Faculty of Health Sciences
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“Dementia inclusivity: Using the experiences of people with dementia and care partners to inform a forum intended to address community attitudes”

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This thesis is presented for the degree
of
Doctor of Philosophy
of
Curtin University

October 2022

Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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October 2022

Abstract

The number of people diagnosed with dementia is increasing globally and, as such, there is an urgent need to find measures that will help meet the increasing long-term care needs of this population. There is however a paucity of literature detailing the expectations of people with dementia which results in care and support measures not being informed by consumer perspectives. In addition, dementia-related stigma amongst community members including health care professionals means people living with the condition are often denied opportunities to be involved in decisions central to their lives. These shortcomings occur despite a paradigm shift in how people with dementia are supported by using a human rights-focused approach to ensure their right to independence, decision-making, and an adequate standard of living is upheld.

This mixed-method research utilised an exploratory sequential design that encompassed four separate studies and an integrative literature review. First, using a qualitative methodology, the research aimed to explore the experiences and perspectives of people diagnosed with dementia and their care partners to gain insight into current and future needs related to care, support and decision-making. A secondary aim emerged, based on findings from the qualitative studies, and a quantitative component was implemented to explore the usefulness of a Dementia Awareness Raising Forum intended to bring about more positive community attitudes towards people with dementia.

An application of the grounded theory methodology was used for the qualitative component of this research. Twenty-four people with dementia and 21 care partners provided data, via semi-structured interviews, that were analysed using a process of constant comparison. An integrative literature review examined the evidence, derived from studies in which people with dementia were included as research participants, to determine their participation in care and support planning. The quantitative component involved the development of the Dementia Community Attitudes Questionnaire (DCAQ) in consultation with experts in the field of dementia, for use at a Dementia Awareness Raising Forum to determine its effectiveness in bringing about positive community attitudes toward people with dementia. Forum attendees included community members, Curtin University staff, students and graduates, and staff working within the aged care sector and in public and private hospitals. Data were collected from forum attendees using the DCAQ before and after the forum. A two-way repeated-measures analysis of variance was employed to determine the overall effect of the forum. Questionnaire score comparisons were limited to item by item only when looking at attitude change at the forum because of the immaturity of the questionnaire. Independent sample T-Tests were used to contrast outcomes between those people who attended the forum and had dementia-related education and those without. Exploratory factor analysis was used to determine constructs within the questionnaire following its implementation at the Dementia Awareness Raising Forum. Data collected at the forum was used to inform the ongoing development of the questionnaire.

People with dementia participating in Study 1 disclosed the experience of losing control upon being diagnosed but sought to maintain a connection to their pre-diagnosis lifestyle and remain self-determining. The nature and extent of the relationship the care partners had with the person with dementia was a significant factor in their ability to act as an advocate to assist the person with the condition to remain self-determining over the longer term. The experience of stigma emerged from both people living with dementia and care partners and was confirmed in the integrative literature review outcomes. Implementation of the DCAQ at the Dementia Awareness Raising Forum revealed the forum’s effectiveness in positively changing attendees’ attitudes towards people with dementia. While participants with previous dementia education had higher baseline scores, those with no previous dementia-related education showed more improved post-forum scores.

Identifying the experiences and expectations of people with dementia is critical to improving awareness amongst care partners, health professionals and the community so that people living with the condition can be actively assisted to achieve optimal quality of life and have their right to self-determination supported. Awareness-raising initiatives are essential to enhancing the inclusion of people with dementia within the broader community, across the trajectory of their condition. Improving dementia-related knowledge within the community can positively enhance attitudes towards people with the condition. The theories of self-determination and person-centred care were applied to findings and recommendations related to research, education, policy and practice are provided. These assist researchers, policymakers, and health professionals to develop strategies to enable people with dementia to maintain connectedness to their pre-diagnosis lifestyle with an endpoint of assisting them to retain where possible, their autonomy and self-determination, and supporting their ongoing social inclusion.

Acknowledgements

I would like to take this opportunity to express my sincere gratitude to the numerous people who assisted and supported me throughout my doctoral studies. First and foremost, to my three supervisors, without your wisdom, relentless support, and guidance this would not have been possible. Associate Professor Chris Toye, your knowledge and expertise within the field have been invaluable, your enlightenment throughout the journey has enabled the completion of a product with the potential to improve the lives of people living with dementia. Emeritus Professor Dianne Wynaden, I thank you for your patience, and leadership and for imparting your knowledge on Grounded Theory, and Associate Professor Ravani Duggan, I am truly grateful for your wise counsel, teaching, and ongoing encouragement that has enabled me to reach the finish line. Thanks also to Diana Blackwood, former faculty librarian to the Curtin School of Nursing, for your assistance throughout the study and Dr. Matthew Albrecht, for sharing your quantitative statistical analysis expertise and guidance during the development of the Dementia Community Attitudes Questionnaire.

I would also like to extend a heartfelt thanks to all the people who gave me some of their precious time to participate in my study. People with dementia and care partners, thank you for sharing your priceless experiences and expectations of living with dementia. To the experts within the field who assisted in the development of the Dementia Community Attitudes Questionnaire, and members of the West Australian community who helped to pilot the tool. To Jason Burton, Dr Maria Foundas and Daniella Greenwood, thank you for sharing your exceptional knowledge on how best to support people with dementia at the Dementia Awareness Raising Forum and to Dennis Frost for providing the invaluable experiential viewpoint to forum attendees.

Thank you to my friends and former colleagues within the dementia support industry who provided advice and direction when called upon. To Associate Professor Bev Ewens, and my friends and colleagues at Edith Cowan University, thank you for your understanding and sharing with me your various PhD journeys, listening to your experiences has truly helped. To Sue, my friend and amazing mentor, I have learnt so much from you and continue to do so and am forever indebted to you. To my friends within my social network, I thank you for your support and listening ear, and to my family, Mum, and Dad, and particularly, my loving husband Tony, and two beautiful children, Madyson, and Jared, thank you for being there, encouraging me throughout my frequent times of distress and for the rock-solid foundation you provided upon which this thesis was built.

This research was supported by an Australian Government Research Training Program (RTP) scholarship. Some financial support was obtained from the WA Nurses Memorial Charitable Trust.

List of Publications

The following publications are included in this thesis:

1. Read, S. T., Toye, C., & Wynaden, D. (2016). Experiences and expectations of living with dementia: A qualitative study. *Collegian*, *24*(5), 427-432. https://doi.org/http://doi.org/10.1016/j.colegn.2016.09.003

2. Read, S. T., Toye, C., & Wynaden, D. (2018). The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia*, 1471301218784806. https://doi.org/10.1177/1471301218784806

3. Read, S. T., Toye, C., & Wynaden, D. (2020). A qualitative exploration of family carer's understandings of people with dementia's expectations for the future. *Dementia*, 147130122092954. https://doi.org/10.1177/1471301220929543

4. Read, S. T., Wynaden, D., Albrecht, M. A., & Toye, C. (2020). Development of the dementia community attitudes questionnaire. *Dementia*, 1471301220977649. https://doi.org/10.1177/1471301220977649

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Permission from the relevant publishers has been obtained to reproduce the four publications included in this thesis.

Table of Contents

List of Tables

List of Figures

Glossary of Terms

Attitude	An attitude is a person’s cognitive, behavioural, and affective response to an object, person, or situation (Breckler, 1984; Rosenberg, 1960).
Negative attitude toward people with dementia	Within this thesis negative attitude refers to the belief that people with dementia lack self-worth, are fully dependent on other people and that little can be done to support them.
Positive attitude toward people with dementia	Within this thesis positive attitude refers to the belief that people with dementia have the ability for sustained independence and can contribute to community with the help and support from health professionals and care partners as required for a time limited period.
Care Partner	This refers to contemporary terminology that represents a family member or significant other who assumes primary responsibility for assisting a person with dementia to sustain their wellbeing. The care partner takes into consideration the person’s desire for sustained independence, and capacity to self-manage their diagnosis thus forming a care partnership and highlighting the changing focus of the care giver role (Bennett et al., 2017). A care partner is an emerging role superseding the traditional family caregiver role. Except for Publication 2 and the Appendices C, E, G and L the term Care Partner is used throughout this thesis.
Transformative Worldview	The researcher’s philosophical belief that guided the research process. Research with an embedded agenda for political change, addresses matters central to power issues and seeks the views of people who have experienced some sort of social oppression (Creswell & Creswell, 2018; Mertens, 2007).
Human Rights (Dementia perspective)	The term ‘human rights’ when used in this thesis is in reference to a dementia perspective. According to the United Nations Convention on the Rights of Persons with a Disability this refers to the right to a standard of living on equal basis with all other citizens, to be autonomous, free from discrimination and to remain socially included with active participation within the community (UN General Assembly, 2007; United Nations, 2006).

Chapter 1

Introduction

Around 50 million people worldwide are living with dementia, with that number expected to increase to 82 million by 2030 and 152 million by 2050 (World Health Organisation, 2020). An earlier forecast based on previous data indicated that there would be 472,000 people in Australia living with dementia in 2021 (Dementia Australia, 2018). In line with global trends, this Australian figure is predicted to grow to 590,000 by 2028 and approximately 1,076,000 people by 2058 (Dementia Australia, 2018). Until a cure for dementia is discovered, care that enables people with dementia to live a life that is meaningful to them must be the focus of service provision and family and community support. Research to identify the long-term person-centred support needs of people with dementia, and how to address these, can help to ensure their best possible quality of life following diagnosis.

The context of what it means to live with dementia is changing. People living with dementia, and their advocates, now actively promote their right to be involved in the decisions that affect their lives and their ability to remain active members of the community (Dementia Alliance International, 2016; United Nations, 2006). Internationally, the human rights-focused paradigm of support for people with dementia is evolving, helping to ensure that their fundamental rights are enshrined and embedded in government policy and practice.

The research presented in this thesis, conducted in Western Australia, investigated the experience of people with dementia. It examined experiences related to the onset of their dementia diagnosis and, the planning of the care and support intended to maintain the person's quality of life during their dementia 'journey'. While people with dementia now actively promote their right to decision-making, encountering dementia-related stigma from within the community can make this difficult (Bryden, 2005, 2015; Herrmann et al., 2018; Swaffer, 2015; Swaffer, 2016; Swaffer, 2018; Taylor, 2007). Therefore, examining community attitudes towards people with dementia was also a focus of the research reported in this thesis.

This hybrid thesis combines peer-reviewed journal publications with traditional thesis chapters. The researcher employed an exploratory sequential design utilising a mixed-method research approach. The thesis includes four research studies identified as Study 1, Study 2, Study 3 and Study 4. An integrative literature review was also completed. This review examined what was known about the participation of people with dementia in the planning of their care and the support they require. While the research reported in this thesis was completed in Western Australia, the findings have relevance across Australia and to other countries with similar health care systems.

As the study took place from 2013 to 2021, the literature presented in this thesis provides the reader with a broad understanding of the evolving context of dementia care and support paradigms in which it was undertaken. Chapter 1 presents an overview of dementia including definitions and diagnosis, symptoms, types of dementia, treatments and interventions plus changing dementia-related care and support paradigms. A background to the study is then presented. Issues related to the human rights of people with dementia are detailed, along with the relevant perspectives of people with dementia and their care partners regarding the person with dementia’s opportunity for decision-making and planning for the future. The research problem statement is provided to explain the phenomenon under investigation, followed by the research aims and objectives, and an outline detailing the four separate studies and the integrative literature review. The chapter includes a discussion of the study’s significance, and a position statement highlighting the stance of the researcher within the research and their assumptions underlying the study. The chapter concludes with an explanation of thesis organisation.

1.1 Overview of Dementia

1.1.1 Defining dementia

Dementia is a syndrome, or collection of varied symptoms, that presents as a range of cognitive changes related to the person’s impaired brain functioning (Banerjee, 2007; World Health Organisation, 2017). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) replaced the term ‘dementia’ with that of ‘major neurocognitive disorder’ and named earlier cognitive impairment as “mild neurocognitive disorder” (American Psychiatric Association, 2013). The change in terminology was made to reduce the stigma commonly encountered by people diagnosed with dementia, in particular younger people, and to recognise that cognitive decline associated with dementia occurs on a continuum, thus facilitating early diagnosis and treatment (American Psychiatric Association, 2013). However, the term dementia continues to be used within the health sector and by lay people within the community and, as such, this term is used throughout this thesis to make the work accessible to a wider range of people who might use this previous term to search for dementia-related resources. Furthermore, dementia is referred to as a condition rather than a disorder throughout this thesis as it is more aligned with the contemporary and transformative viewpoint of how people with dementia wish to be supported, shifting focus from a biomedical model approach to care to one that is person-centred.

1.1.2 Diagnosing dementia and early intervention

Australian clinical practice guidelines (Laver et al., 2016) recommend a timely diagnosis of dementia. Symptoms should be explored and an appropriate referral to a memory clinic made as soon as possible so an accurate diagnosis is more likely to be made (Laver et al., 2016). Most diagnoses of dementia are not made by specialist doctors but occur elsewhere, such as in the hospital setting or by a general practitioner (Guideline Adaption Committee, 2016; Ng et al., 2020; Ng & Ward, 2019). Diagnosing dementia initially requires that historical information is obtained from the person or their family, along with a cognitive assessment and a physical examination. Several medical conditions mimic the early symptoms of dementia and must be excluded before the diagnosis can be confirmed. Therefore, the comprehensive assessment should include a medication review, blood tests, computed tomography (CT) and magnetic resonance imaging (MRI) scans (Guideline Adaption Committee, 2016). A person newly diagnosed with dementia should be offered post-diagnostic support, such as counselling (Shoesmith et al., 2020) and rehabilitation (Cations et al., 2017), provided by health professionals in collaboration with service providers who offer education and support. An individualised care plan that considers the circumstances, symptoms, and functional capacity of the person with dementia, as well as their goals and preferences for treatment and support, is paramount to optimising the person's functional abilities and health outcomes and ensuring an ongoing level of well-being (Guideline Adaption Committee, 2016).

1.1.3 Symptoms of dementia

People diagnosed with dementia experience a range of symptoms (Ulep et al., 2017). Cognitive symptoms may include memory dysfunction; aphasia, a decreased ability to understand and express written and oral language (Ispahany, 2012); agnosia, a failure to recognise familiar elements in the environment such as objects or people (Grand et al., 2011; Larner, 2012); and apraxia, an inability to perform previously learned and coordinated movements (Chandra et al., 2015; Chen & Bailey, 2016). Additionally, impaired executive functioning will lead to the person finding it difficult to plan, problem solve, perform sequential actions, and regulate appropriate behavioural responses when engaging with others (Larner, 2012).

Non-cognitive symptoms include behavioural and psychological symptoms of dementia, abbreviated, and referred to as BPSD (Cunningham et al., 2019; Mushtaq et al., 2016). These include agitation, aberrant motor activity such as wandering and purposeless activity (Nagata et al., 2010), irritability, aggression, and abnormal vocalizations (Cerejeira et al., 2012). As the term suggests, these types of behaviours have traditionally been seen as a symptom of dementia. However, specialists working in the field have come to understand that, rather than a clinical presentation of dementia, these behaviours are a purposeful attempt by the person with dementia to communicate an unmet need, often in response to an environmental stimulus (Burley et al., 2021; Cunningham et al., 2019). This renewed understanding of behaviours exhibited by a person with dementia has led to changes in terminology and consequently BPSD is increasingly referred to as responsive behaviours (Burley et al., 2021; Cunningham et al., 2019; Dupuis et al., 2012; Ontario Ministry of Health, 2007).

Other symptoms commonly experienced by people with dementia include anxiety, depression, and apathy, as well as psychotic symptoms such as delusions and hallucinations (Cerejeira et al., 2012; Di Domenico et al., 2016; Goyal et al., 2018; Mortby et al., 2012). Neurological changes in the brain may disrupt the sleep-wake cycle (Dening & Babu Sandilyan, 2015; Rose, 2010), and people with dementia often experience weight loss, potentially due to hypermetabolism and/or diminished oral motor function (Cerejeira et al., 2012). Additionally, changes in sensory awareness may affect the pleasure of eating (Kai et al., 2015).

People diagnosed with dementia can present with a vast range of cognitive and non-cognitive symptoms and consequently, there are an array of settings in which people with dementia are supported. Such settings include living at home within the community to residing within specialist dementia care units (Masso et al., 2017; Polacsek et al., 2020). Currently, in Australia, 65% of people with dementia reside in the community, with the remainder living in aged care accommodation (Australian Institute of Health and Welfare, 2021). The type of dementia that the person is diagnosed with influences the combination and severity of symptoms experienced, how rapidly these will progress, and the care and support settings required to manage those symptoms to maintain the person’s quality of life.

1.1.4 Types of dementia

Research investigating the epidemiology and pathology of dementia to determine diagnostic criteria has identified four main types of dementia, accounting for approximately 90% of diagnosed cases (Cunningham et al., 2015; Grand et al., 2011). These four types are Alzheimer’s disease, frontotemporal dementia, vascular dementia, and Lewy body disease. Identifying the kind of dementia that a person has can inform the expected disease trajectory, response to treatment, and anticipated support needs. In addition to discrete types of dementia, a person may be diagnosed with mixed dementia, comprising a combination of Alzheimer’s disease and vascular dementia (Custodio et al., 2017; Duong et al., 2017). The remaining 10% of diagnosed dementia cases occur in the context of other neurological conditions including, but not limited to, Huntington’s disease, Creutzfeld-Jakob disease, Parkinson’s disease, and progressive supranuclear palsy (Gale et al., 2018). Most people with dementia are diagnosed when aged 65 years or older, although a sub-set of people aged less than 65 years are diagnosed with ‘younger onset dementia’ (Tondelli et al., 2021).

1.1.4.1 Alzheimer’s disease

The most common form of dementia is Alzheimer’s disease, which is characterised by a gradual onset and progressive cognitive decline (Ulep et al., 2017; Weller & Budson, 2018). The average life expectancy for a person with Alzheimer’s disease is approximately four to eight years from diagnosis, although some people will live up to 20 years after symptoms first appear (Barnes et al., 2018; Ulep et al., 2017). The initial sign of Alzheimer’s disease is usually short-term memory loss (Duong et al., 2017). As the condition progresses the person may experience aphasia, agnosia, apraxia, disorientation, impaired visuospatial and executive function, changes to sleep patterns, loss of appetite, depression, and resultant responsive behaviours (Lanctôt et al., 2017; Ulep et al., 2017).

1.1.4.2 Vascular dementia

Vascular dementia is the second most common form of dementia and is characterised by cognitive impairment resulting from cerebrovascular disease (Venkat et al., 2015). Strand et al. (2018) reported an average life expectancy of approximately four and a half years following a diagnosis of vascular dementia. Symptoms are progressive and depend upon the region of the brain affected (Duong et al., 2017). The most prominent symptoms include confusion, disorientation and difficulty with communication (Duong et al., 2017). A person with vascular dementia may experience depression, anxiety, and a sudden impairment in executive function (Duong et al., 2017; Venkat et al., 2015).

1.1.4.3 Frontotemporal dementia

Frontotemporal dementia (FTD) occurs when a person experiences one of a group of neurodegenerative diseases that include behavioural and language impairments. FTD typically occurs in people aged 45 to 65 years and is the most common cause of younger onset dementia (Bang et al., 2015; Young et al., 2017). Most commonly reported symptoms include behavioural disinhibition, apathy, loss of empathy, perseverative or compulsive/ritualistic behaviours and language impairment (Young et al., 2017). According to Bang et al. (2015), life expectancy in FTD is approximately eight years.

1.1.4.4 Lewy body disease

Lewy body disease (LBD) usually presents in people aged between 60 and 90 years with an average life expectancy ranging from 1.9 to 7.7 years from diagnosis (Grand et al., 2011; Larsson et al., 2018). Psychiatric symptoms such as recurrent visual hallucinations are common, however many people may be reluctant to disclose the onset of these, making diagnosis difficult (Zupancic et al., 2011). People with the condition are more inclined to report cognitive deficits such as reduced attention; impaired executive function; declining visuospatial skills; and spontaneous extrapyramidal motor features, known as parkinsonism, a clinical syndrome that presents with symptoms such as rigidity and bradykinesia (slowed voluntary movement) leading to possible gait disturbance (Bäckström et al., 2018; Bologna et al., 2020; Gomperts, 2016; Zupancic et al., 2011). As such, people with LBD are often misdiagnosed with either Alzheimer’s disease or Parkinson’s disease (Zupancic et al., 2011). Another common symptom is a disturbance in sleep patterns (Chin et al., 2019; Outeiro et al., 2019; Zupancic et al., 2011).

In summary, it is evident that the type of dementia with which a person is diagnosed impacts their prognosis, rate of functional decline and presenting symptoms. Additionally, the underlying pathophysiology and types of cognitive and non-cognitive symptoms experienced throughout the person’s dementia journey will influence the treatments and interventions to which they are more likely to respond.

1.1.5 Treatment and intervention

As mentioned earlier, there is currently no cure for dementia and effective treatments to slow the associated cognitive decline are limited. Nevertheless, emergent pharmacological and non-pharmacological therapies have been shown to improve the quality of life for some people living with the condition. These treatment and intervention approaches will be summarised in the rest of this section.

Medications used routinely to delay the symptom progression include cholinesterase inhibitors: donepezil, rivastigmine and galantamine. Memantine is an alternative pharmaceutical option classed as an N-methyl-D-aspartate (NMDA) receptor antagonist (Ulep et al., 2017). These medications target neurotransmitters in the brain responsible for memory and cognitive function thereby improving the symptoms of dementia or delaying their progression (Livingston et al., 2020; Livingston et al., 2017; Masters et al., 2015; Ulep et al., 2017). This progress in the use of medication allows a prolonged opportunity for some people with dementia to make their care and support preferences known, enabling their continued engagement in their future care planning. Pharmacological approaches, targeted to improving physiological function, can also be supplemented with non-pharmacological strategies to further improve quality of life.

Non-pharmacological interventions have the potential to promote experiences of well-being for people living with dementia and are the recommended first line treatment for those people with the condition demonstrating ill-being (Guideline Adaption Committee, 2016). These include, but are not limited to aromatherapy, an alternative and/or complimentary therapy that uses plant extracts to treat a disease or help to alleviate disease symptoms (Press-Sandler et al., 2016; Scuteri et al., 2017); multisensory stimulation, the use of various tools to stimulate one or more of the five senses to produce positive feelings (Cheng et al., 2019; Cui et al., 2016); music therapy, a therapeutic intervention that aims to enhance a person's well-being (Holden et al., 2019); and animal-assisted therapy, for example using cats and dogs as companions for people with dementia to improve a person's physical and/or mental health (Klimova et al., 2019; Zafra-Tanaka et al., 2019). While the benefits of music therapy for people with dementia have been established, evidence of the effectiveness of aromatherapy, multisensory stimulation and animal-assisted therapy has been mixed, indicating that more research is needed (Guideline Adaption Committee, 2016; Moorman Li et al., 2017; Olley & Morales, 2018).

In addition to specific non-pharmacological interventions, a reablement approach can help to support a person with dementia's well-being. Reablement is a relatively new concept within the context of dementia care. It refers to a time-limited, consumer-centred and goals-oriented approach that aims to maximise the person's independence by maintaining functional ability, regaining lost function where possible, or, alternatively, adapting to the loss of function (Jeon et al., 2018; Jeon et al., 2019; Poulos et al., 2017). The use of a reablement approach seeks to help the person with dementia overcome some of the challenges that come with progressive cognitive decline and to maintain the lifestyle they had before the onset of dementia (Poulos et al., 2017; Swaffer, 2014b). Cognitive training may be encompassed within a reablement approach and is a program of regular activities to sustain or improve one's cognitive abilities, (Bahar-Fuchs et al., 2019; Bahar-Fuchs et al., 2020; Hill et al., 2017; Livingston et al., 2020). Furthermore, physical exercise may improve cognition in people living with dementia, but further research is required to discover the type of exercise, such as cardiovascular or strength-based training, that may be beneficial (Ströhle et al., 2015; Teri et al., 2020). Despite this caveat, there is evidence to suggest that people with dementia can improve their physical fitness with exercise (Lamb et al., 2018).

The combination of pharmacological therapies, non-pharmacological interventions, reablement approaches and exercise to address cognitive decline and promote function and independence offers the opportunity for people with dementia to live well despite their diagnosis. By its nature, dementia care is complex. Pharmacological and non-pharmacological approaches require integration and tailoring to the person’s needs. Furthermore, reablement approaches are founded upon an understanding of the person’s goals. It is therefore important to ensure greater community awareness about how people with dementia can best be supported to use both pharmacological and non-pharmacological interventions to improve quality of life and progress towards their reablement.

1.1.6 Changing dementia-related care and support paradigms

Since dementia was first identified, there has been a range of approaches in the care and support of people with dementia. While the medical model is still the paramount model of care, influences such as human rights and psychosocial interventions now impact care delivery and best practice. The following sections outline the different care and support paradigms and how these have evolved.

1.1.6.1 The medical model

The first identified presentation of Alzheimer's disease was in 1906. A German physician, Alois Alzheimer, was introduced to a 51-year-old, female patient who, over eight months, displayed progressive signs and symptoms of dementia (Jucker et al., 2006). The method by which Dr Alzheimer treated his patient was synonymous with the medical model, a process focused on the recognition of symptoms to identify the cause of a disease (Huda, 2019). Furthermore, doctors, when practising within the medical model, aim to identify clinical problems, predict outcomes and responses to treatment and provide a biomedical explanation for these predictions (Hogan, 2019; Huda, 2019; Shah & Mountain, 2007). Up until the 1930s, there was an increasing trend to routinely admit older people diagnosed with dementia into psychiatric hospitals. This practice was viewed as appropriate given that at that time there was inadequate housing for people with dementia whose presentation of behaviours was seen as unmanageable (Lacey, 1999). Current practice is that people with dementia with severe BPSD are more likely to be admitted to specialist dementia care units to reduce or stabilise symptoms so that they can then move into less intensive residential care settings (Masso et al., 2017). However, the majority of people with dementia do not require admission to a specialist unit and most live at home supported by community services (Polacsek et al., 2020).

1.1.6.2 Integrating psychological care

By the 1960s, clinicians had begun to address the psychological needs of people with dementia. To assist the person to sustain their well-being, researchers and clinicians explored various behavioural therapies and communication techniques. Several of these have been widely applied and evaluated through the decades, providing a motivation to implement more holistic approaches to dementia care.

Taulbee and Folsom (1966) founded ‘reality orientation’ when they sought ways to improve the lifestyle of confused older people residing in a geriatric unit of a hospital. Reality orientation, a therapy still used today, aims to orientate people with dementia to time and place by discussing what is going on within the environment and their personal lives (Panerai et al., 2021). Studies demonstrated improvements to the person’s cognitive functioning following implementation of the therapy (Camargo et al., 2015; Hall & Buckwalter, 1990; Onder et al., 2005). Furthermore, reality orientation has been shown to give a person with dementia a sense of greater control over the environment (Chiu et al., 2018). Care needs to be taken to ensure that the needs of the person are considered (Powell-Proctor & Miller, 1982). Implementing the therapy in a person-centred way is paramount to ensuring the well-being of the person with dementia.

Validation therapy was introduced by social worker and gerontologist, Naomi Feil. In 1963, Feil began work with confused older people living in residential aged care facilities (Feil, 1982, 1985; Feil, 1993). Four years later, Feil (1985; 1993) asserted that it was not possible to orientate people with dementia to reality but instead used validation therapy to affirm what the person believed to be real, and in doing so strengthened the relationship with the person, built trust and limited any distress they may have experienced. By validating what the person with dementia says, a meaningful conversation can be had about what is important to the person (Feil, 1982; Feil, 1993). While some reports and observational studies highlight the effectiveness of validation therapy (Bleathman & Morton, 1996; Hurtley & Pitkin, 2015), other studies have reported insufficient evidence regarding the efficacy of this intervention (Day, 1997; Scanland & Emershaw, 1993; Toseland et al., 1997).

Kiernat (1979), an Associate Professor of Occupational Therapy, used reminiscence therapy to engage older people living in residential aged care who were experiencing confusion. Books, pictures, and objects from previous times were used to stimulate happy memories in confused residents to promote their quality of life. The author did not explicitly state whether any of the confused older residents had dementia, but it is likely, given the setting in which the study was conducted. Implementing reminiscence therapy may ease the disorientation that the person with dementia experiences. The therapy works on the assumption that a person with dementia is able to recall long-term memories of their significant life events and, as such, this recall is used as a form of communication with the person (Cotelli et al., 2012). Evidence suggests that the use of reminiscence therapy on a one-to-one basis may improve cognition and mood for people with dementia, while within a group setting, increased capacity to communicate has been noted (O’Philbin et al., 2018). There is some evidence to suggest that for reminiscence therapy to be successful, a structured approach with the use of aids such as personal life story books are required to improve a person’s well-being. In contrast, a more general reminiscence session, that is less person-centred, with standard reminiscence materials such as reminiscence cards, has proven to be less effective (Subramaniam & Woods, 2012).

1.1.6.3 Evolution of person-centred care

Arguably, the most transformational shift in dementia care came about in the United Kingdom when psychologist Professor Tom Kitwood (1989) conceptualised person-centred care for people with dementia. Similar, to Feil (1993); Kitwood (1989, 1990) challenged the medical model approach to care, arguing that people with dementia should be supported holistically, with an emphasis on their background and unique individuality as a person, rather than their dementia diagnosis. This person-centred approach emphasised the importance of maintaining the person's autonomy and personhood regardless of age or level of cognitive impairment (Brooker, 2003; Kitwood, 1993). This philosophy of care continued to evolve and informed the development of Dementia Care Mapping, introduced by Kitwood and Bredin (1992), as a means by which to evaluate outcomes of the support provided to people with dementia through observation of their level of well-being.

Clinical Psychologist Professor Dawn Brooker (2007) further emphasised the need to value people with dementia for their uniqueness and introduced the VIPS model of person-centred care:

V Values, all people are valued regardless of age or impaired cognition,

I Individualised approach, the uniqueness of all people is recognised,

P Perspective, the perspective of the person living with dementia is considered and,

S Social environment, the social environment in which the person with dementia lives is positive and means they can experience well-being.

The model, based on the principles of person-centred care when integrated into daily nursing care (Røsvik et al., 2011), fosters social environments that help sustain a person with dementia’s independence for as long as possible after diagnosis (Brooker, 2007; Brooker & Latham, 2016).

Despite the push to adopt person-centred approaches to dementia care over many decades, their effectiveness in practice is mixed (Terkelsen et al., 2020). Successful person-centred care is dependent upon adequate staffing levels within residential aged care facilities and, as such, may conflict with organisational budget constraints (Chaudhury, Hung, et al., 2017). This criticism is supported by Sharpp (2008) and Kolanowski et al. (2015) who raised the need for further staff education on person-centred care, and increased communication between staff and family about what is important to the person and how they want to live their lives. Raising staff awareness about what is important to the person with dementia is critical to ensuring the person with dementia’s well-being.

1.1.6.4 Sustaining well-being and introducing the experiential model

Further emphasis is now placed on sustaining the level of well-being of people with dementia (Livingston et al., 2020). Dr Allen Power, a geriatrician, and Clinical Associate Professor of Medicine promotes a model of well-being with seven domains: joy, meaning, growth, security, autonomy, identity, and connectedness. When these domains are applied, they provide a proactive, strengths-based approach to help a person to sustain their well-being and quality of life (Power, 2014, 2017). The importance lies in understanding the experience of dementia as this helps to determine the consumer’s needs (Power, 2017). Dementia causes a shift in the way that people perceive and experience the world around them. While dementia results in functional decline, people with dementia can experience well-being and may retain complex abilities, including autonomous decision-making, long after they receive their diagnosis (Power, 2014, 2017).

1.2 Background to the Study

The rights of people living with dementia and how their choices can be operationalised are increasingly recognised as issues of critical importance. Such rights include how people with dementia comprehend their future and would like to be supported. Similarly, the care partner's perspective is also important. A care partner is either a family member or significant other who assumes primary responsibility for assisting a person with dementia to sustain their well-being, taking into consideration the person's desire for sustained independence and the need to form a care partnership. Determining care partners' understanding of the perspective of the person with dementia, about their ongoing support needs, is vital to providing them with the support they need to assist the person with dementia appropriately. On a broader level, determining how decision-making by people with dementia is supported by the whole community is critical to reducing stigma and maintaining their level of social inclusion. The literature considered in this section addresses (1) human rights issues related to people with dementia, (2) what is known from the perspectives of people living with dementia and their care partners, and (3) what is known about how people with dementia are supported to make decisions about their future.

1.2.1 Human Rights issues related to people with dementia

From a global perspective, the United Nations Convention on the Rights of Persons with a Disability (UN-CRPD) assures people with dementia of the right to a standard of living on an equal basis with all other citizens in all aspects of life (UN General Assembly, 2007; United Nations, 2006). Under this convention, Article 1

(Purpose) broadly defines disability, relating it to long-term physical, mental, intellectual, and/or sensory impairment, thereby clearly covering people living with dementia (Dixon et al., 2018; Sinclair et al., 2019; UN General Assembly, 2007; United Nations, 2006; Wied et al., 2019). As such, this convention specifically Article 3 (General principles), supports the rights of people with dementia to be autonomous and active participants in decisions that concern them, to be free from discrimination and to remain socially included with active participation within the community (Pinkert et al., 2021; UN General Assembly, 2007; United Nations, 2006; World Health Organisation, 2015, 2017). Sustaining a person with dementia's right to social inclusion for as long as possible is critical to maintaining their well-being.

Organisations and individuals who support people with dementia should be accountable to uphold human rights and introduce strategies that align with human rights standards to address these (World Health Organisation, 2015, 2017). Accordingly, global policy statements and clinical guidelines for dementia care articulate a rights-based approach that informs the provision of person-centred services and is responsive to the person's needs (Guideline Adaption Committee, 2016; Healthcare Denmark, 2018; Laver et al., 2016; Ministry of Health, 2020; National Institute for Health and Care Excellence, 2018; Norwegian Ministry of Health and Care Services, 2015). As such, enabling people with dementia to have agency, as outlined within Article 3 of the UN-CRPD, so they can make their future care and support needs known is fundamental to protecting their human rights (United Nations, 2006). This will ensure that they receive services that assist them to maintain a standard of living that supports their health and well-being.

People with dementia should be afforded the right to the same opportunities as all other citizens (Cahill, 2020) including their right to acceptance, autonomy, respect and justice. These rights will assist them to experience good quality of life with appropriate opportunities for growth, development, and rehabilitation across the trajectory of their condition (Bartlett, 2014; CASP, 2014; Cohen-Mansfield, 2021; Egdell et al., 2021; Kontos et al., 2016; Seetharaman & Chaudhury, 2020; Shakespeare et al., 2019; Swaffer, 2015, 2018; World Health Organisation, 2015). Implementation of the UN-CRPD does, however, present some challenges to upholding the rights of people with dementia, due to the relentless impact of dementia on the cognitive ability of the individual. Published literature in the area for the most part fails to provide practical strategies or offer practitioners insight as to how the human rights of people with dementia can be sustained in practice as their level of cognition declines (Charras et al., 2016; Cohen-Mansfield, 2021; Egdell et al., 2021; Seetharaman & Chaudhury, 2020; Shakespeare et al., 2019).

Successful implementation of strategies to support the rights of people with dementia is also dependent upon social policy. While a review of social policy has been undertaken in the United Kingdom to determine its adequacy in upholding the rights of people with dementia (Boyle, 2010; Dixon et al., 2020), such a review has yet to be conducted within an Australian context. However, the recent Royal Commission into Aged Care within Australia does propose a new rights-based Aged Care Act aimed at addressing the well-being and rights of older people, which has the potential to capture most people living with dementia (Royal Commission into Aged Care Quality and Safety, 2021). The reform agenda resulting from the Royal Commission will a) drive policy development and ensure that dementia care and support becomes core business in the aged care system and, b) ensure the rights of those accessing the system, including the right to exercise choice, will be upheld (Royal Commission into Aged Care Quality and Safety, 2021).

Within an Australian context the reframing of the duty of care afforded to people with dementia in residential aged care, to one where there is an increasing focus on their human rights such as their right to self-determination, has been suggested (Steele et al., 2020). However, as a person with dementia experiences significant cognitive decline, maintaining their right to live life on an equal basis with all other citizens, including their right to acceptance, decision-making and non-discrimination will become more challenging. This highlights the essential role of the care partner to advocate on the person's behalf as this becomes necessary. Prior planning and preparation for advanced cognitive decline by the person with dementia and their care partner is an important part of ensuring the maintenance of the person with dementia's human rights.

1.2.2 Perspectives of people living with dementia and their care partners

The move toward a human rights-focused approach has been driven by people living with dementia themselves (Bryden, 2015; Swaffer, 2014b, 2015; Swaffer, 2016; Swaffer, 2018; Taylor, 2007). For example, Kate Swaffer (2015) recalls being advised to give up her lifestyle after being diagnosed with dementia in 2008 but has continued to maintain a view that people should be socially included, facilitated with opportunities to sustain decision- making and to stay engaged in their lifestyle for as long as possible after receiving their diagnosis. However, not all people with dementia have the motivation or ability to stay engaged in their lifestyle. As such, it is important to explore the views held by a wider cohort of people living with the condition to investigate how they wish to lead their lives into the future.

Despite growing awareness about protecting the human rights of people with dementia including their right to acceptance, self-determination and non-discrimination, the experience of social inclusion for many diagnosed with the condition differs. People with dementia report the experience of exclusion (Clemerson et al., 2014; Patterson et al., 2018; Powers et al., 2016) and feel as though they are perceived by others as being stupid, lacking the capacity for independence and autonomous decision-making (Ashworth, 2020; Clemerson et al., 2014; O'Sullivan et al., 2014; Patterson et al., 2018; Riley et al., 2014; Urbańska et al., 2015; Werner, 2014). The applicability of findings from studies in this area does require further consideration as limitations such as small sample sizes (Ashworth, 2020; Clemerson et al., 2014) result in restricted generalisability of the results to other settings (Ashworth, 2020; Clemerson et al., 2014; Patterson et al., 2018). Furthermore, Clemerson et al. (2014) report that some people with dementia participating in their study chose to have their carer present throughout the interview potentially impacting the participants' willingness to disclose necessary detail. Despite these limitations, there is evidence to suggest that stigmatising beliefs held by people living in the community mean they fail to understand how people with dementia may be able to sustain decision-making autonomy and manage their lives into the future. Consequently, further exploration is needed of how attitudes of people within the community can be transformed to facilitate decision-making for people with dementia to assist them with making their future support needs known (Ashworth, 2020).

The dementia-related stigma and the language used that surrounds dementia impact greatly how people, including care partners of people with dementia, perceive their supportive role and may mean they underestimate a person with dementia's capacity for independence and decision-making (Swaffer, 2014a). The progressive cognitive decline associated with dementia will eventually mean that the person’s ability to gather and evaluate information becomes more limited so they will require increasing decision-making support. In this instance the role of the care partner as advocate for the person when they can no longer advocate for themselves is critical (Cognitive Decline Partnership Centre, 2018; Fetherstonhaugh, Rayner, et al., 2019; Samsi & Manthorpe, 2013; Sinclair et al., 2019; Sinclair et al., 2018). This is an important consideration given that many care partners describe decision-making on behalf of a person with dementia as burdensome (Ashton et al., 2016; Dening et al., 2017; Samsi et al., 2014) and report often feeling forced to make decisions that do not align with the person with dementia’s wishes (Carter et al., 2018; Fetherstonhaugh, McAuliffe, et al., 2019; Harrison Dening et al., 2016; Lamahewa et al., 2018; Poole et al., 2018; Shelton et al., 2018). These findings from previous studies were specific to self-selecting, English-speaking participants and transferability may be limited (Carter et al., 2018; Fetherstonhaugh, McAuliffe, et al., 2019; Lamahewa et al., 2018; Poole et al., 2018). As such, further research aiming to ascertain the perspective of the care partner on a person with dementia’s future expectations is critical and how they develop such a perspective needs to be further explored (Fetherstonhaugh et al., 2017).

1.2.3 Decision-making and planning for the future

The ethical principle of justice in health care supports a person’s right to decision-making autonomy that is not negated by a dementia diagnosis (Olejarczyk & Young, 2021). Therefore, how we facilitate decision-making for a person with dementia so they can make their future support needs known requires consideration

(Cohen-Mansfield, 2021; Marx et al., 2010; Olejarczyk & Young, 2021; World Health Organisation, 2017).

When a person is diagnosed in the early stages of dementia, care partners are more likely to engage in shared or supported decision-making with the person about health care, lifestyle arrangements, and how they wish to live on a daily basis (Dening et al., 2017; Fetherstonhaugh, Rayner, et al., 2019; Samsi & Manthorpe, 2013; Sinclair et al., 2019; Sinclair et al., 2018). Despite care partners attempting to ease the decision-making process for the person they support (Fetherstonhaugh, Rayner, et al., 2019; Samsi & Manthorpe, 2013; Sinclair et al., 2019; Sinclair et al., 2018), some people with dementia convey difficulty in establishing, with their care partner, a shared decision-making process that reaches agreement on decisions that need to be made (Fetherstonhaugh et al., 2013; Miller et al., 2016; Sinclair et al., 2019).

When a person with dementia is in the moderate to late stages of dementia, care partners tend to engage in substitute decision-making and make final decisions alone based on what they feel the person would have wanted (Ashton et al., 2016; Dening et al., 2017; Fetherstonhaugh et al., 2017; Fetherstonhaugh, McAuliffe, et al., 2019; Samsi & Manthorpe, 2013; Shanley et al., 2017; Sinclair et al., 2019). Care partners, however, may not fully understand the future care and support expectations of the person with dementia meaning they cannot adequately advocate on their behalf and facilitate opportunities in which their decision-making autonomy, is sustained over the longer term (Hill et al., 2017; Poole et al., 2018; Reamy et al., 2011).

The limited exploration of future care and support expectations of people with dementia, through studies using small sample sizes, indicate that further research is needed to fully understand this phenomenon from the perspective of people living with dementia (Dening et al., 2017; Fetherstonhaugh, Rayner, et al., 2019; Samsi & Manthorpe, 2013). In some instances, data collection using dyadic interviews conducted between a person with dementia and their care partner may have restricted participants' willingness to disclose their true feelings to avoid concerning the other person participating (Dening et al., 2017; Fetherstonhaugh, Rayner, et al., 2019; Samsi & Manthorpe, 2013; Sinclair et al., 2019; Sinclair et al., 2018). As such, further research and awareness raising, as well as education and support for care partners, are needed to explore the experiences and expectations of people with dementia, their processes for decision-making and advance care planning (Carter et al., 2018; Dening et al., 2017; Fetherstonhaugh et al., 2017; Fetherstonhaugh, McAuliffe, et al., 2019; Sinclair et al., 2019; Sinclair et al., 2018). Such awareness raising is crucial to promote decision-making autonomy for the person with dementia over the longer term.

