the participants’ dependence on others.

> *I would never have got through without them ...* [Tanya]

> *Because when you can’t drive, when you can’t go walking by yourself …. I can’t just say “right, I’m off” because you can’t.* [Debra]

> *Because if I’m feeling frightened, I can go and knock on her door ...* [Margarite]

For Debra ‘being there’ also meant having a trusted friend who could advocate for her when she felt vulnerable and marginalised. She described an incident when she felt ‘badgered’ into spending a large amount of money on something she did not need. She felt she was being taken advantage of because she was old and in a vulnerable position due to her dementia, and she regretted not taking a friend with her to advocate for her.

> *I was there by myself. I should have taken [friend] with me, um, and I felt he was badgering me because I was an old lady and I was in a … um, difficult place, you know ...* [Debra]

In the excerpt below, Suzie recognises that her condition may deteriorate, although her use of the word ‘if’ rather than ‘when’ indicates hope and perhaps a reluctance to contemplate the future. If needed, however, she would like to be able to ask a friend for help although there is a hint of not wanting to be a burden implied by the qualifier ‘sometimes’. The implication for friends, therefore, is to be proactive in offering support.

> *Well, I would imagine, that if … if I got to the stage where I was um …. I needn’t help, um, then I’d like to be able to ask for it sometimes*. [Suzie]

Without this support from friends, women described feeling trapped and alone at home.

> *I got into a very depressed state first at the other flat because I’d only been there a week or something and then went into lockdown.* [Tanya]

> *I was always here because I had nowhere to go, no friends – only [name], but she has her own problems, so I didn’t really see much of her.* [Tanya]

> *Keep in touch because I’m a people person. I need people. And that really became quite obvious during the lockdown too ... it drove me mad not being able to go and have a coffee, go and see someone*. [Debra]

At the same time, they didn’t want to feel that they were a burden as illustrated by the following extracts.

> *And I’ve always said ... please don’t make me a have to be. You know like, just …. um, don’t feel you have to come around because you haven’t seen me. Come when you’re free, come when you feel like it because that’s the time we’re all at our happiest*. [Tanya]

> *I hope I can keep doing that because you can’t, you can’t, you know, expect people to be rushing around after you all the time ... I don’t want to make anybody else’s life difficult.* [Debra]

In addition to instrumental support, the women highlighted the importance of emotional support. The ability to talk openly with an understanding friend was cathartic; it helped the women to process difficult feelings and deal with loss, sadness and frustration, enabling them to achieve greater equilibrium and an improved sense of psychological wellbeing.

> *It's good to um, to articulate how you feel about things to someone who understands ... It's helped me articulate what's going on in here and um, um I can see myself; I can figure it out if you know what I mean. I can let it all out and that's what I've got to do.* [Debra]

> *We both cried and laughed and cried and laughed, and even that was good for the soul. It's good to talk about, not only the things that make you happy, but also the things that make you sad. And to share, to have someone to share that depth of your emotions and feelings is quite special as well.* [Tanya]

> *We're all open. We can all talk about our sort of various little wobbles ... I'd rather talk about it openly* [Suzie]

Emotional support manifested itself in other ways too. For example, a friend recognising that one was down, and reaching out or doing something together to help cheer them up. The women were immensely grateful for these acts of 'kindness and compassion'.

> *Sometimes just to take me to the beach or something, turn me around ... be a friend and to be kind and caring and um compassionate* [Tanya]

> *... and [friend] rang from Australia. And you know the lift it gave me – those two old friends ... it was quite a sort of magic little moment.* [Debra]

> *And we go and have lunch at the caf' opposite and then we come back here and have cups of tea and things and they stay for at least three hours, which is very good of them*. [Margarite]

Being able to count on one for social support was especially reassuring. This need for consistency and reliability may be particularly prominent for these women because they experience a great deal of instability in their lives as their cognitive ability and independence is constantly shifting, forever altering what they can and can't do. Furthermore, this loss of functionality creates a sense of vulnerability and insecurity which exacerbates the need for support from others. Therefore, being able to "reliably count on others" is both necessary and reassuring. When contemplating how friends could enhance one's wellbeing, one woman explicitly stated, "stick with them".

> *Well, I've got a few special ones [friends], but those special ones are the ones that are constant* [Tanya]

> *I would just say be around more. Ring me more*. [Tanya]

> *Keep in touch.* [Debra]

> *I think it is the, um the constant – though it doesn't have to be, so to speak, you know very often – but the sort of ... um, but somebody that you can reliably expect to get in touch with you quite often.* [Margarite]

> *You're able to pick up the phone even though you haven't spoken to them for a bit ... and say, "can I talk about this, or can I talk about that, or can we meet for a cup of tea or something?", that sort of thing. You can rely on them.* [Debra]

Help me stay in the world

Friends have a significant impact on one's wellbeing not only by providing instrumental support, emotional support and companionship, but also because they are critical in helping people "stay in the world". For all four women, this was one of their greatest challenges and something they desired and actively strived for.

> *Especially the 'staying in the world thing' because when you can't drive, when you can't go walking by yourself …. I can't just say "right, I'm off" because you can't. Um, those sort of things – that's really important to be able to do that.* [Debra]

In the extract below, this woman highlights how important it is to help people engage in the outside world in a way that is specific to each individual's wish, doing "whatever they like – their things ...". She also alludes to the futility, hopelessness and bleakness of life, "sitting around waiting to die" if one is not interacting with the "outside world".

> *I would keep taking them [friends who have dementia] out. I would. You know it's so important. I don't mean out boozing or doing this or that, but whatever they like. ... their things that they like doing out of the house ... I would take them out walking in the park or go and show them nature. You know, I'd take them out ... I would make sure I had them interacting with not only me, but the outside world. I think that is so extremely important than sitting around waiting to die. Because that's what I felt like here at first. I was so depressed …* [Tanya]

For Suzie, engaging in the outside world provides her with a sense of achievement as well as pleasure, as it is important for her to be as "efficient as she can". Her ability to not only get to the supermarket, but to also 'get back' reinforces the sense of achievement this gives her.

> I *think um interaction, um, I think exercise, walking, going for walking group quite often because I no longer drive, walk to the supermarket and then get back. So those things are important to me. Um, I guess that as efficient as I can be. I'm not quite as efficient as I used to be but still be able to do things like that and get enjoyment out of it.* [Suzie]

For all four women, being engaged in the world is primarily through interaction with people and being amongst people.

> *Seeing people. I love people. I love seeing the people, studying the fashions ... even if it's … I love going to the mall. I love going there and just having a coffee, a latte, um – oh, I love lattes – and a cheese scone or a muffin or something, just looking at the shops ... I just love going out. Love celeb spotting, love fashion spotting.* [Tanya]

> *And we would have a jolly time together, you know. This was during summer of course and we'd um, drink a bottle of wine and um, we'd chat ... Oh, um, he made me feel I was still intelligently engaged with the world.* [Margarite]

Importantly, it is about doing 'normal things' with others and things that had been a part of their lives before dementia. This may be, not only because these activities have given them pleasure in the past, but perhaps also because the familiarity helps them feel like, and hold on to, themselves, particularly as they are constantly adjusting to a different life to that which they had previously.

> *Keeping in touch and doing normal things um, like going for a walk together, if that's what you did, going out for a cup of tea, or a concert, or something like that. Just carry on as normal. And make sure … Help them to stay in the world - that's the biggest thing for me – is Staying in the World.* [Debra]

> *Um I enjoy chatting, talking about what people have done, what they're going to do, um what movies they might have seen um, just general … I guess nothing different from what it used to be like*. [Suzie]

> *Well, well what I like doing with people ... are having really good conversations ... I mean you can gather from this, I can talk a hind leg off a donkey and so can all of my [professional] friends. And that's what we do, that's what we love.* [Margarite]

Friends reminiscing about the ‘good old days together’ helps Suzie remain engaged in both the world and her life by helping her hold on to precious life memories that bring her joy and a sense of continuity.

> *And I really enjoy it when friends come around. I’ve got some friends coming around next week … We travelled together so we’ve got that in common. We’ve gone traveling together and as …we were very much younger, so you often reminisce about all the silly things you did and all the dangerous things you did and all the good things you did.* [Suzie]

Similarly, when friends take the time to share stories about their own lives, their work, their family, the books they’ve read, the trips they’re planning they help keep the women engaged by “bringing the world to them”.

> *I’m interested in things, what people are doing, um you know if they’re going on a trip or something. [Friend] is always interesting ... So, it’s those sort of things that bring the world to you as well.* [Debra]

> *I enjoy chatting, talking about what people have done, what they’re going to do, um what movies they might have seen.* [Suzie]

> *[Friend] would always be reading lots and lots of stuff. And he gets absolutely gripped by it and wants to tell you all about it. It’s marvelous, right?* [Margarite]

> *They [former colleagues] tell me stories about what’s going on, and so on. And that’s always fun ... And they give me various bits of news, like about the latest conference, and things like that.* [Margarite]

Other activities that kept the women engaged in the world were going on outings, exploring new places and being in nature. These simple activities that bring such joy to these women are only possible with the support of caring friends.

> *I still enjoy going to a good movie. We went to a really good one 2 or 3 weeks ago and then had a meal afterwards. That's a very enjoyable thing for me to do.* [Suzie]

> *We got the bus to the city. Then we had a nosey around. Then we sat in the viaduct, sat in the sun for a while. Just those simple things to keep … stay in the world – with what's going on around you - that's really important to me*. [Debra]

> *And I just absolutely ... I love walking, and especially in a beautiful place, out in the fresh air and the beautiful trees … I love trees, and just the beauty ...*
> *And I just love it. And afterwards we go to this amazing café they've got there ... and we sit there, and I'm meeting some really, really, lovely people.* [Tanya]

As shown in the extract below, this woman also actively pursues new experiences and interactions with unfamiliar people in an attempt to 'keep her brain open' and prevent her from 'shrivelling up'. From this, one can infer that even caring community citizens who don't know the people well, can still make a positive difference by engaging with people with dementia.

> *And I think it's really good for me to mix with people I don't know very well because it's … it's keeping your brain open, your senses to what's going on, your experiences. I don't want to …. I don't want to shrivel up ... I need to be in the world, sort of thing.* [Debra]

Friends who enabled the women to remain engaged in the world through dialogue and discussion, story-telling, reminiscing, and taking their friends on outings had a positive impact on the women's wellbeing as evidenced by their comments below.

> *It's like a new lease, a new lease of life, you know*. [Debra]

> *I just felt alive ... It's so important because I mean there is so much tragedy in the world with people and their lives. So, I think it's important to, you know, enjoy yourself as much as you can.* [Tanya]

> *And to me laughing is just so important – it's so precious. To be able to laugh – to have something to laugh about, because for a long time I didn't, I didn't ... They keep me young with their visits and their laughter, love and stuff you know*. [Tanya]

> *Oh well it makes one feels oneself, you know.* [Margarite]

> *... and the really nice thing at the book club, is they said even if you don't read it all, we want you to come and join us, which is really nice. So that's something friends – real friends do.* [Suzie]

Show me I'm worthy

The way others treat people with dementia impacts how they feel about themselves and their sense of self-worth. For these women, self-worth encompassed feeling loved and cared for, and being valued for who they are and what they contribute.

> *I knew that he saved things to tell me, you know when he was reading something. I knew he thought 'ah I'll be able to tell Margarite about that'. Um, and that was just, it's just lovely being wanted.* [Margarite]

> *I think it's always important to tell people that you love, that you love them or to tell the people the nice things that you think about it, to let them know it*. [Tanya]

Considerate actions taken by friends helped Tanya feel valued. Her friends' gesture to bring their wedding forward so that she could attend makes her feel loved and special to them. She seems especially pleased that a young couple in particular value her. This may be because Western society tends to position older people as less worthy, and sadly older people with dementia, even less so. This provides a poignant lesson for all of us.