Advance care planning is a collaborative process central to quality end-of-life care for all people. Such planning offers people with dementia an opportunity to document and share with their care partner and the healthcare team their personal preferences for treatment and support, to be implemented at a time when they can no longer communicate these for themselves (Fetherstonhaugh et al., 2017; Piers et al., 2018; Shanley et al., 2017; Sudore et al., 2017; Van Rickstal et al., 2019). Evidence suggests, however, that advance care planning can be problematic in the context of dementia care and there are barriers to its implementation. Currently, there is a lack of clarity as to when, in the dementia trajectory, is the best time to initiate such discussions (Hirschman et al., 2008; Piers et al., 2018) and uncertainty as to which health professional or service provider should lead the discussion (Beck et al., 2017). Furthermore, health professionals, care partners and people with dementia reportedly lack knowledge in matters related to advance care planning (Bryant et al., 2021; Bryant et al., 2019; Lai et al., 2019; Lee et al., 2019; Perin et al., 2021; Van Rickstal et al., 2019).

While it is apparent that advance care planning is critical for people living with dementia, and that the way forward in this area requires many issues to be addressed, advance care planning is not the only way in which people with dementia can enact their decision-making abilities, given that daily decisions need to be made to manage and live their lives. While research in the area has focused on a person with dementia’s quality of life, and their capacity for decision-making, exploration of how they wish to maintain self-determination over the longer term as it relates to advance care planning appears to have been overlooked. The importance of educating the wider community, keeping in mind that people with dementia, care partners and health care professionals form part of the community, on the benefits of formally discussing with a person with dementia their expectations for future care and support cannot be underestimated. Advance care planning discussions with the person with dementia mean their autonomy can be sustained over the longer term, and they can plan for their future. This strategy will ultimately help to support the role of the care partner as an advocate when the person with dementia can no longer advocate for themselves.

1.3 Problem Statement

Currently, the paradigm of how people with dementia can best be supported is changing, largely due to the recent progress in considering a human-rights-focused approach in the support of people living with the condition. As mentioned, the United Nations Convention on the Rights of Persons with a Disability assures people with dementia the right to a standard of living on an equal basis with all other citizens, which includes their right to decision-making autonomy and self-determination. The cognitive capacity of people with dementia to engage in decision-making and making choices, with the implementation of improved pharmacological and non-pharmacological interventions, means the range of choices they have to live well has extended. However, more needs to be known about how people with dementia understand those choices, their expectations for the future, their capacity for decision-making, either independently or supported, and care partners' understanding of these phenomena so they can assist as necessary. As such, there also needs to be some consideration for the societal context within which choice for people with dementia becomes possible. The attitudes of community members, including care partners and medical professionals, toward people with dementia, often result in their reluctance to engage people with dementia in considering their future. Such attitudes are around the person with dementia's capacity to make decisions, understanding of the dementia trajectory the person is likely to encounter and perceived lack of support available to the person with dementia. Exploring people with dementia's future expectations through research was essential to understand how they wished to be supported to live their lives and be integrated within the community. This perspective would bolster community understanding and strengthen community response and support. Additionally, it was necessary to explore and address community attitudes to overcome dementia-related stigma, regarding the capacity of people with dementia to remain self-governing individuals who continue to contribute to the community, even for a time-limited period, supporting the need for the study reported in this thesis.

1.4 Study Aims and Objectives

1.4.1 Primary aim and objectives

The primary aim of the research was to explore the experiences and perspectives of people diagnosed with dementia and their care partners to gain insight into current and future needs. As such, the following specific objectives evolved from this aim:

1. To explore and describe experiences of dementia and expectations of people with dementia about how they wish to live their lives.
2. To explore and describe care partners' experiences of supporting the person with dementia including their understanding of that person's experiences and expectations.
3. To critically review existing literature that included people with dementia as research participants, when investigating the participation of such people in the planning of their care and support.

1.4.2 Secondary aim and objectives

After reviewing the findings of Study 1 (a qualitative exploration of the perspectives of people with dementia about their experiences and expectations), Study 2 (the experiences and expectations of people with dementia from the perspectives of care partners) and the integrative literature review, a secondary aim emerged to explore the usefulness of a Dementia Awareness Raising Forum intended to bring about more positive community attitudes towards people living with dementia. The following specific objectives were linked to this secondary aim:

4. In the absence of a suitable dementia attitudes questionnaire, to develop and establish preliminary psychometric properties of one that would be suitable for use at a community forum to raise awareness around dementia.
5. To explore the feasibility and effectiveness of a dementia awareness raising forum to positively change community attitudes towards people living with dementia.

1.5 Outline of the Research Project

As indicated earlier, the research consisted of four separate studies and an integrative literature review, reported as a combination of peer-reviewed journal publications and traditional chapters, which are highlighted in this section. Study 1 elicited the experiences, and expectations of people living with dementia (Objective 1, Chapter 3). Study 2 explored care partners' experiences of supporting the person with dementia and their understanding of that person's experiences and expectations about living with dementia (Objective 2, Chapter 3). In Study 3, a search for a suitable questionnaire to evaluate any change in community attitudes towards people with dementia was carried out, with subsequent development of the Dementia Community Attitudes Questionnaire (Objective 4, Chapter 5). In Study 4, the new questionnaire was administered to people attending the Dementia Awareness Raising Forum and provided data that informed further questionnaire refinement, as well as providing indications of the effectiveness of the educational forum on positively impacting community attitudes towards people living with dementia (Objective 5, Chapter 5). The integrative literature review completed as part of this research explored what is known about the participation of people with dementia in the planning of their care and support (Objective 3, Chapter 4).

1.6 Significance of the Research

Investigating the experiences and expectations of people with dementia is critical given that very little is currently known about this from their perspective. To date, research about the needs of people with dementia has largely been conducted from the perspectives of health professionals and care partners. However, the perceived care and support needs of people with dementia differ from those articulated by the care partner and health professional (Armari et al., 2013; Miranda-Castillo et al., 2013). It is a fundamental human right of people living with dementia to be involved in such research initiatives, so their autonomy is upheld, and they are given an opportunity for their voices to be heard (World Health Organisation, 2017). The knowledge gained from this research will equip health professionals with a contemporary understanding of the types of care and support that are meaningful to people with dementia. This will enable appropriate tailoring of services and targeting of resources.

A care partner is usually the closest person to someone who is living with dementia and often knows them best. As such, care partners are well placed to advocate for their family member and to support the person's autonomy appropriately throughout the dementia trajectory. However, care partners can be reluctant to explore and address future care needs with the person with dementia to avoid causing them additional burden (Van Rickstal et al., 2019). Furthermore, a lack of knowledge about advanced care planning and supported decision-making can result in some care partners feeling ill-equipped to take on this advocacy role (Ashton et al., 2016; Van Rickstal et al., 2019). Understanding the perspective of care partners and identifying their knowledge gap through the conduct of this research is useful in assisting health professionals to support care partners, provide them with the necessary education, help them implement strategies to initiate difficult conversations and advocate on the person with dementia’s behalf as this becomes necessary.

In addition to exploring the consumer’s experience and expectations of living with dementia in the 21st century, and care partner understanding of these phenomena, the research significance centres around establishing the feasibility and effectiveness of a Dementia Awareness Raising Forum as a mechanism in which to address community attitudes towards people living with the condition. Furthermore, accessing a suitable tool to robustly evaluate the effectiveness of this initiative to improve community attitudes towards people living with dementia is important to measure intervention success. Such awareness raising and change initiatives are vital given the changing paradigm around how people with dementia can best be supported by exploring their care and support expectations. Community awareness about the human rights of people living with dementia is critical to their social inclusion and sustained quality of life.

1.7 Positioning the Researcher

Positionality is the stance of the researcher within a research study. Detailing the researcher’s position is critical given that it influences what the researcher investigates, how research is conducted, as well as the outcome and results of the research (Holmes, 2020). Furthermore, identifying the positionality of the researcher outlines the influence of the researcher as the research instrument, and means that the assumptions of the researcher can be separated from the lived experiences of the participants.

The desire to explore the experiences and expectations of people with dementia arose from years of working in the dementia support industry. Whilst completing a Bachelor of Nursing approximately twenty years ago I worked as a nursing assistant in a residential care facility and was dismayed at the lack of quality of life experienced by the residents. The scenario outlined below is an example of what I frequently witnessed during that time.

> Residents were awoken early in the morning, assisted into a wheelchair by two people, covered in only a flimsy cotton dignity gown and whisked down to a communal bathroom to have hygiene needs attended to. Residents with reduced capacity to verbally articulate their needs resisted and became agitated.

I wanted to limit the amount of distress experienced by the residents but lacked the understanding and capacity to do this at that time. I needed to understand how the residents felt about their experiences and what they wanted and needed to maintain some degree of autonomy and quality of life.

In more recent years working within the residential aged care setting as a dementia specialist, I witnessed improvements to the standard of living for people with dementia. However, the person-centred care approach often stated as the philosophy underpinning the support provided to people living within residential care environments continued to be rhetoric. The needs of the organisation were prioritised over the needs of the individual. I was again disappointed that person-centred care was limited and there was very little consideration given to the needs of the individual.

In addition to my professional career, elements of my personal life have also influenced my decision to pursue this research. My father has been diagnosed with Alzheimer’s disease. Furthermore, other senior members of my family have demonstrated symptoms that may indicate reduced levels of cognitive functioning, causing concern for the remainder of the family. This concern centres around maintaining independence for the person with cognitive impairment and reducing the potential associated risks. Throughout the conduct of this study, I brought my nursing experience and perspective, time spent working in the residential aged care setting, and experience as a family member of a person with cognitive decline to bear.

1.8 Assumptions Underlying the Study

Views of the investigator, formulated after having worked with people with dementia for approximately twenty years, being exposed to developments in the field of dementia care and reviewing relevant literature as part of the higher degree by research candidacy process, were documented before commencing the research. Documenting these assumptions was deemed to be necessary to reduce any bias in the interpretation of results. Researcher-held assumptions are presented in the following paragraphs.

People seek a diagnosis of dementia because they have a general feeling that something is not right, or they are pressured to because of concerned family and friends. On receiving a dementia diagnosis people feel relieved that there was an explanation for the problems they had recently encountered or a feeling of shock and concern for the future largely due to the stigma that surrounds the diagnosis and fear of the unknown. People with dementia are likely to disclose a basic understanding of the condition and mixed reactions from health professionals, family and friends when discussing their dementia diagnosis with them.

In planning for their future, people express a desire to stay in their own homes and maintain their independence for as long as possible. Some people diagnosed would be keen to become involved in research studies, get their financial affairs in order, spend quality time with family, possibly travel, and reduce any carer burden their care partner and family may experience.

The researcher's assumptions were found to align with findings that emerged from the research reported in this thesis. While the researcher’s perspective did not change, her awareness of participants' grief experience from being diagnosed with dementia and the degree to which they wished to remain connected to their pre-diagnosis lifestyle deepened significantly.

1.9 Thesis Organisation

This is a hybrid thesis, comprising of both traditional thesis chapters and peer reviewed published articles. In total there are six chapters within this thesis that detail an introduction to the study, the qualitative and quantitative components of the study, the integrative literature review that was undertaken and the relevance of study findings discussed within the context of existing evidence. Chapters 1, 2 and 6 are presented as traditional thesis chapters while Chapters 3, 4 and 5 present a series of four peer reviewed published articles. The journals were sought for their readership and impact to enhance translation of study findings into clinical practice both in Australia and the wider international dementia care context. The Australian journal in which one of the articles was published was the “Collegian, the Australian Journal of Nursing Practice Scholarship and Research”, while the remaining three articles were published in the international journal “Dementia". Both these journals were considered appropriate as their core aims were to challenge nurses on emerging areas of interest, and to raise awareness of the lived experience of dementia and inform their care and support, respectively. The “Collegian, the Australian Journal of Nursing Practice Scholarship and Research” and “Dementia” journals recorded impact factors of 2.573 and 2.764, respectively in 2023 and were chosen due to their readership, and likelihood that study findings would then be translated into practice.

Chapter One provided the context for the study via an overview of dementia, describing the rationale for undertaking this investigation and highlighting the changing paradigms related to dementia care and support. Furthermore, this chapter outlined the study aims and objectives, study significance and contextually positioned the researcher.

Chapter Two, the methodology chapter, presents the philosophical worldview which guided the study, the mixed-method research design that was utilised and includes detail on data collection and analysis. Ethical considerations for the study are discussed along with the processes related to data management and disposal.

Chapter Three presents the qualitative component of this mixed-method research approach. This chapter details two publications. Publication 1 is focused on Study 1 and is titled: *Experiences and expectations of living with dementia: A qualitative study*. It addresses Objective 1 and describes the consumer experience of 24 participants living with dementia. The publication highlights participants' feelings of losing control and a desire to stay connected to their pre-diagnosis lifestyle. Publication 2, which details Study 2, titled: *A qualitative exploration of family carer's understandings of people with dementia's expectations for the future,* addresses Objective 2 and describes the experiences of 21 participants who were care partners supporting a person with dementia to maintain their quality of life. This publication highlights the challenge of preserving the autonomy of people with dementia and the importance of relationships when implementing appropriate advocacy on their behalf.

Chapter Four introduces Publication 3. This publication presents the findings of an integrative literature review outlining evidence of people with dementia's participation in the planning of their care and support, where the perspective of the person with dementia was obtained via their contribution as a research participant. This publication addresses Objective 3 and is titled, *The participation of people with dementia in the planning of their care and support: An integrative literature review*.

Chapter Five presents the quantitative component of this mixed-method thesis. This chapter includes Publication 4, which details Study 3 and addresses Objective 4, titled, *Development of the Dementia Community Attitudes Questionnaire (DCAQ).* The publication presents a review of the literature which determined that no suitable questionnaire to evaluate change in community attitudes towards people with dementia could be found. Furthermore, this chapter outlines the implementation of a Dementia Awareness Raising Forum that addresses Objective 5 and details Study 4. The forum was designed to provide new knowledge to members of the community about people living with dementia to determine its usefulness in raising community awareness of dementia and eliciting more positive attitudes. The newly developed dementia attitudes questionnaire was used to evaluate attitude change in forum participants before and immediately after the forum.

Chapter Six details the relevance of the study findings within the context of existing literature and provides recommendations for change within future research, policy development, education, and clinical sectors. Emphasis is placed on the experiences and expectations of people with dementia and on evaluating community attitude change toward people living with dementia.

1.10 Conclusion

The prevalence of dementia is rising within both an Australian and global context and the dementia-related care and support paradigms in how people with dementia can best be supported are changing. Traditionally the medical model approach, which is still used today, guided how people with dementia are cared for but current human rights considerations have now transformed the way people with dementia are viewed by others. Upholding the human rights of people with dementia by exploring their care and support expectations was necessary to ensure that their perspective is understood, and their quality of life in the future is maintained. Chapter 2, which follows, details the mixed-method research design chosen for this study along with the study's methodological foundations. Procedures for recruitment, data collection and analysis, ethical considerations and study rigour are also explained.

Chapter 2

Methodology

Chapter 2 of this hybrid thesis describes the mixed-method design utilised in the research. The research was grounded in a transformative philosophical worldview given the evolving paradigm of dementia care from the predominant medical model of practice to the current human rights-focused approach, which supports the active involvement of people with dementia in decisions affecting their lives for as long as practicably possible. A key consideration of a transformative worldview is to examine the lives and experiences of marginalised groups who often experience discrimination, inequality, reduced levels of involvement in decision-making, or negative attitudes from others (Tashakkori & Teddlie, 2016). Hence this philosophical worldview was aligned with exploring the experience of people living with dementia and their care partners in relation to care needs, decision-making, and planning for the future.

This chapter details the methodological foundations for the research, highlighting the influencing philosophical worldviews and how a mixed-method research approach was selected. It explains how the selected approach was applied across the four studies, outlined in the thesis overview provided in Chapter 1. Ethical considerations are discussed in this chapter in relation to people living with dementia who are considered a vulnerable population group. The methods used across the four studies are detailed, highlighting research designs, sampling and recruitment decisions and strategies, data collection and analysis methods, and aspects of rigour. Ethical considerations are discussed for each study in addition to those presented earlier in the chapter, and processes related to data management and disposal are detailed.

2.1 Research Worldviews

A philosophical worldview describes the researcher’s philosophical beliefs that guide the research approach, using critical thinking to examine what humans know and how they perceive the world around them. Exploring the views of philosophers helps a researcher to understand the foundational underpinnings of acquiring knowledge (Tashakkori & Teddlie, 2016). A researcher’s philosophical worldview emerges from their experiences of the world including their professional background, mentors, and past research endeavours (Creswell & Creswell, 2018). The philosophical worldview provides the general principles of theoretical thinking and self-awareness, all of which obtain knowledge of reality to design, conduct, analyse and interpret research and its outcomes (Creswell & Plano-Clark, 2018). The conduct of research is generally guided by four philosophical underpinnings, namely positivist (or postpositivist), constructivist (or interpretivist), pragmatist and transformative (Creswell & Creswell, 2018). Table 2.1 below provides a summary of these four philosophical worldviews.

Table 2.1

Research worldviews

Research worldview	Definition
Positivist	Uses quantitative methodologies and objective measurements to investigate a phenomenon.
Constructivist	Uses qualitative methodologies and explores the meaning of phenomena developed through the analysis of subjective data.
Pragmatism	Informs both qualitative and quantitative data collection to obtain diverse forms of data allowing for a more enriched understanding of the research problem.
Transformative	Represents an agenda for change. Uses both quantitative and qualitative methods.

The positivist worldview (or scientific method) takes an objective stance, embodied in quantitative methodologies, whereby a researcher uses objective measurements to evaluate a phenomenon or tests a hypothesis using an experimental design and, ‘cause and effect’ thinking (Creswell & Creswell, 2018; Tashakkori & Teddlie, 2016). Conversely, a constructivist worldview explores the meaning of phenomena from the perspectives of research participants, developed through the analysis of subjective data. Participants derive meaning from social interaction with others which, when explored with the researcher, enables the construction of a shared understanding of the phenomena. Research outcomes are the result of individual experiences that develop into a broad understanding of a phenomenon (Creswell & Plano-Clark, 2018; Streubert & Carpenter, 2011; Tashakkori & Teddlie, 2016).

The pragmatic worldview, or pragmatism, is considered important given that it underpins mixed-method research studies (Creswell & Plano-Clark, 2018). Pragmatism informs both qualitative and quantitative data collection and considers that obtaining diverse forms of data, allows for an enriched understanding of the research problem (Creswell & Plano-Clark, 2018; Tashakkori & Teddlie, 2016). The transformative worldview represents an agenda for change, addresses matters central to power issues and seeks the views of people who have experienced some sort of social injustice (Creswell & Creswell, 2018; Mertens, 2007). Similarly, to pragmatism, a transformative approach may use a variety of quantitative and qualitative methods given that positivist structured research theories and the actions of social constructivists may not individually meet the needs of marginalised people within society. An integration of research methods is often required to address the issues of social injustice that people may experience (Creswell & Creswell, 2018; Mertens, 2007). Within the research reported in this thesis, such integration of research methods involved first the exploration of the experiences and perspectives of people diagnosed with dementia and their care partners, to gain insight into current and future needs related to care, support and decision-making using qualitative enquiry. Quantitative methods were then incorporated to determine the usefulness of a Dementia Awareness Raising Forum in positively changing community attitudes towards people with dementia. This also included the development of a questionnaire to determine the forum's effectiveness.

2.2 Adopting a Philosophical Worldview in this Research

The research reported in this thesis was grounded in a transformative worldview that informed the justification for the research study and anticipated significance of the findings. In guiding this research, the transformative worldview represents an agenda for change. The worldview symbolises the need for better awareness, inclusion and understanding of vulnerable people, such as people with dementia, who may have been discriminated against, devalued, and denied opportunities for autonomous decision-making (Creswell & Creswell, 2018; Mertens, 2007). The transformative worldview was adopted to guide the studies reported in this thesis because of the deficits in the lives of people with dementia, including their experience of stigma and the challenges they face surrounding their lack of inclusion within the community. This worldview aligns with the evolution of dementia care from the medical model paradigm to the experiential model and person-centred approaches. Such approaches recognise the autonomy of people living with dementia, ensuring that they have a voice, putting their needs and preferences at the centre of care, and assisting their ongoing level of well-being.

Research within a transformative worldview aims to communicate the needs of a minority group and, using research techniques, translate their views in a way that inspires change within the greater community (Jackson et al., 2018). The transformative worldview was demonstrated in this research by firstly, exploring the needs of people with dementia and disseminating through publications their experiences and perspectives as well as those of their care partners, and secondly by the implementation of a community forum to raise dementia awareness. The forum was seen as an avenue for changing community attitudes towards people living with dementia as it provided an enhanced awareness of their experiences and perspectives in addition to information on the evolving focus of dementia care and support, aligned to developments of the 21st century.

2.3 Mixed-method Research

Mixed-method research is the integration of qualitative and quantitative data which allows the researcher to draw conclusions between the two sets of data to comprehensively answer research aims and objectives (Creswell, 2015; Poth, 2018). Origins of the method stem from the work of Campbell and Fiske (1959) who used multiple sources of data to validate the outcome of their study. The method was formalised in the late 1980s with Greene et al. (1989) exploring mixed-method research design and differentiating the purpose of mixing both qualitative and quantitative methods, and Brewer and Hunter (1989) outlining the steps in conducting mixed-method research. Combining both qualitative and quantitative methods within one research project is seen as a way of overcoming the weaknesses of each methodological approach (Creswell & Creswell, 2018). Qualitative research seeks to discover knowledge that is seen to be evolving and subjective, capturing the complexities of human life or when little is known about the research question under investigation (Flick, 2008; Polit & Beck, 2014). In contrast, quantitative research seeks to investigate knowledge that is seen as neutral, unchanging, and understood through objective measurement of components of a phenomenon (Polit & Beck, 2014).

Integrating both qualitative and quantitative research approaches brings a verifiable edge to the research outcome and richness to the new knowledge acquired (Creswell & Creswell, 2018). Some research objectives cannot be answered solely by qualitative or quantitative research methods. As such, a mixed-method approach offers practicality to employ a range of research methods (Creswell & Plano-Clark, 2018). Mixed-method research follows one of three common designs that are classified by the timing or order in which the quantitative and qualitative components are conducted, and are dependent on the research objectives (Creswell, 2015). Table 2.2, which follows, provides a summary of mixed-method research designs.

Table 2.2

Mixed Methods Research Designs

Research Design	Description
Convergent design	Collection and analysis of quantitative and qualitative data, usually contemporaneously, each set of data then validated against the other.
Explanatory sequential design	Quantitative method followed by a qualitative method. Quantitative methods used to define the characteristics of a phenomenon. Qualitative method then employed to explain the observed associations.
Exploratory sequential design	Qualitative method first used to explore a problem. A quantitative method then employed to verify and test the outcome of the qualitative component.

A convergent mixed-method design involves the collection and analysis of quantitative and qualitative data, usually simultaneously, with each set of data then validated against the other. Further research or review of pertinent literature is then completed to explain any dissimilar results emerging from the two components. An explanatory sequential design typically commences with a quantitative component, such as defining the characteristics of a phenomenon and how they relate, followed by a qualitative exploration to understand and explain the observed relationships and their impact on human experience (Creswell & Creswell, 2018). In contrast, an exploratory sequential design first uses a qualitative method to explore a problem from the perspectives of the people involved. Tentative concepts and ideas are generated, which are then verified and tested through a subsequent quantitative component of the study (Creswell, 2015). This design is useful when little is known of a phenomenon under study, which in this research, was the expectations of people with dementia, the degree to which they participated in the planning of their care and support, and care partners' understanding of these phenomena. Empowering people with dementia to have a voice to identify their lived experience and exploring the evolving role of the care partner in how people with dementia wish to be supported, was first investigated using qualitative research methodology. Typically, the themes established from the qualitative component lead to the development and design of a research instrument, or the development of an intervention that forms part of the quantitative phase of the study (Creswell & Creswell, 2018). The following section provides a more detailed discussion of how a sequential exploratory design was applied in the studies reported in this thesis.

2.4 Application of an Exploratory Sequential Design

A mixed-method exploratory sequential design was selected because a qualitative exploration of the perspectives of people with dementia about their experiences and expectations, was warranted as a first step in the research (Objective 1). An initial review of the literature revealed that little was known from the perspective of people with dementia about their participation in future decision-making, particularly related to advance care planning. Empowering people with dementia to have a voice to uncover their experiences and future expectations which included their involvement in decision-making meant the researcher could ascertain how people with dementia wished to live into the future.

Qualitative methods were also used to explore the experiences and expectations of people with dementia from the perspectives of care partners, and to obtain the care partners' experience of supporting the person with dementia (Objective 2). Exploring such perspectives meant the researcher could develop an understanding of the evolving role of the care partner in supporting the person with dementia, across the trajectory of their condition. The qualitative findings were validated and set in a broader context by considering current literature, uncovering what was known about the participation of people with dementia in the planning of their care and support, accessed via an integrative review (Objective 3).

Quantitative methods were then employed to determine the feasibility and effectiveness of a community awareness raising forum to positively change community attitudes towards people living with dementia. Such a forum has the potential to transform how people within the community understand how people with dementia wish to be supported (Objective 5) and change how dementia support services operate (Plano Clark & Ivankova, 2017). Addressing aspects of findings (Objectives 1, 2 and 3) aligned with the transformative worldview guiding the study which seeks to promote inclusion and understanding of vulnerable people (Creswell & Creswell, 2018; Mertens, 2007). The community awareness raising forum allowed opportunity to use earlier findings to bolster community attitudes to people living with dementia using educational and research techniques (Jackson et al., 2018). A review of the literature did not uncover an appropriate or suitable tool to measure outcomes of the intended forum, which pointed to the need for Study 3, and resulted in the development of a questionnaire to measure community attitudes towards people with dementia (Objective 4). Hence, the research encompassed four separate studies and an integrative literature review as the research progressed from a qualitative approach, using an application of the grounded theory method, to quantitative approaches encompassing a pre-test-post-test quasi-experimental design. Table 2.3 (below) provides a summary of the different studies across this research.

Table 2.3

The organisation of the mixed-methods research

Approach	Components	Aims	Objectives
Qualitative	Study 1	To explore the experiences and perspectives of people diagnosed with dementia and their care partners to gain insight into current and future needs.	1. To explore and describe experiences of dementia and expectations of people with dementia about how they wish to live their lives.
	Study 2		2. To explore and describe care partners' experiences of supporting the person with dementia including their understanding of that person's experiences and expectations.
Literature review	Integrative literature review		3. To critically review existing literature that included people with dementia as research participants, when investigating the participation of such people in the planning of their care and support.
Quantitative	Study 3	To explore the usefulness of a Dementia Awareness Raising Forum intended to bring about more positive community attitudes towards people living with dementia.	4. In the absence of a suitable dementia attitudes questionnaire, to develop and establish preliminary psychometric properties of one that would be suitable for use at a community forum to raise awareness around dementia.

Approach	Components	Aims	Objectives
	Study 4		5. To explore the feasibility and effectiveness of a dementia awareness raising forum to positively change community attitudes towards people living with dementia.

2.4.1 Ethical considerations

Ethical approval to conduct this research was obtained from the Curtin University Human Research Ethics Committee in Western Australia, approval number HR 139/2013 (Appendix A). The study was conducted in accordance with the National Statement on Ethical Conduct in Human Research, designed to regulate the conduct of research in Australia, considering the moral principles of ethics (National Health and Medical Research Council, 2018). Ethical recruitment processes were undertaken across all four studies through informed consent and voluntary participation (National Health and Medical Research Council, 2018). The researcher was mindful of the vulnerability of people with dementia participating in this research and gave this extensive ethical consideration.

The vulnerability experienced by people with dementia is emphasised given the age at which diagnosis is most often made, the stigma they often experience, the loneliness they may encounter and the cognitive decline that occurs (Busso et al., 2019; Day et al., 2020). As such, when participating in research, strategies are required to minimise any psychological harm the person with dementia may experience (National Health and Medical Research Council, 2018). Researchers need to ensure that the benefits to study participation outweigh any risk and this is highly pertinent to people living with dementia due to their vulnerability (National Health and Medical Research Council, 2018). In relation to the risks and benefits of the research presented in this thesis, it was recognised that some people with dementia might find discussing future considerations mildly distressing and that others would feel empowered and welcome the opportunity for this discussion.

Excluding people with dementia from research participation to safeguard their well-being may not be necessary and may mean that important research questions go unanswered (Black et al., 2010; National Health and Medical Research Council, 2018). In this study, it was therefore important for the researcher to speak with people living with dementia to understand their experiences while their capacity to engage with the researcher remained. The researcher, in interviewing people with dementia, demonstrated the value this group could add through research participation and the transformative potential in how they are viewed by others.

People with dementia have the right to autonomous decision-making about whether to participate in research and a dementia diagnosis does not necessarily indicate their lack of capacity to make that decision. However, the cognitive decline a person with dementia experiences results in impaired memory and comprehension, and a diminished ability to engage in abstract thought processes. As such, there are risks in establishing a person with dementia’s capacity to provide informed consent. Research involving people with cognitive impairment requires consent, either from the person, a guardian, or a person or organisation authorised by law (National Health and Medical Research Council, 2018). People with dementia may need more time than others to decide whether they wish to participate in research and to understand their right to refuse to participate (Murray, 2013). Hence, allowing sufficient time was an essential element in obtaining informed consent in this research so that prospective participants could weigh up the risks and benefits of being involved (Murray, 2013). More specific information related to ethical considerations for each study is provided together with the discussion of these studies across the remainder of this chapter.

2.4.2 Qualitative component: Studies 1 and 2

Details surrounding the methodology of Study 1 and 2, which respectively explored the experiences and expectations of people with dementia about how they wished to live into the future, and care partners' understanding of these phenomena, as well as the care partner experience of providing support to the person with dementia, will now be discussed.

2.4.2.1 Research design - An application of the grounded theory method

The grounded theory method has been used extensively to explore a wide and varied array of social phenomena, such as in the fields of mental health (Mostafanejad, 2005; Wynaden, 2007), pain management (Mediani, 2014; Slatyer et al., 2015) and midwifery (Hansson et al., 2019; Hansson et al., 2021). The focus of the research method is to explore the social and psychological processes that result from human interaction and behaviour, to identify the core problem experienced by the group under investigation, and to determine how the individual or group engages to manage the core problem to maintain equilibrium in their lives. Historically grounded theory was developed by two sociologists in the 1960s, Barney G. Glaser and Anselm L. Strauss (1967) as they worked on a study exploring the process of dying and the impact it had on the person and those around them. Glaser and Strauss

(1967) believed that by using grounded theory social scientists would have the means to generate a substantive theory relevant to their research.

The researcher did not set out to develop a substantive theory within the qualitative components of this research (Study 1 and Study 2) and, as mixed-method research was employed, this was beyond the scope of this study. Instead, an application of the grounded theory method was used to guide all stages of the research process for Study 1 and 2 (sampling strategies, semi-structured interviews, use of constant comparative data analysis, and identification of core categories). The use of the method was deemed suitable given that the study involved trying to understand the social and psychological experiences of people with dementia, how they managed the situation of planning for their future and exploring care partners' understanding of these phenomena. Due to the mixed-method approach used, data analysis in the qualitative components stopped when saturation was reached, and core categories and links to sub-categories were identified, as these milestones indicated that the phenomenon under study had been fully explored. The findings were then compared to the existing literature in the area, during the 'write-up' of Study 1 (Publication 1) and Study 2 (Publication 2). These publications provide further detail regarding the use of this methodology and are located in Chapter 3.

2.4.2.2 Population, sampling and recruitment

Within Study 1 and Study 2, participant recruitment targeted people with dementia, and care partners of people with dementia respectively, and used purposeful and theoretical sampling. Purposeful sampling involved recruiting people for study participation based on them possessing experiences related to the research objectives and meeting the inclusion criteria to participate. Participants who are able to provide first-hand experience can inform a rich understanding of the phenomenon under investigation (Streubert-Speziale & Carpenter, 2011). In Study 1, people living with dementia who met the inclusion criteria to participate were recruited via support groups, a variety of public and private health care services and a community radio station. The inclusion criteria encompassed the need for the person to have: a dementia diagnosis, an awareness of the symptoms and diagnosis, the capacity to articulate their experiences and the ability to provide informed voluntary consent to participate. For Study 2, care partners who were included had to speak and understand English and be adults caring for a family member diagnosed with dementia. Care partners were recruited from a range of carer support groups and via a nurse specialist working within the aged care sector. Care partners have been defined in Chapter 1 (Section 1.2) and are further expanded upon in Chapter 3 (Section 3.2) where the evolving role of the care partner is discussed in relation to the change in terminology from carer to care partner. It was anticipated at the outset that approximately 21 and 18 participants would be required for Study 1 and Study 2, respectively to reach data saturation based on studies with similar methodology and sample sizes (Cone & Giske, 2013; Hayter, 2009).

Data elicited from the participants who were recruited via purposeful sampling led to theoretical sampling. Theoretical sampling aims to seek participants who have varied and different experiences to strengthen the findings of the study (Glaser & Strauss, 2012; Polit & Beck, 2014; Streubert-Speziale & Carpenter, 2011). For example, in Study 2 purposeful sampling recruited care partners who were spouses of people with dementia. The long and intimate relationship that spousal care partners had with the person with dementia emerged as a factor that was influencing their understanding of the person with dementia’s expectations about how they wanted to live their life into the future. Therefore, this emerging concept in the data directed the researcher to undertake theoretical sampling seeking participants with differing relationship lengths and levels of intimacy with the person with dementia, such as adult children, to understand different influences on the phenomenon under investigation.

Potential participants for Study 1 and 2 were provided with a research information sheet (Appendix B and Appendix C respectively) and an informed consent form (Appendix D). The researcher explained the study purpose and procedures to potential participants and provided them with an opportunity for questions and consultation with family before they made their decision to participate. To ensure participants made an informed decision to participate, the researcher confirmed their understanding by checking that they were able to articulate what they were required to do if they took part in the research and what the study was about.

2.4.2.3 Data collection and analysis

Demographic data were collected (Appendix E) to ascertain the characteristics of the participant group to aid reporting and transferability of study findings (Polit & Beck, 2014). Characteristics of both participant groups, people with dementia and care partners, are described in Publications 1 and 2 in Chapter 3.

Semi-structured interview guides were used in this research to obtain rich data that explained the experiences and expectations of people with dementia (Appendix F), and care partners’ understanding of these phenomena (Appendix G). A semi-structured interview is a flexible informal approach to questioning using open-ended questions (Polit & Beck, 2014; Whiting, 2008). Employing this data collection method meant that the researcher could prepare questions in advance to help guide the interview, collect data that detailed participant responses to broad research questions, explore participants' thoughts and feelings, and as such obtain more insight to understand participants' points of view (Whiting, 2008). However, implementing semi-structured interviews is not without its limitations. Such interviews can be time-consuming, and an adequate number of people are required for study participation to develop an understanding of the research phenomena (Humphrey & Lee, 2004). The researcher was able to overcome these limitations by allowing sufficient time within the research timeline to complete this stage of the research process, namely recruiting participants, collecting data and analysing data until saturation was reached. Within Study 1 and Study 2 interview guides were used in a flexible way, the order in which questions were asked changed dependent on the person being interviewed as did the phrasing of each question. Interview prompts were used to elicit detailed responses from research participants.

Interviews were conducted in a naturalistic setting, that is a location chosen by the participant so that they were able to feel relaxed and comfortable and, as such, able to disclose their true thoughts and feelings throughout the interview (Polit & Beck, 2014). For most participants, the chosen location for the interview was their own home. In Study 1 the semi-structured interview questions explored participants' experiences of the onset of their dementia, the impact of the diagnosis on their lifestyle, and future expectations of living with the condition. In Study 2, interview questions focused on the support that care partners provided to the person with dementia and the care partner's understanding of the person with dementia's experiences and future expectations of living with the condition. While interviews with family care partners of people with dementia were on average 48 minutes long, interviews with people with dementia lasted for approximately one hour. The length of time spent interviewing research participants is an important consideration, as it means that the participant, throughout the interview, can become increasingly comfortable with the researcher. As such, participants were able to feel at ease disclosing information about the phenomena under study, allowing for more detailed data to be collected (Whiting, 2008).

The constant comparative method of analysis and the coding principles central to the grounded theory approach were used in this research to analyse data (Glaser & Strauss, 1967). Data collection and analysis is a simultaneous process whereby the researcher decides what data to collect next, based on the categories that emerge or become apparent throughout the initial phase of analysis. In this study, the analysis of data involved comparing each interview finding with subsequent participant findings. An inductive data coding process was then used for categorising data to identify core categories, that helped to enhance the understanding of people with dementia’s experiences and expectations, and care partners’ understanding of these phenomena (Birks & Mills, 2013; Glaser, 1992). The process of data analysis commenced with open coding which entailed line-by-line analysis, where new concepts were discovered (Glaser, 1992). Obtaining words or phrases straight from the data formed part of open coding and is referred to as in vivo coding (Streubert-Speziale & Carpenter, 2011). Theoretical coding then followed open coding. The researcher explored the relationship between the categories and organised the categories to clarify the interrelationship between each, leading to the development of theoretical links. The third level of coding, selective coding, was when data were then integrated and further refined conceptually into categories (Glaser, 1978; Glaser, 2001). According to Glaser (1992), the process of selective coding occurs when a core category has been identified.

The write-up of findings followed the identification of the core categories and their link to sub-categories. This iterative process of comparing data resulted in high-level conceptual categories abundant with meaning (Birks & Mills, 2013). Employing a process of constant comparative analysis meant that the data collected were rich and expansive. As such, this allowed the researcher to determine that saturation had been achieved, as following the analysis of data from the final interviews no new information was obtained (Glaser, 2001; Streubert-Speziale & Carpenter, 2011). Within Study 1, data saturation was achieved as the analysis of data gathered from participants continued to portray their experience of loss. For example, their loss of decision-making autonomy, their limited understanding of what the future might hold, and consequent reliance on their care partner when they could no longer advocate for themselves. Data saturation became evident at approximately interview number 19, five more interviews were conducted to confirm data saturation, resulting in a final sample size of 24 participants for Study 1. Within Study 2, data saturation was achieved as the analysis of qualitative data revealed that care partners had very little knowledge of the person with dementia’s future expectations. In addition, the importance of the relationship between the person with dementia and their care partner unfolded, as care partners reported their experience of supporting the person with dementia to maintain their quality of life into their future. Within Study 2, data saturation was evident at approximately interview number 15, but six more interviews were conducted to confirm saturation of data, with a final sample size of 21 participants for this component of the research.

2.4.2.4 Ethical considerations

It was considered that care partners and people with dementia participating in this research could potentially experience distress and, as such, interview questions were developed in consultation with research supervisors to ensure their sensitivity. Potential participants were informed that participation was voluntary, and they were able to withdraw at any time up until the point immediately following interview. For the most part, people with dementia were recruited for study participation (Study 1) soon after they were diagnosed. Consequently, these participants were more likely to be able to provide written informed consent, given that the cognitive impairment they experienced at that time was not extensive, and they could indicate their understanding of what was required of them. All care partners participating in Study 2 provided informed written consent to participate. Information was provided both verbally and in written form, using layperson language to aid participant understanding (Murray, 2013).

Prior to the interview taking place, participants were advised that they were able to discontinue the interview at any stage if the interview process caused them any distress. An adverse events protocol was developed where participants were offered access to counselling services at Alzheimer’s WA, an organisation based in Western Australia that offers counselling, education, and support for people within the community including people with the condition if this was required. However, no participants expressed signs of distress, indicated the need for counselling or withdrew from the study (National Health and Medical Research Council, 2018). Publications resulting from the study did not use participants’ names and participants’ data were de-identified at the time of the interview. These ethical considerations were detailed on the participant information sheet.

2.4.2.5 Rigour and trustworthiness

Trustworthiness assesses the quality of qualitative research and is necessary to provide clarification that research findings accurately portray the viewpoint of the study participants (Polit & Beck, 2014). Lincoln and Guba (1985) identified five criteria for determining the trustworthiness of qualitative research, namely, credibility, dependability, confirmability, transferability, and authenticity.

While credibility refers to the confidence that a person can have in the truth of the research findings (Korstjens & Moser, 2018; Lincoln & Guba, 1985), dependability signifies that the research has been conducted in a way that is consistent and repeatable. As such, replication of the research by others in the same or similar context/s, with the same or similar participants, means findings may be interpreted in a similar way. To establish confirmability the researcher needs to a) demonstrate that findings have stemmed from the data and, b) reveal how conclusions have been attained (Nowell et al., 2017). Transferability signifies the extent to which findings of a study can be applied to other situations, while authenticity emerges when the reader can ascertain a vivid understanding of the phenomenon under study (Polit & Beck, 2014).

There are several ways the researcher ensured the trustworthiness of this research and was able to meet the five criteria as outlined by Lincoln and Guba (1985). Person triangulation assured the credibility and dependability of the study findings as both people with dementia and care partners were asked to disclose their perspectives of the person with dementia’s experiences around diagnosis and expectations for the future. Participants’ interview narratives were audiotaped and transcribed verbatim, enhancing both the credibility and authenticity of the study findings as no data were lost and the perspective of participants was documented (Polit & Beck. 2014). The researcher formed meaningful relationships and had prolonged engagement with participants through allocating time within the interview period for rapport building. Consequently, participants felt comfortable disclosing their experiences. This allowed the building of trust between the researcher and participants and meant that there was sufficient time to develop an in-depth understanding of the participants' points of view (Macnee, 2004; Polit & Beck, 2014). Within Study 1 and Study 2, immersion in sampling, data collection and analysis extended over an approximately 22-month and 6-month period respectively. This allowed researcher immersion the concurrent process of sampling, and data collection and analysis, helping to arrive at the 'truth' in the data and consolidate interpretations through the capturing of a "range of different realities" (Polit & Beck, 2014, p.323), attesting to authenticity.