> *And they [friends] actually brought their marriage wedding forward. They said they couldn't bear me not being at their wedding. That's amazing right? That's amazing. That's great they did that. I mean they're a young couple. We just love each other. We're so, so close.* [Tanya]

Similarly, the fact that a young friend from her past church is "breaking his neck" to come and see her, "writes to her all the time" and "sobbed" when she left affirms her worth. This shows that simple actions from friends, such as writing a letter, telephoning, emailing or coming to visit can help people feel valued.

> *He is only 23 and I'm like a Grandmother to him. And he's breaking his neck to come over and see me ... And so, um all of these … he's only 23 and yet he writes to me all the time ... We just had …. He cried his eyes out when I left. And like he didn't just cry he sobbed.* [Tanya]

> *... and they're always … like she's sending me messages all the time.* [Tanya]

> *I don't know how I would have got through the lockdown, I must say, in total solitude without those telephone conversations. Um, and just thereby know that they care and are thinking of me.* [Margarite]

It was important for the women to feel that the attention they received from their friends was not out of a sense of duty, but rather because their friends enjoyed being in a relationship with them and valued them for who they are. In the excerpt below, Margarite also illuminates how this sort of authentic relationship and exchange "makes one feel oneself".

> *And It’s not – this is the important thing about the conversations, I think. It’s um, I don’t know how I would deal with somebody who obviously, or even not very obviously, but obviously enough for me to feel it, rang because they thought they ought to, and was checking up on whether I was ok , um and sort of groped around about for things to talk about, because they hadn’t really rung up to talk to me about anything, but just to see if I was alright. You know, I can check that one off my list. But [friends] both ring me up to tell me in great detail what happened to them the day before yesterday ... the way friends do ...um, it makes one feels oneself, you know. No one else will do with this, and you’re expected to, and you do, respond in a very idiosyncratic “I knew Margarite would say that” kind of way because that’s, that’s what the friendship’s about.* [Margarite]

> *And I’ve always said ... please don’t make me a have to be. You know like, just …. Um, don’t feel you have to come around because you haven’t seen me. Come when you’re free, come when you feel like it because that’s the time we’re all at our happiest*. [Tanya]

> *I would never ask anyone to, you know, contact me or you know be my friend or anything like that. That’s not in me.* [Tanya]

Having a reciprocal relationship with friends, where one can contribute is important to one’s sense of self-worth. In addition to maintaining an authentic relationship, friends can further enhance this reciprocity by encouraging people to share their views and stories, seeking their input and explicitly acknowledging their contribution. In the extract below, this woman describes how ‘useless’ one feels if one hasn’t got anything to give in return. There is also a sense of resigned vulnerability in her having to accept the indebtedness she feels towards others.

> *Yes! Yes! What I’m giving them. That one’s contributing, we are in harmony, we are enjoying each other’s company. Yes, I’m not just a receiver. I’m a giver … One thing that demented people often say especially if they live on their own, is that they just feel useless, um and if you get in that position where you always feel*

> *that people are giving things to you but you haven't got anything to give back, boy I bet you feel useless ... and one does get sick of smiling sweetly and saying "oh thank you, you're so kind. I don't know what I'd do without you."* [Margarite]

All four women took pride in sharing stories about their reciprocal relationships with friends and the different contributions they make to them.

> *And I think that um, yeah that they, my good friends still enjoy my company* [Suzie]

> *I just was glad that she was able to share that with me and confide in me* ... [Tanya]

> *Oh, I think the other thing is, um that I had something to give him. I mean, I'm his now, dearest and oldest friend*. [Margarite]

> *…. we've had a new grandson, and um [friend] has got two new grandchildren, and so we talk about the kids. So that's a thing we've got in common as well, which is really nice* ... *we've always supported each other.* [Debra]

During the course of the interviews with the participants, unique qualities of each participant became obvious to the researcher, and some of these observable strengths were spontaneously reflected back to participants during the conversation. For example, a wonderful sense of humour, a caring and compassionate nature, a supportive friend, a strong determination to make a positive difference. It became apparent that the women seemed to appreciate these affirmations, and they also elaborated on them, indicating that they recognised these attributes in themselves. By providing appraisal support, friends can highlight and make explicit the many positive qualities and strengths they see in their friends with dementia to remind them of their worth.

In addition to being valued for who one is, being recognised for one's past achievements also contributed to one's sense of self-worth. Friends and colleagues who take the time to discuss one's past accomplishments and contributions, therefore, can help build a sense of pride in people with dementia. One woman expressed her delight and sense of worth she feels because her ex-colleagues are working collaboratively on a project to recognise her life's work. For her, it is the recognition from others that is important, as opposed to actually seeing her life's work per se, as illustrated by her comment below.

> *And in fact, I don't mind, I don't really mind if I don't live to see it come out. I mean the fact that I know it is coming is just fabulous.* [Margarite]

Feeling loved and cared for, and feeling they are valued for who they are as well as for their present and past contributions to family, friends, and society, gives one a sense of self-worth, a purpose and a place in the world aptly summed up by Margarite.

> *And so that really the thought 'oh well, you know, if I die, who will care?' just sort of never crossed one's mind and I think that's awfully important*. [Margarite]

> *Um, and I knew, I really knew I was important to him. I was the, you know, I was what was keeping him alive.* [Margarite]

Summary – How friends can enhance the wellbeing of people in early-stage dementia

This study demonstrates that friends have an important role to play in supporting and enhancing the wellbeing of people with early-stage dementia. Several contributing factors have been identified which broadly fall into four superordinate themes: accept me as I am; be there for me; help me stay in the world; show me I'm worthy.

By better understanding dementia and accepting the changes and limitations imposed by the disease, and by being empathic, compassionate and patient with those who have dementia, friends can help people with dementia to better manage the physical, psychological and social impacts of the disease. Acceptance and understanding provides comfort for these women, and it enables them to 'be themselves' and feel 'normal'. It enables them to hold on to their sense of self-worth and not let the dementia define them.

Friends can support in practical ways by being there to help out with daily activities, and by actively advocating for people with dementia, particularly when their rights and dignity are being threatened. Friends also provide crucial emotional support by actively listening, validating people's feelings and allaying their fears. They provide companionship which is vital to ward off loneliness and depression. Remaining constant in people's lives is very comforting and reassuring to these women; friends, therefore, should 'stick with' people throughout their dementia journey.

A pivotal role that friends play is helping people with dementia remain engaged in the world. For these women, remaining engaged in the world is critical to their wellbeing. As people with dementia become increasingly dependent, they need to rely on others to accompany them on walks, go shopping, attend hobby groups and take them on outings and visit places of interest. All these activities, which many of us take for granted, are essential to help one 'stay in the world'. For people with dementia, their friends are instrumental in making this happen. It is important that these activities are meaningful to the individual, providing pleasure or a sense of achievement, such as activities they engaged in and enjoyed prior to the disease. This can also help them maintain a sense of self by holding on to those things that are familiar to them and which they value. Additionally, friends can also assist by bringing the world to them through dialogue, discussion, story-telling and reminiscing. These positive human interactions are vital to help people with dementia remain engaged in the world around them.

Showing acceptance, providing social support and helping people with dementia to ‘stay in the world’ not only helps them manage their journey with dementia, it also demonstrates to them that they are valued and that their illness does not detract from their worth. Friends can nurture this sense of self-worth by always treating people with dementia with the respect and dignity they deserve; eliciting their views and seeking to understand their wishes; making time to regularly connect with them; honouring the friendship by engaging in an authentic, reciprocal relationship; never making them feel they are a burden; and continuing to affirm their strengths and qualities, and their past and present contributions. In this way, friends can help people feel loved and cared for, and valued for who they are and what they bring.

DISCUSSION

This study sought to understand how friends can enhance the wellbeing of people with early-stage dementia and revealed four superordinate themes: accept me as I am; be there for me; help me stay in the world; show me I'm worthy. These are expanded on below within the context of extant literature and theory and indicate implications for friends.

Accept me as I am

Acceptance is a fundamental and universal human need. According to Rogers all humans have a basic psychological need for positive regard, i.e., to be accepted and respected by others (Cervone & Pervin, 2010; Rogers, 1959). For those who experience a sudden disability, the need for acceptance is heightened as the disability forces one to re-examine one's own sense of self as one attempts to incorporate the new defining characteristics of the illness or disability into one's identity. Unlike those who are born with a disability or illness which has always been a core part of who they are, the participants in this study have had to unexpectedly come to terms with the impacts of dementia on their sense of self. Whilst they acknowledge changes in themselves brought about through loss of memory, functionality and autonomy, and grieve these losses, they also hold on to their former selves, acknowledging past and present roles, their strengths and achievements, and unique personality traits. This is consistent with several studies which show how people in the early stage of dementia attempt to balance their previous selves with an evolving self-concept deploying both self-maintenance and self-adjusting strategies (Clare, Nelis, et al., 2011; Macquarrie, 2005). It is conceivable therefore, that acceptance from others would facilitate their own acceptance of their evolving selves, thereby alleviating some of the psychological distress experienced through loss and incongruence of self.

Additionally, acceptance also helps to counteract stigma. Stigma has been described as an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Link and Phelan (2001) assert that stigma occurs within a power relationship; without power differentials there can be no stigma. According to the attribution theoretical framework, dementia stigma begins with cognitive attributions (stereotypes), followed by emotional responses (prejudices), leading to behavioral reactions resulting in unfair discrimination (Corrigan, 2000).

There is widespread evidence across different cultures, of people with dementia and their carers experiencing stigmatisation and ostracisation (Biggs et al., 2019; Herrmann et al., 2018). Stigma creates profound psychological pain and can delay help-seeking behaviours (Herrmann et al., 2018; Katsuno, 2005; Parker, Barlow, Hoe, & Aitken, 2020; Phillipson et al., 2015). The participants in this study described experiences of being ostracised and stigmatised due to their dementia, causing them deep hurt experienced through a sense of loneliness, abandonment, exclusion and invalidation. Besides social or public stigma, stigma can also become internalised where one takes on the negative beliefs about the condition and one's self. This was evident in this study where two participants made direct reference to themselves as 'being stupid' and all participants referred to feelings of shame, embarrassment and humiliation as a result of declining cognitive ability and functionality. Some participants also chose to withdraw from certain activities, such as going out for lunch with others, to avoid feelings of humiliation and embarrassment even though they desired company and social interaction which they knew was beneficial for them. These avoidance behaviours are consistent with findings in other studies (Clare, 2003; Synder, 2001). Whilst help-seeking behaviour in the literature often refers to seeking medical or professional support (Birt, Poland, Charlesworth, Leung, & Higgs, 2020; Parker et al., 2020; Phillipson et al., 2015), this example can also be interpreted as an illustration of avoiding help by forfeiting these activities. Thus, consistent with other findings, for these participants, stigma resulted in psychological pain and impacted help-seeking behaviours.

Studies show that a lack of understanding from others, misinformation about dementia, and lack of contact with people with dementia contribute to stigma (Herrmann et al., 2018; Tippin & Maranzan, 2019; World Health Organisation, 2015). In the current study participants cite examples of people treating them as if they are ‘crazy’ or not believing they have dementia because they’re ‘talking perfectly normally' or failing to elicit their wishes and making decisions for them. These examples reflect a lack of understanding about dementia. Conversely, empathy, understanding, education and contact with people with dementia, as well as opportunity to engage in critical reflection can counter stigma and its negative impacts (Herrmann et al., 2018; Kontos et al., 2020; McHugh, 2006; Peng, Shen, Vanderbilt, Kim, & Foley, 2020; Tippin & Maranzan, 2019; Williamson, 2016). One study showed that by building empathy, rather than sympathy, young people shifted their exclusively negative view of dementia, resulting in positive change in how they regarded and treated people with dementia (Sabat, 2012). In the current study, participants express positive feelings about themselves and enjoy social activities with others when friends exhibit empathy and understanding about their condition, including acknowledging their limitations due to the dementia. Previous studies have also highlighted the importance of friends accepting these limitations and learning to work around them (Harris, 2012). The present study shows that acceptance from others not only counters stigma, it also creates a sense of self-worth, provides one with a sense of normality, and affirms one’s personhood. The need to be accepted by others and feel ‘normal’ has been emphasised in other studies (Langdona et al., 2007; Steeman et al., 2006).

This conceptualisation suggests that acceptance from friends contributes to people’s wellbeing. This is supported by Patterson’s et al. (2018) meta-analysis which shows that people with dementia can feel outcast and relegated, or included and valued depending on how they are treated by others, and these experiences impact their emotional and psychological wellbeing. This implies the need for a sustained focus on educating lay people about dementia, as well as building empathy and understanding by sharing the lived experiences of people with dementia and creating more opportunities for the wider community to engage with people with dementia.

Be there for me

It has long been established that humankind requires far more than the basic physical needs of food and shelter to ensure one's wellbeing (Bowlby, 2005; Maslow, 1958). Studies show that social isolation is associated with poor physical and psychological health, and having close social connections with supportive friends serves as a protective buffer against some of the devastating impacts of dementia (Harris, 2012). The participants in this study all emphasised the significance of social support for their wellbeing. Without the support of friends, they felt isolated and alone and unable to take part in social activities.

Social support is multifactorial comprising emotional support which encompasses positive affect and empathic understanding; instrumental support which is practical and tangible; educational or informational support; and appraisal support which provides one with feedback (Heaney & Israel, 2008). During the course of the interviews, it became apparent that these women rely on all forms of social support. For example, participants sought additional information about dementia, and participants responded positively to affirmative appraisals from both the researcher and others. The most salient support for these women, however, is instrumental and emotional support.

As they have had to relinquish activities such as driving, which had previously given them freedom and independence, coupled with having to adjust to decreasing functionality in multiple domains of their lives, they are very reliant on others. They need someone to take them to their various hobby groups and wellness activities, and to places of spiritual importance, as well as provide practical support with shopping, meals and medical appointments. Thus, instrumental support serves practical purposes as well as contributing directly to their wellbeing. Whilst they very much appreciate this support from others, they also find it difficult to accept they no longer have the control they once had; this view is commonly expressed by people with dementia (Gorska et al., 2018; Steeman et al., 2006). This suggests that it is important to take care to not further erode control by making decisions for the person with dementia or preventing them from doing activities they are capable of. Studies show these sorts of actions, even if well-intended, can be disempowering and result in premature disengagement or ‘excessive disablement’ (Beard & Fox, 2008; Martin et al., 2013; Sabat, 1994; Sabat & Lee, 2012; van Wijngaarden, Alma, & The, 2019), and self-efficacy (a belief that one can successfully perform an activity) has been well established as an important psychological factor for living well with illness or disability (Rippon et al., 2020). It is worthwhile noting, that none of the participants were reliant on just one person for this support. They recognise that people are busy with their own lives, work and families and they are very conscious of not wanting to be a burden; this is another common theme in the literature (Clare, 2003; Gorska et al., 2018; Synder, 2001). They are comfortable accepting instrumental support from a variety of people whether they be neighbours, acquaintances or long-term friends. Friends and caring others, therefore, have an opportunity to work collaboratively to ensure the person with dementia is surrounded by a supportive network of people who can provide reliable, distributed support.

Alongside instrumental support, emotional support is also crucial to these women. This includes having someone they can openly share their feelings and thoughts with, as well as having people in their lives who can cheer them up and ‘turn them around’ when they are feeling down; someone who will reliably be there for them. For some, emotional support was cathartic; it helped them process difficult feelings and restore equilibrium. A previous study on friendships also found that long-term friendships, in particular, were highly valued by people with dementia, because these tended to be people they could confide in and openly talk to (Harris, 2012). Talking therapy has been shown to be efficacious in reducing symptoms of depression and anxiety, including in those with early to middle stage dementia (Morgan, 2020). Of course, this is not to imply that friends can or should be attempting to fulfill the role of professional therapist, however, the principles of active listening and non-judgement are applicable, and friends can fulfill these aspects. There is strong evidence demonstrating the positive and long-lasting effects of emotional support on one’s wellbeing (Obst, Shakespeare-Finch, Krosh, & Rogers, 2019).

As these women are generally reluctant to impose on others for fear of being a burden, and sometimes feel too low and incapable of reaching out for help, this requires friends to be proactive. Fear of being a burden coupled with stigma and diminished capability may prevent help-seeking behaviour (Tippin & Maranzan, 2019; World Health Organisation, 2015), therefore, it is important for friends to initiate contact. Friends can support by regularly keeping in touch, looking for signs to assess how their friend is doing, be available to listen and re-assure, and do fun things together to help lift their friend when needed. Evidence from other studies, confirm social support and participation in activities both have a positive impact on people with dementia (Pakstis, Kim, & Bhargava, 2018). Studies also suggest that social networks may have beneficial effects on slowing the progression of cognitive decline (Balouch, Rifaat, Chen, & Tabet, 2019; Yates, Clare, & Woods, 2017), and research on older adults shows that emotional support protects cognitive functioning more than tangible support (Ellwardt, Aartsen, Deeg, & Steverink, 2013). Furthermore, life satisfaction for people with dementia is higher in those with good social networks and social support (Clare et al., 2014).

In addition to instrumental and emotional support, one woman in particular explicitly highlighted the need for friends to advocate on her behalf. The need for advocacy, in general, was echoed by other participants through their desire to make a positive difference by contributing to research, and in sharing their views about what a dementia friendly community might look like. Increasingly, people with dementia are taking an active role in advocating for themselves and others with dementia (Seetharaman & Chaudhury, 2020; Weetch, O'Dwyer, & Clare, 2020), although there remains a pressing need for this to be mirrored and reinforced by others in the community. Dementia advocacy has been framed with the concept of social citizenship which, in this context, is defined as “a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level” (Bartlett & O'Connor, 2010, p. 37). From this vantage, friends can take both a reactive and proactive approach to advocacy, sometimes needing to step up in the moment to defend their friend’s rights and other times, proactively advocating for change to create a more inclusive environment which enables people with dementia to be fully participating citizens.

This shows that friends can play a crucial role in enhancing the well-being of people with dementia by providing reliable companionship, both instrumental and emotional support, as well as advocating for people with dementia.

Help me stay in the world

People are social beings and need to have a place in the world. A key goal for all the participants in this study is to remain engaged in the world around them, and to feel their place within it. This finding is replicated in other studies (Gorska et al., 2018; Wolverson et al., 2016) and is supported by the Senses Framework for relational care which posits that people with dementia need to feel a sense of belonging and feel part of things, and have a sense of purpose and achievement, as well as a sense of continuity (Ryan, Nolan, Reid, & Enderby, 2008). Unlike healthy others who perhaps take this for granted, these women are acutely aware of their need to be active in the world, however, they have to work hard to achieve this because so much has been taken away from them through loss of independence and diminished functionality. They, therefore, need to rely on others to keep them engaged in activities that bring them joy, purpose and a sense of accomplishment. For some it is attending church services and meetings, for others, walks in nature and exploring new places or simply going to a café with a friend and enjoying good conversation together. These are simple activities, but they have a profound and positive effect on the women. Participants described how these activities not only give them pleasure, but also a sense of achievement and purpose. It makes them ‘feel themselves’ and ‘feel alive’. This is consistent with previous research showing that social interaction and engagement in activities helps people with dementia feel useful and maintain self-continuity which is important for one’s wellbeing (MacRae, 2011; Matchar & Gwyther, 2014), and it also helps build resilience (Whelan, Teahan, & Casey, 2020).

For these women, being engaged in the world, was shown to be not simply a desire, but a need. Without this, they experienced feelings of loneliness, sadness and despair. These findings are replicated in other research which shows that impoverished environments with little stimulation have an adverse effect on people with dementia, magnifying feelings of apathy, boredom, loneliness and depression (Cohen-Mansfield et al., 2011). Whilst the need for engagement in the world may be common to all people, it is particularly salient for people with dementia because they often have a sense of their world moving further out of reach as their cognition and functionality declines. As the current results show, their desire to hold on to what they value, became a central concern. Kitwood (1997) and others argue that the primary role of those around the person with dementia is to hold them in the world (Cowley, 2018).

For the participants in this study, being in the world is largely through social interaction and by continuing to do those things they have always done and valued. These findings are consistent with other research demonstrating the positive effects of social interaction and engagement in activities, on people with dementia (DeVries et al., 2019; McDermott et al., 2019). A meta-analysis of people's subjective experience of dementia revealed that engagement in activities, social relationships, and a sense of belonging were important for one's wellbeing (De Boer et al., 2007). One study evaluated the effects of different stimuli on levels of engagement in people with dementia. Stimuli included social interaction with another person, interaction with an animal, music activity, reading and engaging in a specific activity pertinent to the individual's own identity, such as watching a cooking programme if one had been a chef prior. All activities resulted in a measurable increase in engagement, however the greatest engagement score was for social interaction with another, followed by identity-specific activity (Cohen-Mansfield et al., 2011). In accordance with the present study, this highlights the potency of social interaction and engaging in activities that are meaningful and valued by the person. Activities, therefore, should be specific to each individual.

A meta-analysis identified key attributes that make activities meaningful for people with dementia include being enjoyable and engaging; suitable to individual's preferences and capabilities; relevant to personal goals; and related to an aspect of the person's identity (Tierney & Beattie, 2020). Studies also demonstrate that people with early-stage dementia can effectively set goals for themselves and they can successfully work towards them with support from others (Clare, Evans, Parkinson, Woods, & Linden, 2011; Evans et al., 2015). Long-term friends usually have the advantage of knowing what is important to the person, however, those who don't, can make an effort to uncover and understand the person's goals, interests and values. This can be achieved through on-going dialogue and life story work focusing on their past, and current and future wishes and aspirations (Kaiser, 2016).

In the present study participants also described how friends can 'bring the world to them' by sharing stories about their own lives or telling them about a book they've read, a movie they've seen, or sharing vacation photos. The people in this study were able to connect with these stories and perhaps experience them vicariously. They were interested and enjoyed hearing about current happenings and future plans as well as reminiscing about the past. In addition to "feeling intelligently engaged in the world" as described by one participant, the sharing of these stories has other benefits. For example, focussing on future events might convey hope and growth and help one feel part of the forward motion of life, whilst reminiscing about the past helps one hold on to, and feel connected to, their life history and social identity. Furthermore, studies show hope can assist one to adjust to life with dementia (Cotter, Gonzalez, et al., 2018) and reminiscence can improve depressed mood and enhance wellbeing (Keating, Cole, & Grant, 2020; Shropshire, 2020). Together, these retrospective and forward-looking stances may help them preserve a sense of self-continuity, which has been shown to be important to people with dementia and their wellbeing (Clare, Nelis, Martyr, Woods, et al., 2013; Crichton & Koch, 2007; Woods et al., 2014).

Clearly, the role of friends in enabling people with dementia to 'stay in the world', engaged in social interaction and meaningful activity that provides pleasure, a sense of purpose and achievement, and a sense of self-continuity cannot be over-stressed. In order for people with dementia to freely participate in activities, however, it is imperative that we create dementia friendly communities where places such as restaurants, shops and recreation centres cater for people with dementia, and where people are welcoming, respectful and inclusive.