Throughout the conduct of this research, data saturation was reached in both qualitative studies. Obtaining data saturation enhanced the credibility and transferability of study findings, as it meant that findings represented a complete understanding of the phenomenon under investigation for this group of participants (Polit & Beck, 2014). Coding and data analysis were checked and validated by supervisors to reduce the researcher's subjectivity and risk of bias (Mackieson et al., 2019). The researcher thoroughly documented the different stages of the data analysis process to enhance the dependability and confirmability of study findings (Polit & Beck, 2014). The researcher ensured authenticity and transferability by presenting the findings in a way that meant the reader could develop an understanding of the phenomenon under study. Participant quotes were used to support the interpretation of study data, helping to establish the confirmability of study findings (Polit & Beck, 2014).

The constant comparative method of analysis was used to guide sampling and the coding of data. Trustworthiness was assured as emerging categories were grounded within the data obtained, adhering to the grounded theory method of Glaser and Strauss, followed across Study 1 and Study 2 (Glaser & Strauss, 1967;

Glaser & Strauss, 2012). Comparing study findings with existing literature in the area is also fundamental to the grounded theory method as it helps to establish if the findings would have meaning to other people in similar situations, enhancing the transferability of study findings (Birks & Mills, 2013; Glaser, 1998; Glaser & Strauss, 2012; Streubert-Speziale & Carpenter, 2011). This comparison of findings against existing literature is provided in Publications 1 and 2 located in Chapter 3 of this thesis.

2.4.3 Integrative literature review

Findings from Study 1 and Study 2 revealed how participants with dementia desired to stay connected to their pre-diagnosis lifestyle, sought decision-making opportunities about their care and support, and how care partners participating in the study knew very little of people with dementia's future expectations. It then became necessary to further investigate these findings by undertaking an integrative literature review. The review explored what is known about the participation of people with dementia, from their perspective, in the planning of their care and support throughout the dementia journey. This helped to contextualise the findings of Study 1 and Study 2 and add an extra data source in line with grounded theory (Macnee, 2004). An integrative literature review was warranted because the dissimilar interventions and methodologies reported in this area made a systematic review difficult. A researcher, in conducting an integrative review, seeks to develop a broad understanding of a phenomenon described in both empirical and theoretical literature and synthesises the literature in an integrative way to create new perspectives about the topic (Torraco, 2016; Whittemore & Knafl, 2005). Such reviews have the potential to contribute to policy development and practice in nursing (Whittemore & Knafl, 2005) Within this research, the integrative literature review involved a search of eight electronic databases and identified papers reporting studies where people with dementia were included as research participants, as this perspective was critically important to explore. The details of the methodology and findings of the integrative literature review are presented in Chapter 4 and includes a peer-reviewed publication, Publication 3.

2.4.4 Quantitative component of this research: Studies 3 and 4

The findings from the integrative review identified very limited evidence regarding people with dementia's participation in their care and support planning. This was despite their desire for sustained decision-making autonomy as detailed in Study 1 findings. The stigmatising belief from others that people with dementia lack decision-making capacity (as unveiled in Study 1), and care partners' awareness of other people's stigmatising behaviours towards their family member who was living with dementia (found in Study 2), meant a subsequent quantitative component to address community attitudes towards this cohort of people was warranted. Therefore, the quantitative component of this research involved the development of the Dementia Community Attitudes Questionnaire (DCAQ) (Study 3, Publication 4 in Chapter 5) and the implementation of a Dementia Awareness Raising Forum at which the questionnaire was administered (Study 4 detailed in Chapter 5). The forum was a facilitated two-hour awareness raising event for members of the community. A panel of keynote speakers with expertise in dementia conducted presentations along with a person with dementia via a pre-recorded video link. Information presented included detail surrounding the dementia human rights movement, early diagnosis, the experiences and expectations of people with dementia and living well with dementia. The forum was conducted in Western Australia (WA) at Curtin University in 2019 in conjunction with Alzheimer's WA. A search of existing literature was undertaken to identify a suitable questionnaire to measure attitudes toward dementia that would be used to evaluate attitude change in community members at the Dementia Awareness Raising Forum, (Publication 4 detailed in Chapter 5). However, no existing questionnaire, reflecting the changing paradigms of dementia-related care and support was identified. The newly developed DCAQ underwent pilot testing, with subsequent refinements, prior to its administration at the forum. The development and testing of the DCAQ are expanded on in the following sections.

2.4.4.1 Study 3 – Development of the Dementia Community Attitudes Questionnaire

A key consideration of a newly developed measurement tool is whether the tool is psychometrically sound, that is the extent to which the tool is both valid and reliable. While validity is the degree to which an instrument measures the constructs it claims to measure, reliability is the extent to which an instrument produces consistent results when measuring an attribute (Macnee, 2004). The COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) initiative, has reached a consensus on terminology and definitions of measurement properties (Mokkink et al., 2010). Explanations around psychometric testing of the DCAQ provided across the following sections have drawn upon the work of the COSMIN group.

Within this study, the developed DCAQ underwent preliminary psychometric testing only. Development of the questionnaire addressed only face and content validity and provided early estimates of internal consistency and construct validity, with data obtained from attendees at the Dementia Awareness Raising Forum. The findings of the psychometric testing are detailed in Publication

4 located in Chapter 5 of this thesis. However, a summary is provided in the following sections to assist the reader.

2.4.4.1.1 Establishing content validity of the new questionnaire

Content validity is the degree to which the content of an instrument adequately reflects the construct to be measured (Mokkink et al., 2010). To achieve content validity, the construct of interest is first defined via a literature search or qualitative interviews. Relevant experts working in the field are then sought and asked to determine if the proposed scale items are indicators of the construct under investigation (DeVon et al., 2007; Mokkink et al., 2010). This process was followed in this study. The questionnaire items used were developed following a review of the literature and expert reference group feedback.

The expert reference group was formulated in conjunction with the research supervisor, CT. Experts residing within Western Australia, New South Wales, Tasmania, and South Australia who had experience in research and questionnaire development, and expertise in working with people with dementia were invited to participate. Six experts were initially approached to participate in the reference group. One invitee did not respond, with the remaining five experts agreeing to participate. Information that detailed what the study was about, combined with a consent form (Appendix H), a draft copy of the questionnaire (refer to Study 3 Chapter 5), and a panel review form (Appendix I) (Mastaglia et al., 2003) were sent to potential expert reference group members so that they could decide whether to participate. Further details around the process used to establish content validity are documented in Publication 4 (located in Chapter 5).

Face Validity is the degree to which the items of an instrument look to be an adequate reflection of the construct to be measured (Mokkink et al., 2010). Given that face validity is a subjective assessment and is considered a weak form of validity, it fails to recognise how the tool measures the construct of interest. Face validity does however provide an opportunity to determine how potential research participants when using the questionnaire may interpret and respond to the items (DeVon et al., 2007). Within this study, the face validity of the questionnaire was first evaluated by the expert reference group, and then during piloting with 10 community members which included people with dementia and care partners of people living with the condition. Changes were made to the tool based on this feedback prior to its use at the forum and are explained in Publication 4 (located in Chapter 5).

2.4.4.1.2 Establishing internal consistency of the new questionnaire

Internal consistency reliability refers to the interrelatedness among the items on a questionnaire, based upon correlations between the different items and the extent to which item responses are similar, related and can be grouped together (Mokkink et al., 2010). Internal consistency of the newly developed questionnaire was demonstrated by using the Cronbach’s alpha coefficient statistic. Cronbach’s alpha can range from zero to one, with zero indicating no relationship between item responses, and a value of one indicating that all item responses are related. For a measure to be determined as internally consistent, an alpha coefficient of 0.7 or above is deemed acceptable for new scales (Boateng et al., 2018; DeVon et al., 2007; Streiner & Norman, 2008). Within this study, the Cronbach’s alpha coefficient statistic for each factor generated by the exploratory factor analysis ranged from 0.709 to 0.855. This is detailed in Publication 4 (located in Chapter 5) and indicates the internal consistency of the DCAQ.

2.4.4.1.3 Establishing construct validity of the new questionnaire

Construct validity refers to the degree to which the scores of an instrument are consistent with a hypothesis, assuming that the instrument measures the construct being investigated (Mokkink et al., 2010). In this study, the researcher determined that the Dementia Community Attitudes Questionnaire measured the construct of attitudes towards people living with dementia. Construct validity was established using factor analysis. Factor analysis is used to determine relationships among a large number of variables on an instrument (DeVon et al., 2007). A factor is a number of test items that can be grouped together (DeVon et al., 2007). Exploratory factor analysis, as undertaken in this research, helped to determine the various factors that defined the construct (Plichta & Kelvin, 2013). Exploratory factor analysis within this research (N=92) generated an interpretable three-factor solution using an oblique rotation procedure in IBM SPSS Statistics (Version 25) that determines whether the factors are correlated. The first factor was titled ‘Engagement’, Factor two ‘Challenges’ and Factor three, ‘Decision-making’. The outcome of the factor analysis is explained further in Chapter 5.

2.4.4.2 Study 4 – The Dementia Awareness Raising Forum

Study 4 involved the conduct of a Dementia Awareness Raising Forum to address community attitudes towards people with dementia. The findings of Study 1 detailed the lack of awareness of people within the community about people with dementia’s capacity for some degree of independence and decision-making. This was evident as Study 1 participants with dementia disclosed that their doctor communicated to their care partner and overlooked their capacity to be involved in health care decision-making. As such, the aim of Study 4 was to explore the usefulness of a community forum in creating awareness and positively changing community attitudes towards people living with dementia. It was anticipated that the forum might improve attendees' attitudes towards people with dementia as it allowed for discussion to take place between attendees and panel members, aiding recognition that people living with dementia can retain agency and independence albeit for a time-limited period. Addressing this aim encompassed Objective 5 of the study, which was to explore the feasibility and effectiveness of a Dementia Awareness Raising Forum to positively change community attitudes towards people living with dementia.

2.4.4.2.1 Research design

The method used to evaluate any change in attitudes towards people living with dementia at the forum was a pre-test-post-test quasi-experimental design using the newly developed questionnaire. Such designs are widely used in research to either compare groups of people or measure a change in people following either an experimental treatment or intervention (Polit & Beck, 2014). A change in item scores was calculated from before the start of the forum to after its conclusion, to obtain an indication of the effectiveness of this kind of intervention, while also providing an opportunity to establish the tool's early psychometric properties using the pre-test data.

2.4.4.2.2 Population, sampling and recruitment

The target population of interest for this component of the research (Study 4) were members of the community who had an interest in dementia irrespective of personal or previous experience with it. Such a population would enable the recruitment of a cross-section of the community to attend the Dementia Awareness

Raising Forum and complete the questionnaire. Convenience sampling was implemented in Study 4 as it is a non-random method of sampling and involves selecting the most readily available people as research participants (Macnee, 2004). Non-random sampling may mean there is a greater risk of bias in the results of the study as the most conveniently placed people to participate may not be representative of the entire population (Macnee, 2004). All avenues for recruitment that were available at the time were used to invite people who might be interested in participating in the study because of personal or professional experiences or academic interest as a way of mitigating the risk of bias and strengthening community representativeness. Members of the community who were on the mailing lists of aged care advocacy groups were invited to attend the forum via email. Event notifications were also sent to employees of aged care community organisations, and public and private hospitals to ensure that individuals who liaised with people with dementia through their work role were captured in this sample. In addition, people within the community, and university staff and past and present students were emailed event invitations. As mentioned previously, this was done to reduce the risk of bias and attract people to the event who may have had limited prior knowledge of dementia, increasing sample representativeness of the wider population.

2.4.4.2.3 Data collection and analysis

Data were collected from forum attendees using the newly developed DCAQ on their arrival at the forum and at the end of the forum proceedings. Attendee demographic details plus their dementia-related education and experience were recorded. Descriptive statistics were used to describe data that detailed attendee characteristics. Independent samples t-tests were used to compare data between two separate groups of individuals, to see if there were statistically significant differences between them (Denscombe, 2003; Plichta & Kelvin, 2013). In this study, the two unrelated participant groups were attendees with previous dementia-related education, (not including people with dementia-related experience) and those without. The means of scores between these two groups were used to distinguish baseline differences in the questionnaire item responses.

Two-way repeated-measures analysis of variance (ANOVA) was used to analyse the data obtained from the questionnaire. Repeated measures analysis of variance (ANOVA) is used to analyse more complicated factorial designs where a dependent variable (within this study the questionnaire items) is measured over multiple time points with the same individual (Plichta & Kelvin, 2013). In this study, the factors in the two-way repeated-measures ANOVA were the intervention (within-subjects factor: pre- versus post-forum, the same person measured over two points in time to determine the effectiveness of the intervention), and previous dementia-related education (between-subjects factor: comparing participants with versus without previous dementia-related education). These two-way repeated-measures ANOVA analyses were used to establish preliminary indications of the potential effectiveness of the Dementia Awareness Raising Forum. In brief, this was done by measuring scores on each item of the DCAQ (dependent variable) to determine: a) a change in attitudes of attendees at the community forum towards people with dementia from before to after the forum, b) whether knowledge change was influenced by participants' previous levels of dementia-related education, and c) whether any change in attitude differed between those who had previously received dementia-related education and those who had not. The results indicated that overall, attendees at the forum had more positive attitudes towards people with dementia following forum proceedings. Participants with previous dementia education had higher baseline scores and those with no previous dementia education showed more improved post-forum scores. A more detailed account of the findings related to the Dementia Awareness Raising Forum is provided in Chapter 5.

2.4.4.2.4 Ethical considerations

For attendees at the Dementia Awareness Raising Forum, an information sheet provided to participants detailed what they were required to do, explained the voluntary nature of participation, the study purpose and, perceived benefits and risks to study participation (Appendix J). The information sheet was written in consultation with the supervisory team to ensure the wording was sensitive to the needs of those attendees who may have been experiencing cognitive impairment and were on the mailing lists of aged care advocacy groups. Participant responses on the questionnaire were non-identifiable as questionnaires were numbered, with no requirements for participants to provide their names. Participant anonymity was therefore maintained. The questionnaire contained both the pre-intervention and post-intervention survey questions as separate sections using different colour-coded pages. As such, pre and post-data could be attributed to the same person. Participants were instructed to complete the pre-intervention component prior to the commencement of the forum and the post-intervention component after the forum before their departure. Attendees’ consent to participate in the research was implied when they completed the survey. Participant event registration details were collected before the event to determine how many people had registered to attend and stored by the University Advancement Team members who assisted with organising the event. This information was collected prior to the event, stored separately by these staff according to university requirements, and was not linked in any way to the data that participants provided for research purposes. The number of people who attended the event was ascertained so that a participant response rate could be determined.

2.5 Data Management, Storage and Disposal

This section details the data management processes applied to all components of the research reported on in this thesis. Data were de-identified as required, kept confidential and stored electronically on a password-protected computer in the researcher's locked office. Data were managed using QSR International Pty Ltd NVivo, and in IBM SPSS Statistics (Version 25) software and stored on the secure research drive at Curtin University. This included, for Study 1 and 2, audio digital recordings that were erased from the handheld digital recorder on which the interviews had been recorded. Hard copy anonymous questionnaires were stored in a secure cupboard, also located in the researcher's locked office. Demographic information was collected prior to the interview (Study 1 and 2) and each sheet was coded using a numerical system to ensure each participant's identity was not compromised. The researcher kept a logbook that identified which participant the number represented, which was stored separately and securely, from the data. Data that was collected in the development (Study 3) and implementation (Study 4) phase of the questionnaire was stored electronically on a password-protected computer and in hard copy format in the researcher's locked office respectively. The primary researcher and the supervisory team were the only people who had access to the records and data collected as a part of this research study.

Data will be stored for a minimum of seven years after the completion of the research as per the Western Australian University Sector Disposal Authority. Following that time, data will be destroyed by shredding hard copy questionnaires and related documents, and by permanently deleting electronic files. The project data management, storage and disposal form part of a data management plan that was developed at the beginning of the research. All data were managed in accordance with that plan.

2.6 Chapter Summary

The research reported in this thesis was guided by a transformative worldview as it aligned with the evolving paradigm of how people with dementia can best be supported. Whilst the initial medical model paradigm is currently used, new experiential and human rights-centred approaches have emerged across this evolving shift in dementia care paradigms. A mixed-method exploratory sequential research design was chosen for this study as it suited exploring phenomena where little is known at the outset, as was the case in this study. An application of the grounded theory method was first used in the conduct of the qualitative component to explore the experiences and expectations of people with dementia, and care partner understanding of these phenomena and their experience of supporting the person with the condition. Subsequently, a pre-test-post-test experimental design was implemented in the quantitative component. This component of the study explored the feasibility and effectiveness of a dementia awareness raising forum to positively change community attitudes towards people living with dementia to help overcome the experience of people with dementia being marginalised. In the chapter that follows qualitative studies that formed part of this research are presented. Chapter 3 details two publications, namely, Publication 1, titled: Experiences and expectations of living with dementia: A qualitative study, and Publication 2, titled: A qualitative exploration of family carer’s understandings of people with dementia’s expectations for the future. These publications will build on the information provided in this chapter by providing a more in-depth account of the experiences and expectations of people with dementia in relation to planning for their future and will highlight care partners’ experiences of the same.

Chapter 3

Qualitative Studies (1 and 2)

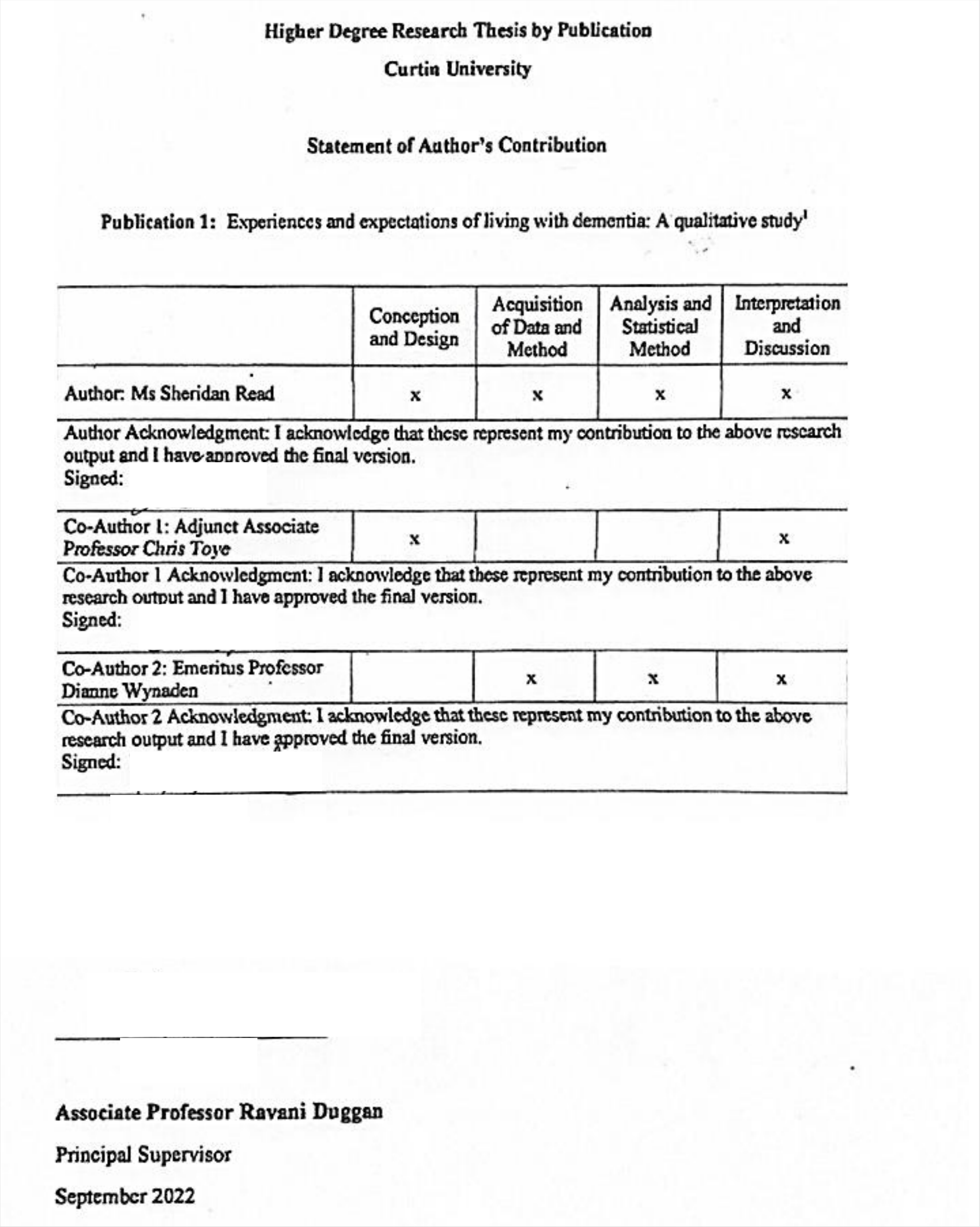
This chapter details the qualitative component of the exploratory sequential mixed- method design used in this research. Studies 1 and 2 and their findings have been published in peer-reviewed journals, Collegian and Dementia respectively, with authorisation from the editors of each journal (Appendix K and Appendix L) for their inclusion in their published format. Study 1 used an application of the grounded theory method and addressed research Objective 1, namely, to explore and describe experiences of dementia and expectations of people with dementia about how they wish to live their lives. Study 2 adopted the same methodology and addressed research Objective 2, which was to explore and describe care partners' experiences of supporting the person with dementia including their understanding of that person's experiences and expectations.

3.1 Study 1 (Qualitative Component)

Study 1 sought to understand, through semi-structured interviews, how participants experienced the onset of dementia symptoms and receipt of a diagnosis, as well as their future expectations of living with dementia. It was important to capture participants' understanding of their future expectations given the paucity of literature that existed in this area. Overall, findings showed that people with dementia who participated in this component of the research had very little understanding of what to expect in the future. Other researchers have also identified that people with dementia lack awareness of matters related to advance care planning which would enable them to make informed decisions and create awareness about their future care and support preferences (Bryant et al., 2019). The detailed findings of qualitative Study 1 in Publication 1 – "The experiences and expectations of living with dementia: A qualitative study" will now be presented.

Publication 1 – Experiences and Expectations of Living with Dementia: A Qualitative Study

Statement of Author's Contribution



Higher Degree Research Thesis by Publication

Curtin University

Statement of Author's Contribution

Publication 1: Experiences and expectations of living with dementia: A qualitative study[1]

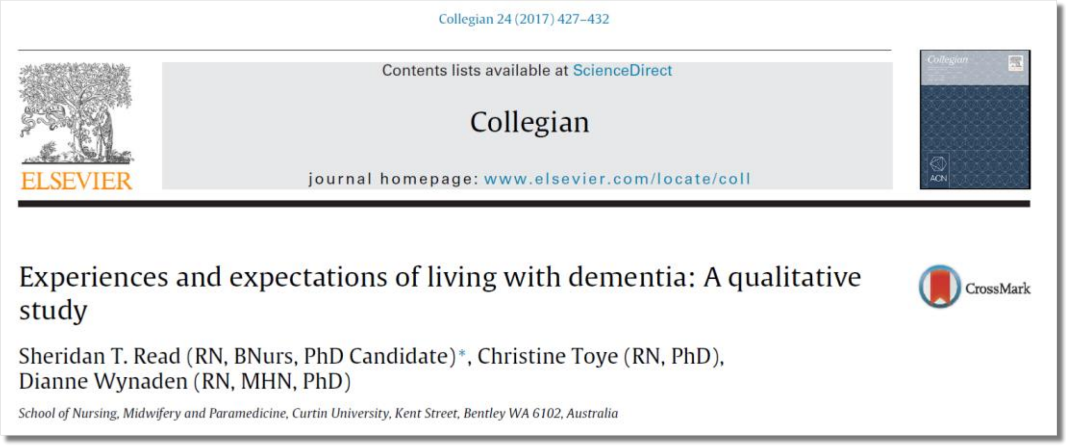
	Conception and Design	Acquisition of Data and Method	Analysis and Statistical Method	Interpretation and Discussion
Author: Ms Sheridan Read	x	x	x	x
Author Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 1: Adjunct Associate *Professor Chris Toye*	x			x
Co-Author 1 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 2: Emeritus Professor Dianne Wynaden		x	x	x
Co-Author 2 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				

Associate Professor Ravani Duggan

Principal Supervisor

September 2022

Permission to include this article in this thesis has been obtained from the publisher (Appendix K).



Collegian 24 (2017) 427–432

Contents lists available at ScienceDirect

Collegian

journal homepage: www.elsevier.com/locate/coll

Experiences and expectations of living with dementia: A qualitative study

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Abstract

Background: There is a paucity of literature detailing the expectations that people with dementia have for the future; therefore the capacity to reflect their views in service provision is limited.

Aim: This paper reports the findings of research that explored and described experiences of people diagnosed with dementia and their expectations of their support needs and how they wished to live their lives.

Method**:** An application of the grounded theory method was used and data were collected from 24 participants using semi structured interviews. Coding principles and the constant comparative method of analysis central to grounded theory were used to analyse data.

Findings: The core problem that emerged was conceptualised as losing control. This concept encompassed loss of role function and independence, uncertainty about the future and fear of being a burden. To manage the problem of losing control, participants engaged in a process of finding meaning where they sought answers to address their concerns and implemented strategies to assist them to maintain connectedness to their pre-diagnosis life for as long as possible.

Discussion: People with dementia have limited knowledge on a likely dementia trajectory and find it difficult to identify their future support needs. Health care providers are required to help people with dementia identify what these needs might be and how they can maintain connectedness to their pre-diagnosis life.

Conclusion: To empower people living with dementia, information needs to be made available to them and their families to help them construct their plans for the future.

Summary of relevance

Problem – Little is known about the expectations that people with dementia have for the future.

What is already known

The progressive decreased cognitive functioning that people with dementia experience limits the time they have to understand dementia and to plan for the future.

What this paper adds

Evidence that this group of people with dementia lacked understanding of their likely dementia trajectory, limiting the extent to which they could identify and address their future support needs and maintain connectedness to society.

Keywords

Advance care planning, Dementia, Grounded theory, Health services, Qualitative research

Introduction and Background

Dementia is the name given to a syndrome or collection of symptoms caused by disorders affecting the brain that result in a gradual decline in cognitive functioning (Banerjee et al., 2007). It is estimated that over 46.8 million people worldwide have some form of dementia with this number expected to rise to over 131.5 million by 2050 (Alzheimer's Disease International, 2015). In 2015, it was predicted that there would be 315,963 people in Australia living with dementia, with this number projected to increase to 942,624 by 2050 (Deloitte Access Economics, 2011).

Recent reports indicate the need for a more timely diagnosis of dementia (Department of Health & Ageing, 2012). It is estimated that between 50% and 80% of people do not receive a formal diagnosis until three years after the onset of cognitive change (Department of Health & Ageing, 2012). How a diagnosis is communicated, and how the person makes sense of the information provided at the time of diagnosis, can impact on their understanding of dementia and their ability to make plans for the remainder of their lives (Stokes, Combes, & Stokes, 2014).

Dementia impacts upon the person's capacity to articulate their needs and therefore to remain central to decision making regarding their future care (Smebye, Kirkevold, & Engedal, 2012). Therefore, it is important to conduct research with people living with dementia while they are still able to articulate their experiences and expectations on how they wish to live their lives. The limited literature in the area suggests that consumers' views differ from those articulated by their caregivers/families (Armari, Jarmolowicz, & Panegyres, 2013) and health professionals (Miranda-Castillo, Woods, & Orrell, 2013).

Previous research including people diagnosed with dementia has focused on their quality of life (Roach & Drummond, 2014), their capacity for decision making (Fetherstonhaugh, Tarzia, & Nay, 2013; Smebye et al., 2012), their day to day needs (Armari et al., 2013; Miranda-Castillo et al., 2013), and their experiences upon receiving a dementia diagnosis (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). However, these studies have not explored the person with dementia's beliefs about their future support needs and expectations for the future.

This research aimed to address this knowledge gap and explore the experiences of people diagnosed with dementia, and their expectations of their support needs and how they wish to live their lives. In this way, it was believed that the voice of this rapidly expanding consumer group could be more clearly articulated to inform the delivery of a person-centered philosophy of care where the person is valued, they are the central focus of care and their voice is heard (Kitwood, 1993).

Methodology

This Australian research used an application of the Grounded Theory (GT) method developed by Glaser and Strauss (2012). The constant comparative method of analysis, central to the GT method, was used to guide data analysis and to allow categories and sub-categories to emerge. GT stems from symbolic interactionism; an approach to the study of human conduct, exploring social processes that are present within human behavior (Charon, 1995). The constant comparative method of analysis allowed the comparison of individual participant's experiences to occur and the identification of common shared meanings of the phenomena under investigation (Glaser, 2001). Finally, the basic social psychological problem and process were identified. Approval was obtained from the Human Research Ethics Committee of one university and relevant health services.

Sampling

Participants were recruited to the study if they had a diagnosis of dementia and provided informed consent to participate. The ability of the potential participant to provide informed consent was evaluated by the researcher during the initial contact. To be offered the opportunity to take part in the study, the person needed to demonstrate their understanding of study participation after this was explained, by re-articulating the study's purpose and describing how they would be able to contribute. Purposeful sampling was initially used to recruit people who met these inclusion criteria from a variety of public and private health services. Following initial data analysis, when categories emerged, theoretical sampling was employed to seek participation from people who still met these criteria but who had unique insights and different experiences; for example, people who had taken on consumer advocacy roles within the community, were diagnosed with dementia at a younger age and/or were proactive in ensuring that their voices were heard. Sampling continued until data saturation occurred, data were rich in descriptions and categories were clearly identified.

Data Collection

Semi-structured interviews were completed in a place convenient to participants and demographic data were collected prior to the interview commencing. The mean interview length was approximately one hour. Field notes and memos were also collected to add contextual meaning to data collected from participants. Questions focused on participants' experiences of the onset of their dementia, the impact of the diagnosis on themselves and their family, plus their future expectations of living with dementia.

Data Analysis

Data analysis commenced with open coding where each participant's experiences were examined (Glaser, 1992). Theoretical coding or second level coding was then employed where inter-relationships among all participants' experiences were identified. Selective coding further integrated and refined the categories and links to subcategories, allowing the basic social psychological problem and process to emerge (Glaser, 1978).

Trustworthiness of Data

The trustworthiness and rigor of data analysis were ensured through adherence to the constant comparative method and coding process outlined in the GT method (Glaser & Strauss, 2012). Furthermore, prior to the research commencing, the principal researcher documented her preconceived ideas about people living with dementia to identify issues that may have impacted on the research. Coding and data checking were validated by other members of the research team to further consolidate the trustworthiness of the data.

Results

Twelve men and twelve women consented to be interviewed between November 2013 and September 2015. Their educational qualifications ranged from primary school certification to doctoral degrees and occupations ranged from tradespeople to professionals. Seventeen participants lived with their spouses, two with a son or daughter and five lived alone. The majority of participants were diagnosed in 2013 or 2014, with Alzheimer's disease (n = 8), Vascular dementia (n = 3), Frontal Lobe dementias (n = 3), Semantic dementia (n = 1) and Posterior cortical atrophy (n = 1). Eight participants did not know the type of dementia with which they had been diagnosed. The basic social psychological problem of losing control and the basic psychological process of finding meaning emerged from the data.

The Basic Social Psychological Problem of Losing Control

The basic social psychological problem was conceptualised as "losing control"; it was expressed by all participants and began before they received a formal diagnosis of dementia. Participants reported experiencing fear and panic as they were confronted daily by situations that were becoming beyond their ability to control. Initially, the loss that participants experienced was not recognised as being permanent as before receiving their diagnosis they expressed hope that there was a solution to the problems they were experiencing: "[I was] hoping that what my problems [feelings of losing control] were, were fixable. . . maybe it is just about finding the right medication" (P7).

After participants received their diagnosis, the expectation of further loss of control became a reality as they knew dementia was incurable: “you can’t cure it [dementia]; I have got dementia for the rest of my life” (P3). The experience of losing control comprised four stages: 1) Loss of role function, 2) Loss of independence, 3) Uncertainty about the future and 4) Fear of being a burden.

Loss of Role Function

Participants expressed that they noticed changes in their ability to carry out their daily roles due to the gradual loss of functional capacity they were experiencing and consequently became increasingly reliant on other people. This further exacerbated participants’ feelings of losing control.

Loss of role function became evident for most participants when they began to notice a decline in their level of functioning at work and experienced difficulty completing workplace tasks. These changes became evident to the person themselves: “I did payroll for ten years [when functioning decline began], there were stages where I couldn’t remember how to do a back pay” (P10) or were identified by others, for example, during a workplace interview:

> In the middle of the interview he said “you don’t remember me do you?” I went “well no sorry” ...He said “we talked three months ago.” I was freaked out [that I had forgotten him]. I was having to scan paperwork [to refer to if my memory failed] so I didn’t [further] embarrass myself (P14).

Loss of role function was also identified when participants realised that they had a reduced ability to drive a motor vehicle. This was distressing as it signified further loss of control and an inability to fulfil their everyday roles, for example, completing tasks such as shopping. Some participants who continued to drive spoke of experiencing a loss of confidence, frustration and a growing realisation of the potential danger to others if they continued to drive: “Why? Why? Why Can’t I get around this roundabout? . . .must have been 7 or 8 times that I tried [to exit the roundabout]. . . I was fearful . . . I was also thinking I am dangerous” (P7). Some participants were less impacted by not being able to drive as they let other people assume the role: “I let [my wife] do all the driving but I still have my ordinary licence, . . . I have given [driving] away myself, no one has told me not to drive” (P4).

Loss of Independence

In losing control participants experienced a change to their level of independence; describing situations when decisions began to be made on their behalf by other people that led to their loss of self-esteem and confidence. One participant received a letter in the mail explaining that her licence was being revoked; she described how this loss affected her:

> I was very annoyed. My [doctor] and everybody says you must communicate you must get out with people, don't lock yourself away and then by taking my licence they just want to lock you in a room . . . that was my only escape my car it is a horrible feeling (P23).

Participants also experienced stigma that intensified their sense of loss of independence; they felt devalued as people assumed that they lacked decision making ability. This stigma was evident when one participant visited her doctor: "He [the doctor] didn't even care if I was there, he was asking [my husband] all these questions. . . he had me [stereotyped] as an imbecile" (P22).

Participants experienced feelings of grief due to their ongoing loss of independence. The grieving process for most participants commenced when they were first diagnosed with dementia as, prior to this, participants thought it was something that could be fixed. One participant explained: "I came home. I cried and I cried. . . it was grieving" (P19). Participants' progressive cognitive decline intensified their loss of independence and grief: "[I am] slowly accepting that there are things that I shouldn't be doing or I can't do, that is a bit sad in itself" (P7). One participant felt the continued grief she experienced was exacerbated by services that did not focus on her wellbeing: "the pathway is set up toward hopelessness . . . every single day there is new grief" (P13). The grief that participants experienced varied; some were more accepting of their diagnosis and grieved less: "I have had my life . . . so whatever . . . happens it just happens. That is Mother Nature" (P 11).

Uncertainty About the Future

Once diagnosed, participants moved into a period of uncertainty that exacerbated their feeling of losing control, questioning how long it would take before they would become fully dependent upon other people. Participants expressed anxiety around the potential total loss of their intellectual capabilities: "[I] hate to think at some point ... I would no longer be able to find my way to the shop" (P7). Participants were anxious about the dementia trajectory, particularly their level of deterioration into the future: "What if . . . it might not be possible . . .to speak or think clearly . . .that is what my fear is" (P8). They spoke of a lack of information provided to them about the progressive nature of dementia from their doctor. One participant explained the response from the doctor when he [asked what will happen in the] future: "they [the doctor] said really they can't tell me, everybody is different" (P 15).

The lack of knowledge that participants had meant that there was a level of uncertainty about the future. Such uncertainty became evident when many participants were unable to articulate what they felt their future support needs might be.

Fear of Being a Burden

Being burdensome to others was of great concern to participants and they discussed their concerns about their family members taking on the time consuming role of carer: “You can’t expect other people looking after you, they have got their lives to lead and they have their jobs to do” (P11). Being a burden on family was so worrisome to participants that some expressed a preference to die: “In a way I probably hope that I die [of something else] before [the] dementia [progresses]. . . I think probably for [my husband] . . . and our boys if I was to die they may think, well, that was a relief” (P16). Participants commented on the timing of when they could choose to end their life, for example: “when it gets to the point that it is obvious to the casual observer that I have dementia, I am done” (P14).

An admission to residential care was also discussed as an option to avoid being a burden. However this was also a reason why some participants articulated a preference to die as they had negative perceptions of living in residential care. One participant viewed nursing homes as restrictive environments: “the only care system I can see . . . is residential prisons . . . she [a relative] is prevented from doing [things] because she has dementia and so it is not safe” (P 18). The quality of care was also negatively perceived by another participant: “I would probably rather kill myself than [go into a nursing home], the current level of care is appalling” (P13).

Basic Social Psychological Process of finding Meaning

In an attempt to manage the experience of losing control, participants engaged in a basic psychological social process titled ‘finding meaning’. In finding meaning participants identified ways of adapting to their new experiences of living with dementia. Not all people had passed through all stages of this process at the time of being interviewed. Those participants who maintained high levels of functioning for longer periods acquired a better range of strategies and were more willing and able to advocate for themselves and others. Finding meaning encompassed three stages 1) Seeking answers, 2) Identifying strategies to manage the problem and 3) Coming to terms with, staying connected and giving back.

Seeking Answers

To find meaning, participants needed to obtain knowledge to overcome their experience of losing control. They did this by accessing the internet and/or visiting their doctor. Once participants had been diagnosed, they read books on dementia and accessed the internet to better understand their condition. These individuals looked to other people diagnosed with dementia, such as consumer advocates, as they were able to offer true insight and empathy on the experience of living with dementia. People with dementia chatted to each other online, accessed blogs or attended support groups and conferences: “I became deeply attached to [the internet] it was really through

Google that I found some excerpts of [another person diagnosed with dementias] writing about living with dementia. . .it was like reading my own story" (P13).

Identifying Strategies to Assist in Managing the Problem

After participants had some understanding of what that their diagnosis meant, they looked to identify strategies to help them to manage the problems they were experiencing. Alzheimer's Australia was one of the main 'go to' organisations for support and there they were able to meet other people living with dementia, which developed a sense of normalcy for them. This interaction with other people living with dementia also helped to manage the stigma they were experiencing; they felt socially included by accessing these services and appreciated the opportunity to be proactive in managing their condition. However, some participants reported negative experiences when attending services, feeling that a nihilistic attitude was sometimes portrayed as there was little that could be done to help. One participant said these services: "set up this chain reaction of hopelessness" (P13).

Participants reported the need to identify strategies to maintain their independence for as long as possible. They used reminders when their memories began to fail that included: calendars, assistive technology, and signs around the house. Strategies to minimise the risk of becoming lost were utilised by participants, such as global positioning system technology or familiar land marks:" I always look for the Bank West" (P7).

Participants articulated the importance of maintaining a positive mindset and described techniques to avoid becoming stressed at situations beyond their control: "if I . . .lose something I try not to [worry] about it . . . oh, I have lost that but I have got to get over that" (P7). Participants also compared their experiences to those of others and expressed gratitude about the positive elements of their lives despite living with dementia. One lady discussed how she felt when she went walking with a friend and her disabled grandson:

> I think to myself, that family . . . is much worse off than I am, I am much luckier than they are . . . that is a major thing for me to be positive . . . I feel really lucky that I have [my husband]. . ., without [my husband] this would be really difficult. (P16)

Coming to Terms With, Staying Connected and Giving Back

Most participants reached a stage where they began to accept their diagnosis and were prepared to make the most of the life that they had left. As participants worked towards this stage they considered their expectations of what would happen to them and what they could do to secure their future. For many people, this was very little as they were unsure of the impact that dementia would have and what future support services they might need. However, several participants toured nursing homes to identify a suitable future residence and one lady explained what action she had taken to secure her future: “[I organised an] enduring power of attorney. . .guardianship. . .updated the will” (P23). Some participants chose not to do anything and left decision making to the family:” It doesn’t worry me and whatever is the best thing for me [my daughter] will do for sure” (P6).

When asked how they wished to live their lives, participants spoke of maintaining some sort of connection to the society in which they lived for as long as possible. For some, this may have been continuing with simple activities that they had undertaken pre-diagnosis: “I would like to get back into the walking group” (P5). For others, this involved assuming less taxing work roles to maintain their sense of purpose and feelings of inclusion. Others took up voluntary work: “Well [paid] work has finished . . . I do it [voluntary work] for the enjoyment, a sense that I can do something, with the gardening, I enjoy that” (P7).

Some participants found meaning through advocating for other people with dementia. Often this was when they identified that they still had something of value that they could offer to other people. Through speaking at conferences, support meetings, writing books, online blogging and taking part in research participants encouraged a more positive outlook living with dementia. Participants recognised that sharing the lived experience of dementia was of great value and one gentleman shared how he felt after presenting his experiences: “Yes I enjoyed it, everyone enjoyed it and I ran into someone at the supermarket after I had done that and they said they had learnt a lot from what I told them (P15).”

Discussion

This study aimed to explore and describe experiences of people diagnosed with dementia, and their expectations of their support needs and how they wished to live their lives. The findings provided additional evidence on experiences of losing control that people with dementia encounter such as loss of role and loss of independence, previously investigated by Harris and Keady (2009) and Roach and Drummond (2014). Findings also provided new insights into participants’ lack of knowledge regarding a possible dementia trajectory, the kind of support that might help meet their needs and the expectation that they would stay connected to their pre-diagnosis lives for as long as possible.

A limitation of the study was that understanding of the dementia trajectory and the support needs that would be encountered was only minimally articulated by participants. In part at least, this seems to have occurred because of a reluctance in health professionals to provide information that would have helped empower the person with dementia to plan for the future within the context of realistic expectations of their future support needs. Health care providers need to offer information tailored to the needs of people living with dementia regarding the potential trajectory that dementia may follow to address this concern.

Advance care planning is one option during which health professionals can help people to meet their future support needs. There have been a number of studies that have focused on advance care planning (Dickinson et al., 2013; Poppe, Burleigh, & Banerjee, 2013), although few have reported on the views of the person diagnosed (Hilgeman et al., 2014). Advance care planning clarifies a person's lifestyle preferences (Poppe et al., 2013), and an advance care directive documents desired medical treatment options for when there may be future incapacity. There are a number of identified barriers to advance care planning including lack of knowledge (Dickinson et al., 2013). Further research is required to explore how these barriers can be overcome and consultation among health care providers is required to decide who initiates advance care planning discussions.

People with dementia expressed a desire to stay connected to their pre diagnosis life and to do so needed to be accepted by other people living in the community. Ongoing education, delivered by Alzheimer's disease support groups, people with dementia and government initiatives is required to limit the stigma of dementia so that people with dementia are accepted and the general public is aware of the early warning signs and have the confidence to seek an early diagnosis and the required support that encourages their continued engagement in society.

There needs to be a continued emphasis on early diagnosis of dementia so that consumers have increased opportunities to improve their health literacy regarding dementia, and to explore treatment options to help maintain their independence for longer. Furthermore, consumers will have increased opportunities to receive education on how they can stay connected to their pre-diagnosis lives for longer and maintain active community participation if desired.

As participants considered how they wished to live their lives, they expressed a desire for service providers to ensure that their needs were considered. Consumer involvement helps to overcome feelings of redundancy (Roach & Drummond, 2014), increases the likelihood that services respond to need and facilitates change in the way that services operate (Dupuis, McAiney, Fortune, Ploeg, & Witt, 2016). Globally, the need to increase consumer involvement in care and support services is evidenced by the increased number of related policies. Australian Government Department of Health and Ageing (2012) policy advocates for consumer directed care; the United Kingdom's Joint Commissioning Framework National Dementia Strategy (Goodchild, 2009) and the New Zealand Framework for Dementia Care (Ministry of Health, 2013) empowers people with dementia to remain central to decision making surrounding their care; US policy highlights the need to reduce stigma and to promote person-centered care (Shih, Concannon, Liu, & Friedman, 2014) and the Norwegian Ministry of Health and Care Services (2015) policy is based upon the needs of the user as defined by the user.

As participants articulated their future lifestyle preferences, some expressed a desire to be granted the right to die. This highlights the need for society to revisit related legislation that facilitates a person's decision making on ending their life. A failure to include people with dementia in decision making may mean they fail to adjust to living with the condition and consider ending their life prematurely (Draper, 2015). Some literature has indicated that family members who become proxy decision makers are likely to consent to treatment that may prolong the lives of the people for whom they provide care (Williams, Dunford, Knowles, & Warner, 2007). Conversely, empowering people with dementia with knowledge regarding the dementia trajectory, raising their awareness that maintaining connections is possible throughout the dementia journey and supporting the uptake of advance care directives will allow them to signal if and when life prolonging treatments should be withheld.

Conclusion

Globally, the number of people with dementia is increasing and there is a push to identify how services can meet their long term care needs in ways that are consistent with consumers' wishes. This paper provides insight into the experience and expectations of people living with dementia and demonstrates a requirement for the empowerment of people living with dementia so that they can be autonomous in decision making related to their future needs.

Acknowledgements

The author would like to acknowledge the 24 participants who took part in this component of the research and spoke of their experiences and the West Australian Nurses Memorial Charitable Trust for financial assistance.

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3.1.1 Summary

The experiences and expectations of people with dementia are relatively unexplored phenomena and, as such, this article provides a unique contribution to knowledge in the area. This study provided Australians who were living with dementia an opportunity to voice their experiences and support expectations. An application of the grounded theory method was employed, which focused on the psychological and social factors surrounding the experiences of people with dementia; this meant an in-depth understanding of such matters was unveiled. People with dementia participating in Study 1 reported feelings of losing control as their ability to sustain their independence continued to diminish, but to manage this problem they employed a process of finding meaning whereby they sought strategies to help maintain a connection to their pre-diagnosis lifestyle. These study findings have led to a greater understanding of how people with dementia wish to live their lives following receipt of their diagnosis, the information they need to do so and how people with dementia can best be supported. This newly discovered knowledge means that clinicians and policymakers will be better equipped to support people with dementia and (through the development of policies) promote change in the way that people with dementia are viewed by others. Empowering people with dementia with the information they need to come to terms with their diagnosis, and to live a life that is meaningful to them, with support from their care partner and health professionals as required, is paramount to helping the person sustain their quality of life.

3.2 Study 2 (Qualitative Component)

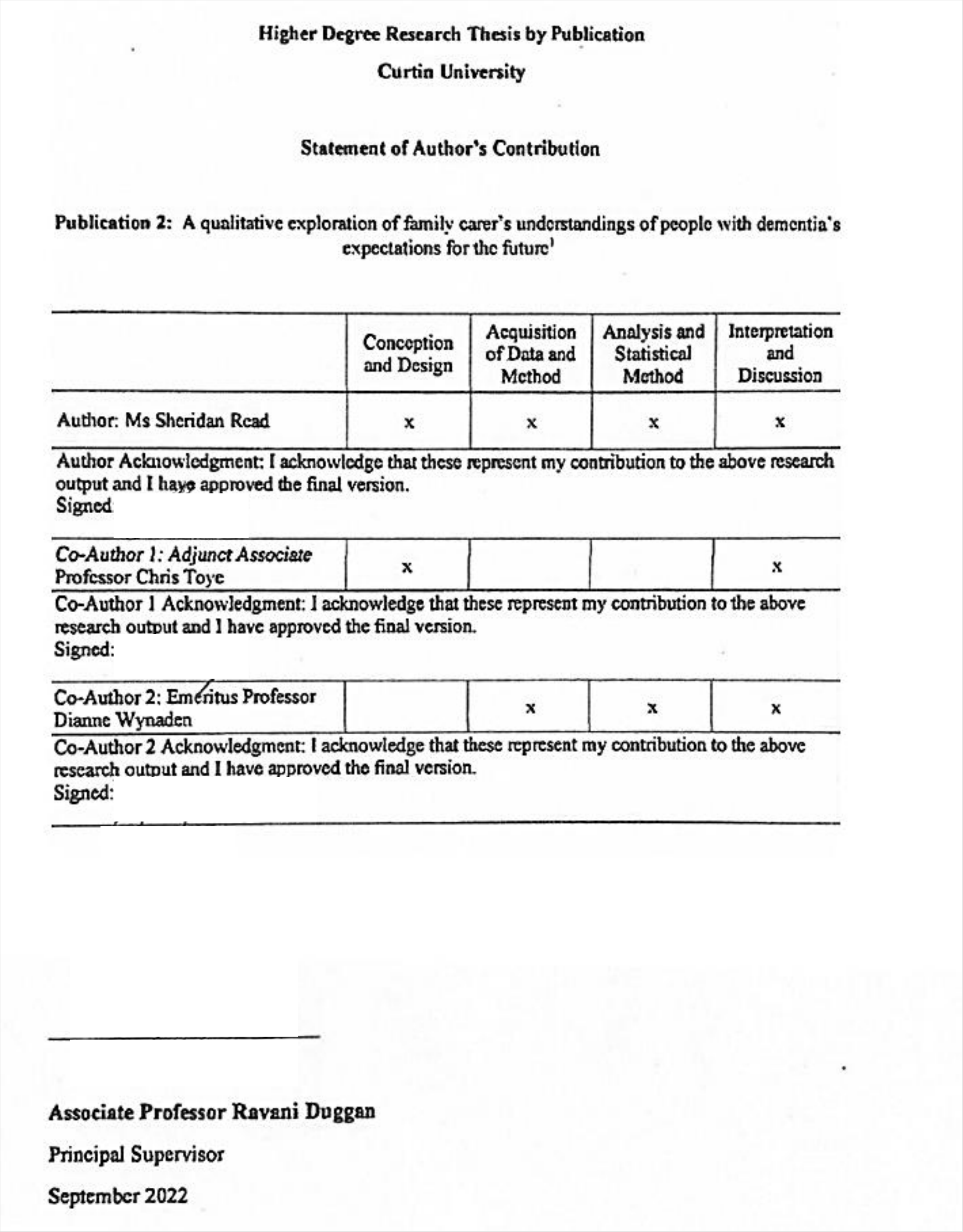
In Study 2, the perspectives of care partners were explored using semi-structured interviews. Specifically, care partners were asked to talk about their understanding of the person with dementia's future expectations and, as such, their preparedness to take on the role of advocate for the person living with the condition when the person could no longer make decisions or speak for themselves.

Traditionally, care partners were referred to as 'family carer' or 'carer' and represented a family member or some other close contact who supported the person with dementia and assumed their decision-making and assisted them with daily living. Within the published papers included in this thesis, the term family carer was used as this was the terminology understood at the time of publication. However, the use of this terminology was at that stage on the cusp of change, aligned with the paradigm shift as detailed in Chapter 1, in how people with dementia are viewed and best supported. The emphasis has now moved to that of a care partnership, reflecting the changing power dynamic, with the preferred terminology of 'care partner' (Bennett et al., 2017). The progressive nature of cognitive decline related to dementia means that the person with dementia has a gradually increasing need for support to sustain their independence as their dementia progresses (Fetherstonhaugh et al., 2013; Samsi & Manthorpe, 2013). The notion of the care partner is one where a family member or significant other assumes primary responsibility for assisting the person with dementia to maintain their well-being, taking into consideration the person's desire for continued independence and supporting the person as required (Bennett et al., 2017).

Qualitative interviews allowed the researcher to capture the experiences of care partners which to date had been relatively unexplored, particularly within this changing context of dementia caregiving. Care partners identified a lack of knowledge or situations that were beyond their control, which often inhibited their capacity to support or advocate for the person living with dementia effectively. Publication 2 “A qualitative exploration of family carer’s understanding of people with dementia’s expectations for the future” provides the detail of these findings and is now presented.

Publication 2 – A Qualitative Exploration of Family Carer's Understandings of People with Dementia's Expectations for the Future

Statement of Author's Contribution



Higher Degree Research Thesis by Publication

Curtin University

Statement of Author's Contribution

Publication 2: A qualitative exploration of family carer's understandings of people with dementia's expectations for the future[1]

	Conception and Design	Acquisition of Data and Method	Analysis and Statistical Method	Interpretation and Discussion
Author: Ms Sheridan Read	x	x	x	x
Author Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed				
Co-Author 1: Adjunct Associate Professor Chris Toye	x			x
Co-Author 1 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 2: Emeritus Professor Dianne Wynaden		x	x	x
Co-Author 2 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				

Associate Professor Ravani Duggan

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September 2022

Permission to include this article in this thesis has been obtained from the publisher (Appendix L).

Article

Dementia
0(0) 1–16
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A qualitative exploration of family carer's understandings of people with dementia's expectations for the future

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Abstract

Background: There is little evidence that outlines how family carers understand the person with dementia's perspective, values and anticipated future needs. Whilst people with dementia should be consulted about their own quality of life and care values, carers – otherwise known as care partners – require such understandings to ensure that the support the person receives into the future upholds their quality of life and is consistent with what they desire.

Aim: This research aimed to explore and describe family carers' experience of supporting the person with dementia to maintain their quality of life by understanding how carers developed an awareness and understanding of the person with dementia's expectations for the future and what they believed was important for the person to whom they provided care.

Method: Using an application of the grounded theory method, data were collected from 21 carers during semi structured interviews and analysed using constant comparative analysis.

Findings: Four categories emerged from the data: Knowing the person, Process of decision making, Maintaining normalcy and quality of life and Out of their control.

Discussion: This study provides insights into how carers developed awareness of the expectations of people with dementia. Findings also illuminate carers' perspectives of the changing nature of decision making during the dementia trajectory.

Conclusion: Understanding the perspective of the person living with dementia is essential to facilitate advocacy and support that is 'person centred' now and into the future. Assisting carers to incorporate this perspective into caring has the potential to be better facilitated by health professionals and merits further investigation.

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Keywords
dementia, carer, advocacy, quality of life, qualitative research, care partner

Introduction and background

Dementia is a syndrome estimated to affect more than 46.8 million people worldwide, with that number predicted to reach 131.5 million by the year 2050 (Alzheimer's Disease International, 2016; de Boer et al., 2012). In Australia, dementia is the second leading cause of death and, in 2017, an estimated 413,106 people were living with the condition (Brown et al., 2017). In 2016, the cost of dementia to the community was $14.25 billion. This amount includes indirect costs such as those related to the carer experience (Brown et al., 2017). Carers are people who provide support, which is usually unpaid, to a friend or family member living with dementia (Bennett et al., 2017). In the process of providing such support, carers may experience loss of income, emotional distress and social exclusion (Brown et al., 2017). As dementia progresses, it impacts upon decision making capacity because of a decline in cognitive function and impaired judgement, plus a reduced ability to reason and retain information (Samsi & Manthorpe, 2013). Despite this limitation, people with dementia still wish to maintain control of their lifestyle by upholding their quality of life and decision making autonomy for as long as possible (Dening et al., 2013; Karel et al., 2007; Read et al., 2017). Whilst people with dementia should be consulted about their quality of life and future expectations, at some stage it is likely that family carers will become the person with dementia's proxy decision maker (Banerjee et al., 2007; Dening et al., 2013; Karel et al., 2007; Samsi & Manthorpe, 2013).

A person's ability to maintain their quality of life and live well after receiving a diagnosis of dementia is dependent upon the knowledge and understanding of health professionals and the level of post diagnostic support they and their carer are offered. People diagnosed with dementia report that their ability to live well with dementia can be limited when health professionals state that there is little that can be done given the degenerative nature of the condition (Read et al., 2017; Swaffer, 2014, 2018). However, internationally, consumer advocacy groups are now actively promoting the rights of people living with dementia. This stance is supported by the World Health Organisation which promotes a human rights based approach for people living with dementia and outlines their right to independence and decision making autonomy as well as equal access to public spaces and services (UN General Assembly, 2007; World Health Organisation, 2017).

The shift to living well with dementia and maintaining a good quality of life has broad implications for those diagnosed and for their families (Swaffer, 2018; World Health Organisation, 2017). People with dementia express a desire to participate in research to articulate their lived experience, expectations for the future, and their desire to remain independent for as long as possible (Chang et al., 2015; Harris & Keady, 2009; Karel et al., 2007; Miranda-Castillo et al., 2013; Read et al., 2017; Roach & Drummond, 2014). In response, supported decision making policy guidelines in Australia outline how health professionals and carers can assist people with dementia to maintain their decision making autonomy as their level of cognition declines (Cognitive Decline Partnership Centre, 2018; Fetherstonhaugh et al., 2017; Reamy et al., 2011; Samsi & Manthorpe, 2013). Such an approach may empower people with dementia to maintain control over their lives for a longer period as they can take an active role in voicing their choice of support and services for a longer period.

Perceptions within the general population that people with dementia lack the capacity to make decisions or maintain their independence can predetermine how a carer relates to the person and views their caring role (Benbow & Jolley, 2012). However, such perceptions are challenged by the increasingly espoused view that people with dementia merit support to remain an equal partner in decision making and help identify what is needed to maintain their quality of life for as long as possible (Bennett et al., 2017; Dupuis et al., 2012; Piersol et al., 2016). For example, they should be encouraged to appoint a proxy decision maker at the time of diagnosis and explain their wishes in preparation for when their ability to make decisions is diminished. Carers have, at times, indicated that they feel ill prepared to serve as a person's proxy and struggle with decision making on their behalf, which highlights the importance of people with dementia from the time of diagnosis actively planning for their future and communicating their future expectations to carers so they are able to advocate accurately on their behalf when they need to (Poole et al., 2018).

The caregiving literature has focused on the area of carer burden and carers' experiences of supporting a person with dementia (de la Cuesta-Benjumea, 2011; Martin et al., 2011; Pittalis et al., 2017; Sutcliffe et al., 2016). There is some evidence on how the perspectives of the person with dementia differ to those of their carer on what might be important to the person following their diagnosis (Hill et al., 2017; Poole et al., 2018; Reamy et al., 2011). However, there is limited evidence on how carers understand the person with dementia's perspective, values and what the person diagnosed believes will be their future needs (i.e., their expectations; Ashton et al., 2011; Fetherstonhaugh et al., 2017). Exploring this topic is vital to facilitate support for carers to help ensure that the care the person with dementia receives is consistent with what they desire. This article reports the findings of research conducted to explore and describe family carers' experience of supporting the person with dementia to maintain their quality of life, by understanding how carers developed an awareness and understanding of the person with dementia's expectations for the future and what they believed was important for the person to whom they provided care.

Methodology

This research, completed in Western Australia, utilised an application of the Grounded Theory (GT) method developed by Glaser and Strauss (1967) to guide data collection, sampling methods, analysis and emergence of categories from the data to tell participants' stories. GT was chosen as it focuses on the social and psychological context of the phenomenon under investigation which (to date), remains relatively unexplored. The role of the researcher is to conceptualise and provide a description of the phenomena under study and then look to how concerns can be addressed. The researchers did not set out to develop a substantive theory but used the GT method to guide all stages of the research process. Approval to conduct the study was obtained from the Human Research Ethics Committee at Curtin University in Western Australia.

Sampling

Participants were recruited via dementia support groups for carers and through an advertisement about the research played over a community radio station. An information sheet detailing what the study was about and what was required of study participants was provided to people who had expressed interest in study participation. Potential study participants were asked to read the information and were provided with an opportunity to ask questions before signing a consent form signifying their agreement to participate. Purposeful sampling was initially used to recruit participants who met the general inclusion criteria for the study. These participants spoke English, were adults and cared for a family member diagnosed with dementia. All participants recruited using purposeful sampling were spouses caring for their partners. In line with the GT method, data collection and analysis occurred concurrently using the constant comparative method of analysis and, as categories began to emerge, theoretical sampling was employed to recruit participants who had different or more expansive experiences. For example, adult children who were carers were sought as they provided unique insights into the caring experience.

Data collection

Interviews were conducted between November 2016 and May 2017. The location in which the interview was conducted was chosen by the participant to ensure that they felt relaxed to share their experiences and insights (Macnee, 2004). A semi structured interview guide was used to ensure the format was consistent across interviews. Demographic data were also collected. The mean interview time was 48 minutes. Data collection ceased when saturation was reached, no new information was being obtained and the four identified categories were rich in participant descriptions (Macnee, 2004).

Data analysis

The constant comparative method of analysis that is central to the GT method was used to analyse each interview and compare data between all interviews. Data analysis moved the data from description to conceptualisation, to uncover the underlying meaning and the emergence of categories that described participants' experiences (Glaser, 2001). Using open coding each line of the interview was read and comparison of incident to incident and incident with developing concepts was made. Second level or theoretical coding was then utilised to explore the relationship between these concepts and developing categories. The third level of coding, selective coding then integrated and further refined the categories and assisted the researcher to make interpretations about participant experiences (Glaser, 2001). NVivo was used to assist in data management (Streubert & Carpenter, 2011). Four categories were identified that described participant experiences: Knowing the person, Process of decision making, Maintaining normalcy and quality of life and Out of their control.

Trustworthiness of data

The trustworthiness of data was ensured by adhering to the GT method as outlined by Glaser and Strauss (1967), researcher checks of the data and researcher consensus over the categories that emerged. The interview guide ensured all participants were asked similar questions. The findings were also compared to current knowledge in the area.

Results

Twenty-one people agreed to participate in this study and provided informed written consent. Fourteen carers, who were spouses of people with dementia were recruited using purposeful sampling, seven adult children were captured using theoretical sampling. Most participants were wives ($n = 11$), whilst husbands ($n = 3$), daughters ($n = 5$) and sons ($n = 2$) of people living with dementia also participated. Participants' ages ranged from 34 to 81 years. Fourteen family members lived with the person for whom they provided care. At the time of data collection, participants' experience of caring ranged from one to 17 years. The country of origin for most family carers was Australia ($n = 11$), the remainder came from the United Kingdom ($n = 5$), India ($n = 2$), New Zealand ($n = 1$), Canada ($n = 1$) and South Africa ($n = 1$). Nineteen participants had attended an education session about dementia and 13 participants knew of other people living with dementia. Participants' educational qualifications ranged from high school certification to doctoral degrees and their job status ranged from office workers and trades people to professionals.

Category 1: Knowing the person

Knowing the person consisted of three components: the duration of the relationship, communication within the relationship and the type of relationship. The importance of the duration of the relationship was raised frequently by study participants, the longer participants knew the person the greater the understanding they believed they had about the person with dementia's support needs and expectations into the future. One participant explained 'I mean we have been married 50 years, so we know each other backwards' (FC15).

Participants who had known the person they cared for over a long period spoke confidently about a range of lifestyle factors that were essential to ensuring the person's quality of life. Such factors impacted on the person with dementia's day-to-day activity: 'I know my mother very well, what food she likes and what music she likes, she doesn't really have to tell me all those things, I know what she likes and doesn't like' (FC08). Participants also spoke about having knowledge of what would affect the person's quality of life into the future such as their future preferred treatment options: 'We would both be in agreement that there was no point in just prolonging life. We can't see the point of just having somebody being tube fed and unconscious. He [participant husband] would agree with that' (FC12).

Communication within the relationship was another component of *Knowing the person* and related to how well the carer knew what was important to the person with dementia. The methods and frequency of communication within the relationship varied between participants. Some people reported that conversations about what was important to the person into the future did not occur at the time a diagnosis was made, nor had it been previously discussed: 'I know nothing about his [husband] expectations for the future, I don't even know if he has expectations. He hasn't spoken to me about his expectations, whether he's actually consciously thought about them, I don't know' (FC01). One spouse spoke about the difficulty in not having had those conversations:

> We should have sat down and talked about it before there was any of the Alzheimer's disease on the horizon. That would have been the easy time to do it because once her (wife) memory was impaired it became more difficult. (FC03)

Other participants chose to engage in conversations about the future with their family member with dementia at a time when they were conversing well and experiencing lucid moments: 'When he [husband] had a good moment it would be about three years ago'. I said to him 'What are we going to do about funerals?' (FC05). One daughter spoke about her father's reluctance to speak about what might happen in the future until he was very unwell in hospital:

> When he [father] was really sick [in hospital], we did have the odd lucid moment. He did sort of start talking about what happens after he dies and if we could take his ashes. He's never really talked more than that and he never wanted to engage in that kind of conversation. (FC16)

Some participants reported more frequent conversations about future expectations and for some, this was well before there were any signs of the presence of dementia: 'We've always discussed things, often we would camp out in the bush and just sit and talk' (FC11). One son commented about frequent: 'open discussions with the family' (FC09) about what his parents wanted into the future. Whilst some participants reported that they had conversed with each other about what was important for them into the future, few felt it necessary to ensure that what their family member wanted was also in writing. One spouse explained a conversation she had with her husband not long after he was diagnosed with dementia:

> "We need to put that in writing and get a health care directive done. We need to get our wills sorted out". At that stage he [husband] could still understand it enough to go to a solicitor and do that. (FC11)

The *type of relationship* the family carer had with the person was also an important consideration in how well they knew the person. Sons or daughters undertaking the caring role who did not live with their parent reported that they were not fully aware of their parents' situation, and therefore were not in the best position to assist them. One son caring for both his parents who had dementia spoke about them covering up their health problems so as to not concern the family. This meant that now he was not in a position to discuss things with his parents: 'Very often mum would say "We can't come, dad is not well" or ... "We just don't want to go". I think she realised dad wasn't coping and didn't want us to see dad's losing it' (FC09).

Category 2: The process of decision making.

The second category identified was the *process of decision making*. Throughout the interviews carers communicated the understanding that eventually the person they cared for would lose their decision making capacity and the process of decision making would change, meaning the person would be at greater risk of not being able to independently obtain their future needs. The process of decision making encompassed three components, *person with dementia's involvement*, the *family carer as decision maker,* and *extended family decision making.*

Carers spoke about the need to ensure that their family member was involved in decision making for as long as possible so they were able to maintain their independence and dignity. One carer explained:

> As [long as] he [husband] is capable he will be involved in any decisions we make. Eventually I'm going to have to make decisions without him but I want him to be part of the process. I can do

> it, but I don't think that gives him any dignity. I want him to maintain his dignity as much as possible. (FC06)

Another carer spoke about the need for her husband to go into residential care and how he was involved in that decision making process. Not only did this preserve the person's dignity and independence it also relieved some of that decision making burden for the carer.

> [Husband] was lucid enough to know what was going on and I sat down next to him and said "[husband] I've got something to say to you. It's up to you; you make the decision, [to go into residential care]. They've come up with this [room] in [the facility]; it's your own room". He said "Well I'm getting too much, my legs are getting worse. Phone them and say we'll take it". I said "Now you're absolutely sure?" "Yes", so he made the decision, but I still found it hard. (FC14)

Family carer as decision makers was the second component of the *Process of decision making.*

Participants spoke about how their role in decision making would become greater as eventually the person to whom they provided care for would experience further cognitive decline and loss of insight. One participant discussed upholding her husband's dignity by involving him in decision making for as long as possible but realised that eventually decision making would become more of her responsibility:

> [If] it gets to a stage where I can't shower him, I think the recognition that he's [husband] going to need help is gradually going to [go] down. He will [have to] accept that I can't [and] someone is going to come in and shower him. (FC06)

Participants discussed the need for *extended family decision making.* As a person lost their decision making capacity, participants talked about the need to unite family members when more complex decisions needed to be made, to ensure they were in the person's best interest and what they would have wanted. One daughter explained:

> You kind of have to go with your instinct and us as a family knowing who mum is. Fortunately things like clothes or haircuts, we've kind of just kept going with what she has had. When it came down to residential care and asking those really big questions, it was everyone together round the table, what do we think mum would have wanted?. (FC18)

Participants reported the need to unite family members when decisions needed to be made that may have gone against what the person would have wanted:

> It was important for both my sister and I to be there when we had that conversation so it wasn't sounding like I was putting him [dad] in a nursing home or she was pushing to put him in a nursing home. He [dad] would perceive it like that so we had to both be there unified. (FC16)

Participants discussed calling on additional family to help make difficult decisions they were not expecting to have to make and when they were not sure if the decision they were making was meeting the person's expectations:

> She [mother] was in the emergency ward overnight and the registrar asked me "How far do you want to go if she were to have a heart attack or something like that?" I wasn't expecting that sort

> of question and I said "Can I get back to you tomorrow?" I spoke to my brother and we both agreed that she could go. If she needs antibiotics or something fine, definitely not having tubes put down her neck (for tube feeding). (FC08)

Category 3: Maintaining normalcy and quality of life

Participants spoke about maintaining normalcy and quality of life in the context of helping the person with dementia to meet their needs. This category consisted of three components: independence and self-esteem, staying connected and maintaining physical and mental wellbeing.

Participants discussed the importance of helping the person with dementia to maintain their independence and self-esteem by encouraging them to contribute to their household roles even if they were not able to maintain their former standard in completing them. One spouse explained:

> She [wife] tries to do a bit of washing up but she just doesn't remember the hot water and detergent. She'll get a sponge and just wipe it around the dish and put it away when it's still got bits and pieces on it. When she goes to bed I end up having to wash them again. (FC03)

Other participants discussed maintaining independence in the context of introducing home modifications to help the person with dementia stay at home for longer without the need for assistance. Participants identified maintaining independence as a key element in upholding their family member's quality of life and put systems in place:

> What we ended up doing was providing more facilities in the house. We lowered the shower so mum could get in without having to take a step. We tried to provide all those things to help them [mum and dad]. They just refused to let anyone provide them with support. They were very independent. (FC09)

Maintaining normalcy and quality of life also encompassed a person with dementia to *stay connected* to what was important to them. Care partners identified the importance of their family member to maintain their connections and helped them to do this in a number of ways. One participant talked about ensuring that his wife stay connected to her social network of friends through book club:

> The ladies from the book club they know that she [wife] doesn't read the book, but you know she enjoys the chat. One (lady) she'd have known for more than 40 years. They keep a bit of an eye on her but they know she's not altogether [has dementia]. (FC03)

Participants talked about the person with dementia's strong desire to stay connected to their home. Some family carers discussed this in the context of them not wanting to go into a nursing home, 'Well she [mother] was not going into a home, she was categorical about that. This [her house] is her pride and joy you know she built [it on] her own personal wealth' (FC17).

Maintaining normalcy and quality of life also encompassed a carer assisting a person to *maintain their physical and mental health.* One carer talked about preserving health in the context of finding a cure or searching for alternative therapies to delay any further cognitive decline that his wife may experience:

> We've [tried] naturopathic stuff and whether that's helped we'll never know. I'll never die saying, "we should have done this, we could have done that. We even spoke to my doctor, [who was using] a rheumatic type drug [for people with dementia]. (FC15)

Participants identified the importance of advocating to other people on behalf of their family member with dementia to ensure that their needs were met. This may have been whilst they were unwell in hospital. One care partner spoke of the anxiety related disorientation her father experienced whilst he was in hospital:

> Sometimes [he will say] that he's [father] being poisoned or that they're going to hang him. His paranoia takes him in that direction. So I have to let the nurses know what he's thinking . . . and that he needs reassurance and they try and reassure him. He'll calm down a little bit, but not always. (FC16)

Similarly another participant talked about her role change to one of being an advocate after her mother moved to residential care to ensure that her mother's quality of life and day-to-day needs and wants were maintained: 'it then was just about educating others on what we knew of mum because she couldn't talk and say actually I like my hair done this way or I don't want to go to the church service on Sunday' (FC18).

A husband discussed advocating for his wife when out in public to preserve her dignity and address the stigma, with living with the condition:

> That is why I tell people so they can have a better understanding. I say look she is not stupid, she's got dementia, and she is a long way into it, so treat her with respect and if you don't get a response from her. It is not because she is stupid, or doesn't want to answer. (FC15)

Category 4: Out of their control

In this category, participants described a change in circumstance and consequently could no longer help the person to sustain their quality of life and live the life they wanted to lead. This category encompassed two aspects, *No longer possible* and *Not knowing*.

Carers described situations where they were not in a position to help the person with dementia meet their needs and wants as what they wanted was no longer possible. One participant spoke about her father's desire to remain living at home but now because of ill-health this had become no longer possible:

> He's [father] not capable of going home. He certainly wouldn't be able to live with us. If he would be well enough to go to a nursing home we could relocate him in a place that he would feel comfortable in. I know that whatever transition it would be rough because it's something that he didn't want. He probably would express agitation but it is out of [our] hands. We have to go with it. Dad has to go with it too. (FC16)

A son talked about his parents' need to stay together and his desire to try and reunite them but their deteriorating health had prevented this from happening:

> The important thing for them was to be together. [Dad would say] "When mum's gone, I do not want to live anymore". They never envisaged this plan. We weren't around when dad made his statement to the social worker when he said he couldn't cope with mum. The ideal solution for us would be for them to at least be together [but reuniting mum and dad] is only going to happen if dad loses his aggression. (FC09)

A daughter spoke about advocating for her mother's needs whilst she was resident in a nursing home as no longer possible: 'People don't take you seriously. It's like we're just family, we're not a doctor what would we know. Well actually we're talking about a person we know very well' (FC18).

The second component of *Out of their control* was *Not knowing*. Participants described the conversations they would have liked to have had with the person they cared for when they were more easily able to communicate their needs and wants. For carers, not knowing this information now made the caring and advocacy roles and upholding their quality of life more difficult as they did not know what the person would have wanted:

> Questions around palliative care because dad and I just have no idea and we've never discussed it with her [mother]. I have learned it is [important] to have those conversations. It then empowers the person. If mum had had that conversation with myself or dad I would then confidently be able to say we've done this in accordance to the discussion that we had. (FC18)

Another participant spoke about wanting further clarity about what was important to her father at the end of life:

> It would have been nice to sort out exactly what he [participant's father] wanted. We knew that he didn't want to go to a nursing home and if he died he wanted his ashes to be scattered with mum. He did make a list of things that we needed to do but really the list wasn't that complete. (FC16)

Discussion

This research aimed to explore and describe family carers' experience of supporting the person with dementia to maintain their quality of life, by understanding how carers' developed awareness and understanding of the person with dementia's expectations for the future and what they believed was important for the person to whom they provided care. The study was undertaken at a time when there was increasing recognition of the need to support preservation of the autonomy of people with dementia and when little investigation of carers' understanding of such perspectives had previously been undertaken (Cognitive Decline Partnership Centre, 2018; World Health Organisation, 2017). Preserving the autonomy of people with dementia (Keeling, 2016; Nicholson, 2017) changes the emphasis of the caring role, which has been further highlighted within this study, and builds on a small but existing body of knowledge into how family carers develop an awareness of the changing nature of decision making between the carer and the person with dementia, and the role of the carer as the condition progresses (Fetherstonhaugh et al., 2017; Miller et al., 2016; Samsi & Manthorpe, 2013).

Participants in this study reflected on what they needed to do to help sustain the person with dementia's quality of life, and supported them to maintain their independence and decision making. This finding aligns with literature that details what people with dementia desire to maintain their quality of life (Dening et al., 2013; Karel et al., 2007; Read et al., 2017; Roach & Drummond, 2014). Whilst those diagnosed with dementia, particularly when the diagnosis is recent, maintain capacity to be autonomous and take ownership of self-care requirements (Mountain & Craig, 2012; Toms et al., 2015), the support they require from their care partner gradually increases as their cognition declines (Bennett et al., 2017; Roberto et al., 2011).

Participants within the study identified that a long-standing relationship with the person to whom they provided care impacted significantly on their perception of what they felt was important to that person to sustain their quality of life, even if conversations about the person with dementia's future expectations had not taken place. Similarly, in Boyle's (2013) study, participants (spousal carers of people living with dementia) commented on the ease of decision making when they were in a long-standing marital relationship with the person receiving care. Despite a carer's perceived understanding of the person with dementia's future expectations carers are not always accurate in determining what a person with dementia feels they need or values most following their diagnosis (Miranda-Castillo et al., 2013; Reamy et al., 2011). Furthermore, the longevity of a relationship between carer and care recipient cannot guarantee a mutual understanding of the person with dementia's future expectations given the relationship strain that may develop as care needs increase (Miller et al., 2018; Sebern & Whitlatch, 2007). It is important to recognise that a person with dementia's perspective on what is important may change once diagnosed (Fetherstonhaugh et al., 2017; Fried et al., 2007). An ongoing dialogue between the care partner and person with dementia about future support requirements therefore needs to be encouraged for as long as is feasible.

Study participants discussed their changing role to that of an advocate as the person to whom they provided care lost their decision making ability, and this then became increasingly necessary as the person with dementia transitioned into long term care. Katz et al. (2013) reported that carers often advocate for their family member's need for cognitive stimulation in residential care environments. Staff communication with family as the person transitions into long-term care becomes critical, as families have the information regarding the person's future expectations and are able to advocate for what they need. Family carers and the wider family network are the experts in knowing the person and health professionals need to rely on this partnership so they can effectively meet the person with dementia's needs (Benbow, 2012).

Few participants within this study reported that their family member living with dementia had advised of their end of life wishes or implemented advance care planning (de Boer et al., 2012). Implementing advance care plans helps to preserve the autonomy of the person diagnosed and their quality of life at the end of their life when they can no longer inform the care partner what they require (Bennett et al., 2017; Roberto et al., 2011). Advance care planning may reduce the burden felt by care partners who are then more easily able to become their advocate as the person's needs and wants have been formally discussed and documented (Ashton et al., 2016). These findings are transferable to other life limiting conditions, such as cancer, where there is a need for advance care planning as people experience a loss of ability to communicate and diminished decision making capacity (Sizoo et al., 2012).

In summary, this study has highlighted the changing nature of the carer role, as a person with dementia moves from maintained capacity for independence to a gradual need for support to ensure their needs are met. This changing nature of the carer role supports the need to review how the role is conceptualised, and use of terminology surrounding the culture of support that is offered to people with dementia. For example, use of the term carer implies that a person is a passive recipient of care which may fail to align with a person with dementia's desire for independence. The shift to the term 'care partner' however, implies that a person diagnosed does have some capacity for independence, does not always need a carer to meet their needs and signifies that care is shared (Bennett et al., 2017). The new focus on care partnership requires implementation of strategies by the care partner to support a person with dementia's decision making, enhance their independence and strengthen their involvement within the care partnership (Cognitive Decline Partnership Centre, 2018; Landau et al., 2010; Murphy & Oliver, 2013). First however, care partners' need to understand the person with dementia's desire for autonomy and capacity to make decisions and implement choices without risk of harm (Greener et al., 2012; McCormack, 2001; Samsi & Manthorpe, 2013). A care partner's perception of autonomy, and ability to assist the person with dementia to maintain their independence may be influenced by their relationship with the person and any conflicting views they may have with extended family members who are called upon to assist (Berry et al., 2015; Miller et al., 2018). Furthermore, care partners' perception of autonomy may be enhanced with access to health professional support and information regarding the implementation of supportive strategies (Landau et al., 2010; Murphy & Oliver, 2013).

Conclusion

Dementia is a complex syndrome that impacts upon people's decision making capacity. At some point a person with dementia will require a proxy decision maker to make decisions on their behalf. Involving the person with dementia in decision making surrounding the planning of their future expectations is critical to upholding their quality of life. This article provides insight into care partners' understanding of people with dementia's future expectations and highlights the challenge of preserving the autonomy of people with dementia and implementing appropriate advocacy on their behalf. To address this challenge, support tailored to the individual context of caregiving is required to help ensure that the perspective of the person with dementia is both understood and acted upon.

Acknowledgement

The author would like to acknowledge the 21 participants who provided consent and agreed to be interviewed for this study and spoke openly of their experiences.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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3.2.1 Summary

This study uncovered care partners' understandings of the person with dementia's future care and support expectations and what they believed was important for the person living with the condition to help sustain their quality of life. Again, as this is a relatively unexplored area study findings provide a unique contribution to the body of literature about these phenomena. Furthermore, the methodology employed meant that in-depth study findings of the psychological and social issues relevant to the care partner's experience were revealed. The relationship a person with dementia had with their care partner and how decisions were made within that relationship were significant factors in the care partner being able to ascertain the person with dementia's future expectations and, as such, to help preserve the autonomy of the person with dementia into their future. Unveiling the care partner's understanding of the person with dementia's future expectations, within the context of the evolving care partner role, is critical as it helps to inform policymakers, educators, and clinicians about how care partners can best be supported to assist the person with dementia to sustain their independence.

3.3 Discussion of Qualitative Component Findings

The evolution of the dementia-related paradigms of support for people with dementia from the medical model approach (Shah & Mountain, 2007) still used today (Foster, 2019), to one where the human rights of people with dementia are considered to be of primary importance (World Health Organisation, 2017) is indicative of the transformative world view as described in Chapter 1. This increased awareness of the human rights-focused approach in the support of people with dementia reflects their desire to stay connected to their pre-diagnosis lifestyle, be independent and remain in control of decision-making regarding how they wish to live their lives (Swaffer, 2015). Study 1 and 2 findings unveiled the impact of stigma, and the importance of relationships in ensuring the well-being of the person with dementia. A lack of knowledge as to what the future might hold was evident for both the person with dementia and their care partner and consequently made planning for the future difficult. These findings are considered in more detail within the following section and recommendations for change are highlighted.

Stigmatising beliefs within the community around what it is like to live with dementia greatly impacts the capacity of people living with the condition to live well (Gove et al., 2016). The degenerative nature of dementia means that people with dementia may be seen as completely dependent on others and therefore childlike but this is not necessarily so (Edvardsson et al., 2008; Gerritsen et al., 2018). Study 1 participants (people living with dementia) revealed that health professionals failed to direct questions to them believing that they lacked the capacity to respond. The attitudes and approaches that health professionals have toward people with dementia influence these individuals' ability to realistically consider the trajectory of their condition, their support needs, and the resources at their disposal to enable functioning and planning for the future. Health professionals can shape how care partners and the community, in general, perceive and respond to people with dementia. Hence it is important that health professionals across all levels of care have appropriate knowledge about dementia and contemporary approaches to care, and an understanding of how their attitudes and roles shape how people with dementia visualise their futures and how these individuals are perceived by others. The experience of stigma was also voiced by care partners (Study 2 participants) who spoke of observing negative reactions from family and friends during interactions with the person with dementia. Combatting dementia-related stigma extends from policy developers and community organisations who advocate on behalf of this cohort of people to members of the community. Reducing stigma is critical to changing the way people with dementia are viewed by others in the community and to upholding their human rights and promoting their social inclusion (World Health Organisation, 2017).

The relationship between a person with dementia and their care partner was a significant factor in Studies 1 and 2, in helping a person with dementia to sustain their quality of life, with similar findings reported by Boyle (2013). The outcome of Study 1 identified that most participants with dementia desired to find meaning in their lives following their diagnosis. They sought ways to overcome the loss of control that they experienced, to uphold their different societal roles, remain socially included, participate in decision-making and, as such, maintain a sense of normalcy within their lives. Similarly, care partner participants within Study 2 appeared to instinctively assist the person with dementia to continue with their pre-diagnosis lifestyle for as long as possible. The intimate relationship that most care partners had with the person with dementia meant they were easily able to assist the person meet their needs within the context of their cognitive decline. These study findings indicate the need for dementia-specific services that provide a sense of normalcy for the person with dementia and their care partner. An example of such a service is dementia cafes which provide a social connection for people with dementia and their care partner, in a community space, to address the common feelings of isolation experienced as a result of a dementia diagnosis. Attendance at such cafés provides people living with the condition and their care partners a safe, non-judgemental environment in which to interact with others in a similar situation to theirs over a cup of coffee or tea, or lunch. They can receive and provide peer support through engaging with other attendees and sharing their day-to-day experiences. Café attendees learn from each other, and experience an enhanced ability to cope, reduced stress, sustained well-being and social health, and an enriched relationship (Innes et al., 2021).

Findings from Study 1 and Study 2 revealed that the relationship with the health care professional was important for both the person with dementia and their care partner. People with dementia participating in the study were dependent on health care professionals for information regarding what a future dementia trajectory might entail so they could engage in future decision-making. Study 1 participants disclosed that they failed to receive such information and, as a result, could not make their care and support needs known to their care partners. This in turn made care partners' attempts to advocate more difficult. Care partners, when aware of the person with dementia's care and support requirements, revealed a desire to connect with the health professional so they could inform them of the needs and wants of the person living with the condition when that person could no longer advocate for themselves. This three-way relationship between the person with dementia, their care partner and health professionals forms a dementia care triad. Effective communication between the three members of the dementia care triad results in improved health care outcomes for the person who is diagnosed and decreases care partner burden (Adams & Gardiner, 2005; Jensen & Inker, 2015; Johnsson et al., 2019; Shelton et al., 2019; Tuijt et al., 2021).