Show me I'm worthy

A number of factors may contribute to one's sense of self-worth e.g., physical attractiveness and strength, scholastic achievement and career success, being loved and admired by others, mastering a new skill or accomplishing a goal, and possessing virtues valued by society. These attributes of worthiness are shaped by socio-cultural factors at both the macro and micro levels and therefore vary across cultures and between individuals within the same culture. Some factors may remain important to people's sense of self-worth throughout their life, whilst others may become less important across different life stages. For example, physical attractiveness may be highly valued and sought after in one's teens, but insignificant to one's sense of self-worth in later life. Erikson's stages of development suggest that in later years, people's sense of self-worth transitions from a pre-occupation with generativity, or productivity to one of ego integrity where one strives to feel a sense of satisfaction and worthiness with how one has lived their life (Berk, 2004). The negative outcome of this stage is despair where people are overwhelmed with regret. Retelling one's life's story and reaffirming one's contribution, therefore, may help people with early-stage dementia achieve ego integrity.

Other life-changing events, such as developing a chronic illness like dementia, may also alter those factors that were previously considered important to one's sense of self-worth. As people adjust to having dementia and the impacts of diminished functionality, these shifts in perceived value may be adaptive provided they are realistically attainable. This was evident in the present study where participants focused on those things they could do, for example going to the supermarket on their own, or learning a new skill, like cooking, rather than focusing on those things they couldn't do.

They also focused on their personal qualities and strengths, such as being organised or having a wonderful sense of humour. As will be explained, however, one's sense of self-worth is predominantly dependent on others, rather than the person with dementia.

Self-esteem has been conceptualised as one's evaluation of one's personal worth or value, and has been described as both a trait which is relatively stable over time and as a state which is temporary and susceptible to fluctuations (Fairlamb, 2020). Intrinsic self-worth is associated with positive wellbeing, whereas contingent self-worth can be maladaptive (Fairlamb, 2020). Several theories have been posited as to what drives humankind's need for self-worth or self-esteem. One view is that children internalise parental views of what constitutes 'good', and as they are dependent on parents, this drive for self-esteem is adaptive. Theorists argue, that beyond childhood and the ensuing realisation that parents can no longer be protective, people need self-esteem to counter threats from their awareness of their own vulnerability and inescapable mortality (Greenberg, 2008). Humanistic theories provide an alternative view, asserting that self-esteem is driven by a need for growth and optimising human potential. Irrespective of whether people strive for self-esteem to minimise anxiety or to maximise potential, the need for self-worth appears to be universal (Greenberg, 2008) and remains important to people with dementia. Steeman's et al. (2013) longitudinal study of people with early-stage dementia identified 'being valued' as a central theme across time.

In the present study, self-worth centred around participants feeling loved and wanted by others through a reciprocal relationship, and being recognised for who they are, the qualities they have, and the contributions they make, both past and current. Similar findings have been found in other studies with people with dementia (Sabat et al., 1999) and Harris's (2012) study also found reciprocal or mutually rewarding relationships to be an important contributor to maintaining the friendship. Taylor (2017) interviewed friends of people with dementia directly and found that those who maintained and continued to nurture their friendship were motivated by a moral commitment not only to their friend, but also to themselves; thus, they continued to enjoy a reciprocal relationship.

In the current study, when people consult the women, elicit their views and include them in conversations and activities, this affirms their worth. Conversely, when friends fail to consult them and exclude them from conversations and activities, this makes them feel devalued and worthless. This highlights that there are tangible actions friends can take to demonstrate the worthiness of people with dementia. It also illustrates how fragile one's sense of worth can be, and therefore, how important it is for people to be mindful of their actions and the impact they have on people with dementia. In this context, it is useful to think of self-esteem in people with dementia, predominantly as a state which is sensitive to how others treat them and how they are socially positioned. Self-esteem in people with dementia is, therefore, created and destroyed by those around them.

It is common for people with dementia to experience threats to their self-esteem (Patterson et al., 2018), particularly in a hypercognitive Western society which values cognition above other aspects of self (Post, 2000), and an individualistic culture which emphasises independence over interdependence (Hofstede, 1983; Somech, 2000). People often feel inadequate because they are regularly confronted with diminishing capabilities, such as the sudden inability to find a word and express themselves or undertake daily activities independently. This was evident in the present study where participants expressed feelings of embarrassment and some chose to withdraw from social activities that threatened their self-esteem. A review of interventions that help build resilience in people with dementia, underscores the importance of others actively building self-esteem in the person by ensuring activities are skill appropriate and manageable, and by focusing on the person's strengths, giving positive feedback and creating a psychologically safe environment where people feel comfortable to try something out, knowing they can make a mistake without being judged (Whelan et al., 2020). This too was apparent in the current study where participants expressed their comfort in knowing they could participate in a book club without needing to remember the book or even read it.

Friends, therefore, are essential to supporting people with dementia to build, or at least, maintain their self-esteem by involving them in purposeful activities, emphasising their valued qualities and contributions, and continuing to nurture a reciprocal relationship. The role of others in helping to preserve and build self-esteem in people with dementia is iterated in previous studies (Sabat et al., 1999; van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2016) and the impacts of self-esteem on the wellbeing of people with dementia is well evidenced (Rippon et al., 2020).

The overall findings in this study are further supported by a meta-synthesis of qualitative studies exploring people's lived experiences of living with early-stage dementia. As in the current study, acceptance and understanding from others, having a sense of belonging, feeling valued and loved, and being engaged in meaningful activity were important factors in supporting people's wellbeing (Steeman et al., 2006).

Summary

In exploring the findings from this study within the context of extant literature, and as illustrated through other supporting studies, it is evident that the need for acceptance, social support, self-worth and remaining engaged in the world is important, not only to the women in this study, but more broadly to people with dementia. Furthermore, when considering the supporting theories of attachment and belonging, and the need for self-esteem, these needs are not exclusive to people with dementia; they are basic human needs applicable to all. This shows that what people with dementia need, on one level, is no different to people in general. It is suggested, however, that these needs, although universal, are more salient for people facing early-stage dementia for several reasons: 1) their need for acceptance is heightened as they are struggling to adjust to a disabling condition which throws into question their identity as they have known it, and they are suddenly confronted with stigmatisation which excludes, marginalises and invalidates them; 2) their need for social connection is also emphasised as they lose autonomy and become increasingly more dependent on others for social support to manage daily activities, counter negative feelings and loneliness; 3) as their world moves further out of reach through loss of cognition, functionality and relationships, their need to stay actively engaged in the world becomes a central concern; 4) faced with progressive decline and due to internalised stigma, their self-esteem is fragile and, therefore, their sense of worth needs to be continually reaffirmed.

As shown through the discussion section, each of these themes (acceptance, social support, self-worth and a need to be engaged in the world) can stand on its own, located within existing theory, and elucidating its relevance and significance to people in early-stage dementia, as well as pointing to specific practices friends can adopt. Despite this, it is also apparent that these themes are all interconnected as depicted previously in Figure 1. This interconnected relationship is explained below.

The theme of acceptance seems to be fundamental to the other themes. If we cannot show acceptance, understanding and tolerance for people with dementia, then it becomes virtually impossible to provide social support which effectively meets individuals' tailored needs. For example, if we do not understand and accept the limitations imposed by the disease, then we may fail to recognise the need to support our friend in doing their grocery shopping or accompanying them on a walk because they cannot negotiate it on their own, or demonstrating patience because it takes them longer to undertake a task. Similarly, if we do not understand and accept the array of emotions and insecurities a person with dementia might experience, then we may miss cues and fail to see the need to provide crucial emotional support. Acceptance and understanding requires us to put ourselves in the other person's shoes and empathise with them. Empathy, in turn, enables us to vicariously experience another's situation, albeit in a superficial and significantly diminished manner, and it reminds us that we too could be faced with a similar fate. This awareness of our own vulnerability, together with our humanity, can help us to critically reflect on, and call into question, our own biases and prejudices, thereby arresting stigma and its devastating impacts. In addition to challenging our own prejudices and behaviours, it can also propel us to advocate for our friends with dementia and more broadly, for a more inclusive society. If we can accept people with dementia as they are, recognising their individual strengths and limitations, their values, wishes and aspirations, then we can provide effective instrumental and emotional support which meets their needs, and we can also facilitate their acceptance of themselves and ultimately societal acceptance.

Similarly, without acceptance *and* social support, we cannot be instrumental in helping to keep people with dementia engaged in the world through activities that give them pleasure, a sense of achievement, purpose and self-continuity. From an acceptance perspective, we need to understand the specifics of what is important to our friend with dementia and respect their values, wishes and goals to ensure that activities are both meaningful and manageable for them. From a social support perspective, we need to proactively allocate and dedicate time for our friend with dementia and enable them to regularly engage in meaningful activity. Thus, helping to keep people engaged in the world requires both acceptance and social support. This also means that we need to advocate for a dementia friendly community, where people with dementia are free and able to participate to the fullest extent in recreational, vocational, educational, spiritual and civic activities.

If we are successful in fulfilling our duty of care to friends and others with dementia as described in the preceding paragraphs, then it follows that 'accepting people as they are', 'being there for them' and 'helping them remain engaged in the world' signals to them they are worthy. From this perspective, self-worth can be viewed as intricately related to the other three themes and interdependent with them. At the same time, it is also important to recognise this as a theme in its own right, because it is important to the people in this study, and to people with dementia in general; and because there are specific practices that we can adopt to help build self-esteem, such as focusing on their strengths, acknowledging the person, eliciting their views and reaffirming their worth. (It is no co-incidence that the theme titles are presented using action-orientated verbs, thereby reinforcing the need for us to take individual action).

First and foremost, however, self-worth can be reinforced by honouring the friendship by simply treating the person normally and continuing to nurture the relationship and the reciprocity of the friendship. It is inconceivable to imagine that one would forsake a friend if they were to develop cancer, or suddenly lose their vision or their ability to walk unaided. Surely friends would stand beside their friend wanting to support them in a time of need. No doubt, they would feel sad for what has befallen their friend because they care about them, but that sadness or illness would not diminish their friendship. They would continue to value the friendship and their friend, and cherish their shared history and reminisce together; they would continue to enjoy each other's company, confide in one another and do things that they could still do together and accept those things that were no longer possible; and they would make adjustments and accommodations. Why would this be any different for someone whose memory may be failing, or who may struggle to find a word or navigate their way home? Surely, we owe it to our friends who have dementia to 'stick with them' throughout their life journey. As Margarite said, "I think love can do it".

Practical Implications

A strength of this study is its pragmatic focus making it easily translatable into action. The focus on real lived experiences of people with early-stage dementia with a specific focus on positive friendship interactions means that the findings are grounded in real human experiences, thereby making it easy for people to relate to. Even if people cannot identify with dementia, despite its growing prevalence, people can identify with the fundamental human needs of acceptance, social connection, self-worth and being part of this world. Furthermore, people of all ages and backgrounds can identify with being a friend. This makes the findings of this study relatable to people in general. Whilst these findings may well have relevance to healthcare professionals, for example, in guiding psychosocial interventions and care policies and practices across different settings, be they outpatient clinics, day centres or residential care centres, the primary target audience for the findings from this study is lay people in general.

It is not only the focus and findings of this study that make this relatable to lay people, but also the methodology deployed because it brings to life the very real challenges people with early stage dementia experience. The personal stories, individual quotes and the way it is threaded into a human narrative helps build empathy, which is a critical starting point for being able to accept people with dementia, understand their needs and provide the support they need to enhance their wellbeing. The general public do not need a large scale quantitative study to galvanise them into action. People are emotionally affected by a single human story or a single human quote which can be sufficient to shift one's mindset and stigmatising views.

The results from this study, therefore, can be used in public campaigns to raise awareness of dementia and illuminate the personal, human needs of those with early-stage dementia, whilst also demonstrating the similarity and commonality of these needs across humankind, and thereby reduce the 'them' and 'us' divide. Revealing extracts and poignant quotes can be lifted and incorporated with relevant imagery to effectively communicate key messages and engage the community. This would support one of the key strategic objectives in the New Zealand Dementia Action Plan 2020-2025, specifically building accepting and understanding communities (Robertson et al., 2020). The stories of people with dementia actively and productively engaged in life activities, pursuing goals, would also help depict a more positive and realistic image of people with early-stage dementia to counteract narrow conceptualisations of dementia which reinforce negative stereotypes and fuel stigma. Whilst targeted primarily for those without dementia, this positive, more realistic portrayal of people with early-stage dementia may also give those living with the disease, and their families, a sense of hope and realisation that one can continue to thrive and enjoy a fulfilling life.