To make appropriate decisions, accurate and adequate information is required. Most study participants with dementia expressed a desire to remain connected to their pre-diagnosis lifestyle which included control of decision-making (Fetherstonhaugh et al., 2013). Yet these participants recognised that some decision-making might eventually need to be handed over to others. Care partners participating in the study also realised that they would one day need to take on an advocacy role (Samsi & Manthorpe, 2013). Therefore, both people with dementia and their care partners required effective access to relevant information to enable planning for the future. However, participants with dementia (Study 1) revealed feeling uncertain about their future. This knowledge deficit about what the future may entail for people with dementia had a flow-on effect on their care partner. The person with dementia was unable to determine what their future support needs were likely to be and, therefore, was unable to discuss these with their care partner. Similar to findings reported by Fetherstonhaugh, McAuliffe, et al. (2019), decision-making by the care partner on behalf of the person with dementia became problematic when they had to make decisions that did not align with the person’s wishes. Within Study 2, care partner participants disclosed situations that were out of their control and decisions being made often to uphold the person’s safety and the safety of others that were contrary to what the person wanted (Read et al., 2020). For the most part, participants within Study 1 reported in this thesis did not disclose an awareness that care partners may make decisions on their behalf contrary to their wishes.

These findings raise the question of why people with dementia do not receive information from their health care professional about the likely dementia trajectory, so they can participate in the planning of their care and support. Health professionals are required to empower people with dementia by providing information necessary for their continued involvement in their care planning, from diagnosis through to the end of life. The ability of people living with the condition to make decisions about their future promotes their autonomy and aligns with the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the World Health Organisation's (2017) global action plan on the public health response to dementia. Consequently, the recommendations for change that follow are likely to be helpful.

3.3.1. Recommendations for change

Firstly, overcoming the dementia-related stigma that exists within the community is essential to improving people's attitudes towards people with dementia. Stigma may impact health professionals' willingness to diagnose dementia early. Gove et al. (2016) reported that general practitioners tend to stereotype people with dementia as people who experience little quality of life and appear unaware that people with dementia can live well, at least for a time-limited period. An early diagnosis is imperative so that the person with dementia can seek information and plan for their future while their cognitive capacity remains. Consequently, government funding directed towards community organisations, such as Dementia Australia and Alzheimer's WA (Western Australia), that would allow them to create campaigns aimed at combatting dementia-related stigma is critical. Such campaigns include advertisements in the media and dementia awareness-raising forums that promote what it means to live well with dementia.

Secondly, health professionals' beliefs about a person with dementia's lack of decision-making capacity, or nihilistic attitudes that little can be done once a person is diagnosed, need to be overcome (Bacsu et al., 2020; Gove et al., 2015). The role of the health professional in assisting a person with dementia and their care partner to adjust to change that comes with a dementia diagnosis, improve their health literacy and identify strategies, such as the implementation of advance care planning to sustain their well-being over the long term, is critical (Piers et al., 2018). The disclosure of such detail by the health professional is recommended in the Australian Clinical Practice Guidelines for Health Professionals (Guideline Adaption Committee, 2016).

Thirdly, education and training to assist health professionals to understand what it means to live well with dementia and develop their capacity to engage in dyadic counselling with the person with dementia and their care partner are paramount. Dyadic counselling is a process of support provided to the person with dementia and their care partner. It helps the person diagnosed to participate in their care and support planning, facilitates effective communication between the person with dementia and their care partner, increases their awareness of available services and provides support in managing the day-to-day effects of the diagnosis (Whitlatch et al., 2006). Dyadic counselling will help ensure that the quality of life of the person living with the condition and their care partner is upheld, enabling their ability to plan for their future (Tsolaki et al., 2010).

Fourthly, research examining the perspectives of health professionals involved in the diagnosis process is essential. Such exploration will enable an understanding from the health professionals' perspective of how they liaise with the person with dementia and their care partner during and after the diagnosis process. It will also help to reveal health professionals' understanding of the needs of people with dementia and highlight the difficulties health professionals might face when supporting this cohort of care recipients. This evidence is necessary to inform further development in the area of advance care planning to assist people diagnosed with dementia to maintain independence and quality of life as practicable.

The World Health Organisation's (2017) global action plan on the public health response to dementia aims to address stigma and guide communities in improving the lives of people living with dementia. It states that people with dementia should receive care that aligns with their wishes and outlines the need for a person-centred system of support that includes long-term care. Attitudes to dementia and in particular stigma are barriers to people with dementia who are seeking support and planning for the future (Alzheimer's Disease International, 2019). Changing people's attitudes to dementia and identifying the degree to which people diagnosed are offered opportunities to be involved in the planning of their ongoing care and support is therefore critical. Findings from Study 1 and Study 2, reported in this thesis, indicated a paucity of opportunities for people with dementia and their care partners to engage in such planning. This pointed to the need for a review of existing evidence related to the perspective of people with dementia in the planning of their care and support with service providers, as the next step in the exploratory sequential mixed-method design used in the study reported in this thesis. This further evidence was sought during the conduct of an integrative literature review that is described in the following chapter of this thesis. Identifying such information helped to establish the degree to which people with dementia are involved in their care and support planning and whether services are conducive to meeting their needs, informing practice change in service development as required. The review was conducted to identify, critique, and synthesise relevant research findings that explored the degree to which people with dementia are involved in their care and support planning, helping to sustain their autonomy into the future.

3.4 Conclusion

Qualitative studies 1 and 2 used an application of the grounded theory methodology to uncover the experiences and expectations of people with dementia and care partners' understandings of these phenomena. In Study 1 participants with dementia disclosed the experience of loss and sought ways to find meaning and overcome the loss that they experienced. In Study 2 the significance of the relationship between the care partner and the person with dementia was highlighted as a key factor in the care partner's capacity to identify the person's expectations and long-term support needs. Both, people with dementia and care partners lacked knowledge about the potential dementia trajectory the person might encounter which led to difficulties in planning for the future. People with dementia need information about the potential dementia trajectory so they can then participate in the planning of their care and support, upholding their fundamental human right to remain central to decisions that concern them. Health professionals play an integral role in partnering with people with dementia and their care partners and providing appropriate resources and support to assist them with planning and living positively with dementia for as long as possible. Chapter 4 that follows presents the integrative literature review that was conducted as part of the study reported in this thesis. It details Publication 3, titled: "The participation of people with dementia in the planning of their care and support: An integrative literature review". This chapter also expands on the methodology used to undertake the integrative literature review in addition to presenting its findings.

Chapter 4

Integrative Literature Review

Chapter 4 presents an integrative literature review completed to compare the findings of Study 1 with existing literature that examined the experiences of people living with dementia. Evident within Study 1 findings was that participants (people living with dementia) identified that they were not engaged by their health professionals to consider their future. The integrative literature review (Objective 3) was therefore conducted to identify what was currently known about the participation of people with dementia in the planning of their care and support. The integrative literature review is presented as Publication 3 and has been published in the peer-reviewed journal ‘Dementia’. Authorisation was granted by the editor of the journal for the article to be included in this thesis in its published format (Appendix M).

The integrative literature review was conducted in the context of the evolving dementia care paradigm that has seen a shift from the strong focus on the medical model of support toward a more person-centred human rights-focused approach (United Nations, 2006). The latter approach advocates that the lived experience of people with dementia be used to inform health care policy, and care and support strategies. As such, the integrated literature review reported in this thesis only incorporated studies where people with dementia were included as research participants so that a true reflection of their perspectives could be obtained. Due to the increasing prevalence of dementia worldwide and the widespread care paradigm shift evident globally, it was also important to access the international literature as part of this integrative literature review. The researcher was able to compare the findings of the integrated literature review with those from Study 1 and Study 2, which identified an experience of unwillingness by health professionals to engage the person with dementia in the planning of their ongoing care and support. This had a flow-on effect to their care partners who felt uninformed about future care and support preferences and unable to effectively advocate for the person living with the condition.

4.1 Literature Review Method

There are several literature review methods that a researcher can undertake to help facilitate evidence-based practice in health care. Such reviews include narrative reviews, integrative reviews, scoping reviews, concept analyses, realist reviews and systematic reviews (Coughlan et al., 2013). Conducting a literature review is essential to identify and summarise sources of information about a phenomenon (Liberati et al., 2009; Moher et al., 2009). Identifying the type of review to undertake is important as while all literature review methods share certain characteristics, such as collecting and analysing information on a topic, they have different qualities that require consideration (Coughlan et al., 2013).

A narrative review aims to identify and interpret information on a chosen topic (Coughlan et al., 2013). While this is similar to all literature review methods, the process in which a narrative review is undertaken is less rigid and the topic under review may be either broad in nature or more specific (Ferrari, 2015). This process aligns with the characteristics of a scoping review which, similarly, is non-systematic in how it is conducted, but, in contrast, may involve stakeholder consultation (Anderson et al., 2008; Coughlan et al., 2013). Scoping reviews are descriptive in nature, and do not involve quality appraisal of the evidence presented or recommend those interventions which are proved most effective (Coughlan et al., 2013).

A concept analysis is a review method whereby concepts of interest relevant to a phenomenon are examined with the aim of developing further clarification of the concept’s meaning (Cronin et al., 2010). Comparable to other research review methods, a clear search strategy is required but, in contrast, a multitude of sources can be accessed including, but not limited to, dictionaries and the media, resulting in large amounts of data being obtained. The review process involves analysis and synthesis of the literature but, unlike other review methods, an exemplar is created to demonstrate the newly defined concept (Coughlan et al., 2013).

Realist review methods are an alternative review methodology employed to explore complex interventions and their theories, with the aim of identifying why an intervention worked or did not work (Pawson et al., 2005). A realist review begins with the identification of a review question but unlike other review methods, such as a systematic review, this is not fixed, and additional questions may arise as data is analysed. Systematic reviews differ in that their method is precise and replicable by others, ensuring consistency and transparency. Studies that are eligible for inclusion within a systematic review are identified before the review has begun and only those studies that are assessed as high quality are included. Findings from the studies are analysed and the strength of the evidence is determined (Coughlan et al., 2013).

An integrative literature review was conducted as part of the research reported in this thesis given that this type of review methodology may be broad in scope, pulls together past research, draws a conclusion about the chosen topic and reframes the way people think about a specific issue within health care, leading to changes within policy and practice (Torraco, 2005; Whittemore & Knafl, 2005). Similar to systematic reviews, integrative reviews are rigorous in their approach and as in the case of concept analyses, literature obtained as part of the review is not solely from empirical research and, can include theoretical and conceptual literature along with studies that employ varying research methodologies (Coughlan et al., 2013; Whittemore & Knafl, 2005). Each article obtained as part of an integrative review undergoes a quality appraisal and comparison despite the complexities that come when diverse sources of literature are included as part of the review. Conducting an integrative literature review as part of this research was necessary given that exploring what was known about the participation of people with dementia in the planning of their care and support required the researcher to conduct a broad search of the literature and draw on studies that employed diverse methodologies. Whilst conducting an integrative literature review can include grey literature the researcher was looking to identify the representativeness of people with dementia in the peer reviewed publication of research evidence to help the reader conceptualise this phenomenon, namely, people with dementia's participation in the planning of their care and support (Whittemore & Knafl, 2005).

4.2 Integrative Literature Review Methodology

Outlining strategies employed in conducting an integrative literature review is essential in establishing the rigour of the review process and the quality of the piece of work. Whittemore and Knafl (2005) have further developed the five-stage framework to establish the rigour of literature reviews originally formulated by Cooper (1998), highlighting the complexities of conducting an integrative literature review. The integrative literature review reported in this thesis was conducted according to the conceptualisation proffered by Whittemore and Knafl (2005) and was guided by their five stages. However, due to the limited number of papers retrieved as part of this review, there was reduced capacity to analyse the data and present the findings as suggested by Whittemore and Knafl (2005). Instead, the data were divided into sub-groups and themes during the analysis stage, with the presentation of findings and review conclusions detailed in narrative format throughout the published paper.

4.2.1 Problem identification stage

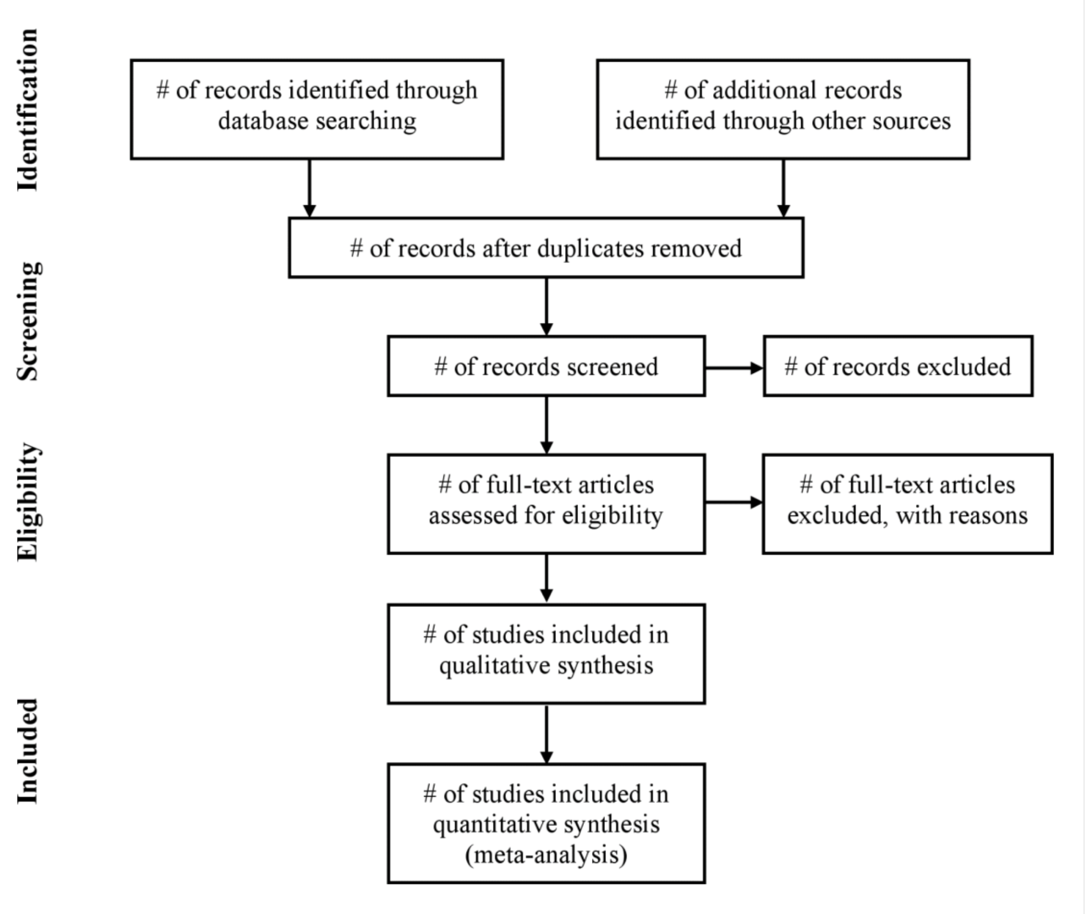
Before commencing any type of literature review, identification of the review purpose and problem to be addressed is required. Within the conduct of an integrative literature review, this should be done with clear focus and boundaries given that this type of review may encompass a number of issues and include studies that have employed diverse methodologies (Whittemore & Knafl, 2005). The integrative literature review reported in this thesis sought to explore what was known about the participation of people with dementia in the planning of their care and support throughout the dementia journey from their perspective. As the researchers (authors) were looking to solely establish the perspective of the person with dementia, studies that provided only observations of people with dementia, or other people's reports of choices, actions, perspectives, or opinions that they assumed to belong to a person with dementia, were excluded.

4.2.2 Literature search stage

A search strategy that is well defined is necessary to ensure the rigour of the review process (Conn & Rantz, 2003). In the conduct of an integrative literature review, the search strategy needs to be clearly documented (Conn et al., 2003; Jadad, 1998). The details of the search strategy and selection criteria used in the conduct of this literature review are provided in the published article included in this chapter. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method was used to report the process of conducting the review, organise the procedure of eliminating literature that did not meet the inclusion criteria, and provide a visual representation of the method. PRISMA consists of a 27-item checklist and a diagram (Figure 4.1) for authors to populate with information that details the papers retrieved as part of the review (Moher et al., 2009).

Figure 4.1

PRISMA flow diagram



Note. This figure details reporting items for systematic reviews and meta-analysis. From "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and T. P. Group, 2009, *PLoS Med*, *6*(7), p.3 (https://doi.org/10.1371/journal.pmed.1000097). CC BY-NC.

The literature search flow in the included article uses a PRISMA flow diagram (located on p. 695 of the published article) to document details of the retrieval, review and inclusion process of relevant literature for the integrative literature review reported in this thesis.

4.2.3 Data evaluation stage

Determining the quality of articles retrieved as part of an integrative review is complex given the diversity of sources that may be included. The quality appraisal of each article is dependent on the sampling frame. The use of multiple quality criteria instruments to determine the quality of each article may be required (Whittemore & Knafl, 2005). Within the review conducted as part of this thesis, the appropriate Critical Appraisal Skills Programme (CASP) checklists were employed to determine the quality of studies using either qualitative or quantitative research designs (CASP, 2014). The Mixed Methods Appraisal Tool (MMAT) was used to determine the methodological quality of mixed-method studies that were included (Pace et al., 2012). The assessment criteria of the tools included, but were not limited to, determining if the studies clearly outlined research aims and objectives, if data analysis was sufficiently rigorous and if the sampling strategy was adequate (CASP, 2014; Pace et al., 2012). The primary researcher and a member of the supervision team (CT) assessed the quality of each article using the tools. The strengths and weaknesses of each of the studies that were included are presented in the published article included in this chapter.

4.2.4 Data analysis stage

The process of data analysis within an integrative literature review should be systematic and iterative. Analysing the data involves allocating the data into subgroups (Tashakkori & Teddlie, 2016; Whittemore & Knafl, 2005). Within the integrative literature review conducted as part of this research, subgroups were formulated based on how people with dementia participated in the planning of their care and support. The data were then extracted based on what it meant for people with dementia to participate in their care and support planning, which facilitated the opportunity to compare data within the primary sources (Whittemore & Knafl, 2005). In comparing the data, themes were established that centred around what it meant for people with dementia to live well and what they wanted from services that assisted in the planning of their care and support. Such themes included sustaining health, independence, decision-making, and staying socially and meaningfully engaged. The final stage of data analysis is the synthesis of established themes integrated into a conclusion. The reader is then able to ascertain to a greater degree conceptual understanding of the phenomenon. The review conducted as part of this research unveiled three ways in which people with dementia participated in the planning of their care and support which indicated their desire for sustained self-determination. These were their participation by attending education programmes (Roberts & Silverio, 2009; Snyder et al., 2007), setting goals in cognitive rehabilitation therapy (Clare et al., 2011) and contributing to advance care planning (de Boer et al., 2012; Dening et al., 2013; Hilgeman et al., 2014; Karel et al., 2007). These approaches are discussed in detail in the publication of the integrative literature review included in this chapter.

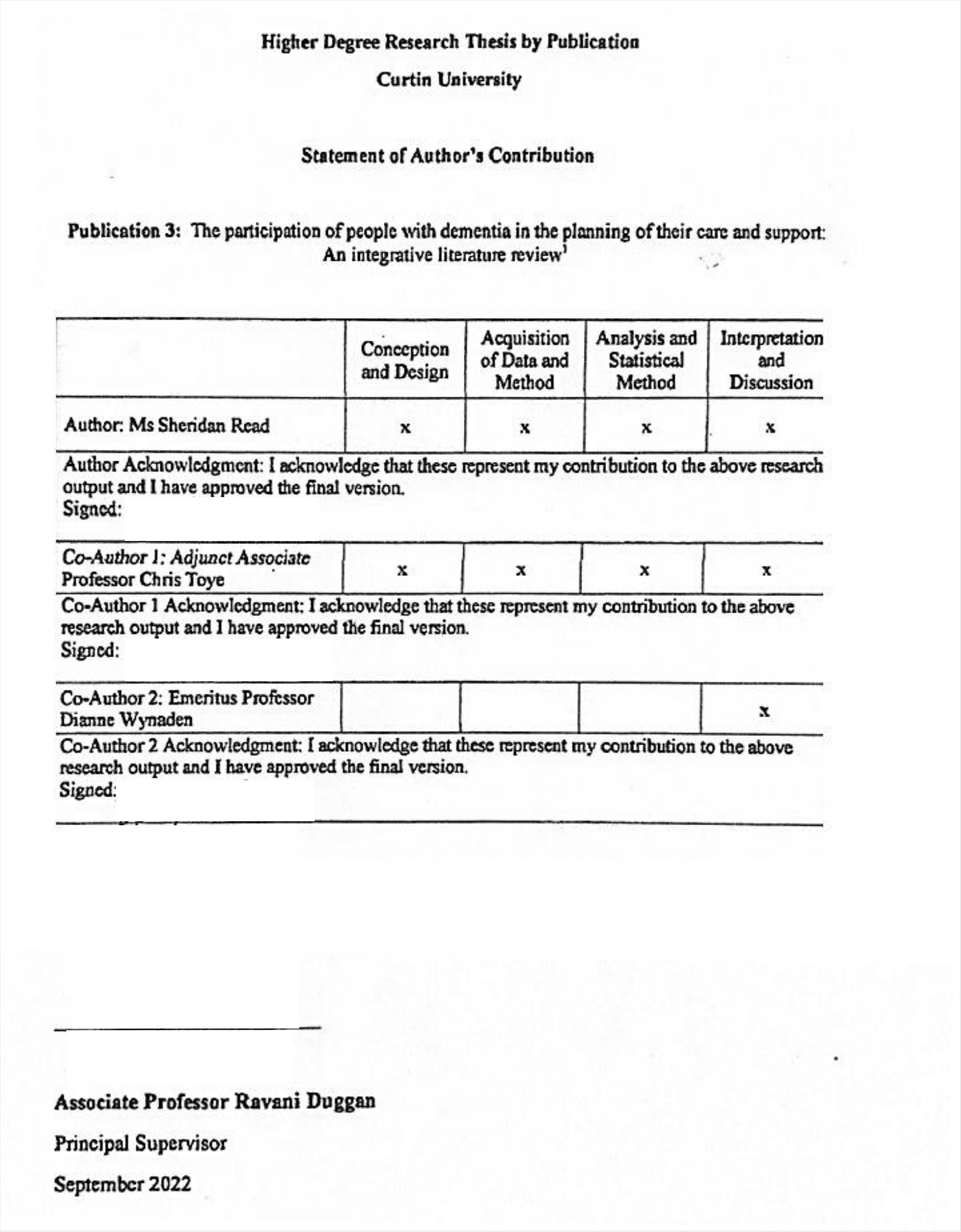
4.2.5 Presentation of findings

While Whittemore and Knafl (2005) suggest that the integrative review conclusions can be detailed in either a table or diagrammatic format, the limited number of papers retrieved as part of this review meant that the findings and conclusions could be presented in a narrative format, as indicated previously. Details from each of the primary sources are outlined in the presentation of findings within the published article which provides evidence to support the conclusions that were reached. The review was limited in that it included only studies published in peer-reviewed journals. Further reviews exploring this topic that also capture information within grey literature to further broaden the conceptual understanding of this topic are necessary. While the included studies assisted the authors to address the phenomenon under study, their methodological qualities varied. The presentation of findings is detailed in the following section which contains the integrative literature review as a published article:

> Publication 3 – 'The participation of people with dementia in the planning of their care and support: An integrative literature review'

Publication 3 – The Participation of People with Dementia in the Planning of their Care and Support: An Integrative Literature Review

Statement of Author's Contribution



Higher Degree Research Thesis by Publication

Curtin University

Statement of Author's Contribution

Publication 3: The participation of people with dementia in the planning of their care and support: An integrative literature review[1]

	Conception and Design	Acquisition of Data and Method	Analysis and Statistical Method	Interpretation and Discussion
Author: Ms Sheridan Read	x	x	x	x

Author Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version.
Signed:

Co-Author 1: Adjunct Associate Professor Chris Toye	x	x	x	x

Co-Author 1 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version.
Signed:

Co-Author 2: Emeritus Professor Dianne Wynaden				x

Co-Author 2 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version.
Signed:

Associate Professor Ravani Duggan
Principal Supervisor
September 2022

Permission to include this article in this thesis has been obtained from the publisher (Appendix M).

Article

Dementia
2020, Vol. 19(3) 691–707

DOI: 10.1177/1471301218784806
journals.sagepub.com/home/dem
SAGE

The participation of people with dementia in the planning of their care and support: An integrative literature review

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Abstract

Background: People with dementia continue to voice concerns that health professionals are reluctant to engage with them about the planning of their care and support. Instead, their perspective is that such plans are often made by others and fail to reflect their wishes.
Objective: This review aimed to examine investigations of the participation of people living with dementia in the planning of their care and support, when they have also provided study data.
Methods: An integrative literature review was conducted to identify, critique, and synthesise relevant research findings. Eight electronic databases were searched to identify peer reviewed journal articles that met inclusion criteria. In addition, reference lists of included articles were searched, and a subject expert was consulted about any possible omissions.
Results: From the 346 articles accessed, seven met inclusion criteria for review. The quality appraisal showed that one article reported only pilot data; several more reported small sample sizes; and, in two instances, there was a lack of information about the psychometric properties of data collection tools and about recruitment and attrition rates.
Conclusions: There has been limited investigation of the participation of people with dementia in the planning of their support when they have also contributed research data. Findings provide some evidence of their participation by attending education programme, setting goals in cognitive rehabilitation therapy and contributing to advance care planning.

Keywords
dementia, review, personal autonomy, decision making, advance care planning

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Introduction

The progressive nature of dementia, which is characterised by disturbances to memory, thinking and behaviour (World Health Organisation, 2012) means that, historically, this group of people has been regarded as having limited capacity for self-determination (Kitwood, 1997). However, there is now a growing body of evidence and pressure from consumer organisations that dismisses this historical stance as stigmatising and promotes the importance of people with dementia participating in planning their future care and support (Dementia Alliance International, 2016; Fetherstonhaugh, Tarzia, & Nay, 2013; McCabe & Bradley, 2012; Smebye, Kirkevold, & Engedal, 2012). Yet, despite this evidence, stigmatising attitudes prevail and people with dementia continue to voice concerns that health professionals remain reluctant to engage with them in this important process (Hamann et al., 2011; Miranda-Castillo, Woods, & Orrell, 2013).

The deteriorating cognitive capacity experienced by people with dementia means that there is limited time for them to understand their diagnosis and consider the future (Dening, Jones, & Sampson, 2011). Failure to facilitate the understanding and reflection of the person with dementia during this critical 'window of opportunity' means that other people, such as family carers, often become substitute decision makers. Family carers may be asked to take on this role prematurely to alleviate the decision making burden for the person with dementia (Whitlatch & Menne, 2009). Furthermore, substitute decision makers may lack knowledge and confidence and, as a result, make uninformed decisions that fail to reflect the needs and preferences of the person with dementia (Samsi & Manthorpe, 2013).

This article focuses on how people with dementia have been supported to participate in planning of their care and support, when they have also had the opportunity to contribute to research investigating this participation. Within the context of this article planning of care and support refers to how people with dementia have been consulted and engaged to maintain their physical, mental and social health now and into the future to sustain their independence and quality of life (Miranda-Castillo et al., 2013; Read, Toye, & Wynaden, 2016). Preservation of independence in this way means that the person's feelings of self-worth and control may be maintained for longer (Read et al., 2016) with increased decision making autonomy, coping ability and acceptance of the diagnosis (Menne, Tucke, Whitlatch, & Feinberg, 2008; Snyder, Jenkins, & Joosten, 2007).

Gill, White, and Cameron (2011) highlight the desire of people with dementia to participate in the development of services. Globally, there has been a shift in government health policies promoting increased consumer involvement in planning and development of support services (Department of Health and Ageing, 2012; Goodchild, 2009; Ministry of Health, 2013; Norwegian Ministry of Health and Care Services, 2015; Shih, Concannon, Liu, & Friedman, 2014). In Australia, in 2015, a Consumer Directed Care (CDC) service model was created to give people, including people with dementia aged over 65, more autonomy and control over their choice of services (Department of Health and Ageing, 2012). However, there remains little documented evidence regarding how satisfied people with dementia are with this CDC model or its implementation (Low & Fletcher, 2015). In the United Kingdom, Lakey and Saunders (2011) express fears that CDC is unachievable for people with dementia due to the complexity of accessing the system and the lack of support available.

A failure to consult people with dementia on the care and support required means they may lose control over their chosen lifestyle, a denial of their basic human rights

(Boyle, 2010). The United Nations Convention on the Rights of Persons with Disability (2006) is now being used to ensure that people with dementia have access to the same rights as the general population, such as rights to autonomy, independence, and freedom to make choices (Dementia Alliance International, 2016). This aligns with the citizenship approach whereby people with dementia are granted opportunities to interact and contribute to society (Marshall & Tibbs, 2006). There is also a move towards viewing dementia as a disability with health professionals using rehabilitation approaches to help people overcome the physical and social barriers that inhibit them from accessing care and support and maintaining their quality of life (Beard, Knauss, & Moyer, 2009).

The growing trend towards addressing the need for early diagnosis of dementia increases a person's access to support and advice (Prince, Bryce, & Ferri, 2011) plus their capacity to make decisions (Bronner, Perneczky, McCabe, Kurz, & Hamann, 2016); it also allows them to secure support to maintain their quality of life for longer (Read et al., 2016). To ensure that people with dementia are given every opportunity to preserve their autonomy by participating in care and support planning, a summary of investigation into current practice is required to inform plans for future research and practice in this area. A literature review was therefore completed to answer the question: 'What is known about the participation of people with dementia in the planning of their care and support throughout the dementia journey from their perspective?' The perspective of the person with dementia was obtained via their contribution as a study participant.

Methods

An integrative review was undertaken for this work because of the disparate interventions and research methodologies documented in this area (Kirkevold, 1997; Whittemore & Knafl, 2005). Integrative literature reviews are conducted to identify and integrate knowledge and understanding of current evidence based practices relevant to a particular phenomenon in order to develop a more detailed understanding of the topic (Kirkevold, 1997).

Search strategy and selection criteria

Articles eligible for inclusion in the review were published in peer review journals and reported studies using either qualitative, quantitative or mixed methodologies. Systematic reviews reporting such studies were also eligible for inclusion. Included articles needed to report investigations into the involvement of people with dementia in the planning of their care and support. Participants in included studies had a diagnosis of progressive dementia and were aged 18 years or older. Consistent with articulating the voice and obtaining the perspective of the person with dementia, data from these participants needed to have been analysed separately from those obtained from any other included participant groups.

Articles published in English from 1 December 2005 through until 31 January 2016 and originating from Australia, New Zealand, United Kingdom, Ireland, United States of America, Canada and Western Europe were eligible for inclusion due to these countries' comparable health care systems, cultures and dementia care strategies. The rationale for restricting included articles to those published in the previous 10 years was due to the development, during that time period, of the consumer directed care philosophy within the community care sector and the concurrent drive by the dementia consumer movement to ensure that people with dementia are afforded the same human rights as other citizens (Dementia Alliance International, 2016; Department of Health and Ageing, 2012).

Search strategy

Eight electronic databases; Medline, Cinahl, Pubmed, Informit, Proquest, Science Direct, Web of Science and Scopus were searched to identify articles that might meet the inclusion criteria. Reference lists of included articles were searched and an expert working in the area of dementia care was consulted about any articles that might also be eligible. The search terms were determined after detailed discussions with a very experienced health librarian. Consistent with the focus on how people with dementia have been supported to participate in planning of their care and support the following search terms were used: (dementia patient OR dementia client OR person with dementia) AND (Advance care directives OR Advance care planning) AND (self-directed OR patient autonomy) AND (service user). Appropriate MeSH terms were identified and used for each database.

Two authors were involved in all three stages of the process that determined the inclusion or exclusion of articles accessed. First, all retrieved titles and abstracts were screened. Second, full text versions of any articles with the potential to meet the inclusion criteria were retrieved for further (independent) review by both authors. Third, the decisions of the authors were compared, and any differences were resolved by returning to the article under review and further discussion.

Data extraction and review

A data collection form was designed to record extracted data from each included article. The data collected included title, author(s), study design and type, purpose and aims of the study, sample size, site of participant recruitment, inclusion and exclusion criteria, data collection methods and tools, data analysis and key findings. The two authors independently extracted the data from each article and met to resolve any differences by returning to the article. Articles included in this review employed varying methodologies so multiple criteria were used to assess their quality (Whittemore & Knafl, 2005). The Critical Appraisal Skills Programme (CASP) was used to guide the evaluation of the quality of studies that used either qualitative or quantitative methodologies (CASP, 2014). Mixed methods studies were evaluated using the Mixed Methods Appraisal Tool (Pace et al., 2012).

Results

The initial search accessed 346 articles (titles and abstracts) and, following review, seven articles met the inclusion criteria. Four of these studies were conducted in the United States of America (Hilgeman et al., 2014; Karel, Moye, Bank, & Azar, 2007; Roberts & Silverio, 2009; Snyder et al., 2007), one in the Netherlands (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2012) and two in the United Kingdom (Clare, Evans, Parkinson, Woods, & DPhil, 2011; Dening, Jones, & Sampson, 2013). The PRISMA flow chart, Figure 1, illustrates the selection process and Table 1 outlines the characteristics of included studies.

This review identified three approaches to including people with dementia in the planning of their care and support when they were also invited to provide study data. The first approach was found in two articles and included education and support programme for

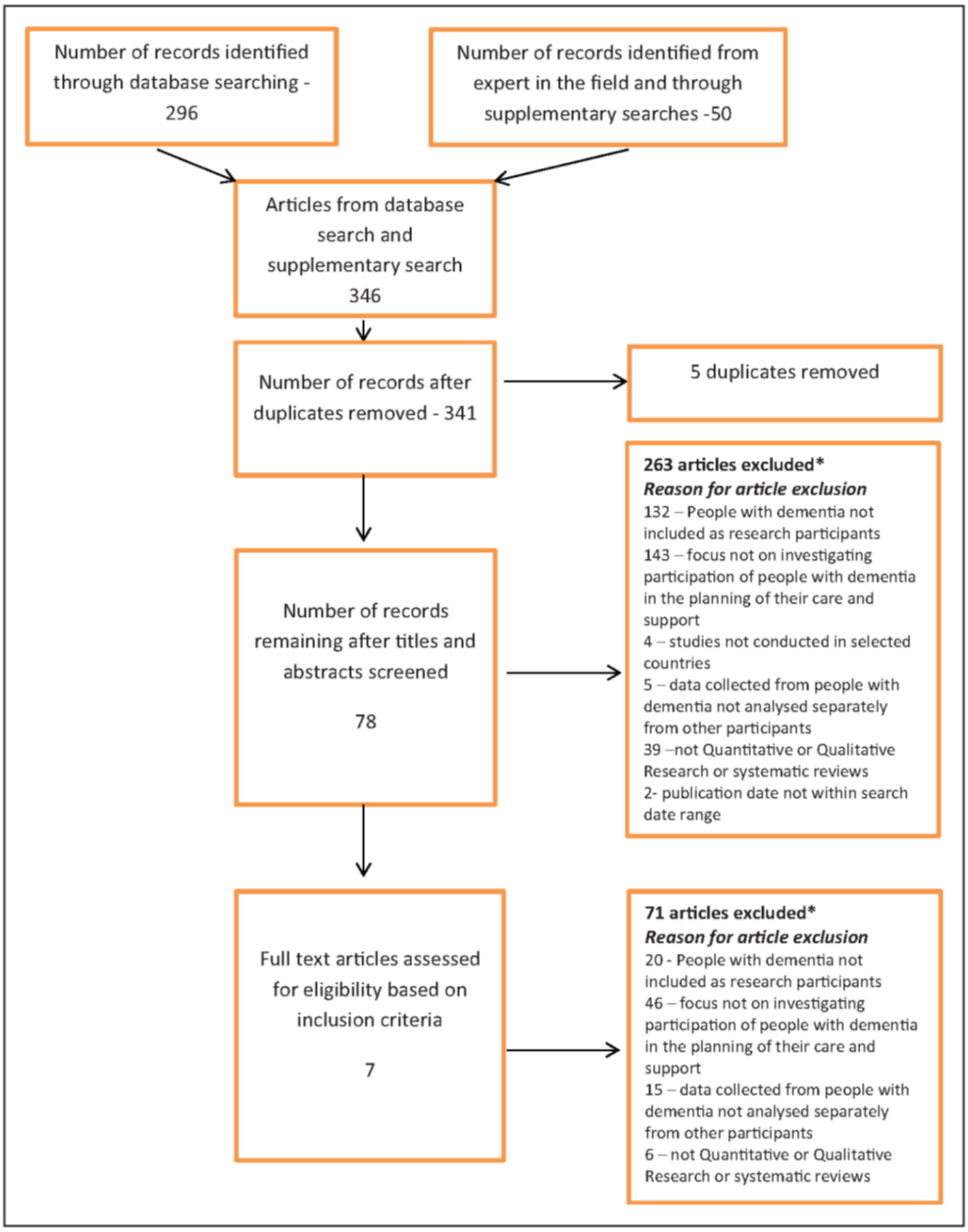

Figure 1. Literature search flow.

people with dementia. One education and support programme comprised four sessions including information on advance care planning and lifestyle changes (Roberts & Silverio, 2009). The other programme was unstructured, with discussion topics initiated by participants or based upon known concerns for people with dementia (Snyder et al., 2007).

The second approach was documented in one paper and focused on client directed goal setting in cognitive rehabilitation (Clare et al., 2011). Goal setting empowers the person to

Table 1. Characteristics of included studies.

Article author	Sample size	Intervention, study design and data analysis	Inclusion criteria	Data collection	Key findings
Roberts and Silverio (2009)	Person with dementia, $n = 37$ Care partners, $n = 37$	Education and support programme evaluation Quantitative study – descriptive statistics T tests, chi square tests, analysis of variance	Dementia and capacity to participate in the programme with care partner	Modified assessment tools administered, Margaret Blenkner Research Centre Caregiver Strain Instrument	Programme rated highly Person with dementia – attitude changes evident post programme completion, modified driving habits and more regular physical activities. Dyads – person with dementia and care partner commenced advance care planning post programme completion
Snyder et al. (2007)	Person with dementia ($n = 70$)	Education and support programme evaluation Mixed methods study Descriptive statistics and content analysis	Dementia & capacity to participate in the programme	Mixed methods survey administered orally collecting both qualitative and quantitative data	People appreciated learning, socialisation, improved coping, small percentage interested in future planning
Clare et al. (2011)	People with early stage Alzheimer's disease, $n = 69$ (22 assigned to receive cognitive rehabilitation)	Mixed methods study – goal setting in cognitive rehabilitation Content analysis Descriptive statistics, Analysis of	Dementia Acetylcholinesterase-inhibiting medication No psychiatric or neurological disorder	Canadian Occupational Performance Measure administered	Person with dementia choose goals to help maintain independence End of therapy – increased performance and satisfaction rating of tasks required to accomplish goals

(continued)

Table 1. Continued

Article author	Sample size	Intervention, study design and data analysis	Inclusion criteria	Data collection	Key findings
		covariance, probability measure and *t* test			46% goals fully achieved 50% partially achieved 4% not achieved
Dening et al. (2013)	People agreed to participate, $n=26$ Attended, $n=17$ Person with dementia, $n=9$ Carers, $n=8$	Advance care planning – qualitative nominal group method Collation of themes and content analysis	Dementia diagnosis, English, consenting, family carer participation	Generation and discussion of ideas – group format	Value in maintaining relationships, independence, safety, autonomy, identity, comfort. Considering future preferences challenging
Hilgeman et al. (2014)	68 dyads referred – final numbers Intervention group dyads, $n=11$ Comparison group dyads, $n=8$	Advance care planning pilot study randomised two group comparison design; intervention (reminiscence and advance care planning) phone contact intervention (–control group) Analysis of covariance	Dementia diagnosis English, consenting, family carer participation 55 years or older	Assessment scales completed Bath Assessment of Subjective Quality of Life in Dementia (BASQID) Quality of Life in Alzheimer's Disease (QOL-AD) Cornell Scale for Depression in Dementia (CSSD) Meaning in Life Scale Emotional Support and Anticipated Support Health related quality of life Euroqol-5 (EQ-5D)	Intervention group less depressive symptoms, increased QOL (BASQID) Self-reported anxiety, social engagement and quality of life, no meaningful difference at post treatment assessment – (QOL-AD) Less decisional conflict or discomfort with advance care planning More supported in decisions and increased coping.

(continued)

Table 1. Continued

Article author	Sample size	Intervention, study design and data analysis	Inclusion criteria	Data collection	Key findings
				Decisional Conflict Scale (DSC) Index for Managing Memory Loss (IMMEL)	
Karel et al. (2007)	Person with dementia, $n = 88$ Controls, $n = 88$	Advance care planning Mixed methods study Thematic analysis, frequency distributions, interim correlations and factor analysis	Dementia, English, consenting family carer participation Excluded mental or physical health problems	Participant interviewed, and survey administered	Person with dementia happy to talk about the future, Value in quality of life, independence, Maintaining health and relationships
de Boer et al. (2012)	Individuals – early stage Alzheimer's disease, $n = 24$	Advance care planning qualitative study Thematic analysis	Dementia, English, consenting family carer participation Excluded – language problems, depression	Semi structured interviews	Balancing hopes & fears, Limited future planning, Fear loss of independence & control, Value quality of life

maintain their decision-making autonomy and decide upon therapeutic goals for cognitive rehabilitation. Cognitive rehabilitation encompasses structured practice of standard tasks with the use of strategies to maximise people's functional capacity, social participation and quality of life (Clare et al., 2011; McGilton et al., 2013; Rabadi, Rabadi, Edelstein, & Peterson, 2008; Snyder et al., 2007).

Four articles identified a third approach that explored the participation of people with dementia in advance care planning initiatives (de Boer et al., 2012; Dening et al., 2013; Hilgeman et al., 2014; Karel et al., 2007). Advance care planning is a process that allows people with dementia to express future care and support preferences to family members and/or health professionals while their decision-making capacity is retained (de Boer et al., 2012; Dening et al., 2013; Karel et al., 2007).

Presentation of findings

The first approach – Education and support programme

When investigating the participation of people with dementia in education and support programme, Roberts and Silverio (2009) used a prospective, longitudinal cohort quantitative research design (Macnee, 2004; Polit, Beck, & Hungler, 2001; Schneider, Haber, LoBiondo-Wood, & Whitehead, 2013) with data collected at three time points from participants: at baseline, then at four weeks and three months following programme completion. Snyder et al. (2007) implemented simultaneous mixed methods research incorporating triangulation, using rating scales and open ended questions. This type of approach reduces the risk of error in research findings and credibility is enhanced when multiple sources of data lead to the same conclusion (Schneider et al., 2013).