Additionally, the themes and specific supporting behaviours uncovered through the analysis are easily translatable into specific actions and practices that friends and others can adopt to enhance the wellbeing of people in early-stage dementia. To make it easily accessible, these can be summarised and depicted in a simple diagram (as shown in Figure 2 below) and disseminated through pamphlets, newsletters and online resources available on relevant websites such as Dementia New Zealand and Alzheimer's New Zealand, and thus serve as a guide for friends of people with dementia. These might also be made available through GPs, public libraries and community centres. They could be issued to different businesses and outlets who wish to adopt a dementia friendly strategy, be more inclusive and create a dementia friendly environment.

The findings from this study could also either form the basis for, or be incorporated into, a specific educational or training session to be delivered by organisations such as Dementia Auckland, Dementia New Zealand and Alzheimer's New Zealand, specifically aimed at friends. Similarly, these educational sessions could be delivered in corporates and other businesses as part of their diversity and inclusion strategy. Given the ageing workforce in New Zealand, more and more people will be diagnosed with dementia whilst they are still at work. Increasingly, organisations are striving to create more inclusive environments for minority groups such as those with disabilities and the LGBTQIA+ community. With dementia prevalence rising, and through strong advocacy, there will be increasing pressure for organisations and businesses to create dementia friendly environments as well. Irrespective of whether some are motivated by social responsibility or commercially competitive drivers, this would provide a tangible demonstration of their commitment and equip all employees with a simple framework to support them to engage effectively with people with dementia, whether they be family members, friends, customers or colleagues at work.

Although this study focused specifically on how friends, in particular, can enhance the wellbeing of people with early stage dementia, the guiding practices, principles and behaviours uncovered through this study are clearly useful to family, colleagues, acquaintances and the general public. Therefore, this guide could equally be introduced in schools and adapted to be age-appropriate. Not only would this be useful for young students who have grandparents and other family members directly impacted by dementia, but it would also help develop in young people, a better understanding of, and appreciation for people with dementia and their needs. This would help normalise and ultimately destigmatise dementia, and create a more inclusive generation enabling people with dementia to be treated with dignity and respect. The findings from this study would also be useful for advocacy groups to help drive change in how people with dementia are treated in society thereby enabling them to achieve better quality of life, increased life satisfaction and enhanced wellbeing.

In summary, the findings from this study have practical applications which can be used to: 1) raise public awareness, build empathy and counteract stigma; 2) provide a simple framework and guide to educate and support friends, family and others to adopt practices that enhance the wellbeing of people with dementia; 3) provide a tool for corporations and businesses to create dementia friendly places; 4) foster a more understanding, caring and inclusive generation and society enabling people with dementia to live well, be accepted and valued, connected to their community and afforded full social citizenship rights.

- Try to understand my situation
- Accept my limitations
- Be patient with me
- Respect my wishes

- Keep in touch
- Help me when I need
- Advocate for me
- Stick with me

- Interact with me
- Do normal things with me
- Help me do the things I value
- Treat me normally

- Include me
- Elicit my views
- Acknowledge me
- Engage in a reciprocal relationship with me

Figure 2: Diagram depicting how friends can enhance wellbeing in people with early-stage dementia

Limitations of this Study

Whilst this study has provided an in-depth account of how friends can best support people with early-stage dementia through participants' own accounts of their personal lived experiences there are a number of limitations with this study. These are outlined below.

Recruitment and Small Sample Size

Although IPA advocates for small sample sizes with an ideographic focus, and supports even single-case studies (Smith, 2011a; Smith & Eatough, 2012), the sample size in this study is it too small to generalise to others. This is a common limitation of qualitative methods which frequently use small sample sizes, however, the strength of the qualitative approach in this study is its effectiveness in capturing rich data from individuals' own lived experiences, and it gives voice to those who are often silenced. Furthermore, when multiple qualitative studies with small sample sizes produce similar findings, they can collectively strengthen generalisability. At the same time, it is important to acknowledge the heterogeneity of people with dementia. Whilst they may share a common experience in that they all have dementia, each person has their own unique experiences, history, wishes and needs.

Whilst the sample size was always intended to be small in accordance with IPA, it was hoped to have at least twice as many participants, however, this became a challenge due to the COVID pandemic which first delayed the research and then interrupted it when it was underway. Although this would not have made a difference in terms of generalisability, it would have provided a broader range of voices and potentially reinforced the findings in this study or alternatively highlighted other important factors. Unfortunately however, it became impossible to interview people due to national and regional lockdowns. As stated previously, methods other than face-to-face interviews were considered, such as by zoom or telephone, but these were deemed inappropriate for the target audience due to potential technology and ability constraints. Additionally, it was felt that face-to-face was important to establish rapport, create a safe environment and build trust between researcher and participant. Even when lockdowns were lifted it was difficult to recruit because the target group was considered particularly vulnerable from a COVID perspective due to their age and confounding health issues. Recruiters were presumably wary about approaching potential participants to engage in a face-to-face interview. Likewise, potential participants and their family may have been reluctant to participate because of the perceived risk associated with close social contact. Despite going back to the recruiting organisation a number of times, ultimately only four people participated in this study. Whilst every voice counts, and each participant has made a valuable contribution to the research, a larger sample size would have been preferable. Despite these limitations, it is encouraging to note that similar findings to this study have been replicated in other studies.

Notwithstanding the unique obstacles and challenges presented by the COVID pandemic, participant numbers may have been increased had relationships been established with multiple recruiting organisations, such as GPs and memory clinics, rather than relying on one organisation, even though it was a primary dementia organisation. Broader recruitment strategies should be considered for future studies.

Participant Characteristics

Whilst the intention was always to focus on a small homogenous group as per IPA recommendations, (i.e., those with early stage dementia in a similar age-group), participants who chose to participate were all Pākehā women in their 70s. This study therefore, did not provide any opportunity to explore potential differences or similarities that may exist across gender or ethnic backgrounds, even if numbers had been greater. Likewise, this study did not seek to gather information on the type of dementia, socio-economic status, or specific personality characteristics, all of which, could possibly present nuanced findings, but again this would have required a larger number of participants. Additionally, all participants who elected to participate were service users who arguably may have access to better support than those who are not affiliated with Dementia Auckland, and therefore their experiences and needs may be different. Finally, it is acknowledged that those who volunteer to participate in research have unique personality and circumstantial characteristics, and findings, therefore, may not represent the majority who do not volunteer.

Research Method and Researcher Bias

Another limitation is that the researcher, although under supervision, conducted the research and analysis on her own, independently interviewing participants and interpreting the data and findings. Qualitative analysis is inherently subjective because the researcher is the instrument for analysis (Starks & Trinidad, 2007), and whilst the issue of subjectivity is not only applicable to qualitative studies, and is not necessarily problematic (Gough & Madill, 2012), it is acknowledged that this study relied on the subjective views of a single researcher. Furthermore, rather than themes revealing themselves through the data, the researcher is active in generating these (Braun & Clarke, 2019). Therefore, the themes and underlying interpretations in this study are based solely on the researcher's interpretation which is confined to her worldview and her ability to make sense of participants' accounts and their own sense-making. IPA acknowledges this and makes explicit the role of the researcher's beliefs in interpretation of the data. Additionally, the researcher's humanistic values and own experience of losing her mother to dementia would have shaped the focus of this research. The research question itself demonstrates a bias and an assumption that friends can positively impact the wellbeing of people with dementia.

Although the researcher was diligent in practising reflexivity and maintained a reflexive journal to raise awareness of these biases and either acknowledged them, or put in place strategies to counteract them, it is recognised that there will always be blind spots one cannot see. In the hermeneutical approach, self-reflection is critical to uncover biases and assumptions, not to bracket them as in descriptive phenomenology, but rather to recognise them as an essential part of the interpretive process (Laverty, 2003). Additionally, although the researcher repeatedly reviewed the data against each theme to check its validity, confidence in overall validity of the findings may have been strengthened if at least one other researcher conducted an independent analysis allowing for investigator triangulation of the data.

Social Context

The final limitation to be acknowledged, is that in the case of one participant in particular, her husband sat beside her throughout the interview. Whilst he did not participate in the interview unless the participant sought his input, it is possible that his presence and rare comment may have affected how she responded. Likewise, another participant’s husband sat in a room nearby within hearing distance for the first quarter of the interview, enabling the participant to occasionally confer with him. In both these cases, the presence of their husbands may have influenced some of their responses. It was, however, necessary for their own comfort to enable a support person of their choice to be with them throughout the interview if they wished, and this was made explicit in the information sheet that was sent to all potential participants.

Future Research

The current study is a preliminary study only. It would be beneficial to replicate this study with a more diverse and much larger number of people to get a broader understanding of how friends can enhance the wellbeing of people with early stage dementia in Aotearoa New Zealand. Future research should also investigate differences and similarities by gender, ethnicity and socio-economic status so that the needs of all New Zealanders can be met.

New Zealand is an increasingly diverse country. Māori, the indigenous people of Aotearoa make up 16.5% of the population, Asians 15.1%, Pacific Islanders 8.1% and Pākehā (New Zealand European) 70.2% , Middle Eastern / Latin American / African 1.5%, Other 1.2% (Statistics New Zealand, 2020). (Figures do not equal 100% as some people identify with more than one ethnicity). Unlike the dominant Pākehā culture, which is individualistic, Asian, Pacific and Māori cultures embrace collectivism (Podsiadlowski & Fox, 2011). Understanding friendship needs and social support for people with early stage dementia from within this paradigm may provide important new insights.

Furthermore, risk factors for dementia, such as socioeconomic deprivation, educational level, diabetes, hypertension, obesity, stroke, smoking, alcohol intake, and head injury are more predominant in Māori and Pacific populations (Cullum et al., 2018). A study at a memory clinic in South Auckland showed that Māori and Pacific people with dementia presented to the service at a younger age than Pākehā, and Pacific people presented with more advanced dementia (Cullum et al., 2018). There is a pressing need to better support these communities. Research with different cultural groups must be conducted in a culturally safe way, specific to each group. For Māori this means following Kaupapa Māori, which embraces Te Ao Māori (Māori worldview) and the principle of ‘for Māori, by Māori’.

Another important avenue for research would be to conduct a longitudinal study following a cohort from early stage dementia through to middle stage and then late stage to understand how their wishes and social support needs might change over time. Having a more comprehensive understanding of evolving needs would inform types of social support systems needed and provide more comprehensive guidance for friends to support people throughout their life journey.

Conclusion

This study adds to, and strengthens the literature on critical wellbeing and social relationship factors for people in early stage dementia, and also demonstrates the relevance and applicability of these factors within a New Zealand context. It shows people in early stage dementia have unique insights into what is important to them for their own wellbeing. People with dementia should be enabled to continue to take an active role in research that affects them; their collective voice should be strengthened in policies and strategies that impact them.

This study demonstrates the critical role that friends play in enhancing the wellbeing of people in early stage dementia and highlights specific practices friends can adopt. It shows how acceptance from friends can help people with dementia counter internalised stigma and help them adjust to a changing conceptualisation of self. It elucidates how social support (both instrumental and emotional) helps people manage daily activities, and counter loneliness and negative emotions. It highlights how acceptance from friends together with social support enable people with early stage dementia to remain actively engaged in the world, which is critical for their wellbeing. Collectively, these factors contribute positively to a sense of self-worth which is an important aspect of wellbeing. Ultimately, this study identifies important actions, each of us can take to ensure people with dementia are treated with dignity and respect, and kindness and compassion.

"It's the way you talk to us, not what you say, that we will remember ... your smile, your laugh, your touch are what we will connect with. Empathy heals"
Christine Bryden, PhD

(person with dementia, author and dementia advocate)

(Bryden, 2005, p. 138)

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APPENDICES

Appendix 1 – Risk and Mitigation Plan

Dementia Study: How friends can enhance the wellbeing of people with early-stage dementia - Potential Risks and Mitigation Plan

Risk	Mitigation
Ability to give informed consent	• Restrict study to people in early-stage dementia. • Provide clear usable information and check carefully that they are truly consenting. • Use 4 key questions based on the Older Adults Capacity to Consent Research (OACCR) scale used in previous research with people with dementia in New Zealand: 1. *What is the purpose of the research?* 2. *Tell me some things you may be asked about?* 3. *What are the things that might worry you about taking part in the research?* 4. *If you don't want to, do you have to take part in the research?* If people can't answer 1 and 4, they are excluded.
Confidentiality	• Participant names to be protected. Participants will be referred to as Participant 1, 2, 3 etc. in transcripts and all written documentation. • Store material in a safe, locked environment. • Dispose of file containing personal details. • Apply standard protocols of confidentiality as specified in Code of Ethics.
Inadvertently triggering negative feelings	• Use Appreciative Inquiry approach which focuses on strengths and possibilities. • Ensure clinical expert is on hand, i.e., identify caseworker for each person upfront and agree when and how to contact them if needed. Make this explicit and transparent to all participants. • Proactively check-in during the interview to make sure they are happy to continue. • Advise participants that they do not need to answer all questions and to let me know if they are feeling any discomfort. • Be on the lookout for any signs of distress (e.g., tears; agitated body language; expressions of anger, sadness or anxiety; negative thoughts; expressed concerns) and pause

Risk	Mitigation
	or halt the interview as needed. Check-in with the person and ask if they would like to take a break and what support they might need (e.g., a cup of tea and different focus; their support person; a change of scene). Be empathetic. Advise caseworker. • Consider exclusion from the study if it's too distressing for the person
Lack of support from family / carer for this research	• Provide explicit brief for the family clearly explaining the study (purpose, risks, counter-measures, procedures, ethics). • Provide opportunity for family members, support people and participants to ask any questions (in person, via email or telephone). • Discuss family concerns/reluctance with participant and determine whether they wish to proceed with the study (it is seen as important to ensure self-determination for these participants). If they do wish to proceed, inform the family of their decision and ask what the family / carer would need to feel more comfortable with the study and, where feasible, work together to address. If the participant prefers not to proceed without family support, then exclude them from the study.
Feeling coerced	• Gain Informed Consent using OACCR scale. • Re-iterate that it is their right to choose whether or not they want to participate.
Perceived power imbalance between researcher and individual	• Establish rapport; explicitly acknowledge the individual as the expert in their lives; make explicit that their perspectives are what is important; researcher is learning through them. • Enable support person to accompany them should they chose (e.g., family member / carer) • Emphasise their rights - they can choose to not answer any questions and stop whenever they like.
Perceived as culturally inappropriate	• Acknowledge limitations of my own worldview. • Appreciate individual differences, and recognise and be open to other worldviews. • Conduct myself in a respectful manner • Be open to feedback. • Limit study to English speaking people to minimise risk of misunderstanding. • Seek appropriate cultural advice through my supervisor.

Risk	Mitigation
Inadvertently working outside of one's competence	• Maintain strict professional boundaries confined to research, not clinical. • Disclose upfront limits of scope with individual and family member • Have a clinical expert available to refer the person on to should they require clinical support (i.e., their own caseworker)
Researcher biases (e.g., seeing what I expect to see based on my own research and beliefs)	• Adopt a reflexive approach and maintain a reflexive diary. • Debrief with supervisor & remain open to being challenged. • Check my interpretation with participants & peers. • Deploy sound scientific research methodology.

Appendix 2 – Letter to Recruitment Organisation

28 June 2020

Ms Rhonda Preston-Jones
Clinical Lead
Dementia Auckland
Level 4, Suite 5
58 Surrey Crescent
Grey Lynn
Auckland 1021

Dear Ms Preston-Jones,

Further to our previous email correspondence, I'd like to thank you and Dementia Auckland for agreeing to support my study on "how friends can enhance the wellbeing of people in early-stage dementia" by helping me gain access to potential participants. As explained in my earlier communications I am seeking approximately 8 participants for this study. When the research is complete, I will share my findings with Dementia Auckland.

I am pleased to advise that I have now gained approval from Massey University Human Ethics Committee. Letter of approval is attached.

As agreed previously, could you please send out a general request to Dementia Auckland staff asking them to contact anyone who might be eligible. I realise that it would then be up to the participants or their carers to make contact with me directly. Please see attached the final briefing and information sheet, together with my contact details.

If feasible, I would also welcome the opportunity to attend one of the workshops you run for people with dementia and / or their carers to share more information about my research.

Thank you again for your support. I am committed to making a positive difference for people with dementia.

Kind Regards,

Anne Silva

Appendix 3 – Draft email prepared for Dementia Auckland to send to potential participants

Dear [NAME]

Massey University is conducting a study on how friends can enhance the wellbeing of people in early-stage dementia and are keen to speak to people in early-stage dementia to get their views on how friends can enhance their wellbeing.

As I thought you may be interested in this study, I am sending you this invitation to participate in an interview with the researcher.

It is hoped that the findings from this study will provide guidance to others on how they can best support their friends who have dementia.

If you would like to participate in this study, please see the attached information sheet which provides more details about the study and what is involved.

If you are interested or have any questions please contact the researcher, Anne Silva on [email address] or via telephone on [telephone number]

Kind Regards,

Appendix 4 – Participant Information Sheet

Massey University Study
How friends can enhance the wellbeing of people in early stage dementia

INFORMATION SHEET

Hello,

My name is Anne Silva. I am a researcher completing my Masters in Psychology under the supervision of Professor Christine Stephens at Massey University. I am interested in supporting people with dementia to live well in the community.

What is this study about?
I am doing research with people in the early stages of dementia, to understand how friends can enhance their wellbeing.

Invitation to participate
If you have been diagnosed with early-stage dementia and want to participate in this research, please contact me by email or telephone. Please see contact details below:

Email: [email]
Telephone: [Tel no]

QUESTIONS YOU MAY HAVE:

Why am I being invited to participate?
You have received this invitation and information sheet through Dementia Auckland because they believe you may meet the criteria for this study.

Who can participate in this study?
Anyone who has been diagnosed with early-stage dementia and wants to be interviewed as part of this study.

Do I have to participate in this study?
No. You choose whether or not you want to participate.

Is there any benefit for me personally to participate in this study?
You may find it beneficial to share your views on how friends can enhance your own wellbeing. You may also want to contribute to research aimed at improving the wellbeing of people with dementia.

Is there any disadvantage to me if I choose not to participate?
No.

If I choose to participate in this study, what's involved?
I would like to interview you in person for no more than 1 hour. The interview will be recorded with your permission. I would be happy to interview you in your home or other place you nominate, such as your local library or community centre, or at Massey University in Albany, when convenient for you.

What happens if I don't feel comfortable during the interview?
My aim is that you do feel comfortable throughout the interview. If at any stage, you need a break, or wish to stop, your wishes will be respected. If you would prefer to have someone you know with you, you are welcome to bring them along to the interview. If you need additional support, I will ensure your caseworker is appropriately informed.

Will my information be confidential?
Yes. Your name will not be linked to interview notes or transcripts. Notes and transcripts will be stored in a secure place. The file containing your personal details, such as name and contact details will be deleted.

What happens to the information I provide?
Notes and transcripts from your interview, and that of others, will be analysed for themes to help identify practical ways friends can enhance the wellbeing of people in early stage dementia.

Summary findings will be shared with Dementia Auckland and any participants in this study (such as yourself) who would like to receive this. Summary findings will be emailed or posted to you (whichever you prefer), on request.

The findings will also be used as part of a master's research thesis, and potentially presented in academic journals and at scientific conferences to grow understanding of how friends can enhance the wellbeing of people with dementia.

What rights do I have?

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time;
- ask any questions about the study at any time before, during and after participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- ask for the recorder to be turned off at any time during the interview;
- be given access to a summary of the project findings when it is concluded.

What can I expect from the researcher?

- To uphold your rights;
- To honour your views and treat you with respect and dignity at all times;
- To maintain high ethical standards;
- To work hard and maintain a focus on enhancing the wellbeing of people with dementia.

Who do I contact if I have any other questions, or wish to participate in this study?

If you have any questions or would like to participate in this study, please contact:

Anne Silva
Researcher
Massey University
Email: [email addresss]
Tel: [Tel no]

OR

Dr Christine Stephens
Professor of Social Science Research
Massey University
Email: c.v.stephens@massey.ac.nz
Tel: 0800 100134 (freephone)

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 20/16. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz

Appendix 5 – Screening Tool for Capacity to Consent among Older Adults

The original questions from the Older Adults Capacity to Consent to Research (OACCR) scale developed and validated by Lee (2010):

1. What is the purpose of this study?
2. Tell me some things that you will be asked to do in this study?
3. What are the risks or discomfort that you might face from participation in the study?
4. If you don’t want to, do you have to be in this study?

The modified questions used in recent New Zealand research with people with dementia (E. Smith et al., 2019):

1. What is the purpose of the research?
2. Tell me some things you may be asked about?
3. What are the things that might worry you about taking part in the research?
4. If you don’t want to, do you have to take part in the research

Appendix 6 – Interview guide and structure with potential questions for consideration

Interview Guide

Tips for Interviewing people with dementia:

Generally, people in early stage dementia, with mild cognitive decline, should be able to participate fully in the interview outlined below. However, depending on the type of dementia, the course of the disease, and individual differences, one will need to tailor the interview to each individual. This might mean adjusting the language, volume or pace of the interview. Below are some general tips for interviewing people with dementia, however, it is important to check in with the person directly and not make assumptions.

- Find out what time of day works best for the person. There may be times when they feel more alert and have more energy to engage in an interview.

- Avoid visual or audio distractions such as having a TV or radio playing in the background.

- Sit close by where the person can clearly see you, your eyes and your mouth.

- Take the time to connect in with the person and truly see them for who they are, understanding not only their current context and culture, but also their history, and their wishes and future aspirations.

- Speak directly to the person, not their carer or support person.

- Keep questions concise and ask one question at a time.

- Speak clearly and not too fast, but make sure you don’t come across in a patronising manner.

- Be aware of potential sensory decline as part of natural aging and make sure they can hear you.

- Adjust the tempo and volume to meet their unique needs.
- Be patient and give the person time to respond – don’t interrupt.
- Help them find the word if they need, in a natural, conversational way
- Offer encouragement and reminders and prompts as needed.
- If the person doesn’t understand the question, repeat it in a different way.
- Pay attention to body language and tone, being sure to come across as friendly, calm and relaxed
- Be self-reflective and willing to confront your own biases.
- Be on the lookout for any signs of distress or fatigue and be prepared to pause or halt the interview.

At all times, adhere to the four key ethical principles outlined by the New Zealand Psychologists Board, 2012: 1) Respect for the dignity of persons and peoples; 2) Responsible caring; 3) Integrity of relationships; 4) Social justice and responsibility to society.