In both articles, the data provided by participants with dementia showed an improvement in their knowledge of dementia following programme completion (Roberts & Silverio, 2009; Snyder et al., 2007), although the former (Roberts & Silverio, 2009) indicated that the degree of improvement was not statistically significant, potentially due to the small sample size. In the article by Snyder et al. (2007), participants reported via quantitative rating scales and narrative reports they were better able to cope following completion of the programme. Although Roberts and Silverio (2009) reported no significant change in participants' coping ability, they found that participants made positive behavioural and attitudinal changes post programme completion, such as modifying driving habits and increasing their level of physical activity. Participants were therefore more informed following programme completion and better able to independently adjust their lifestyle to maintain their health, coping ability and sustain their quality of life through meaningful engagement. Snyder et al. (2007) determined a positive social impact from group participation for people with dementia during their mixed methods evaluation.

There are numerous challenges to undertaking research when investigating initiatives to help people living with dementia (Hubbard, Downs, & Tester, 2003) including a paucity of tools created and tested for use with this population. Most tools used by Roberts and Silverio (2009) had been developed for use in other contexts and were modified for their study, without always establishing the reliability and validity of the revised tools. Moreover, whilst Snyder et al. (2007) clearly described the questions asked, and developed and piloted the tool that they used with people with dementia, they also failed to report the tool's psychometric properties.

The study conducted by Roberts and Silverio (2009) was strengthened by follow-up data collection that helped to demonstrate the sustained effectiveness of the intervention. However further clarity about recruitment and attrition would have been helpful in both this article and that authored by Snyder et al. (2007). The study conducted by Snyder et al. (2007) was strengthened by the provision of information to interviewers to ensure that surveys were administered consistently, limiting the likelihood that some participants may have received more explanation then others and thereby reducing potential bias inadvertently introduced by the researchers (Schneider et al., 2013).

Although there were indications of benefits from the data collected from people with dementia in the studies authored by Roberts and Silverio (2009) and Snyder et al. (2007) study limitations such as small sample sizes and the use of tools for which psychometric properties are yet to be established means that further investigation is merited.

The second approach – Client directed goal setting in cognitive rehabilitation

The authors of the single study investigating goal setting used simultaneous mixed methods and addressed three aims to: (a) determine if people with Alzheimer's disease are able to identify meaningful and relevant rehabilitation goals; (b) explore the goals participants deemed necessary for cognitive rehabilitation therapy; and (c) identify how effective the therapy was in helping people with Alzheimer's disease achieve their goals (Clare et al., 2011). People with dementia chose goals that helped to maintain their decision making autonomy and independence. Goals were primarily related to the support of memory function and the completion of practical activities such as how to operate cooking appliances. Additionally participants chose goals to maintain orientation and general well-being, for example, managing disruption to sleep wake cycles. Cognitive rehabilitation therapy proved to be effective in helping participants achieve their goals with 96% of goals either fully or partially achieved on completion of the therapy (Clare et al., 2011).

The methods used in Clare et al.'s (2011) study were primarily quantitative however some qualitative data were obtained. The article failed to detail any methods undertaken by the researcher to avoid interviewer bias. This is important because a person's experience of dementia potentially impairs their ability to communicate, meaning that they may require assistance with completing research tools and therefore be inadvertently influenced by the researcher (Hubbard et al., 2003). A standardised instrument, the Canadian Occupational Performance Measure (COPM) was used to collect quantitative data; a tool that has confirmed validity and test–retest reliability in this population (Cup, Scholte Op Reimer, Thijssen, & van Kuyk-Minis, 2003).

The study proved successful in helping people with dementia work towards achieving their goals. Further studies replicating this approach are required, as are studies exploring the degree to which a person with dementia can sustain their functional capacity to complete tasks and at what point reassessment of goals is required.

The third approach – Advance care planning

When investigating advance care planning, two studies used qualitative methods (de Boer et al., 2012; Dening et al., 2013) and one study used mixed methods (Karel et al., 2007) comparing data from people with and without dementia. The final study (Hilgeman et al., 2014) was a pilot study using a two-group comparison design; participants were randomised to receive either the main intervention (reminiscence and advance care planning) or a minimal support phone contact intervention (control condition). Hilgeman et al. (2014) sought to determine if the main intervention decreased symptoms of depression and anxiety and/or increased participants' quality of life and satisfaction with the advance care planning process. After accounting for baseline differences, symptoms of depression were lower in participants who received the main intervention. The group receiving the main intervention also rated less discomfort with the process of advance care planning and felt more supported in decision making (Hilgeman et al., 2014).

These studies explored various methods in seeking input from people with dementia in regards to their future planning (de Boer et al., 2012; Dening et al., 2013; Hilgeman et al., 2014; Karel et al., 2007) and explored the values and preferences of people with dementia towards end of life care and advance care planning (de Boer et al., 2012; Dening et al., 2011; Karel et al., 2007). The findings indicate that people with dementia valued continued quality of life into the future and are able to express their future support needs in order to maintain their health, be independent, maintain control over future decision making, stay socially connected and meaningfully engaged (de Boer et al., 2012; Dening et al., 2013; Karel et al., 2007).

Although Hilgeman et al.'s (2014) article reported pilot work, the methodology was robust and clearly explained. Whereas the articles reporting qualitative methodologies (de Boer et al., 2012; Dening et al., 2013) failed to detail approaches addressing researcher bias, such as the bracketing of ideas (Polit et al., 2001), de Boer et al. (2012) used a team of dementia care specialists when creating a questionnaire requesting qualitative data so that wide ranging perspectives could be captured in participants' responses. Two of these studies recruited participants exclusively from health or memory services, which limit the extent to which results are transferable to other settings (de Boer et al., 2012; Dening et al., 2013). Hilgeman et al. (2014) and Karel et al. (2007) recruited participants from more diverse sources, such as via the newspaper and independent living centres. Karel et al. (2007) integrated the qualitative and quantitative data, a key goal in mixed methods research (Schneider et al., 2013), but failed to provide contextual information regarding the setting of data collection. Transparency of the study environment is necessary to demonstrate rigour and prove that the environment has not influenced participants. Moreover, a comprehensive description of the study environment informs the transferability of study findings (Macnee, 2004).

Small participant numbers were noted as a limitation in most of these studies, which were also small in number, indicating limited empirical evidence and a requirement for further studies investigating advance care planning for people with dementia before there is sufficient guidance to inform practice in this area.

Discussion

Having people living with dementia drive service development and participate in their care and support planning is important to ensure that services are person centred and meet the client's needs (Kitwood, 1997). To determine the extent to which studies exist that both include people with dementia as study participants so that their 'voice' or perspective can be reported and investigate their participation in planning their care and support, an integrative literature review was conducted. Since inclusion in planning initiatives did not always guarantee an opportunity for the voice of people with dementia to be identified very few papers could be included in this review.

A limitation is that the review only included studies reported in the peer reviewed literature, in recognition of the quality of this body of work. Nonetheless, it is recognised that additional reports many have been accessible in the grey literature, especially given that this is a newly emerging research topic, and that researchers themselves are still grappling with the best ways to access data from people with dementia that are both ethically sound and scientifically robust. The significance of these findings highlights the need for further inclusion of people with dementia in the planning of their care and support but more importantly the need to research and gather evidence that continues to detail what this means for them and their preferences on how to be included so health providers and dementia support workers avoid making assumptions on the matter.

The papers that were included detailed what is important to people living with dementia and how health professionals might engage and assist them to plan their future and live the life they want to lead. Overall, although the quality of included articles varied, their inclusion assisted the authors to answer the question posed in this review. Within this review the quality of two studies was limited due to a lack of information regarding psychometric properties of the research tools and recruitment and attrition rates. Moreover, one pilot study, and several studies with small sample sizes indicated that further work in the area is needed. The knowledge gained from these studies indicates that there are short to medium term interventions available to people with dementia to preserve their quality of life. Such interventions include information seeking on matters such as preserving health, maintaining functional capacity to complete tasks independently and accessing advance care planning initiatives to help maintain control over the life span.

Importantly there needs to be some consideration that other interventions may be available for people with dementia but have not been included because programme engaging people with dementia in care and support planning are seldom evaluated by obtaining data from programme participants. This suggests that there needs to be a shift in our attitudes toward people with dementia as this impacts upon the care they are offered. The view held that people with dementia maybe incapable of participating in care and support planning and research evaluating these programme is a reflection of the stigma associated with dementia (Alzheimer's Society, 2008).

The stigma surrounding a dementia diagnosis must be addressed so that health providers understand that people with dementia are capable of care and support planning and need an early diagnosis so they have time to process what living with the diagnosis means (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). People with dementia can then experience an increased period of wellness while their decision making capacity is retained and health professionals can outline potential future support options (Wolfs et al., 2012). A failure by health professionals to actively offer support negatively impacts the person with dementia leaving the person feeling defeated, fearful and with no means to preserve independence and quality of life (Swaffer, 2015).

Health services for people with dementia need to be better evaluated from their perspective by either qualitative or quantitative research so that the voice of people with dementia is obtained and health professionals can effectively meet their needs. Evidence suggests that people with dementia have limited knowledge on advance care directives and often rely on families to make decisions on their behalf (de Boer et al., 2012). Consequently health professionals need to extend their focus to future care planning with further training for health professionals so they can be better prepared and more confidently engage their clients, particularly around the terminal nature of the condition (Dening et al., 2011). People with dementia need access to trained counsellors to help come to terms with their diagnosis and understand the means in which they can maintain control of their life through use of advance care planning. Health professionals need to explain to people recently diagnosed what living with dementia actually means, overcoming any stigmatising preconceptions and focusing the discussion around preserving quality of life throughout the dementia trajectory (Chang et al., 2009). People with dementia need to be consulted on what constitutes a good quality of life for them and then assisted to maintain that quality of life through interventions such as those uncovered in this literature review.

People with dementia who have retained decision making capacity have the ability to control their lifestyle and opportunities to do this need to be provided through more person focused service provision. Recent research has explored the personal goals of people living with dementia and whether these goals are obtainable (Jennings et al., 2016; Khayum & Wynn, 2015; Reuben & Tinetti, 2012). Goal directed cognitive rehabilitation services are becoming increasingly available for people with dementia but are in the early stages of implementation (International Federation on Ageing, 2015). Further promotion of the effectiveness of these services and (International Federation on Ageing, 2015; United Nations, 2006) further implementation of goals by the person with dementia will be a significant step forward in people with dementia participating in their care and support planning.

Further research is required to ensure that people with dementia's quality of life is preserved at the end of life when a person maybe experiencing reduced capacity for communication and decision making. Limited evidence of the use of advance care plans for people with dementia means that they are potentially denied the opportunity to have a voice and participate in care and support planning for their long-term future. Further person focused research is required around the implementation of advance care plans and what is acceptable to this group of clients. Moreover, people with dementia need to be better informed about advance care planning so they are aware that this option is available to them. Health professionals, friends and families need to be prepared to come to terms with their own moral responsibilities to consider the needs of the person with dementia first despite whether it conflicts with what they feel is in their best interest (Hughes et al., 2014).

Conclusion

This review identified a limited body of empirical work exploring people with dementia's successful engagement in opportunities to both have a voice and plan for their future through participation in care and support planning. The review did however identify that people with dementia do participate in care and support planning through attendance at education and support programme. Goal setting opportunities in cognitive rehabilitation are possible but the degree to which preserving quality of life at the end of life with advance care planning initiatives requires further investigation. For people living with dementia, the preservation of quality of life is important and they have a desire to do this by maintaining health, staying connected and conserving independence and control. Health care providers are able to ensure that people with dementia's quality of life is retained by asking what is important to them and engaging them in care and support planning.

Key points

- People with dementia have decision making capacity for a time limited period and need to be well informed about future support options during that period.
- People with dementia value support to maintain quality of life and preserve their independence and wellbeing for as long as possible.
- Very limited published research including people with dementia as participants has investigated their involvement with the planning of their care or support.
- Findings from studies investigating education and support sessions, goal setting, and the development of advance care plans provide promising indications of a person with dementia's capacity to identify how they wish to live their life into the future.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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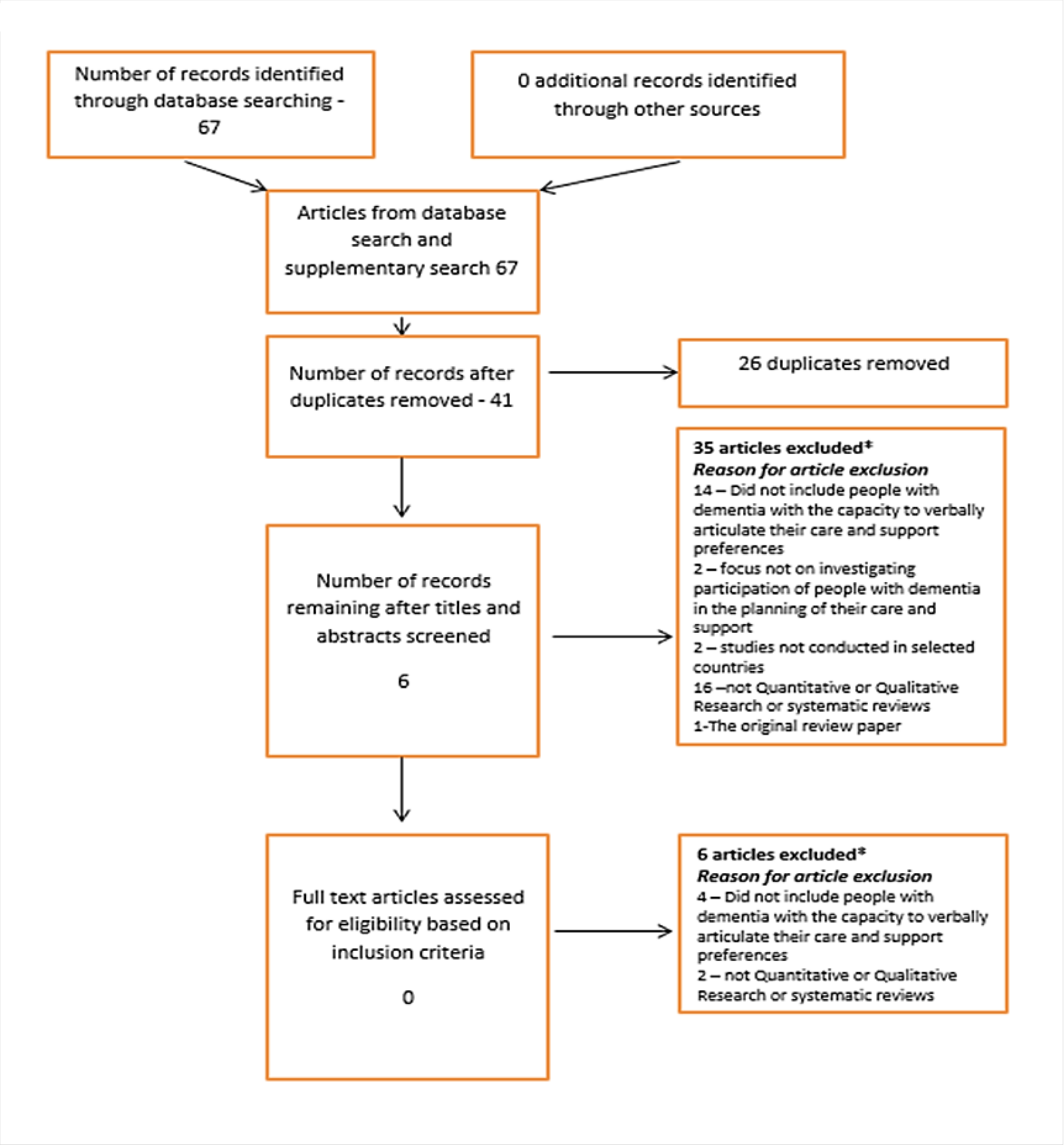
4.3 Additional Review of Literature since Publication

The integrative literature review (Publication 3) was undertaken in January 2016 following the completion of Studies 1 and 2. To update the findings, supplementary searches were subsequently undertaken to identify literature published between the 1st February 2016 and 14th December 2020 using the same methodology as detailed in Publication 3. Sixty-seven additional articles were identified and retrieved. Following the removal of duplicates (n=26), the titles and abstracts of the remaining 41 papers were screened and 35 papers were excluded. Six papers were retained and subjected to full-text review, which revealed that none met the integrative literature review inclusion criteria (Appendix N). Figure 4.2 below details this process of literature retrieval, quality assessment and inclusion for analysis and presentation.

Figure 4.2

Additional Review of Literature – Literature search flow diagram



4.4 Integrative Literature Review Discussion

The lack of literature meeting the inclusion criteria for the review is a significant finding and indicates that research exploring people with dementia's participation in the planning of their care or support from the perspective of people with dementia, either does not occur, fails to include people with dementia as research participants, or is not published in peer-reviewed journals. The integrative literature review validated the findings of Study 1 as uncovered articles indicated only minimal recognition by health professionals of the need to include people with dementia in plans for their future. While there is an emphasis now on consumer involvement in planning care and support requirements, research concerning this remains limited. People with dementia participating in Study 1 reported not being empowered to consider their future, and consequently, as uncovered in Study 2, did not discuss this with their care partner, the person most likely to advocate on their behalf when required. Despite the changing paradigm of care for people with dementia, the literature review indicated that they continue to have little input into the care they receive. It is therefore likely that services do not meet their needs, despite best practice guidelines recommending person-centred service provision (National Institute for Health and Care Excellence, 2018).

The integrative literature review did however show that there is some evidence to suggest that people with dementia may be participating in their care and support planning and engaged in service evaluation. Despite this the limited number of papers retrieved as a part of this review may indicate that some researchers or service providers undervalue people with dementia as research participants. As such, they may fail to appreciate the capacity of individuals living with the condition to engage in their care and support planning or service evaluation, or do not recognise established processes that support them to participate in these practices. Moreover, the difficulty in obtaining the person with dementia’s informed consent given the progressive cognitive decline they experience, and the potential increase in burden from research participation they may encounter (King et al., 2016), pose additional challenges to overcome. It is imperative, however, that people with dementia are diagnosed early so that they can participate in care and support planning, service evaluation and research while their capacity to do so remains. Research that explores and evaluates the participation of people with dementia in the planning of their care and support is critical. Findings from this group of healthcare consumers, will elicit their input into care planning and ensure services are responsive to their needs (Shepherd et al., 2019).

While key findings of this review indicated that people with dementia may be participating in care and support planning through their attendance at education programmes (Roberts & Silverio, 2009; Snyder et al., 2007), setting goals in cognitive rehabilitation therapy (Clare et al., 2011) and contributing to advance care planning (de Boer et al., 2012; Dening et al., 2013; Hilgeman et al., 2014; Karel et al., 2007), there is very limited evidence to support this. Despite this limitation, these are significant findings in that they indicate there are avenues for people with dementia to live well with sustained autonomy, at least for a time-limited period. However, identifying health professionals' knowledge about these interventions and how health professionals may engage a person with dementia in these processes is yet to be established. Further research with funding support from governing bodies examining the effectiveness of these interventions and how health professionals can best be supported to implement such interventions is required so evidence can inform further development in this area. There also needs to be some consideration of health professionals' capacity to diagnose dementia early so that these interventions can be implemented in advance, resulting in a person with dementia's quality of life potentially being sustained for longer, and allowing them an increased length of time in which they can consider and plan for their future (Robinson et al., 2015).

The dementia-related stigma that exists impacts the attitudes of service providers and health professionals, their willingness to diagnose dementia and their understanding of the capacity of people with dementia to participate in the planning of their care and support (Piver et al., 2013). As a result, this impacts people with dementia being provided with such opportunities to actively engage in decision-making about their care. Health professionals are reported to have greater stigmatising beliefs about people with dementia compared to lay people within the community (Piver et al., 2013). Consequently, doctors are inclined to delay diagnosing and offering treatment for dementia, stereotyping people with the condition as if they were in the advanced stages and unable to communicate or contribute to the community (Cahill et al., 2008; Gove et al., 2017; Vernooij-Dassen et al., 2005). When health professionals do diagnose dementia, they are likely to exclude the person from care planning due to their belief that little support can be offered. Despite this people within the community reportedly do want to know if they have dementia and prefer to stay connected to their pre-diagnosis lifestyle, remaining self-determining and in control of decision-making (Read et al., 2016; Robinson et al., 2014).

People with dementia are further stigmatised by people within the community. This is more likely if the community member has not had a personal relationship with a person with dementia or if the person is in the later stages of the condition and perceived by others to lack the ability to complete a task (Herrmann et al., 2018; Phillipson et al., 2014; Piver et al., 2013; Werner, 2006). Such stigmatising attitudes toward people with dementia, and a lack of knowledge about what it means to live with dementia in the current context means people may be less likely to seek a dementia diagnosis (Herrmann et al., 2018) as they may perceive dementia to be untreatable and a normal part of ageing (Devlin et al., 2007). When a person is diagnosed their emotional and behavioural reaction may perpetuate the stigma that exists by them ignoring their symptoms (Aminzadeh et al., 2007). Furthermore, media portrayal of people with dementia is often negative which exacerbates dementia-related stigma (Devlin et al., 2007). Not only is the stigma of dementia directed at people with the condition but their care partners are also stigmatised, experiencing shame and fear of judgement (Navab et al., 2013; Werner et al., 2010).

How to overcome the stigma that exists within the community, bearing in mind that service providers and health professionals form part of the community, and change community attitudes towards people with dementia, requires contemplation. The findings from Study 1 and Study 2, as well as the paucity of research involving people with dementia in the planning of their care and support as evidenced by the integrative review conducted as part of this research, justified the next stage of this research which encompassed the development of the contemporary Dementia Community Attitudes Questionnaire and implementation of the Dementia Awareness Raising Forum. The forum was designed to inform members of the community about people with dementia’s desire to stay connected to their pre-diagnosis lifestyle and, as such, remain in control of decision-making for as long as possible. An evaluation of the forum was conducted to determine its usefulness to promote more positive attitudes toward people with dementia, and to raise community awareness about the fundamental rights of people with dementia to guide their future, their capacity to do so and how they can be supported. The development of the Dementia Community Attitudes Questionnaire (Study 3) resulted from the requirement to evaluate the effectiveness of the forum as no suitable existing questionnaire could be found. The development of the questionnaire and the awareness-raising forum are reported in detail in Chapter 5.

4.5 Conclusion

A review of published literature on planning for dementia care and support identified very little evidence from the perspective of people living with the condition as research participants. These findings indicate the need for change and more inclusive engagement of people with dementia in their care and support planning so they can remain self-determining and inform their future support needs while still able to. This aligns with a human rights-focused approach and the person-centred philosophy of care that has been widely promoted to ensure that the voice of the consumer living with dementia is heard and valued (Kitwood, 1993; United Nations, 2006). Addressing community attitudes through the conduct of a Dementia Awareness Raising Forum and evaluating its effectiveness by administering the Dementia Community Attitudes Questionnaire was seen as a way of helping to overcome dementia-related stigma, and facilitating community inclusion of people with dementia in their future care and support decision-making and the community as a whole. Chapter 5 that follows provides a detailed account of the community awareness-raising forum and newly developed questionnaire.

Chapter 5

Quantitative Studies (3 and 4)

Chapter 5 introduces Studies 3 and 4, which form the quantitative component of the research reported in this thesis. It details the development of the Dementia Community Attitudes Questionnaire and its implementation at the Dementia Awareness Raising Forum. The chapter includes one publication (Study 3), published in the peer-reviewed journal ‘Dementia’, which outlines the development of the Dementia Community Attitudes Questionnaire (DCAQ). Authorisation was obtained from the editor of the journal to include the article in this thesis in its published format (Appendix O). Furthermore, the chapter includes a detailed explanation of the Dementia Awareness Raising Forum (Study 4) and a discussion of the forum outcomes.

The findings of the integrative literature review, presented in Chapter four, revealed that the exclusion of people with dementia from the planning of their own care and support persists, at least in the context of studies that included people with dementia as research participants. This finding raised questions about the extent to which health professionals, and the wider community have engaged in the shift from the previously pervasive paternalistic medical model of care to person-centred approaches, when supporting or providing care to people living with the condition. The supplementary review of the literature that included publications up to December 2020, also indicated a continuing exclusion of people with dementia.

The lack of participation by people with dementia in decision-making about their own care and support, revealed in the literature review, was considered alongside findings from Study 1 and Study 2 reported in this thesis. Study 1 findings revealed that participants with dementia wanted to remain connected to their pre-diagnosis lifestyle, with self-determination being central. However, participants within Study1 detailed experiences that made this difficult, for example, they reported feeling undermined by their doctors when health information was directed away from them to their care partners. In Study 2, care partners reported experiences such as stigmatising attitudes from other people within the community directed toward the persons they supported. These findings identified the need for further studies and a secondary aim emerged to explore the usefulness of a community awareness-raising forum in positively changing community attitudes towards people living with dementia. A review of existing literature failed to uncover a suitable existing questionnaire to evaluate community attitudes towards people with dementia. This shortcoming informed the specific objectives linked to the emerging secondary aim. Hence, study Objective 4 sought to develop a suitable dementia attitudes questionnaire and to establish its preliminary psychometric properties for use at a community awareness-raising forum related to dementia (Study 3). Study Objective 5 then focussed on exploring the feasibility and effectiveness of the Dementia Awareness Raising Forum to positively change community attitudes toward people living with dementia (Study 4).

Raising awareness about people with dementia’s capacity for self-determination, and thereby changing attitudes of people within the community towards people living with the condition, was seen as essential to further shift the changing paradigm of how these individuals are best supported. Conducting the Dementia Awareness Raising Forum was anticipated to be one way in which attitudinal change could be achieved. The forum was specifically designed to provide contemporary understandings of what it means to live with dementia, recognising that pre-existing understandings might vary considerably among forum attendees.

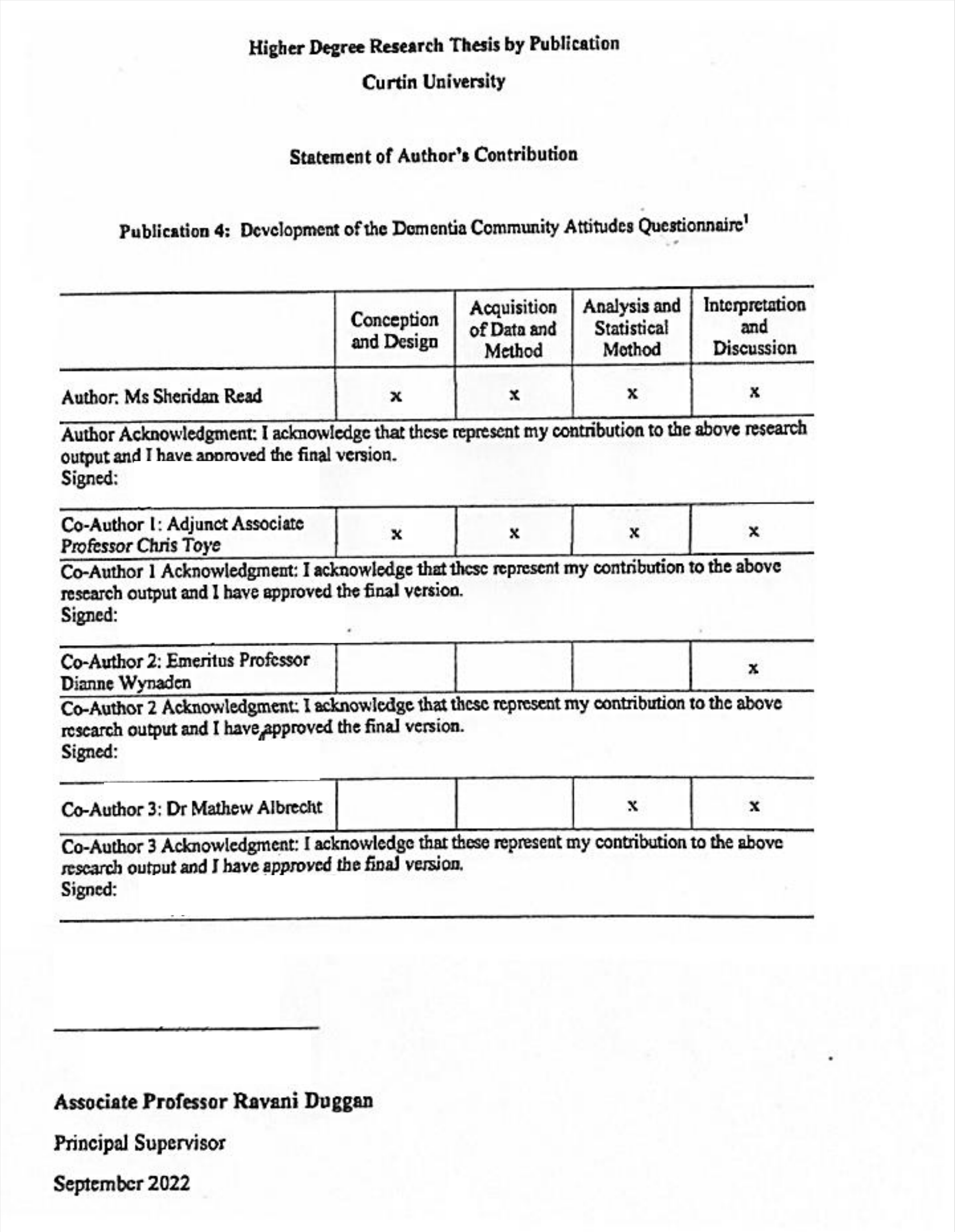
Ensuring that community members had contemporary information on people with dementia’s capacity for self-determination was viewed as likely to bring about more positive attitudes towards this group. This change was essential to further shift the paradigm that informs how formal and informal support is provided. The usefulness of the forum was evaluated in terms of both the effectiveness and feasibility of running such events. Section 5.1 that follows details the obtaining of a measure of attitude change (Study 3, Objective 4), while the exploration of the feasibility and effectiveness of the Dementia Awareness Raising Forum is expanded on in Section 5.2. This includes the structure and content of the forum (Study 4, Objective 5).

5.1 Development of the Dementia Community Attitudes Questionnaire – Study 3

As indicated, in keeping with the objective to measure attitudinal change at the forum, a search for a suitable questionnaire was completed. As no existing questionnaire that aligned with the current context of how community members view and support people with dementia was identified, the researcher decided to develop the new Dementia Community Attitudes Questionnaire (DCAQ). The following published peer-reviewed journal article details the search conducted to identify an existing dementia attitudes questionnaire, and the process completed to develop the new questionnaire.

Publication 4 – Development of the Dementia Community Attitudes Questionnaire

Statement of Author's Contribution



Higher Degree Research Thesis by Publication

Curtin University

Statement of Author's Contribution

Publication 4: Development of the Dementia Community Attitudes Questionnaire[1]

	Conception and Design	Acquisition of Data and Method	Analysis and Statistical Method	Interpretation and Discussion
Author: Ms Sheridan Read	x	x	x	x
Author Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 1: Adjunct Associate Professor Chris Toye	x	x	x	x
Co-Author 1 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 2: Emeritus Professor Dianne Wynaden				x
Co-Author 2 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				
Co-Author 3: Dr Mathew Albrecht			x	x
Co-Author 3 Acknowledgment: I acknowledge that these represent my contribution to the above research output and I have approved the final version. Signed:				

Associate Professor Ravani Duggan

Principal Supervisor

September 2022

Permission to include this article in this thesis has been obtained from the publisher (Appendix O).

Article

Dementia
2020, Vol. 0(0) 1–18

DOI: 10.1177/1471301220977649
journals.sagepub.com/home/dem
SAGE

Development of the dementia community attitudes questionnaire

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Abstract

Background: What it means to live with dementia is changing. Autonomy, independence and continued community involvement are now recognised goals. As a result, new initiatives are required to support people with dementia to sustain their quality of life, update community understanding and reflect resultant change in community attitudes. Measuring the impact of such initiatives can help determine the extent of their success, inform needs for further intervention and, ultimately, shape policy.

Objective: To discover – or, if this could not be achieved, develop – a questionnaire measuring community attitudes towards people with dementia reflecting these newly recognised goals in terms of both content and expression.

Methods: A four-stage approach was used in this research: a scoping review of the literature, questionnaire development and expert review, questionnaire piloting, including with people living with dementia and their families, and preliminary psychometric testing.

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Results: The review failed to retrieve a suitable existing questionnaire. A ten-item questionnaire, the Dementia Community Attitudes Questionnaire was developed, content validity was established by expert review and piloting led to refinements. Exploratory factor analysis ($N = 92$) generated an interpretable three-factor solution. Cronbach's alpha coefficient for Factor 1, Engagement, was good (0.855); for Factor 2, Challenges, and Factor 3, Decision-Making, reliability was acceptable (0.785 and 0.709, respectively).

Conclusion: Supporting people with dementia to sustain their quality of life requires new initiatives and suitable measures to evaluate their impact. The Dementia Community Attitudes Questionnaire was developed with input from people with dementia, their families, and relevant experts. Items reflect current opportunities for people with dementia to retain their independence, autonomy and community engagement for as long as possible. Following further psychometric testing, this new questionnaire may be useful to evaluate such initiatives.

Keywords

questionnaire, attitudes, community, quality of life, dementia

Introduction and background

Dementia is a global public health priority. In 2015, there were approximately 47 million people diagnosed with the condition worldwide. Estimates suggest that this number will increase to 75 million by the year 2030 (World Health Organisation, 2017). The World Health Organisation (2017) continues to promote the need for further dementia awareness raising initiatives to help overcome dementia-related stigma. People's attitudes influence the ways in which they interact with those people living with the condition. These attitudes are based upon their knowledge of dementia, their observation of people living with dementia and how people with dementia are treated by others (Gerritsen et al., 2018). In turn, the way an individual experiences dementia is partly determined by their social environment and the attitudes of those people with whom they associate (Cheston et al., 2016).

People diagnosed with dementia are required to manage both their symptoms and the associated stigma attached to the diagnosis. Historically, dementia has been seen from a biomedical viewpoint, that is as a degenerative disorder resulting in a decline in a person's functional capacity (Edvardsson et al., 2008). Emphasising a person with dementia's loss of ability and increased dependency can influence how they are viewed by others, for example as being deemed unworthy and childlike (Edvardsson et al., 2008; Gerritsen et al., 2018). People with dementia also report experiencing discriminatory behaviours, such as avoidance and segregation (Milne, 2010). Negative language is often used when talking about dementia and during media representations (Brookes et al., 2018; Van Gorp & Vercruysse, 2012). The stigma associated with ageing and mental illness also compounds such negative views (Gerritsen et al., 2018; Kitwood, 1997; Phillipson et al., 2014).

Globally, over recent decades, there has been a shift in people's understanding of dementia, driven in part, by people diagnosed with dementia speaking publicly about their experiences. These consumer advocates continue to speak for all people with dementia to be included in decisions that affect their lives (Bryden, 2004, 2015; Rohra, 2014; Swafer, 2016; Taylor, 2007). Assisting the autonomy of people with dementia by promoting their inclusion in decision-making has been reflected in consumer directed care policies worldwide, for example in Norway (Norwegian Ministry of Health and Care Services, 2015), the United Kingdom (United Kingdom

Department of Health, 2013), Australia (Australian Department of Health and Ageing, 2012) and New Zealand (New Zealand Ministry of Health, 2013). Such consumer-focused policy is indicative of attempts made to reverse dementia-related stigma and discrimination. Furthermore, the World Health Organisation (2017) has endorsed a human rights–based approach for people with dementia and the move to view dementia as a disability (UN General Assembly, 2007). A human rights–based approach aims to safeguard rights for independence, social protection and an adequate standard of living for people with dementia and their care partners, providing new meaning to living with the condition (World Health Organisation, 2015, 2017).

People with dementia have reported wanting to maintain their independence, stay connected to their pre-diagnosis lifestyle and remain involved within their community (Read et al., 2016). This continued involvement becomes more feasible when the community is dementia-friendly. A dementia-friendly community is one that promotes the inclusion of people with dementia, empowers them to live the life they want and adapts the social and physical environment so that it is more easily accessible by people with dementia (Heward et al., 2017; Kaufmann & Engel, 2016; World Health Organisation, 2017). Alzheimer's Disease International (2015) outlined the principles of dementia-friendly communities and stated that for people with dementia to remain included within their community local businesses need to consider the needs of people living with the condition. Central to the successful development of such communities is the participation of people with dementia (Buckner et al., 2019; Woodward et al., 2018), but to evaluate the effectiveness of the communities, further research is required (Buckner et al., 2019).

The changing context of living with dementia to one where people are offered post-diagnostic support that includes opportunities to live well, remain engaged and independent, requires initiatives to address broader (community) understandings about what it means to live well with dementia and a shift in societal attitudes to create sustainable dementia-friendly communities (McParland et al., 2017). An attitude is a person's cognitive, behavioural and affective response to an object, person or situation, reflecting what they know; their beliefs and perceptions and how they respond (either positively or negatively), both physically and emotionally. These three components of attitude form the tripartite model or three-component view of attitude (Breckler, 1984; Rosenberg, 1960). Using questionnaires to measure attitude change can help guide the need for further interventions, but the relevance of these questionnaires to the current context is critical (Denscombe, 2003). In addition, the need to avoid language or terminology that is inadvertently offensive or stigmatising is critical, not least because people with dementia themselves, as valued members of community, may be asked to complete these measures (Denscombe, 2003).

A range of existing questionnaires evaluates people's attitudes towards dementia and/or related care approaches (Aihara et al., 2016; Cheston et al., 2016; Kinney et al., 2017; Phillipson et al., 2014; Tan et al., 2012), including those of healthcare workers (Mason et al., 2016; Staples & Killian, 2012; Travers et al., 2013; Wang et al., 2018) and students (Kimzey et al., 2016; Lundquist & Ready, 2008). However, as we move into a new era of supporting people with dementia, ensuring that such questionnaires evaluate attitudes within this new context is required. The purpose of this study was to discover an existing questionnaire that had relevance in 2020 or – if this could not be identified – develop a questionnaire measuring community attitudes towards people living with dementia that aligned with the new era of support and, in doing so, used terminology unlikely to cause offence to anyone experiencing this condition.

The article explains the four-stage approach used to develop the questionnaire. Stage 1, scoping review, examined existing questionnaires. When no suitable questionnaire was found, the following processes were followed: Stage 2, questionnaire development, including establishing content validity; Stage 3, piloting; and Stage 4, preliminary psychometric testing. Ethics approval was obtained from the Curtin University Human Research Ethics Committee.

Stage 1 scoping review

Aim

The aim of Stage 1 was to review existing questionnaires used to measure community attitudes towards people with dementia.

Design

A scoping review of the literature was undertaken, given the authors were looking to: (a) discover specific elements of the topic and (b) establish the extent to which any appropriate measures existed in the published literature (Munn et al., 2018).

Methods

Inclusion and exclusion criteria. Articles eligible for inclusion in the scoping review were written in English and published in peer-reviewed journals between 1 January 1996 and 31 December 2019. The rationale for selecting this date range was based on work by Lintern (2001), who identified that there were no validated dementia-specific scales published before her work in 1996. Consistent with the process recommended in the COnsensus-based Standards for the selection of health Measurement Instruments procedure (Prinsen et al., 2018), only articles reporting scale development studies, specifically designed to establish the psychometric properties of questionnaires measuring people's attitudes towards people living with dementia, were included. A person's attitude to dementia encompasses their understanding of dementia and/or how they feel about and respond to people diagnosed with the condition (Breckler, 1984). Articles reporting studies that involved scale development designed to measure health professionals' or health professional students' attitudes toward people living with dementia were excluded. Furthermore, the authors chose not to consider literature that detailed scales of other stigmatising conditions, given the uniqueness of dementia-related stigma and the historical context that (a) surrounds the use of language that is demeaning and (b) the belief that dementia causes a person to experience a loss of self (Kitwood & Bredin, 1992).

Search strategy. Six electronic databases, CINAHL, Embase, MEDLINE, PsycINFO, Scopus and Web of Science were searched from 7 May 2019 until the 11 May 2019 to identify articles that met the inclusion criteria. A suitably experienced librarian was consulted to confirm appropriate use of search terms. The following search terms were used (dementia OR Alzheimer's OR vascular dementia OR Lewy body OR frontotemporal) AND "scale development" AND (attitude OR knowledge).

The first and fourth authors identified which articles met the inclusion criteria. In the first instance, titles and abstracts of all articles retrieved were screened. Second, the complete text of each of the articles that met the inclusion criteria was screened. The authors screened these articles independently and then met to compare decisions. Any disagreements were resolved by returning to the article for further review and discussion.

Data extraction and review. Data were extracted and reviewed from each of the included articles to determine the questionnaire domains and how these were identified. A data collection form was created to record the following: article title, authors, study aims, questionnaire domains and domain development process. The two authors extracted data independently and met to discuss and resolve any differences by revisiting the article.

Consideration of the questionnaires for current use. In a process involving the first and fourth authors working independently, the questionnaires outlined in the six included articles were examined. There were three main considerations:

1. Were the three components of attitude outlined in the tripartite model (Breckler, 1984; Rosenberg, 1960) (cognitive, behavioural and affective responses) addressed?
2. Were items included that addressed the issues of the autonomy, independence and continued community involvement of a person with dementia?
3. Were there any concerns that the language or expression used in the items of the questionnaire might be stigmatising or inconsistent with the current understanding of what it means to be living with dementia?

Results

The initial search retrieved 75 articles. Following removal of duplicates and review of each article's title and abstract, 14 remained. Subsequently, a full text review of the 14 articles was undertaken with six articles identified as having met the inclusion criteria. Studies reported within the six articles were conducted in the United States of America (Carpenter et al., 2009; O'Connor & McFadden, 2010), Australia (Annear et al., 2015, 2017; Baker et al., 2018) and the United Kingdom (Griffiths et al., 2018). Figure 1 outlines the article selection process.

There were five questionnaires described in the six articles: (1) the Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009), (2) the Dementia Attitudes Scale (O'Connor & McFadden, 2010), (3) the Dementia Knowledge Assessment Scale (Annear et al., 2015, 2017), (4) the Kids Insight into Dementia Survey (Baker et al., 2018) and (5) the Adolescent Attitudes towards Dementia Scale (Griffiths et al., 2018). None of the five existing questionnaires were considered suitable for current use. In particular, two questionnaires (Annear et al., 2015, 2017; Carpenter et al., 2009) only addressed knowledge of dementia, two were worded for use only with children or adolescents (Baker et al., 2018; Griffiths et al., 2018), and it was felt that the remaining one (O'Connor & McFadden, 2010) was not entirely consistent with the new era of support for people living with dementia. The reviewing team was concerned that consistent with the new era of support for people with dementia, items included in the questionnaire should be available for use within communities that include people living with dementia, those whose friends or relatives have been diagnosed with the condition and those who may be experiencing some symptoms (and therefore considering seeking a diagnosis). The reviewers were concerned that the item in the questionnaire developed by O'Connor and McFadden (2010) 'I am comfortable touching people with ADRD' was potentially offensive in this context. To a lesser extent, this was the case for the items: 'It is possible to enjoy interacting with people with ADRD' and 'People with ADRD can feel when others are kind to them'. Use of the term 'difficult behaviours' was similarly of concern, with 'responsive behaviours' now widely recognised as more appropriate (Herron & Wrathall, 2018). However, a review of the established questionnaire domains provided the initial basis for further questionnaire development.