(Alzheimer’s Organisation, n.d.; Bryden, 2005; Nazarko, 2015; University of Queensland Dementia Care, 2012)

Interview Structure with Potential Questions for Consideration for Final Interview Script

	Focus	**Guidelines**	**Example**
INTRODUCTION	Establish Rapport	• Greet the person warmly • Introduce yourself • Ask how they are • Establish commonality • Thank them for participating in this study	Hello / Kia ora. Lovely to meet you. My name is Anne Silva. Thank you for meeting with me.
	Set Expectations	• Explain /Re-explain who you are, why you are here and the purpose of the interview • Confirm confidentiality • Advise that the interview will take about 1 hour • Check ok to record • Check whether they would like to receive a summary of the findings and if so, how	I am doing some research through Massey University and Dementia Auckland to understand how friends can support people with early-stage dementia and enhance their well-being. I am keen to understand your views. Thank you for agreeing to be interviewed. You are one of X number of people who has chosen to be interviewed for this study. To protect your identity and ensure confidentiality, your name will not be used in any of the transcripts, findings or recommendations. If you wish, I will send you a summary of the findings as soon as I have completed the research. Would you like to receive a summary of the findings? *If YES:* Would you prefer this to be sent to you via email or posted out to you? The interview will take approximately 1 hour. If okay, with you I would like to record our interview so that I don't miss anything or forget anything. Is that okay with you?

			You can ask for the recorder to be turned off at any time during the interview.
	Check for informed consent	Use the Older Adults Capacity to Consent to Research (OACCR) questions (If the person can't answer questions 1 or 4 then they will be excluded from the study on the basis that they are unable to give informed consent)	I am going to ask you a few questions to make sure you are happy to take part in this research and that it is your choice to do so. Can you tell me please: 5. *What is the purpose of the research?* 6. *Tell me some things you may be asked about?* 7. *What are the things that might worry you about taking part in the research?* 8. *If you don't want to, do you have to take part in the research?*
	Re-iterate their rights	Remind them about their rights (refer to Participant Information Sheet)	• If there is any question you don't want to answer, you don't have to answer it; • You can withdraw from the study at any time or stop the interview whenever you want. • Please feel free to ask any questions at any time; • you can ask for the recorder to be turned off at any time during the interview. Do you have any questions?
I	Get to know the person	• Commence with broad open questions to understand the person.	

NTERVIEW QUESTIONS		• Find commonality and share with the person to further build rapport an reciprocity.	
	Appreciate the impact of dementia on the person	• Use open and closed questions	• When were you diagnosed with dementia? • What has that meant for you? How have things changed for you? • What challenges have you experienced? • How have you coped with these challenges? • What might help overcome some of these challenges? • How might friends be able to support?
	Identify opportunities to enhance well-being	• Focus on specific concrete example with friend. • Use appreciative inquiry type questions that focus on strengths and possibilities.	• Can you think of a time recently when you felt really well and happy? • Can you tell me about a time recently when you with a friend and felt really happy? What were you doing? • What was it about that experience that made you feel so happy? • What's helps you keep well and happy? • What do you enjoy doing? • What would you like to do more of? • What would you like less of? • If you could wave a magic wand, what would your friends do to help you keep well and happy? • What do you think might get in the way of friends doing things that would support you to be well and happy? • If you had a friend with dementia, what would you do to help them keep well and happy? • What advice would you give to friends who want to know how they can support?

C L O S E	Acknowledge their contribution	• Thank the person for their time • Acknowledge the insights they have shared • Affirm their expertise • Highlight the value of their contribution • Confirm how they wish to receive a summary of the study and set expectations that this could take about six months	Thank you very much being so generous with your time and sharing your insights and advice. This has been extremely valuable. You have made a worthwhile contribution. I hope that by sharing the findings from this research, we can begin to educate the wider community on how friends can enhance the well-being of people with dementia. When the project is complete, I will send a summary of the findings to you. Please note that, as there are other people to interview, this could take about six months. Thanks again for your time.

Appendix 7 – Interview Sheet

INTERVIEW SHEET

Purpose of Study

I am doing some research through Massey University and Dementia Auckland to understand how friends can support people with early-stage dementia and enhance their wellbeing. I am keen to understand your views. Thank you for offering to be interviewed.

Confidentiality

To protect your identity and ensure confidentiality, your name will not be used in any of the transcripts, findings or recommendations.

Receiving Summary Findings

If you wish, I will send you a summary of the findings as soon as I have completed the research. Would you prefer this to be sent to you via email or posted out to you?

Time Allocation – Set Expectations

The interview will take approximately 1 hour.

Permission to record

If okay, with you I would like to record our interview so that I don't miss anything or forget anything. Is that okay with you?

You can ask for the recorder to be turned off at any time during the interview.

Informed Consent

I am going to ask you a few questions to make sure you are happy to take part in this research and that it is your choice to do so.

Can you tell me please:

1. *What is the purpose of the research?*
2. *Tell me some things you may be asked about?*
3. *What are the things that might worry you about taking part in the research?*
4. *If you don't want to, do you have to take part in the research?*

- If there is any question you don't want to answer, you don't have to answer it;
- You can withdraw from the study at any time or stop the interview whenever you want.
- Please feel free to ask any questions at any time;
- you can ask for the recorder to be turned off at any time during the interview.
- Do you have any questions?

Questions

1. Think of time you've really enjoyed being with a friend or doing something with a friend. Tell me about it. What was it that you enjoyed so much? What did your friend do that made that time so special? What did you most appreciate? How did it make you feel?

   (Ask probing questions to encourage the participant to elaborate on the details to achieve clarity and to stay close to the lived experience)

2. If you could wave a magic wand, what would your friends do to help you keep well and happy?

3. What do you think might get in the way of friends doing things that would support you to be well and happy?

4. What advice would you give to friends who want to know how they can support? How might your friends support your wellbeing? What would you like them to do? How would you like them to be?

5. What's important for your wellbeing?

**

6. If someone you cared about deeply developed dementia, how might you enhance their wellbeing? What might you do? How do you think that would be important for their wellbeing? What's important for your wellbeing?

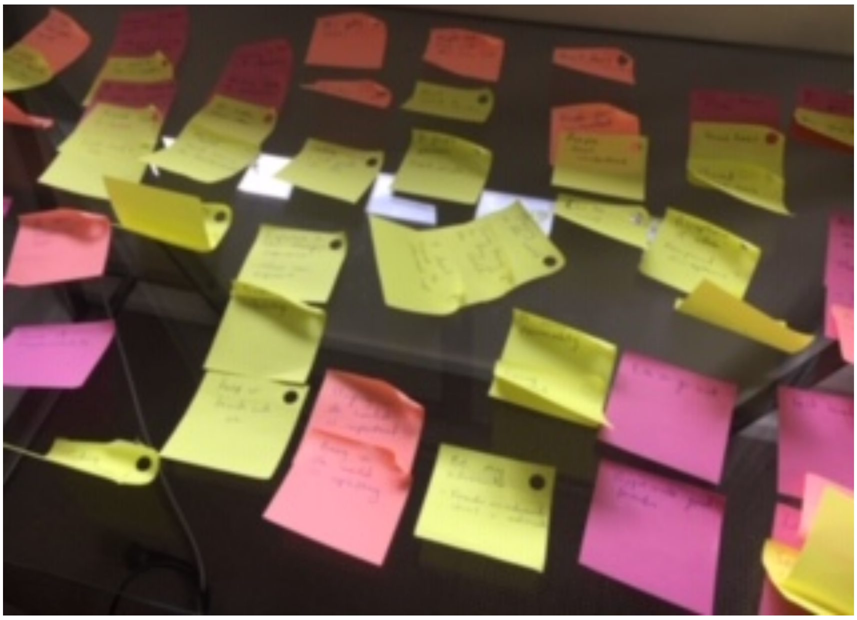
**

Conclude & Acknowledge
Thank you very much being so generous with your time and sharing your insights and advice. I hope that by sharing the findings from this research, we can begin to educate the wider community on how friends can enhance the wellbeing of people with dementia.

When the project is complete, I will send a summary of the findings to you. Please note that, as there are other people to interview, this could take about six months.

Thanks again for your time.

Appendix 8 – Participant A Summary Analysis



Emerging Themes/ Groupings from post-it notes

Feeling Valued	I have something to give My Life matters I was his reason for living I was important I am recognised and valued Valued for being me Lost friends If I die ‘who will care’ never crossed my mind.
Feeling loved	Feeling loved and cared for It’s lovely being wanted I was his reason for living He wants to share with me Connect with me because of me In some ways treat me like a child – with love & patience If I die ‘who will care’ never crossed my mind.
Maintaining Self	Values me for me Makes one feel oneself Valued for being me – no one else will do I’m still a [profession] A [professional is what I am Love to talk – it’s what we [professionals]do I’m still [name]

	In some ways I went on being a child ... Although not really a child We're not too bad – can't tell who has dementia
Lonely	Find yourself retired with no place to go No longer a place to go to How does one make friends? Too busy to develop a social circle Illness prevents me socialising Friends drop you Was devoted to parents / sacrifice for parent Lost friends
People hurt you	Friends drop you Some are selfish They don't want you being a burden
Sense of hopelessness	Sense of hopelessness Facing own mortality Feeling frightened Grief – loss of parent, loss of friends Going through a bad patch It's embarrassing & humiliating Feeling useless – if you've got nothing to contribute Sick & tired of smiling sweetly and saying 'thank you, you're too kind'
Being engaged in the world	Makes me feel like I'm intelligently engaged in the world He's interesting Intellectually stimulated Stories about what's going on Interesting talkers Keeps me engaged in the world Keeps me engaged & current in [profession] Values intelligence
Practical challenges I face	Don't drive so need to take a bus and walk to supermarket I'm still quite stupid with computers (can't manage online shopping) No, I'm sorry I can't come out to lunch. It's not a practical thing I can manage anymore". Worry about forgetting to take my pills
Being a burden	She didn't want me around her neck She dropped me because I developed dementia
Responding to dementia	**A shock to me** • Came as a dreadful shock to me • I never went back to that doctor!

	- [specific illness] - I think it was a kind of psychological reaction to having discovered I had dementia / my brain angry with the fact that I have dementia **Taking Control** - Then that's taking it in my hands and saying "I'll tell you what we're going to do with you". - I can do something with dementia (contribute to research) **Feeling Useful** - I can be useful - I can make a contribution **Recognising Limitations** - My memory now is just totally hopeless - He's becoming odd himself - I suspect it is sometimes very tiresome, listening to the same things again and again and again, or what have you. - we *know* we're being stupid most of the time. We're not too bad – can't tell who has dementia
People I can count on	People I can reliably count on to keep in touch She took care of me (when I was sick) Stick with me
What I need from friends	Stick with me Don't push me / pressure me Be patient & loving Accept me as I am (with my limitations) I am still [name] Reach out to me (telephone, email) – women are better at keeping in touch On-going relationship & conversation Take time to be with me Make time to see me Reciprocal relationship Having good conversations together Socialising together (a meal together, a drink together) Someone I can reliably count on
Comfort of old friends	Talk about anything & everything with old friends It's as nice as breathing Comfort of talking with old friends The way friends do Feels close even though she is not here

My sort of people	**Commonality** - Common profession - sort of person I get on with. - Book club – my sort of people

Higher Level Theme	
Responding to dementia / Coming to terms with dementia	A shock to me Recognising Limitations / practical challenges I'll show you / taking control Being useful
Lonely	Friends drop you Loved ones die Find yourself retired No place to go
Sense of hopelessness	Feeling useless Afraid Waiting to die
Holding on to self	Professional me Family me Valued for being me I'm still me
My needs	Being engaged in the world Feeling loved Feeling valued
Friends can make a difference	Comfort & familiarity of old friends Someone I can reliably count on Stick with me Be patient & loving Accept me as I am Reach out to me Take time to be with me A reciprocal on-going relationship & conversation Having good conversations together Socialising together (a meal together, a drink together)

Superordinate Themes around how friends can enhance your wellbeing?