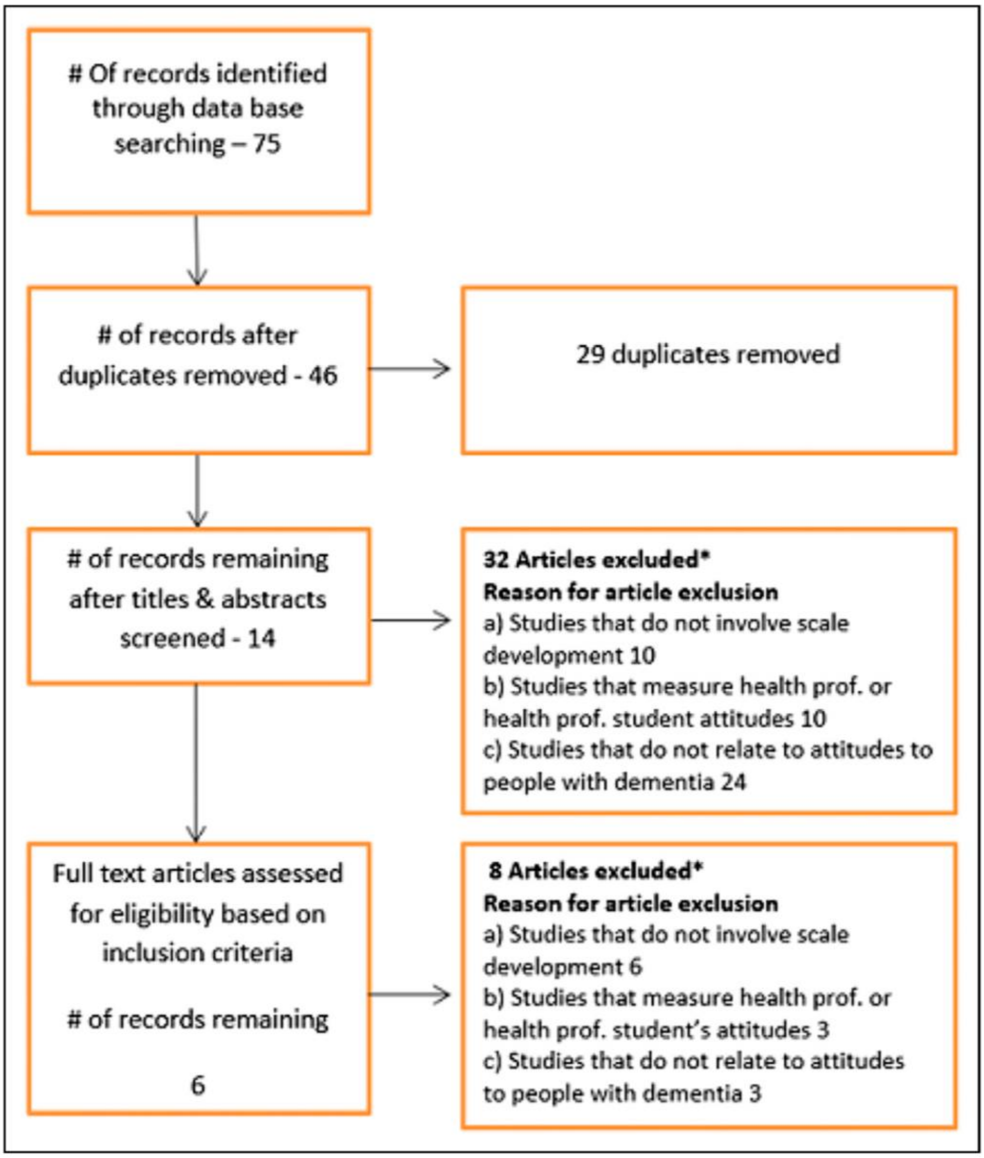

Figure 1. Literature search flow – scoping review. *Please note that some articles were omitted during the screening process for more than one reason; therefore, the number of excluded articles does not equal the number of articles detailing their reason for exclusion.

Stage 2 questionnaire development and initial review

Aim

The aim of Stage 2 was to develop a new questionnaire measuring community attitudes towards people with dementia.

Method

Content development. Relevant domains addressed in the reviewed questionnaires were considered in relation to the current context of living with dementia (as outlined in the background to the study) and the related use of language and terminology. The following domains were considered to be relevant to a new measure of community attitudes towards people living with dementia: knowledge and understanding (Baker et al., 2018; O'Connor & McFadden, 2010), personhood (Baker et al., 2018), treatment and management (Carpenter et al., 2009); care considerations (Annear et al., 2017), caregiving (Carpenter et al., 2009), stigma (Baker et al., 2018), communication and behaviour (Annear et al., 2017), life impact (Carpenter et al., 2009), social comfort (O'Connor & McFadden, 2010) and perception of dementia and empathy (Griffiths et al., 2018). Each of these domains was also identified as related to at least one of the three components of attitude (affect, behaviour and cognition) (Breckler, 1984; Rosenberg, 1960). Items addressing each of these domains were developed for inclusion in a draft questionnaire that: (a) was considered brief enough to be feasible for use when evaluating community-based initiatives, such as public forums; (b) addressed the issues of the autonomy, independence and continued community involvement of people living with dementia and (c) used language specifically intended to avoid stigma or the causing of offence to people living with dementia or their families. 12 items were included in the resulting draft questionnaire.

Response scale. A 10-item Likert-type response scale was used. While providing participants with this number of response options can mean completing the questionnaire is more time consuming, it provides participants with greater opportunities to accurately indicate their point of view and allows for enhanced statistical analysis with the potential for a greater spread of scores and greater detection of a change in scores over time (Preston & Colman, 2000).

Expert reference group. Five nursing or allied health Australian researchers experienced in scale development and with knowledge of dementia were invited by email to participate in an expert reference group to assist in the development of the questionnaire. An information sheet and consent form were also included. The participants each provided a signed consent form to the researchers. The expert reference group members were asked to comment on the newly developed questionnaire's content validity and review each of the 12 questions for clarity and validity using an evaluation framework (Mastaglia et al., 2003). The expert reference group was also asked to comment on the appropriateness of scoring responses and whether the order of questions was suitable (Macnee, 2004; Mastaglia et al., 2003; Polit et al., 2001).

Results

Feedback provided by the expert reference group led to refinement of the draft questionnaire. Changes were made to Items 2, 5, 10, 11 and 12. Items 3 and 6 were reported to be similar to Items 4 and 5, respectively, and were removed from the questionnaire leaving 10 items following feedback from the expert reference group (see Table 1).

Table 1. Questionnaire item development.

Item no	Questionnaire items developed for expert review
1	I have some understanding of what it would be like to live with dementia
2	I recognise that symptoms of dementia extend beyond memory loss
3	There are a range of treatments that can reduce symptoms related to dementia
4[a]	Medication is the only treatment that can reduce symptoms of dementia
5	There are strategies that can help people with dementia manage their lives
6[a]	Memory aids are the only strategies that can help people with dementia
7	We all have the potential to improve the lives of people living with dementia
8	Supporting independence is one way to help a person living with dementia
9[a]	If a person has dementia, they need assistance all the time
10	People with dementia contribute a lot to our communities
11	People with dementia have the right to take part in discussions about their future
12	Obtaining a diagnosis of dementia can empower the person to plan for the future
Item no	**Adapted items following expert review**
1	I have an understanding of what it would be like to live with dementia
2	Symptoms of dementia extend beyond memory loss
3[a]	Medication is the only treatment that can reduce symptoms related to dementia
4	There are strategies that can help people with dementia in their everyday life
5	We all have the potential to improve the lives of people living with dementia
6	Supporting independence is one way to help a person living with dementia
7[a]	If a person has dementia, they need assistance all the time
8	People with dementia can contribute to our communities
9	People with dementia have the right to be involved in making decisions about their future
10	A diagnosis of dementia can assist the person with planning for the future

[a]Denotes items reverse scored as statements designated as incorrect.

Stage 3 questionnaire piloting

Aim

The aim of Stage 3 was to establish the questionnaire's face validity and ensure that the questionnaire items were easily understood by a range of people and acceptable to those living with dementia.

Method

Sampling. Ten members of the West Australian community, including two people with dementia, four care partners of people with dementia and four members of the community not directly related to someone with dementia, were invited to complete the draft questionnaire. Alzheimer's WA, a locally based community organisation, assisted in the recruitment of people with dementia and care partners. Participants were asked to read an information sheet about the study, which detailed what they would be required to do, and sign a consent form to signify their agreement to participate.

Data collection: cognitive interview verbal probing technique. The researcher asked the participants to first complete the questionnaire and then, using cognitive interviewing (Willis, 1994, 2005), went through the items with each participant using the pilot questions. The cognitive interview verbal probing technique was used as it was more suitable and potentially less complicated for participants with dementia (Willis, 1994, 2005). Participants were asked to comment on whether the questionnaire items were easy to understand, if items measured what was intended in their development, if any items were leading (prompted a person to respond in a particular way) (Denscombe, 2003) or were difficult to answer and if response options were appropriate (Macnee, 2004; Polit et al., 2001). Items 5 and 6 were reported to have leading content, and Item 9 was reported to be difficult to answer. Feedback on the formatting of the questionnaire provided by one participant with dementia also led to changes. These changes enhanced the usability of the questionnaire for people with cognitive impairment by refining the wording and how items were spaced throughout the questionnaire.

Results

Table 2 presents the 10 items as included in the Dementia Community Attitudes Questionnaire (DCAQ) after the refinements that followed piloting. The included items were mapped against the three components of the tripartite model of attitude (Breckler, 1984; Rosenberg, 1960) as well as the domains that were identified as relevant in the five existing questionnaires retrieved via the scoping review (Annear et al., 2015, 2017; Baker et al., 2018; Breckler, 1984; Carpenter et al., 2009; Griffiths et al., 2018; O'Connor & McFadden, 2010) (See Table 3).

Table 2. Questionnaire items included in the dementia community attitudes questionnaire after refinements following pilot testing.

Item no	Final questionnaire item
1	I have a good understanding of what it would be like to live with dementia
2[a]	The main symptom of dementia is always memory loss
3[a]	Medication is the only treatment that can reduce symptoms related to dementia
4	There is a range of strategies that can help people with dementia in their everyday life
5	I have the potential to improve the lives of people living with dementia
6	People with dementia can contribute substantially to their community
7	Maintaining independence is one way to help a person living with dementia
8[a]	People with dementia need assistance all of the time
9	People with dementia have the right to be involved in supported decision-making about their future
10	For people with symptoms of dementia, a diagnosis can inform planning for the future

[a] Denotes items reverse scored as statements designated as incorrect.

Table 3. Final questionnaire items and selected relevant domains from existing questionnaires mapped against the three components of attitude.

Attitude component	New questionnaire item	Domains from existing questionnaires
Affect	Item 1 I have a good understanding of what it would be like to live with dementia	Empathy/Life impact/Knowledge and understanding
Cognition	Item 2 The main symptom of dementia is always memory loss	Knowledge and understanding
	Item 3 Medication is the only treatment that can reduce symptoms related to dementia	Treatment and management/Life impact/ Knowledge and understanding
	Item 4 There is a range of strategies that can help people with dementia in their everyday life	Treatment and management/Life impact/ Knowledge and understanding
	Item 6 People with dementia can contribute substantially to their community	Care considerations/Social comfort/Life impact/Knowledge and understanding
	Item 8 People with dementia need assistance all of the time	Perceptions of dementia/Life impact/Stigma/ Personhood Knowledge and understanding
	Item 9 People with dementia have the right to be involved in supported decision-making about their future	Care considerations/Communication and behaviour/Personhood/Life impact/ Knowledge and understanding/Stigma
	Item 10 For people with symptoms of dementia, a diagnosis can inform planning for the future	Care considerations/Life Impact/ Communication and behaviour/Knowledge and understanding/Personhood
Behaviour	Item 5 I have the potential to improve the lives of people living with dementia	Knowledge and understanding/Perceptions of dementia/Social comfort/Life impact/Stigma
	Item 7 Maintaining independence is one way to help a person living with dementia	Care considerations/Life impact/Stigma/ Knowledge and understanding

Stage 4 preliminary psychometric testing

Aim

The aim of Stage 4 was to undertake preliminary psychometric testing of the DCAQ to help establish construct validity.

Method

Intervention. A facilitated dementia awareness raising public forum was held at an Australian University on 2 October 2019. The forum aimed to increase community awareness and understanding of living with dementia and, in this way, to have a positive impact upon attitudes towards people living with dementia. A description and evaluation of the forum is described elsewhere (paper under review).

Sampling. A convenience sample of participants was invited to attend the forum via email and social media.

Data collection. An information sheet and a copy of the questionnaire were provided to attendees upon their arrival at the forum. Using the newly developed 10-item questionnaire (paper and pencil format), data were collected from attendees prior to and following the forum. Attendees provided their consent to participate by completing the questionnaire.

Data analysis. Missing values were imputed for four participants (representing <1% of data) using the standard imputation procedure in the Statistical Package for Social Sciences (SPSS; IBM SPSS Statistics for Windows, version 25.0), which uses a regression-based approach. Exploratory factor analysis was conducted to identify constructs within the newly developed questionnaire. Pearson correlations were calculated from the data and items with a large number of low correlations $|r| < 0.3$ were excluded. Data were also screened for multicollinearity (i.e. high correlation between pairs of variables), with the determinant score (a check for multicollinearity) above 0.0001. Sampling adequacy (i.e. a test for determining whether the sample size is large enough) was assessed using the Kaiser–Meyer–Olkin test (KMO = 0.86, with KMO values >0.5 indicating a sufficient sample size), and Bartlett's test of sphericity was statistically significant ($p < 0.001$) indicating the data had a patterned relationship. Sampling adequacy was assessed on the diagonal element of the anti-correlation matrix, with all values >0.5. Communalities for all items were >0.2. The number of factors to extract was based on the number of factors with eigenvalues >1 (indicating that the factor explains more variance than a single variable) and through examination of the scree plot (a plot of the eigenvalue of each factor). Both orthogonal (varimax) and oblique rotations were evaluated (i.e. constraining the final solution to uncorrelated factor structure or allowing correlation between the factors), with the final solution fitted using an oblique rotation using the 'oblimin' procedure in SPSS. Reliability (internal consistency) coefficients using Cronbach's alpha were calculated for each of the extracted constructs.

Results

Questionnaire responses were from 92 out of a possible 112 people who attended the forum (82%). Of these 92 people, 75 were female and 17 were male and the age range was 22–82 years (M = 51.01, SD = 13.997).

Exploratory factor analysis. Table 4 presents the correlation matrix for all items from the questionnaire. Item 1 (understanding of what it would be like to live with dementia) did not correlate with

Table 4. Correlation matrix for questionnaire items.

Correlation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Q1										
Q2#	−0.11									
Q3#	0.09	0.51**								
Q4	0.13	0.19*	0.59**							
Q5	0.26**	0.21*	0.39**	0.62**						
Q6	0.18*	0.23*	0.42**	0.62**	0.63**					
Q7	0.18*	0.20*	0.37**	0.60**	0.58**	0.60**				
Q8#	−0.04	0.56**	0.65**	0.49**	0.42**	0.42**	0.40**			
Q9	0.08	0.27**	0.63**	0.58**	0.39**	0.45**	0.45**	0.51**		
Q10	−0.00	0.14	0.40**	0.29**	0.18*	0.19*	0.32**	0.29**	0.55**	

#Denotes questionnaire items that were reverse scored. *Denotes statistically significant correlations (one-tailed).
$^{*}p < 0.05$, $^{**}p < 0.01$.

Table 5. Factor loading pattern matrix.

Pattern matrix			
	Factor 1	Factor 2	Factor 3
Q2 The main symptom of dementia is always memory loss		0.973	
Q3 Medication is the only treatment that can reduce symptoms related to dementia		0.601	
Q4 There is a range of strategies that can help people with dementia in their everyday life	0.754		
Q5 I have the potential to improve the lives of people living with dementia	0.889		
Q6 People with dementia can contribute substantially to their community	0.870		
Q7 Maintaining independence is one way to help a person living with dementia	0.798		
Q8 People with dementia need assistance all of the time		0.720	
Q9 People with dementia have the right to be involved in supported decision-making about their future			0.667
Q10 For people with symptoms of dementia, a diagnosis can inform planning for the future			0.956

any other item at a level above $r > |0.3|$ and so was excluded from the factor analysis. The remaining nine items possessed communalities >0.67.

There were three factors with eigenvalues >1, which was consistent with examination of the scree plot, and explained 75.4% of the variance. The oblique rotation was deemed most interpretable (compared to the varimax rotation). The factor loadings from the pattern matrix are presented in Table 5, with loadings below 0.5 masked.

On review of item groups, Factor 1 was named Engagement and comprised items consistent with community engagement for people with dementia (recognition of the potential of people with dementia and of the role for the community to help ensure that this potential is reached). Factor 2 was titled Challenges and comprised items acknowledging that symptoms resulting from dementia require support and intervention. Factor 3 was termed Decision Making and comprised items relating to the desire of people with dementia to remain central to decision-making. Factor 3 contained fewer than three items but was retained as a factor because the pairwise correlations between the two items (Items 9 and 10) were greater than 0.5 (See Table 5). Reliability for each factor was acceptable (>0.7) to good (>0.8), with Cronbach's alpha for Factor 1 = 0.855, for Factor 2 = 0.785 and for Factor 3 = 0.709, albeit Factor 3 only contained 2 items (Boateng et al., 2018).

Discussion

This article describes the early development of the Dementia Community Attitudes Questionnaire to measure community attitudes towards people living with dementia. The questionnaire is sufficiently brief to be useful when evaluating community-based initiatives and aligns with the current and evolving paradigm of living with dementia. Consistent with this paradigm, the questionnaire also uses language deemed acceptable to people with the condition. The work followed a review of the literature that identified five dementia attitude or knowledge questionnaires, all of which encompassed some items deemed unsuitable for current use with adults in the general population to measure attitudes towards people with dementia. However, the work underpinning the existing questionnaires provided established domains that were relevant and valuable to the process of developing a new measure. The consultation that occurred with members of the expert reference group during questionnaire development and piloting by community members means that the new questionnaire is contemporary and suitable for use within the current context of living with dementia. Preliminary psychometric testing of the questionnaire has identified three factors explaining 75% of the variance. The first factor was titled 'Engagement', Factor two 'Challenges' and Factor three, 'Decision-making'. The items in the questionnaire were also consistent with the constructs of attitude (i.e. cognition, behaviour and affect) described in the tripartite framework (Breckler, 1984; Rosenberg, 1960).

Evidence suggests that adults in the general population tend to believe that only limited support can be offered to people with dementia once they are diagnosed and that doctors have been less inclined to diagnose dementia for this reason (Moore & Cahill, 2013). Policy makers and people working within the education sector who implement use of the questionnaire may develop a greater understanding of the extent to which this phenomenon (otherwise known as nihilism) exists (Pentzek et al., 2009) within the community, by noting participant responses to questionnaire items that suggest it is possible for a range of support to be offered to people once they are diagnosed. Broadening people's understanding about this dementia-related issue impacts on people's attitude to dementia and addresses the cognitive construct of attitude (Breckler, 1984).

In the longer term, the new questionnaire may be used as a tool to measure the impact of dementia-friendly communities on attitudes towards people living with dementia. An entire societal response is required to create dementia-friendly communities. Members of the community need to be aware that despite a dementia diagnosis, people diagnosed often retain functional capacity that is sufficient to enable their ongoing community participation, with support, if this is what they desire – at least for a lengthy period. Item 5 (I have the potential to improve the lives of people living with dementia) aims to measure people's awareness of the personal contribution they can make (with support as required) to ensure that people with dementia are included within the community. Item 6 (people with dementia can contribute substantially to their community) directly reflects a change in the paradigm of how we support people with dementia, recognising their right and capacity to remain active participants within the community if that is their desire (Heward et al., 2017; World Health Organisation, 2017).

There are study limitations that require consideration. Replication of the factor analysis using a confirmatory factor analysis approach within a larger sample is required to test the factor structure of the questionnaire, given the low sample size of the study. Furthermore, establishing convergent validity against other measures that use the same (or similar) constructs to determine a positive correlation would provide additional confirmation (Streiner & Norman, 2008). While Item 1 (I have a good understanding of what it would be like to live with dementia) on the questionnaire was deemed to be important as it aligned with the pre-established domain of empathy, the item was removed from the scale, given that its scores had low correlation with remaining questionnaire items. Future development of the questionnaire may seek to explore the domain of empathy, given its relevance to providing effective person-centred support to people with dementia (Ratka, 2018). As the third factor, 'Decision-making' encompassed only two items, additional items addressing this construct would be considered for inclusion in the future, given its relevance to the current human rights–focused approach in the support of people living with dementia. As the final version of the DCAQ consists of nine items, there is scope to add items without making the questionnaire too lengthy.

People with dementia have expressed the desire for continued self-determination (de Boer et al., 2012; Dening et al., 2013; Karel et al., 2007). How we assist people with dementia to sustain their independence requires the creation of new initiatives and environments that support autonomy (Ryan & Deci, 2017). Ongoing questionnaire development and standardised measures are required to evaluate the impact of new initiatives (Baker et al., 2018; Griffiths et al., 2018; Silverstein &

Sherman, 2010; Whitlatch et al., 2017). It is hoped that the DCAQ, following further psychometric testing and refinement, will assist in evaluating ongoing dementia awareness raising campaigns that aim to reduce dementia-related stigma and improve the attitude of people within the community towards people living with the condition.

Conclusion

The context of what it means to live with dementia is changing and, as such, a change in societal attitudes towards people with dementia is required. This study details the development of a Dementia Community Attitudes Questionnaire that is current, aligns with the new era of support for people living with dementia and aims to measure community attitudes to people living with the condition. Measuring the impact of awareness raising initiatives can help to guide what further information is required to continue to strive for attitude change and ensure that people with dementia are included within our communities.

Acknowledgements

We extend our thanks to members of the Expert Reference Group who kindly provided their time to review and assist in the development of the questionnaire. Associate Professor Anne Whitworth, Curtin University; Dr Claire Eccleston, University of Tasmania; Professor Lily Xiao, Flinders University; Dr Pam Nichols, Curtin University and Professor Yun-Hee Jeon, The University of Sydney. Similarly, our thanks also extend to those people within the West Australian community who kindly provided their time to assist in the piloting of the questionnaire and Diana Blackwood, faculty librarian for the School of Nursing, Midwifery and Paramedicine at Curtin University for her assistance throughout the study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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In summary, the DCAQ was implemented at the Dementia Awareness Raising Forum to investigate the effectiveness of the forum in positively changing community attitudes towards people living with dementia. Determining the usefulness, viewed as including feasibility as well as effectiveness of such interventions, to positively effect attitude change is vital to advancing the changing paradigm of how people with dementia can best be supported. The following sections provide more detailed information on the implementation of the Dementia Awareness Raising Forum (Study 4), allowing insight into its feasibility.

5.2 Implementation and Feasibility of the Dementia Awareness Raising Forum – Study 4

Research with well-publicised findings is required to broaden the community's understanding of what it means to live well with dementia. Disseminating research findings in a variety of formats is one approach to increase people’s understanding of this phenomenon and improve community attitudes towards people with this condition (Phillipson et al., 2016). Evaluating awareness-raising initiatives, specifically designed to provide the most up-to-date and accurate information available, is essential to establish their usefulness. Feasibility and effectiveness can both be viewed as aspects of usefulness in this context. As such, the forum’s feasibility, that is the practicality of such an approach, and its effect on attitudes towards people with dementia were explored. The forum was implemented and evaluated, documenting:

a) how potential attendees were identified and invited;
b) the forum’s organisation and components, namely, the presentations that were provided, and by whom;

c) who attended, including their demographic characteristics;
d) the process of data collection and analysis, and,
e) comparisons in DCAQ item scores from immediately before to immediately after the forum to evaluate elements of attitude change, and any variation in attitude change between people with or without prior dementia-related education.

The feasibility of this forum, that is how practical it was to reach the audience sought to attend and to hold the forum itself, is addressed in the Discussion section of this chapter, expanding on points (a), (b), and (c) above.

5.2.1 The Dementia Awareness Raising Forum

The forum was conducted in October 2019 at Curtin University, in partnership with the Curtin Ageing Research Network (a multidisciplinary collaboration of researchers at Curtin University), and Alzheimer's Western Australia (WA). The title of the forum was *Dementia: Living Well and Staying Connected*.

5.2.1.1 Identifying and inviting potential attendees

Invitations were sent via email to community members whose details were included in mailing lists held by Alzheimer's WA, other WA-based carers' support organisations, aged care advocacy groups, and Curtin University. Staff at Curtin University, alumni, and current students from the University's School of Nursing were also notified of the event. The first author's professional and organisational contacts were utilised to ensure that invitations also reached individuals who interacted through professional roles with people with dementia. Hence, employees of aged care community organisations and public and private hospitals also received event invitations via email.

5.2.1.2 Forum organisation and components

The event was organised in conjunction with the Curtin University Advancement Team, which manages event registrations, event promotion and catering. A briefing document (Appendix P) was provided to event speakers and staff from the University Advancement Team assigned to help organise the event. A short synopsis of the event (Appendix Q) was provided to the corporate events team for event promotion purposes. The corporate events team created an order of proceedings document that was designed for and issued to the facilitator of the event (Appendix R).

The facilitator of the event was tasked with the role of Master of Ceremonies and keeping the event’s proceedings as per the program schedule. The forum proceedings commenced with the facilitator welcoming attendees and running through housekeeping procedures. This was followed by a speech from the then incumbent Deputy Pro Vice-Chancellor for the Faculty of Health Sciences. Presentations were given by four speakers with expertise in the field of dementia care, and a person living with dementia via a pre-recorded video link. The biographies provided by each presenter at the time of the forum are included as Appendix S. Upon completion of speaker presentations, the facilitator commenced a panel discussion and a question-and-answer session (Refer to Figure 5.1 below) with a pre-determined panel discussion script (Appendix T).

Figure 5.1

Panel presentation at the Forum

The facilitator’s role here was to enable audience participation, using the script to manage the panel discussion if audience participation was not forthcoming. On completion of the question-and-answer session, the Facilitator/Master of Ceremonies delivered closing remarks. A summary of speaker presentations is provided in the following section.

Speaker 1 – Ms Daniella Greenwood

Ms Daniella Greenwood (Figure 5.2 below), was a dementia care and support consultant, published author and keynote speaker. The focus of Daniella’s presentation and contribution to the forum was on the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007; United Nations, 2006), and the dementia human rights movement. Daniella spoke of changing dementia-related paradigms and the move away from a paternalistic viewpoint where decisions are made on behalf of people with dementia to one of empowering the person with autonomous supported decision-making (Cognitive Decline Partnership Centre, 2018).

Figure 5.2

Daniella Greenwood presenting at the Forum

Speaker 2 –Ms Sheridan Read

Ms Sheridan Read (Figure 5.3 below), was the primary researcher and PhD candidate for the research reported in this thesis. Sheridan’s presentation detailed some of her PhD study findings including the experiences of people with dementia from the onset of their diagnosis, their future expectations, what it means to be living with dementia within the current context and how best to support people living with the condition. The presentation (Appendix U) included the consumer voice through a pre-recorded video link. Dennis (a person living with dementia) spoke of his experiences with having the condition.

Figure 5.3

Sheridan Read presenting at the Forum

Speaker 3 – Dr Maria Foundas

Dr Maria Foundas was at the time of the forum a Consultant in Aged Care and Rehabilitation. Maria's presentation at the forum detailed new knowledge in early diagnosis. The presentation included the importance of early diagnosis of dementia so that a person can, a) seek information and support, b) identify strategies to maintain function and independence in the community, and c) access medication that may help.

Speaker 4 – Mr Jason Burton

Mr Jason Burton (Figure 5.4 below), at the time of the forum, was the Head of Dementia Practice and Innovation at Alzheimer's WA. The detail presented by Jason at the forum focussed on the person-centred care philosophy and emphasised that rather than a model of care this approach was instead a way of thinking. Jason described how the well-being of people with dementia could be better supported through use of the Eden Alternative Domains of Well-being (Power, 2014, 2017).

Figure 5.4

Jason Burton presenting at the Forum

5.2.2 Implementation of the Dementia Community Attitudes Questionnaire

5.2.2.1 Data collection

Data were collected from forum attendees using the newly developed questionnaire (Appendix V) both before and after the forum. Participants were asked to provide demographic details as part of the questionnaire and indicate if they had any dementia-related education, either formal or informal; or any dementia-related experience, as someone living with dementia or knowing/supporting a person with dementia. For each of the 10 items on the questionnaire, attendees were asked to rate their level of agreement or disagreement using the response scale where 1 represented a Strongly Disagree (SD) response and 10 represented a Strongly Agree (SA) response. Responses were non-identifiable as participants were not asked to record their names. However, data from each participant prior to and after the forum could be matched as both sets of questions were presented as separate sections in one document. Ethical approval was obtained from the Curtin University Human Research Ethics Committee. An information sheet, included as an appendix in

Chapter 2, explaining the purpose of the study, what was required of participants and that participation was voluntary was provided to attendees upon their arrival. Participants were advised of the consent process, with consent implied if participants returned the completed questionnaire at the end of the forum. Attendees were also provided with details of a counselling service that they could access through Alzheimer’s WA in case presentations or evaluation of the content raised concerns or created discomfort for them.

5.2.2.2 Analysing data

Data were entered into the Statistical Package for Social Sciences (SPSS) (IBM, 2011) version 5 for analysis. Descriptive statistics summarised the characteristics of attendees. The items that were negatively worded were reversed scored before analysis. Independent samples T-Tests were used to contrast baseline differences between participants ‘with’ versus ‘without’ dementia-related education. Two-way repeated-measures analysis of variance (ANOVA) was used to determine the overall effect of the intervention (intervention effect: pre- versus post-forum scores [within-subjects factor]), and whether there was an interaction of the intervention with education (comparing participants ‘with’ versus ‘without’ dementia education [between-subjects factor]). Missing data for the 10 questionnaire items comprised less than 1% of data for both the pre-test and post-test responses and were imputed using the standard imputation procedure in SPSS, which uses a regression-based approach (Dowrick et al., 2015). There was one participant with a missing value for the dementia-related education variable; this value was not imputed; the value was omitted from the analyses comparing those with pre-existing dementia-related education to those without. Alpha, used to determine whether the relationship between a set of variables is statistically significant, was set at a level of .05 (Polit & Beck, 2014).

5.2.2.3 Forum attendees

Questionnaire responses were received from 92 out of a total of 112 attendees, with an 82% response rate. Participants' ages ranged from 22 to 82 years (M = 51.01, SD = 14), there were 17 (18.5%) males and 75 (81.5%) females. When asked to detail dementia-related experience and education, 15.2% (n = 14) of respondents indicated having no dementia-related experience, with 35.9% (n = 33) indicating no dementia-related education. The respondents with a positive response to having dementia-related experience included, 1.1% (n = 1) indicating having dementia, 20.7% (n = 19) who knew someone with dementia, and 63% (n = 58) reported having a family member/friend experiencing dementia and/or supporting a person with dementia either at home or at work. With regards to dementia-related education, 63% (n = 48) reported formal work-related education, and 10.8% (n = 10) had received informal education to help them support family/friends with dementia. One of the survey respondents did not complete the question about dementia-related education.

5.2.2.4 Questionnaire scores at baseline

Table 5.1 (below) presents baseline item score means for participants with and without dementia-related education. Analysis indicated that people with dementia education scored significantly better on all items except for Item 10 (For people with symptoms of dementia, a diagnosis can inform planning for the future). There were no significant differences at baseline between male and female participants.

Table 5.1

Baseline questionnaire differences by education

	Participants with prior dementia-related education (n=58)		Participants with no dementia-related education (n=33)						
Question	Mean	Standard Deviation	Mean	Standard Deviation	Mean Diff	SD Diff	T – Value	P - Value	Confidence Interval
Q1. I have a good understanding of what it would be like to live with dementia	6.73	2.14	4.64	1.93	2.05	0.44	4.65	<0.001	1.17, 2.93
*Q2. The main symptom of dementia is always memory loss	5.69	2.74	4.45	1.89	1.24	0.49	2.53	.013	2.20, 0.27
*Q3. Medication is the only treatment that can reduce symptoms related to dementia	7.83	1.57	6.23	1.94	1.62	0.39	4.15	<0.001	2.40, 0.84
Q4. There is a range of strategies that can help people with dementia in their everyday life	9.22	1.01	7.74	1.85	1.45	0.34	4.21	<0.001	0.76, 2.15
Q5. I have the potential to improve the lives of people living with dementia	8.83	1.35	6.67	2.05	2.12	0.39	5.38	<0.001	1.33, 2.91
Q6. People with dementia can contribute substantially to their community	8.24	1.66	6.52	1.87	1.75	0.39	4.53	<0.001	0.98, 2.53

Question	Participants with prior dementia-related education (n=58) Mean	Participants with prior dementia-related education (n=58) Standard Deviation	Participants with no dementia-related education (n=33) Mean	Participants with no dementia-related education (n=33) Standard Deviation	Mean Diff	SD Diff	T – Value	P - Value	Confidence Interval
Q7. Maintaining independence is one way to help a person living with dementia	8.53	1.55	7.15	2.12	1.38	0.42	3.30	<0.002	0.54, 2.23
*Q8. People with dementia need assistance all of the time	6.88	1.87	5.72	1.71	1.17	0.40	2.96	<0.004	1.96, 0.38
Q9. People with dementia have the right to be involved in supported decision-making about their future	9.31	1.19	7.85	1.94	1.46	0.37	3.93	<0.001	0.71, 2.21
Q10. For people with symptoms of dementia, a diagnosis can inform planning for the future	8.74	1.74	8.61	1.34	0.14	0.33	0.41	0.68	-0.52, 0.83

Note: * denotes that the statement is designated incorrect

5.2.2.5 Pre- and post-forum comparisons

Table 5.2 (below) shows that the forum had a positive impact on the attitudes of attendees towards people with dementia, with scores for most items showing a statistically significant increase irrespective of the presence or absence of previous dementia-related education. Items 2 (The main symptom of dementia is always memory loss), 4 (There is a range of strategies that can help people with dementia in their everyday life), 5 (I have the potential to improve the lives of people with dementia), 6 (People with dementia can contribute substantially to their community), 7 (Maintaining independence is one way to help a person with dementia) and 9 (People with dementia have the right to be involved in supported decision-making about their future) demonstrated statistically significant interactions between time (pre versus post) and education. This indicated that forum attendees with no prior dementia education showed a greater improvement in post-forum scores compared to attendees with dementia education on these items. Only Item 8 (People with dementia need assistance all the time) did not show any significant improvement in main effect (0.12) or interaction effect (0.72). Item 4 (There is a range of strategies that can help people with dementia in their every-day life) showed significant improvement in interaction effect (0.035) only indicating that forum attendees with no prior dementia education showed a greater improvement in post-forum scores compared to attendees with dementia education on this item.

Table 5.2

Intervention and Interaction effect

	Time (Pre vs Post) – main effect of intervention					Time by Education – interaction effect				
Question	**df$_n$**	**df$_d$**	**F value**	**p value**	**Partial-η^2**	**df$_n$**	**df$_d$**	**F value**	**p value**	**Partial-η^2**
Q1. I have a good understanding of what it would be like to live with dementia	1	89	33.3	<0.001	0.27	1	89	3.4	0.068	0.037
Q2. The main symptom of dementia is always memory loss	1	89	16.0	<0.001	0.15	1	89	4.2	0.043	0.045
Q3. Medication is the only treatment that can reduce symptoms related to dementia	1	89	7.1	0.009	0.074	1	89	2.7	0.11	0.029
Q4. There is a range of strategies that can help people with dementia in their everyday life	1	89	3.0	0.087	0.033	1	89	4.6	0.035	0.049
Q5. I have the potential to improve the lives of people living with dementia	1	89	10.9	0.001	0.11	1	89	6.6	0.012	0.069
Q6. People with dementia can contribute substantially to their community	1	89	40.0	<0.001	0.31	1	89	4.6	0.035	0.049
Q7. Maintaining independence is one way to help a person living with dementia	1	89	47.2	<0.001	0.35	1	89	10.4	0.002	0.11
Q8. People with dementia need assistance all of the time	1	89	2.5	0.12	0.027	1	89	0.12	0.72	0.001

Question	Time (Pre vs Post) – main effect of intervention					Time by Education – interaction effect				
	df_n	df_d	F value	p value	Partial-η^2	df_n	df_d	F value	p value	Partial-η^2
Q9. People with dementia have the right to be involved in supported decision-making about their future	1	89	21.1	<0.001	0.19	1	89	14.9	<0.001	0.14
Q10. For people with symptoms of dementia, a diagnosis can inform planning for the future	1	89	15.0	<0.001	0.14	1	89	0.36	0.55	0.004

Note: * denotes that the statement is designated incorrect

5.3 Discussion

There is a multitude of ways in which to raise public awareness about a topic including the use of the media, conducting lecture and case presentations, posting information on online websites and using social media (Eberhardt et al., 2022; Larsen, 2022; Piniewski-Bond et al., 2003). Such initiatives are necessary to share research findings, engage members of the community about issues that need to be addressed, create new ways of thinking, provide networking opportunities, and facilitate the exchange of ideas and attitude change. Conducting public forums including those based within the university sector is also an effective way to do this and has the potential to attract a wide range of people who are interested in a topic (Sievert et al., 2018; Teteh et al., 2019). The Dementia Awareness Raising Forum conducted as part of the research proved to be of interest not only to people working in the healthcare industry but also to friends and relatives of people with dementia, with a person living with the condition also attending the event. The detailed proceedings at this facilitated event, with the distribution of event invitations to a wide cohort of people, as well as securing expert speakers demonstrate the potential feasibility of conducting such quality events to positively impact community attitudes toward people with dementia.

Evaluating awareness-raising initiatives is essential to determine their effectiveness and identify what knowledge people have about a particular health condition and what further information they may require to live well or assist others to do so (Grimmett et al., 2014; Larsen, 2022). Given that people with dementia were likely to attend the event it was imperative to have a measure that was contemporary and unlikely to be offensive, hence necessitating the development of the new Dementia Community Attitudes Questionnaire as outlined in Study 3. Similar to findings of a community program designed to improve knowledge on hepatitis B infection, directed toward new refugees in Australian communities (Sievert et al., 2018), the outcome of the evaluation reported in this thesis indicated that the forum was useful and had a positive impact. Only two items from the questionnaire, Item 4, included to determine whether participants thought there were strategies that could help people with dementia, and Item 8, ascertaining whether participants thought people with dementia need assistance all the time, showed no statistically significant main effect of the forum. The reason for the limited impact in these areas may relate to pre-existing knowledge levels of forum attendees, given the relatively high number of correct pre-forum responses, or to the limited coverage of this information during the forum. Item 4 did show a significant time-by-education interaction, meaning that forum attendees with no prior dementia education showed a greater improvement in post-forum scores compared to attendees with dementia education. This demonstrated further support for the effectiveness of the forum in positively changing community attitudes towards people with dementia.

Participants with no dementia-related education had significantly larger improvements in their scores post-forum compared to those with dementia education for Items 2 (The main symptom of dementia is always memory loss), 4 (There is a range of strategies that can help people with dementia in their everyday life), 5 (I have the potential to improve the lives of people with dementia), 6 (People with dementia can contribute substantially to their community), 7 (Maintaining independence is one way to help a person with dementia) and 9 (People with dementia have the right to be involved in supported decision-making about their future) (Table 5.2 - Intervention and Interaction effect). Participants with dementia-related education might be expected to have a better grasp of these issues than the group with no previous education, this was seemingly substantiated by the findings (Gazmararian et al., 2003). These items sought to measure people's awareness of what it means to be living with dementia today, while also addressing the benefits of community engagement and independence (Phillipson et al., 2019). Both topics were covered explicitly during the presentation by the four speakers and the person living with dementia. Including a person with dementia to provide a presentation allowed forum attendees to gain some insight into the lived experiences and ability of people living with the condition to contribute despite their dementia diagnosis. While not all people with dementia have functional capacity enabling their participation at community events, the study reported in this thesis has demonstrated that such consumer input is feasible. It is also pivotal in facilitating a change in community attitudes towards people with the condition as they demonstrate their capacity to engage in society (Phillipson et al., 2019). Similar initiatives conducted in the future would benefit from consumer representation in the planning of such events. This would give ownership to people with dementia and assist with ensuring the content delivered is politically correct and that their desire for self-determination is communicated.

To enhance community awareness and improve attitudes towards people with dementia information presented at community forums may need to target participants depending on their level of dementia-related education as a way of improving the usefulness of such events. Study findings reported in this thesis demonstrate that awareness-raising forums are feasible and that previous dementia-related knowledge influences attitude change. Hence, it is important to consider this aspect with targeted recruitment of forum attendees aligned with bespoke educational offerings. A focused approach, cognisant of forum attendee characteristics is likely to further improve forum effectiveness in positively impacting attitudes toward people living with dementia. Additionally, similar studies that include intervention comparison groups where participants receive one of two or more interventions (e.g., forum attendance, reading materials, web-based learning packages) and outcomes are compared can help to establish the most effective ways of changing community attitudes towards people living with dementia. A limitation of the evaluation in the present study was that, despite a robust development process, the new DCAQ requires further testing to confirm its psychometric properties. Due to the questionnaire's immaturity, mean and standard deviation differences for baseline item scores were calculated but not an overall sum of these scores (Dowrick et al., 2015). While Items 4 (There is a range of strategies that can help people with dementia in their everyday life), and 8 (People with dementia need assistance all of the time) showed no significant change for main effect, scores for these items did show some improvement post-forum meaning that a larger sample size may have resulted in significant change. Hence, further research is needed to explore these aspects using the newly developed DCAQ with larger sample populations.