Accept me as I am	Be patient with me
Keep me engaged in the world	Engage in conversation with me Socialise and do things together with me
Show me I’m valued	Take time to be with me Stay in touch with me
Show me I’m loved	Stick with me and be there for me

Appendix 9 – Participant B Summary Analysis

Groupings of Post-it Notes / Emerging Themes

Letting Go	Coming to terms with Loss Things I can no longer do I used to be in control I was responsible Shared loss of control Lost half of me A part of me Driving was a part of me
Coming to terms with dementia	Something's wrong Got Lost Sense of Responsibility It's better than others Other's pain & suffering [It] runs in the family I'm pretty normal now Getting back to normal I have to look after myself Wanting to help It's getting worse
Staying in the world	Routine is the framework of life Doing things to stay in the world I don't want to shrivel up Staying in the world is important Being in the world is uplifting A new lease on life Exposure to new things / experiences Books are interesting Keeping current
Doing normal things	A sense of normality Doing normal things
Don't want to be a burden	People are busy with their own lives Don't want to be a burden
Keep in touch with me	Keep in touch with me
Please understand me	Don't deny I have dementia People don't understand
Ups & downs of life	Ups & downs of life

	Hard times Shared hard times
I need people to interact with me	Doing things person Likes to go out A people person I need people Hiding myself is not good for me Felt lonely
Being friendly & helpful	Practical support from friends Friendly & helpful Friends support one another People are friendly and supportive Reciprocal support of friends
People I can rely on	You can count on good friends You can rely on them Can count on him
Advocate for me	Be my advocate Friends as advocate Husband as advocate Taking advantage of me
People like me	Lots in common Something in common Things in common People like me
Accept me as I am	Familiarity & acceptance of old friends Acceptance – not having to explain yourself They understand me Accept & understand Acceptance of others / Reciprocal acceptance Can be myself
Old friends are comforting -like a comfortable old shoe	Long history together Longevity of friends History of solid partnership with husband Familiarity & comfort of old friends Familiarity of people Comfortable place to be with people I know

Friends are uplifting	Camaraderie of people Appreciate good friends Lucky / blessed to have friends Friends give such a lift Magic moments with friends

Higher Level Theme	Sub Themes
Coming to Terms with Dementia	Others are worse off I have to look after myself now Letting go • Things I can no longer do • I used to be in control • Driving was a part of me • It’s getting worse little by little
My needs	Staying in the world • Interacting with people • Doing normal things • New experiences • Keeping current Being understood and accepted People I can rely on Routine and structure I don’t want to be a burden
Familiarity & comfort of old friends	Understand me and accept me as I am Shared history • ups and downs of life • lots in common We support each other
Friends make such a difference	Help me stay in the world / bring the world to me Keep in touch with me Do normal things with me Be kind and help me Be an advocate for me


How can friends enhance your wellbeing
Help me stay in the world
Keep in touch with me
Do normal things with me
Be an advocate for me
Try to understand me
Accept me as I am
Help me when I need it
Be there for me
Provide some structure in my life

Appendix 10 – Participant C Summary Analysis

Emerging Themes from Post it Notes

Accept me as I am	Takes me totally as I am Accepted by everyone No discrimination Friends take me as I am Accept my limitations I can be myself – I'm not embarrassed I might repeat myself but that's me If friends don't accept it, then just move on Just accept me as I am Treat me as a friend I'm no different to other people I'm still me (my personality endures)
Friends stick with me	Keeping in touch Treat me as a friend Love having friends come around – something to look forward to So much to catch up on – that's nice Lots in common Reminisce about the good old times Include me Good to him and good for him Treated him like normal
Friends support me	Came to stay with me when [alone] Cook a meal for me
Accept I have AD	Let me talk about it openly It's easier being upfront about it I would tell friends what to expect – it comes on gradually, doesn't it? Understand where my difficulties are
Doing normal things	Chatting about normal things (films, what we've done, what we're going to do) Doing normal things – nothing different from what it used to be like Going for a walk, having a coffee together, going to a movie Just treat me as a friend

	Love having friends come around – something to look forward to So much to catch up on – that's nice Reminisce about the good old times
Coming to terms with dementia	I don't want AD but I have it Make every day count I just take it as it comes Dementia is different but it's not something to fear It's different – you will forget sometimes You get used to having to note things down otherwise you forget
Things I can no longer do / Acknowledging Limitations	I might repeat myself but that's me Sometimes I forget things Feel foolish sometimes They used to see me on top of things People might exclude me because they think things are over my head Worst thing about AD is how much you forget – you have to write things down Not confident travelling anymore
People like me	Things in common Understand each other Can be ourselves
My Needs	Need to interact with others To be as efficient (competent?) as possible Enjoy people and interacting
Avoid things I find difficult / Compensatory Strategies	Prefer small numbers – not crowds Things I don't understand I'd rather be comfortable in my shoes
Things I can still do	Emails I don't have problems engaging with people
Reciprocal friendship / equal relationship	My good friends still enjoy my company We both initiate contact
Feeling Insecure	I've always been frightened of the dark but more so now. Don't want to be alone - someone there to help. Unsure about going places now Worry about [name] dying before me I wouldn't want to stay in the house

	Need a carer – want more people around Worry about getting lost Scared to travel – scared I might lose carer
People can be hurtful	Horrible how some PWD are treated as if they're dotty – it's horrible, unnecessary & hurtful People exclude me because they think things are over my head – let me decide
It could be worse	Having dementia is better than other crippling diseases where there's no cure; that's different – they would need lots of love and understanding
Help me when I need	Let me ask for help when I need it
Lots in common	Fun and camaraderie Enjoy being with the group People who understand Laugh together about our various wobbles
Need people to understand	A lot of people think that if you have dementia you're already la-la in la-la land – they don't understand. If someone has dementia and they don't belong to a group, or have got family that don't understand, I think that would be awful.
Let me decide	Let me decide whether I want to be part of something or not – don't exclude me because you think it's over my head.
Readying my head for visitors	Readying my head for visitors Tidying and preparing Something to look forward to

Higher Level Themes:

Coming to Terms with Dementia	Acknowledging Limitations Things could be worse If friends don't accept it, just move on Make every day count I just take it as it comes
Challenges I face	Feeling insecure Being in crowds Not understanding - things go over my head No longer being efficient
My needs	Interacting with people Feeling as efficient as I can Letting me decide Accept me as I am
Friends can help	Accept me as I am Stick with me Keep in touch Treat me like normal Support / help me when I need Understand my difficulties Understand what dementia is and isn't Have a reciprocal / equal relationship Include me - let me decide
People like me	Things in common People who Understand Can be ourselves Camaraderie


Accept me as I am
Engage in a reciprocal relationship with me
Understand my difficulties
Include me
How you can ehance my wellbeing
Treat me as normal & do normal things with me
Stick with me
Keep in touch with me
Help me when I need

Appendix 11 – Participant D Summary Analysis

Emerging Themes

Hard Times	• Couldn't find a place I could afford • Tough times financially • Forced out of my place • Forced retirement • Nowhere to go • Lockdown was tough – I needed touch • Used to be depressed • Break up • That scarring is always in your mind • Scared of [them]
Instrumental Help / Emotional Support	• Helped me pack & move • Would never have got by without them • Stayed with them • Helped me find a place • Need someone to give me a ride to church • I can't get to places myself anymore • Lift my spirits – take me to the beach to turn me around • Share the good times and the bad – even that's good for the soul • Having someone to share your emotions with is special
Feeling Blessed	• Felt at home • Feel blessed to have this home • Now have a lot to be grateful for and look forward to. • Not ready to go yet (die) • Blessed to have travelled • Blessed to have had such lovely friends – we just loved each other
Lots in common	• We're all women – can talk about anything & everything • We have lots of laughs together • Common problems • [same profession], bonded straight away • We're all the same – laugh a lot, talk a lot & share funny stories • Part of a special community. • Each of us were broken in some way that others would try and heal • None of us were perfect • Closeness through shared, profound experience
Not my people	• Can't chat to these people • They just don't get it – my sense of humour

Acknowledging I have dementia	• Knew I had dementia before the doctors told me • Disorientation • Couldn't recognize places • I'd get lost and cry – it was terrifying • Thought I had dementia / Knew I had dementia • Doctor confirmed Alzheimer's • Used to drive but can't now • Takes me longer to walk now (depends on health) • Was more able before when I was young • Acknowledging limitations
Keep me interacting in the world	• Lively interaction with others is most important • Love church -nice to go out to church for chats • Love the walking group - meeting some really lovely people • Walking in nature amongst the beautiful trees – I love trees • Going to the café and having a latte with delicious scones • Laughing is so precious • They keep me young with visits, laughter and love • Love seeing people & studying the fashion • Listening to others' conversations • Made me feel alive. • Their things that they like doing • Keep me engaged in the world – love animals & nature • I just Love going out • Love celeb spotting, fashion spotting, trees and nature walks. • Love travelling – exploring and day trips – that's so me • Going out, having fun, letting your hair down • Fun times – going out for a meal or drink • Even to visit the next rubbish dump – just to get away •
Self-worth Things I can still do Chuffed with myself	• I'm a fast walker • I did it all on my own • I did that all myself – packed up and sold stuff • Chuffed with myself • I'm very organized • Manage by myself • Glad that she could share with me & confide in me • They wanted me - couldn't bear me not being at their wedding • Values me – breaking his neck to come and see me • Values me – he writes to me all the time. • Values me – sobbed when I left • I have an amazing long-term memory • Came back to see me • My sense of humour • I can stand up to [person]

Good Times	• Had a brilliant life • Best place to be • Best time of my life • Beautiful friends • We were very social
Self-identity	• [removed for confidentiality]
Challenges I face	• Hard to manage change of environment • Stressed – can't take things in as well as I used to • Stressful managing documentation • Not good at equating time • Feels like I've been here 10 years but it's only a few months • Problems with my knees and dizziness from the dementia medication • Can't get to church in wet weather – hated that • Can't manage stairs anymore • Too much info clutters my brain • Acknowledging limitations – can't differentiate time • I've also had hard times • Still have problems getting lost
Special People bring me to life	• A joy to see any time • they brighten me up - when they go they take all the sunshine away • Heartbroken without them • Fun time together / Doing Fun things • I can share with them • They can help heal those bits that are broken. • Love, love them coming over • They are the ones that bring me most to life • Bring me to life with love, care and laughs • Laughing is so precious • Make me laugh • Friends and family are what make a place great
People are busy with their own lives	• People are busy with their own lives • She's got her own issues
Feeling no pain / Escape	• Joy of laughter • Laughter is good for the soul • Laughter uplifting • Having fun is so important because so much tragedy in the world • Felt no pain after a few drinks • Even to visit the next rubbish dump – just to get away
Feeling down	• I'd want to curl up and let myself die – that's not me

	• I was so depressed –I felt I was sitting around waiting to die – not how I pictured spending the rest of my life.. • if she doesn't come I'm going to be so disappointed. • Oh my gosh what am I going to do now?". No friends, nothing to do, no arrangements made. I'd hate to be like that.
Changing Relationships	• Changing relationship with [friend] • Lost touch • Relationship got lost
Acceptance	• She still loves me the same • I care for her but … • Tolerance for others – they need to live too • Still love her even if I don't like how she is sometimes. • We accept each other's different ways • Think it's always important to tell people that you love them or the nice things about them.
That's what friends do	• Just be around more • True friends keep in touch • If you're a true friend you wouldn't just ring every few months or not bother • I love it when they reach out to me • Special friends are the ones who are constant • Special friends value me – brought their wedding forward so I could attend • Help friends in a crisis • Friends who love each other & can speak openly about all sorts of things. • Keep them engaged in the world – keep taking them out • Doing whatever they like. • I'd make sure they were interacting, not just with me but with the outside world – not sitting around waiting to die. • Just to be a friend • Kind and caring and compassionate
Don't want to be a burden	• Don't make me a have to be • Don't want to be that needy person • Come when you're free and when you feel like it • Don't want them to suffer seeing me like that. • I wouldn't give advice to friends to tell them how to support me.


Share the good times and the bad
Take me out and do fun things together
Let me share my emotions
Be kind and caring and copassionate
How friends can ehance my wellbeing
Be around more
Keep me engaged in the world
Keep in touch / reach out to me / be constant
Help me when I need it
Show me you value me