There also needs to be some consideration of the limitations of the forum itself and whether the forum attendees were a true representation of the general population. While invitations were sent to community members whose details were included on mailing lists held by Alzheimer's WA, other WA-based carers' support organisations, and aged care advocacy groups, this would indicate that those community members may have some pre-existing knowledge about the topic due to their experience of living with the condition and may not necessarily include those community members who have no dementia experience or knowledge/education at all. A feasible strategy for the future would be to promote the event via alternative media sources, such as newspapers and online social media platforms that have the potential to attract a wider sector of the community with possibly less or no dementia-related knowledge or experience. While the forum did have a positive impact on changing community attitudes towards people with dementia, and the event was of a high calibre with event proceedings professionally conducted and with expert presenters, the event did require extensive networking and high-level organisational support to achieve this. Such support proved to be a strength in the study reported in this thesis and feasible in its context, however, lack of organisational event support and paucity of network contacts might prove to be a limitation in other settings. A mitigating strategy for future endeavours would be to include additional online forum accessibility to increase the number of attendees and recording of the event for asynchronous community viewing to enhance content exposure.

5.4 Conclusion

This chapter has highlighted that ongoing knowledge dissemination within the community about living well with dementia is critical to ensure that the autonomy of people with this condition is respected, support is provided appropriately, and community inclusion is demonstrated. Evaluation of the process of knowledge dissemination is essential to determine what further information people in the community need to ensure their understanding of what it means to live well with the condition. The dementia awareness-raising initiative detailed in this thesis demonstrated a positive attitude change and was evaluated using the newly developed DCAQ, designed using language acceptable to people with the condition to not perpetuate dementia-related stigma. While the Dementia Awareness Raising Forum resulted in positive attitude change, the content presented at future similar initiatives should ideally be targeted towards attendees based on their pre-existing knowledge and levels of previously obtained dementia-related education. Measures used to evaluate such awareness-raising initiatives need to a) align with contemporary thinking on how we can best support people with dementia and, b) be psychometrically sound. Chapter 6 will detail collated key findings of Studies 1 to 4 and the integrative literature review set within the context of the self-determination and person-centred care theories. Recommendations for research, education, policy and clinical practice on how best to support people with dementia within the 21st century are also provided.

Chapter 6

Discussion

The purpose of this chapter is to bring to the fore and inter-relate key findings from Studies 1 to 4 (detailed in Chapters 3 and 5 respectively) and the integrative literature review (detailed in Chapter 4), highlighting the new knowledge that has emerged to support care provision to and inclusion of people with dementia. The chapter also identifies the strengths and limitations of the research and provides appropriate recommendations, directed at people working in research, education, policy development and clinical practice. In response to a person with dementia's desire for sustained normalcy and quality of life, as identified throughout the conduct of this research, the application of two theories, the Theory of Self-Determination and the theory of Person-Centred Care, has been deemed to be relevant and will be discussed in the following sections. Suggestions are raised for how care partners of people with dementia, health care professionals and the wider community can be informed and supported to assist people with dementia. The application of the findings from the study reported in this thesis expands the body of knowledge around how people with dementia can maintain their self-determination and consider their future care and support needs and are embedded throughout the discussion in this chapter.

6.1 Summary of Study Findings

The study detailed in this thesis explored the experiences and expectations of people with dementia, to identify how they would like to live their life into the future, to understand how they coped with the experience of a dementia diagnosis, and what the diagnosis meant in the context of them planning for their future

(Study 1). The neurodegenerative nature of dementia means that people diagnosed can remain self-determining for a time-limited period and are reliant on others to advocate for them into the future when their ability to be involved in decisions becomes constrained. This led to the conduct of Study 2 which sought to better understand the care partners' perspectives of the person with dementia's future expectations. The insight into care partners' level of awareness of the person with dementia's future care and support needs, and care partner preparedness for their future advocacy role was important to enable the provision of adequate support and appropriate care across the dementia trajectory (Study 2).

Findings from Study 1 and Study 2 were that participants with dementia and their care partners had very little understanding of what to expect following receipt of a dementia diagnosis and consequently were unprepared to plan for their future (Read et al., 2016; Read et al., 2020). An integrative literature review was then completed to evaluate current evidence of the involvement of people with dementia in planning their care and support. The review was particularly interested in research where people with dementia provided data as research participants and unfortunately demonstrated little evidence of people with dementia's participation in care and support planning in this context. This highlighted the need to inform health care professionals, researchers and community members of the capacity of people living with the condition to continue to be self-determining and to participate in planning for their future care (Read et al., 2016, 2018). To overcome the exclusion experienced by people with dementia and promote a collaborative and person-centred approach to service development, a Dementia Awareness Raising Forum was conducted and evaluated to determine its usefulness in bringing about more positive community attitudes towards people with dementia (Study 4). As no suitable tool was found to assist with the evaluation of the forum, the Dementia Community Attitudes Questionnaire (DCAQ) was developed (Study 3) for this purpose.

‘Maintaining Normalcy and Quality of Life’ was a theme that unfolded throughout this research as people with dementia sought to continue being self-determining and ensuring a connection to their pre-diagnosis lifestyle. Care partners of people with dementia, health professionals, and the wider community were identified as key stakeholders to enable people with dementia to remain self-determining. The relationship between the person with dementia and their care partner was identified to be a significant factor impacting the process of the person maintaining self-determination (Read et al., 2020). Stigmatising attitudes of health professionals influenced their willingness to assist people with dementia to maintain self-determination and a degree of normalcy in navigating the course of their lives. This in turn influences how people with dementia view themselves and their lifestyle, and how people within the community treat people with the condition (Gove et al., 2016; Gove et al., 2017; Piver et al., 2013; Read et al., 2016). Dementia-related stigma is an important consideration as it leads to a negative stereotyped portrayal of people living with the condition and influences the degree to which they are provided with opportunities for self-determination and whether the care they receive is person-centred (Low & Purwaningrum, 2020; Read et al., 2016). Consequently, the theories of self-determination and person-centred care were applicable to the study findings and their application is detailed in the following sections.

6.2 Application of the Theories of Self-Determination and Person-Centred Care

Sustained normalcy and quality of life encompassed people with dementia’s desire to remain connected to their pre-diagnosis lifestyle and hence, the relevance of the Self-Determination Theory. Application of the theory of Person-Centred Care was then deemed appropriate given that person-centred care is a mechanism by which to support a person with dementia's self-determination. Additionally, both these theories aligned with the paradigm shift of dementia care and support provision toward a human-rights focussed approach. Implications for clinical practice, policy, research and education, and recommendations for how to manage the dementia trajectory to improve a person with dementia's self-determination and assist them to live according to their wishes are considered within the context of these theories.

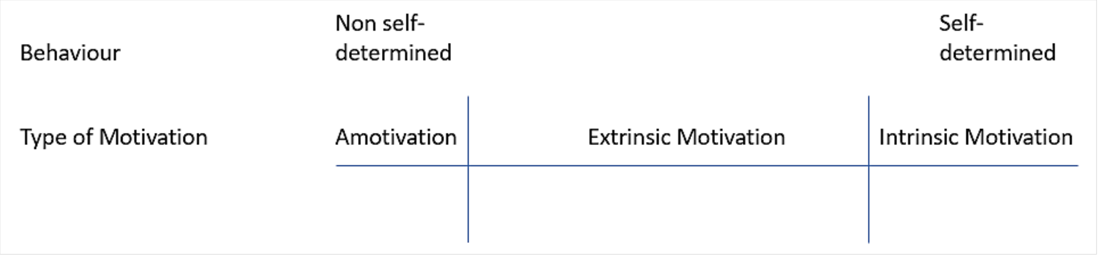
6.2.1 Self-Determination Theory

The Self-Determination Theory (SDT) formally introduced in the mid1980s by Edward L. Deci and Richard Ryan explores how motivation impacts human behaviour and identifies contextual factors that facilitate or undermine a person's capacity for self-regulation and having control over one's life (Dattilo et al., 2018; Deci, 1985; Ludvigsson et al., 2020; Ryan, 2017; Ryan & Deci, 2000b). The theory has been applied to various social contexts including those of older adults regarding their residence within nursing homes (Altintas et al., 2016; Ferrand et al., 2014; Kloos et al., 2019), their participation in exercise programs (Jones et al., 2020; Lee et al., 2017), and influenza prevention (Chung et al., 2017), their experience of homelessness (Dennis et al., 2012) and the older person's challenges to ageing, adaption, and leisure (Dattilo et al., 2018). The application of the Self-Determination Theory to this research is relevant given that the findings of Study 1 demonstrated people with dementia's desire for sustained normalcy and quality of life, connection to their pre-diagnosis lifestyle, and sustained self-determination at least for a time-limited period (Read et al., 2016). Application of the theory is necessary to assist care partners and health professionals with the knowledge required to provide person-centred support and assist a person with dementia to maintain self-determination and quality of life (Reeves et al., 2008).

The Self-Determination Theory assumes that humans are curious, active, and social beings and this does not necessarily change for people living with a dementia diagnosis (Deci, 1985; Read et al., 2016). It suggests that a person’s behaviour is dependent on how they are motivated. When applied to the context of supporting a person with dementia and in light of findings from Studies 1 and 2, a person with dementia is potentially motivated by their desire to remain, where possible, self-determining and connected to their pre-diagnosis lifestyle. How people are motivated can be represented on a continuum, as depicted in Figure 6.1 that follows.

Figure 6.1

The Self-Determination Continuum



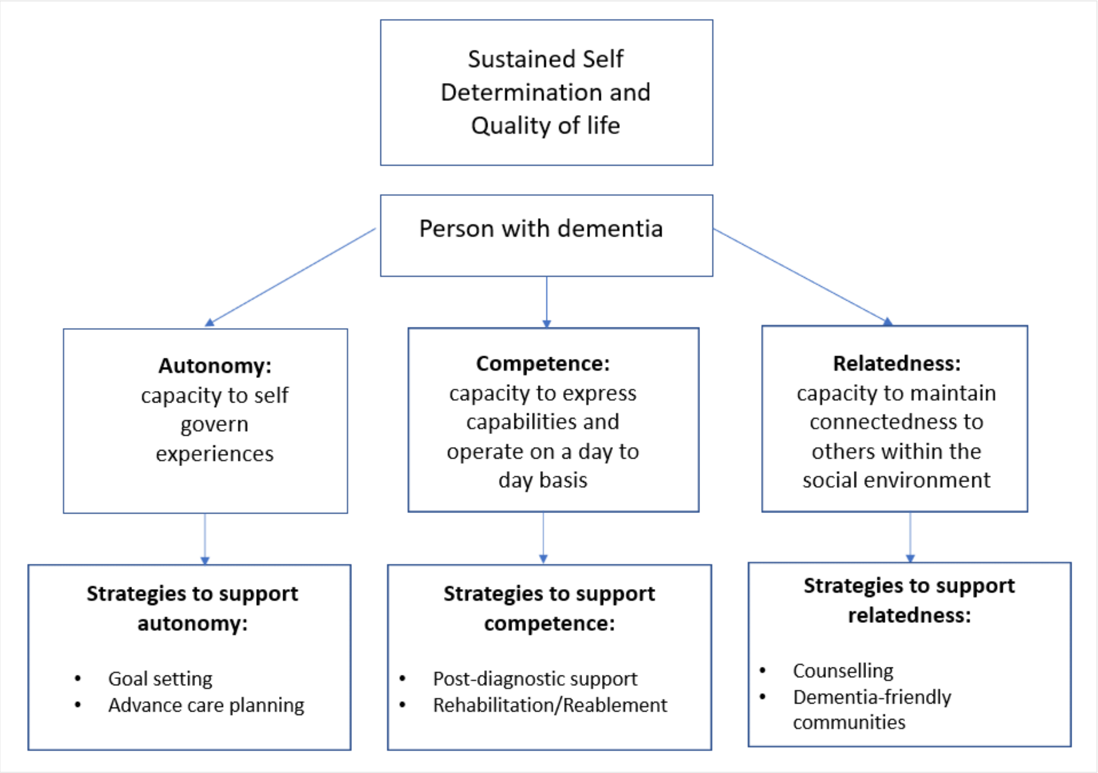
Note. This figure details the self-determination continuum showing the type of motivation and the behaviour a person may be demonstrating. Adapted from “The "What" and "Why" of Goal Pursuits: Human Needs and the Self-Determination of Behaviour,” by E. L. Deci, & R. M. Ryan, 2000, Psychological Inquiry, 11(4), p.227 (https://doi.org/10.1207/S15327965PLI1104_01).

Amotivation, at one end of the continuum, represents a person’s lack of motivation, they appear disinterested and lack any intent to engage in an activity. Extrinsic motivation, in the middle of the continuum, occurs when a person expects a reward or result from completing an activity, such as obtaining respect from others, improving the way they look, or attaining a good health status. Extrinsically motivated people are less likely to maintain a commitment to changing their behaviour (Deci & Ryan, 2000; Ryan & Deci, 2000b). Intrinsic motivation, however, the most self-determined motivation, is situated on the right-hand side of the continuum and occurs when a person receives a sense of satisfaction and enjoyment from completing an activity. People who are intrinsically motivated experience personal growth and well-being and, are more likely to feel competent and cope well. Assisting a person with dementia to sustain intrinsic motivation means they are more likely to work towards sustaining a connection to their pre-diagnosis lifestyle. Intrinsic motivation is sustained when a person's three psychological needs for autonomy, competence, and relatedness are met (Deci, 1985; Deci & Ryan, 2000; Ryan, 2017; Ryan & Deci, 2000a, 2000b). How well a person with dementia is able to meet these psychological needs is dependent upon both the physical and social environment in which they are situated. An environment that does not facilitate fulfilment of these psychological needs means a person's capacity to perform well is impaired, they are more likely to experience amotivation and physical and mental ill-being.

The three psychological needs of autonomy, competence, and relatedness are required to uphold a person's quality of life and well-being as they engage in the world around them. In the context of supporting people with dementia, as identified within Study 1 findings, these psychological needs contribute to their capacity for self-determination and sustained normalcy and quality of life (Deci, 1985; Read et al., 2016; Ryan, 2017; Ryan & Deci, 2000b). The very nature of a dementia diagnosis means that people with the condition experience cognitive decline, with a diminishing capacity to complete tasks and relate to others. The result is that their level of competency and safety is then questioned by others, causing carers to exert control over people with dementia in their homes or highly regulated institutional residential care environments. Such controlled environments mean a person with dementia is forced to relinquish their autonomy leading to emotional dysregulation, helplessness and amotivation. Application of the Self-Determination Theory is necessary to help care partners of people with dementia and health professionals identify strategies in which they help the person meet their psychological needs of autonomy, competence and relatedness, maintain intrinsic motivation, self-determination and well-being. Figure 6.2 below outlines strategies to help enable a person with dementia to sustain self-determination.

Figure 6.2

Application of the Self-Determination Theory to support a person with dementia



Further detail on the strategies identified in this figure, that align with the principles of the Self-Determination Theory and how care partners, health professionals and the wider community can ensure a person with dementia's sustained self-determination is presented below and in section 6.3 of this chapter.

With the right physical and social environment and with people skilled in how best to support them, people with dementia can achieve wellness and good quality of life aligned to where they are in relation to the trajectory of their condition (Ryan, 2017).

6.2.1.1 The three psychological needs

Autonomy is a fundamental human right and is described as having the ability to, or perception of, self-governing experiences, behaving and engaging in decision-making, and maintaining control in a way that is congruent with interests or values. An autonomous person is more likely to be self-confident, perform better and sustain a change in their behaviour (Deci & Ryan, 2000; Ryan, 2017; United Nations, 2006). A person with dementia can for a time-limited period engage in decision-making and advance care planning about how they may wish to live their life and as such uphold their autonomy and quality of life (Read et al., 2016).

Competence refers to the capacity of a person to express their capabilities, feel effective, and operate on a day-to-day basis which is often stalled when challenges are overly difficult, and the physical and social environment is not conducive to success (Ryan, 2017). The capacity of a person with dementia to feel and be competent may be hindered not only by the physical and social environment but the neurodegenerative nature of the condition and over time their decreasing capacity to complete tasks as they used to (Duong et al., 2017). The implementation of strategies by the care partner and health professionals, including those that aid a person with dementia’s reablement and rehabilitation, is essential for the person with dementia to sustain feelings of competency and maintain a good quality of life for as long as is feasible.

The final psychological need of relatedness represents the capacity of a person to maintain and feel a sense of connectedness to others within the social environment, to form a group with, and be respected by, people with whom they associate (Ryan, 2017). Relatedness is an important consideration in the context of supporting people with dementia given that it indicates the need for a feeling of belonging and a sense of self-worth when interacting with others (Read et al., 2016; Roach & Drummond, 2014). It is important that communities are dementia-friendly and people within the community are trained in how best to communicate with and support people with dementia so that a person with dementia feels that sense of relatedness, are guided in ways that enhance their competency, have their psychological need upheld, and can sustain self-determination.

Assisting care partners, health professionals and the wider community to identify ways to support people with dementia through the lens of the Self-Determination Theory is necessary so they can assist those diagnosed with the condition to maintain their three psychological needs, achieving self-determination and well-being. In that way care and support principles can be formulated to inform best practice within the context of these psychological needs and given their centrality to autonomy and well-being, should continue to be considered within a person-centred care framework.

6.2.2 Theory of Person-Centred Care

The application of the Theory of Person-Centred Care to this research is relevant given that the very essence of a person with dementia’s desire to be self-determining and to remain connected to their pre-diagnosis lifestyle is that they are autonomous and central to decisions that concern them. Person-centred care and support provided to a person reflects their preferences, needs, and values and is a concept that has been adopted by a range of health professionals (Kittelson et al., 2020; Ranner et al., 2016; Santana, 2018). Person-centred practice is the basis for Principle 2 of the Code of Conduct for Nurses in Australia. It instructs that nurses partner with people and their care partners to enable shared decision-making and appropriate person-centred care and support that is based on evidence and safe standards of practice (Nursing and Midwifery Board of Australia, 2018). While the concept has been described using various terminology, such as patient-centred care (Scholl et al., 2014), the origins of the concept date back to 1961 with the work of psychologist Carl Rogers who used a person-centred approach in his psychotherapy and counselling (Rogers, 1961).

Within the context of supporting a person with dementia, as detailed in Chapter 1, the term Person-Centred Care was coined by the late social psychologist and gerontologist Professor Tom Kitwood who challenged the medical model approach to dementia care and support (Kitwood, 1993, 1997). Kitwood was the first to apply the concept of personhood to people with dementia. Personhood encompasses what it means to be a person and considers the uniqueness of each person that, (when acknowledged) enhances the person’s well-being. Kitwood (1997, p. 8) defines personhood as the “standing or status that is bestowed upon one human being, by others, in the context of a relationship and social being”. In his work, Kitwood looked to identify the relationship between the person with dementia and those around them, and the behaviours exhibited by the health care professional that would be detrimental to or enhance the person with dementia’s well-being.

‘Malignant social psychology’ is a term Kitwood (1997, p. 8) used to describe the depersonalised ways in which other people engaged with people with dementia, for example, disempowerment, denying the person with dementia opportunities to use their unique remaining functional abilities. Kitwood recognised the necessity of considering the person with dementia’s psychological needs including, their need for trust from others, security, inclusivity, opportunities to engage in occupations necessary for normal life and to uphold their identity in order to help overcome their inability to meet these needs themselves (Kitwood, 1997). While Kitwood founded his theory through the observation of people with dementia in residential care settings, the theory of person-centred care is transferable to all people living with a dementia diagnosis. This is evidenced by the experience of participants in the study reported in this thesis of being undermined and under-acknowledged when consulting with their doctor (Read et al., 2016). Health professionals when considering the personhood of care recipients should ensure the person’s right to self-determination is respected and that the care they provide is person-centred.

While the work of Kitwood laid the foundation for the development of the VIPs model (Brooker, 2003, 2007), presented in Chapter 1, where person-centred care was further defined, other frameworks have been created highlighting the importance of providing a person-centred care approach. For example, the Senses framework was developed to enhance care for older people (Nolan et al., 2006; Nolan et al., 2004). The principles of the framework are applicable across a range of settings and transferable to people living with dementia considering their need for security, continuity, belonging, purpose, significance, and fulfillment in life (Gillis et al., 2019; Nolan et al., 2006; Stewart et al., 2022). The framework aims to provide optimal care to the older person and considers their self-determination and involvement in care and support goals and evaluation of agreed plans of care. The significance of the framework, however, is that it extends to consider the needs of the care partner and older person within a dyadic relationship and that of the health professional, in the triadic relationship. The relationship between the older person, care partner and health professional is considered in order to ensure optimal care and support is provided to the older person and that their self-determination is sustained (Nolan et al., 2006; Nolan et al., 2004). Similarly, further work in the area by McCormack and McCance (2006) explored person-centred care in the hospital setting and identified the attributes of the nurse including their communication skills and commitment to the profession as important. A care environment that facilitates a person's self-determination through shared decision-making and values the person's perspective to ensure their well-being and satisfaction with care is also necessary (McCormack & McCance, 2006).

6.3 Application of Theories and Recommendations for Practice

Considering the Theory of Person-Centred Care and support within the context of the Self-Determination Theory is critical as the degree to which a person with dementia values their autonomy and wishes to stay connected to their pre-diagnosis life may vary. Health professionals and service providers need to be person-centred in their approach, consider how each individual is motivated and partner with them to identify how they want to live their lives (Clare, 2017; Clare et al., 2011). How care partners of people with dementia, health professionals, and the greater community are supported to help people living with the condition remain self-determining with sustained quality of life and contribute to the ongoing paradigm shift in the way that people with dementia are supported, needs further consideration, and is detailed in the following sections.

6.3.1 Dementia dyad

A dyad is a relationship between two individuals such as in the case of a person with dementia and their care partner (Martire et al., 2010). The experience of living with a dementia diagnosis, or caring for someone living with the condition, can result in a decrease in quality of life over the course of the dementia trajectory, especially considering the cognitive impairment a person with dementia experiences as they seek to sustain self-determination, and the impact this has on their care partner (Bonds et al., 2021).

Care partners' capacity to advocate on behalf of a person with dementia, when the person can no longer make decisions or advocate for themselves, is dependent upon the dyadic relationship they have with the person, the type and duration of the relationship, how well they know the person, including how decisions are made and the communication that takes place within that relationship (Read et al., 2020). Characteristics of the dyadic relationship may affect relationship-related outcomes such as quality of life and capacity to cope with life stressors (Feeney & Collins, 2015; Randall & Bodenmann, 2017; Sbarra & Coan, 2018). This has significant implications for the person with dementia and their care partner given the progressive nature of a dementia diagnosis and the change in their roles that becomes evident as the person diagnosed experiences cognitive decline (Quinn et al., 2013; Read et al., 2020; Stockwell-Smith et al., 2019). How care partners relate and interact with the person impacts their capacity to provide person-centred support and assist the person with dementia to maintain self-determination (Read et al., 2020).

6.3.1.1 Relatedness and the dementia dyad

The level of relatedness between a person with dementia and their care partner is crucial. Open communication assists the care partner to ascertain the person with dementia’s future care and support expectations and enable their sustained autonomy and self-determination into the future. New knowledge generated within Study 2 findings suggests that care partners may be under-prepared to advocate for the person, not knowing their future expectations and potentially making decisions on their behalf that do not align with their wishes (Read et al., 2020). Counselling-based interventions designed for people with dementia and their care partners are required that strengthen their relationship upon receipt of the diagnosis and encourage their consideration of long-term advance care planning (Ashton et al., 2011; Ashton et al., 2016; Moon & Adams, 2013; Orsulic-Jeras et al., 2019; Read et al., 2020; Whitlatch, 2011). Completion of advance care plans by a person with dementia soon after diagnosis, while their decision-making remains intact, outlines how they wish to live their life and supports their self-determination over the longer term (Poppe et al., 2013). Completion of such documentation means the care partner will have the required information to deliver person-centred support, seeking assistance from health care professionals as and when required. Care partners will then be better prepared to advocate for the person with dementia’s self-determination with ease, limiting their potential experience of stress or burden. Such interventions are necessary given that dementia dyads are unclear as to what to expect in the future and are often unaware of the support that can be provided (Górska et al., 2018; Macleod et al., 2017; Peel & Harding, 2014).

6.3.1.2 Communication and implications for self-determination

An impaired ability to communicate can severely affect a person with dementia’s capacity to convey decisions and remain self-determining. The process of communication is two-way whereby people exchange information through both verbal and non-verbal means. Due to the neurodegenerative nature of dementia, communicating becomes difficult for a person who is diagnosed resulting in an impaired ability to find words, express sounds, comprehend information, initiate conversation, and form ideas (Downs & Collins, 2015). Such communication deficits may impact a person with dementia’s relationships, participation in social activities, and experience of relatedness towards their care partner and other people within the community (Mioshi et al., 2013). There are strategies however that can be implemented by the care partner to help improve a person with dementia’s capacity to communicate their needs including the use of short sentences, appropriate body language, and limiting environmental distractions (Conway & Chenery, 2016). Implementation of such strategies is essential for the care partner to implement to help ascertain the person with dementia’s future care and support expectations, so they can provide person-centred support and help the person sustain decision-making and self-determination.

6.3.1.3 Decision-making as key to autonomy and self-determination

Having the capacity for decision-making is key to autonomy and self-determination and a person’s fundamental human right (United Nations, 2006). People with dementia reportedly do wish to contribute to decision-making (Fetherstonhaugh et al., 2013) but due to the experience of cognitive decline another person will need to take on that responsibility at some point in time, usually their care partner. Decision-making on behalf of a person with dementia is a gradual process and progresses from supported decision-making whereby care partners provide people with dementia the information and time they need to make decisions, (Davidson et al., 2015) to substitute decision-making where care partners take on decisions that need to be made (Samsi & Manthorpe, 2013). Decision-making processes between the person with dementia and their care partner impact their dyadic relationship and may mean support is required, in particular for the care partner who seeks to facilitate a person with dementia’s right to autonomy and self-determination but ensures any risks are mitigated and they encounter no harm in the process (Beauchamp, 2019; Webb & Dening, 2016).

6.3.1.4 The care partner's role in sustaining competency

A person with dementia may experience disengagement upon diagnosis resulting in isolation and boredom (Cohen-Mansfield & Jensen, 2018). Care partners have a critical and complex role in supporting the person to overcome these experiences and assisting them to maintain meaningful activity and well-being. To do so care partners are required to determine the person with dementia’s level of functional capacity, which may vary from day to day, the amount of help they may require, and the level of safety needed (Oliveira et al., 2019). Care partners' involvement in establishing such details to empower the person with dementia is complex and means they may require education from a range of health care professionals. Further research is required in this space to explore the complexity of this care partner advocacy function and to identify the detailed information that care partners require to help the person with dementia maintain self-determination. The role of the health professional in supporting the dyad also needs further exploration to provide evidence to help support health care professionals’ dementia care practices.

6.3.2 Health care professionals

Health care professionals are key members of the community who can shape how people with dementia see themselves and how members of the wider community perceive those diagnosed with the condition. It is therefore pivotal to examine the attitudes of health care professionals towards people with dementia, determine their knowledge of dementia and how they relate to people with the condition to enhance their ability to facilitate the person with dementia's self-determination.

6.3.2.1 Enhancing relatedness

It is crucial that people with dementia and their care partners are offered post-diagnostic support on receipt of the diagnosis. This will help the person with dementia overcome the challenges they experience in maintaining their self-determination. It will also ensure that care partners are supported as they assist the person with dementia to remain self-determining (Read et al., 2016; Read et al., 2020). The relatedness between a person with dementia, their care partner, and health professional is a key consideration in the person with dementia and their care partner understanding not only the condition but what they need to do to live well. Health care professionals need to counsel both people with dementia and their care partners upon receipt of their diagnosis to enable the person with dementia to self-manage their diagnosis and the care partner to support them as this becomes necessary. The process commences with the health care professional assisting the person with dementia and their care partner to identify their information needs during the process of providing the dementia diagnosis and detailing a likely condition trajectory to help with preparing for what to expect in the future.

6.3.2.2 Continuing the shift to Person-Centred Care

Historically, a medical model approach to treating someone with dementia tended to centre on the degenerative nature of the brain first whereby a person with dementia was judged by their declining functional ability (Kitwood, 1988). In line with the evolving paradigm of how people with dementia are best supported, there needs to be a continued shift in what was previously a paternalistic approach adopted by health professionals to one that is collaborative to ensure the person's needs are met. Health professionals need to continue to provide care and support that is person-centred, and strengths-based, considering the person's remaining functional capacity and capability to remain self-determining and participate in their care and support planning. Person-centred collaborative care means that the person with dementia is consulted, they are provided with information about what to expect in the future and assisted with decision-making so that their autonomy is maintained and, the care and support provided reflect their wishes (Fazio et al., 2018; van Lieshout et al., 2015). How people with dementia respond to the services they receive, if services help to sustain their self-determination and quality of life, how best to engage the person with dementia in this process and the impact this has on their care partner needs to be further explored (Morrisby et al., 2021; St-Amant et al., 2012) to enable ongoing improvements to dementia care provision.

6.3.2.3 Early diagnosis to support self-determination

Research that investigates mechanisms to support a timely diagnosis by physicians is critical. Receiving an early diagnosis will assist people with dementia to work towards acceptance of their diagnosis, provide an opportunity to consider their future care and support needs, and assist them to maintain self-determination over the longer term. It will also allow more time, prior to cognitive decline, for open communication between the person with dementia and their care partner to establish care and support preferences. Care partners will then have the required information to advocate on the person with dementia's behalf when they can no longer do so for themselves and help the person maintain self-determination over a longer period into the future (Milne, 2010; Read et al., 2016).

6.3.2.4 Stigma impacting self-determination

Stigmatising beliefs and attitudes of some doctors mean they tend to delay diagnosing dementia or fail to discuss it out of concern for the welfare of their patients (Gove et al., 2016; McLaughlin & Laird, 2020). There is a tendency for some doctors to believe that there is little that can be done to support the person once they are diagnosed which impacts on the person with dementia's coping ability, opportunity for self-determination and their preparation for the future (Gove et al., 2016; McLaughlin & Laird, 2020). Furthermore, studies have demonstrated that there are doctors who believe that people with dementia will be devalued by society, discriminated against and as such have little quality of life (Gove et al., 2016; Gove et al., 2017; McLaughlin & Laird, 2020). Such views, albeit with a protective intent, have the potential to hinder care provision and increase experiences of dementia-related stigma. These negative views need to be overcome so that health professionals can better support people with dementia and their care partners to obtain ongoing optimal quality of life (Cations et al., 2020; Walmsley & McCormack, 2016).

6.3.2.5 Self-management programs enhancing self-determination

Self-management programs are those that educate, assist, and empower the person with dementia to sustain self-efficacy and self-determination, including their competency to maintain day-to-day roles and live well (Laakkonen et al., 2016; Mountain, 2017; Mountain & Craig, 2012). A person with dementia who self-manages their diagnosis maintains their autonomy through making necessary lifestyle decisions that centre around how they wish to live their life, such as engaging in activities that limit their stress. One such program is the SHARE (Support, Health, Activities, Resources, and Education) program for people with dementia and their care partners where a person with dementia's present and future care values are explored through a counselling-based care planning initiative. Study findings indicate that the SHARE program is a feasible way for a person with dementia to engage in future care planning. The program facilitates improved communication between the person with dementia and their care partner and increases the dyad's health literacy enhancing their dementia-related knowledge including knowledge of resources that are available to help them (Orsulic-Jeras et al., 2019).

6.3.2.6 Goal setting as a tool for self-determination and person-centred care

Future care planning by the person with dementia in consultation with their health professionals can be carried out within the context of goal setting to facilitate self-determination and person-centred care. The goal attainment scale can be used by the health professional to elicit and measure personal goals established by the person with dementia. Goals to improve quality of life and sustain self-determination might include strategies to continue living at home or remaining in the workforce, enhancing mental stimulation and physical activity (Jennings et al., 2016; Jennings et al., 2018; Reus et al., 2016; Ritchie et al., 2018; Stamou et al., 2021). Enabling the person with dementia to set their own goal means that it will be more personally relevant and more easily achievable when the right support is provided (Clare et al., 2011). Once a person’s goals have been established health professionals and service providers can implement person-centred strategies that will enhance the person’s capacity to enable them to sustain self-determination and maintain a connection to their pre-diagnosis lifestyle, empowering care partners to assist them to do so (Edmunds et al., 2009; Lee et al., 2016).

6.3.2.7 Interventions to maintaining competency

Rehabilitation or reablement interventions, facilitated by the interprofessional healthcare team, are required to assist the person with dementia to maintain competency and as such self-determination for as long as is feasible. Such person-centred interventions are required when an individual experiences limitations to daily functioning due to a health condition, and aim to prevent or slow functional decline and improve or maintain functional capacity. Personal goals are established by the person with dementia and person-centred strategies, which are strengths-based, are implemented by the health care professional enabling the person with dementia to realistically live the life they want to lead. Strength-based strategies are those that consider a person’s remaining functional capacity. Furthermore, a person’s aspirations, reflected within the context of personally set goals to be achieved, are contemplated alongside their immediate environment, which provides the necessary resources and opportunities to live well (Rapp & Goscha, 2012). Strategies include skills training, modification of the home environment for ease of navigation, and the use of assistive technology, items that when used enable people with dementia to complete tasks independently (Aspinal et al., 2016; Australian Government Department of Health, 2020; Clare, 2017; Heinemann et al., 2020; Hobson, 2019; Jeon et al., 2017; Ryan, 2021). One such approach includes the I-Harp program (Interdisciplinary Home-based Reablement Program), which has shown positive results in goal attainment, improved mobility, and independence (Jeon et al., 2020). The program is primarily facilitated by occupational therapists and nurses but input from other members of the inter-professional team, such as physiotherapists, speech pathologists or psychologists occurs as required. The program uses the principles of person-centred care and aims to improve the person’s ability to care for themselves, exploring their cognitive and physical function, and the home environment. In addition, the program seeks to provide support to the person with dementia’s care partner. Similarly, the COPE program (Care of the Person with dementia in their Environments), facilitated by occupational therapists and nursing staff, aims to increase the person with dementia’s functionality with day-to-day tasks and decrease care partner burden (Gitlin et al., 2010). Such person-centred programs are strengths-based and transform the way in which care and support are provided to a person with dementia. The focus is on a person with dementia’s functional capacity rather than their functional decline.

6.3.2.8 Raising health professional awareness – post-diagnostic support

While it is crucial that people with dementia and their care partners are offered post-diagnostic support on receiving their diagnosis to help them maintain self-determination and good quality of life, health practitioners may be unaware of the support that is available or that rehabilitation intervention is achievable (Cations et al., 2020; Gresham et al., 2021). Further research is required to develop post-diagnostic dementia care and support pathways and build evidence of the effectiveness of programs that are strengths-based and work towards the reablement of a person with dementia. Such evidence will help transform health professionals' understanding of the benefits of goal-directed strengths-based programs, demonstrate their feasibility and assist health professionals to incorporate such measures into their care provision (Cations et al., 2018; Clare, 2017). How we educate health professionals and care partners about the care and support needs of people with dementia, and the post-diagnostic support that can be offered is critical to enabling them to help the person with dementia maintain self-determination. Health professionals acquiring such knowledge means that they will be better able to assist the person or refer them to alternative services to receive the help they require. Embedding information, detailing the post-diagnostic support that can be offered to a person with dementia, within university health professional curricula is essential to avoid the development of stereotypical attitudes that little can be done to support people with dementia. Furthermore, consumer involvement in curriculum development is also an important consideration that when implemented helps health care professionals see the person with dementia holistically and beyond their dementia diagnosis (Classen et al., 2021; Happell et al., 2019). Such initiatives, as demonstrated through the Dementia Awareness Raising Forum presented in Chapter 5, facilitate a paradigm shift, diminish attitudes of stigma, and transform how people with dementia are viewed and supported.

6.3.3 Community

Members of the wider community, including care partners and health professionals, play an integral part in helping a person with dementia sustain self-determination. Community attitudes towards people with dementia impact the degree to which communities include them socially and support them to live well. There is evidence to suggest that people within the wider community perceive the likelihood of stigma when asked how they thought they would feel if diagnosed with the condition (Piver et al., 2013). Care partners of people with the condition report feelings of shame and embarrassment, and experience stigma and carer burden simply by the association of supporting a person with the condition (Werner & Abojabel, 2019; Werner et al., 2012). Care partner experiences of stigma directed towards people with dementia were also confirmed in Study 2 findings reported in this thesis (Read et al., 2020). Consequently, people with dementia fail to seek formal and informal support from others, deny there is a health-related problem for fear of being judged by others and tend to sever ties with people they know leading to social isolation impacting their capacity for sustained normalcy and quality of life (Liang et al., 2021; Lopez et al., 2020; Sun et al., 2014; Werner et al., 2020). Friends and family of people with dementia tend to avoid them, lacking the capacity to relate to them due to their impaired cognition, further perpetuating the person's experience of social isolation (Sun et al., 2014; Werner et al., 2020).

6.3.3.1 Centrality of self-determination

Members of the community need to be informed that it is possible to live well with dementia with sustained self-determination at least for a time-limited period. Living well with dementia is dependent upon a person's outlook on life, and their overall health, and encompasses the person's continued connection to their pre-diagnosis lifestyle, social inclusion, and contribution to the community in some way (Clare et al., 2018; Quinn et al., 2022). Studies have demonstrated that community members fail to understand that dementia is not a natural part of ageing and modifying lifestyle habits, such as, eating a healthy diet, reduces your risk of developing the condition (Cations et al., 2018; Glynn et al., 2017; Reitz & Mayeux, 2014; Smith et al., 2014; Tan et al., 2012; Werner et al., 2015). Furthermore, as detailed in Chapter 1, some strategies can be implemented following receipt of a dementia diagnosis, such as music therapy, that enhances well-being (Holden et al., 2019). When community members, which include people living with dementia, are informed of what is possible they are more likely to collectively rally policy makers and governments to ensure action is taken and that people with dementia and their care partners are supported to live well (Lawlor, 2018). This has been demonstrated where increased awareness raising around cancer screening and treatment has led to improvements in public knowledge, increased preventative self-examination intervention, and improved help-seeking behaviours (Casey et al., 2010; McCullagh, 2005; Vasudev et al., 2004). Similar awareness raising around living well with dementia will help to shift the negative discourse that currently exists and improve care and research initiatives. This in turn will lead to earlier assessment and diagnosis and help improve the quality of life of people with the condition, enhancing their capacity to remain self-determining individuals for as long as possible (Lawlor, 2018).

6.3.3.2 Raising public awareness to support community inclusion and self-determination

Raising public awareness about dementia can be done in several ways and is a key factor in reducing associated stigma, improving community members' attitudes towards people with the condition and their willingness to support the person's sustained self-determination. The development and implementation of education curricula, targeted to address and raise awareness of dementia-related stigma is necessary and has proved successful (Herrmann et al., 2019). Conducting community awareness-raising forums is another way in which to increase dementia awareness (Daly et al., 2018; Lawlor, 2018). This has been demonstrated within Study 4 (albeit with some limitations) of the study reported in this thesis, through the implementation of a Dementia Awareness Raising Forum. The forum (reported in

Chapter 5) provided some insight into how useful such an event might be. Further studies have identified that contact with people with dementia improves people's attitudes towards people living with the condition (Cheston et al., 2019; Goldman & Trommer, 2019). Targeted public health dementia awareness campaigns led by people living with the condition, through film, the arts, and changing public policy have also proved to be effective (Hand, 2019; Phillipson et al., 2019; Prins et al., 2020; Reynolds et al., 2017; Stites et al., 2018). Evaluation of the usefulness of such initiatives, for example through the implementation of questionnaires designed in a way that is acceptable to people with the condition and that does not perpetuate dementia-related stigma is necessary. The new DCAQ, developed in this present study and reported on in Chapter 5 offers an instrument for exactly this purpose. While it requires further ratification of its psychometric properties, its usefulness in evaluating awareness-raising initiatives is clear. Such evaluations help determine what further information people require about dementia, so they can help facilitate a person with dementia's connection to their pre-diagnosis lifestyle and capacity for self-determination (Cowan, 2021; Heger et al., 2020; Lawlor, 2018).

6.3.3.3 People with dementia as educators

The involvement of people with dementia in education initiatives is a relatively new phenomenon and provides people living with the condition an opportunity for social inclusion, contribution to the community and self-determination (Russell, 2020). This is different to the field of mental health where the advantages of consumer involvement in education are well reported, particularly within the tertiary sector (Classen et al., 2021; Happell et al., 2019). A person with dementia choosing to educate and speak publicly upholds their autonomy, competence, and relatedness to others, and therefore, self-determination. It also assists with reconceptualising the way they see themselves and how they are perceived by others as they create new expressions of what it means to live with their disability, challenging stigma and discrimination (Anderson, 2006; Russell, 2020). The consumer as educator enhances participant empathy and knowledge to better engage with the person they are supporting and provide better person-centred care. The wider result is a community that has an improved holistic understanding of what it means to live with the condition (Classen et al., 2021) and subsequently fewer attitudes that perpetuate dementia-related stigma. Clinicians working in this space need to consider conducting forums, such as the one detailed in Chapter 5, to raise awareness about dementia by using presenters diagnosed with the condition (Phillipson et al., 2019) that can speak of their lived experiences.

6.3.3.4 Dementia-Friendly Communities enabling self-determination

Establishing Dementia Friendly Communities (DFC) is another way in which to raise dementia awareness and enable community members to assist people with dementia overcome negative experiences and ensure their social inclusion and self-determination. Communities that are dementia-friendly enable people with dementia to fulfill their potential and maintain independence as much as possible, and support care partners as they assist them to do so (Alzheimer's Disease International, 2016; Dröes et al., 2017). Such communities offer people with dementia activities and services that are responsive to their needs, challenge stigma and raise dementia awareness for community members, including employees of businesses and services (Darlington et al., 2021; Phillipson et al., 2019). The built environment within these communities promotes a person with dementia’s capacity for wayfinding and as such, their well-being (Boumans et al., 2022; Chaudhury, Cooke, et al., 2017; Fisher et al., 2018). Given the rising prevalence of dementia within our community, people diagnosed with the condition will become more visible to all members of the community (World Health Organisation, 2017). Consequently, additional government funding provided to community organisations that provides dementia advocacy and much-needed education to the community, such as Dementia Australia, is necessary so that they can continue to pursue the work they do in reducing dementia-related stigma and connecting with local government to establish communities that are dementia-friendly.

6.4 Strengths and Limitations

It is important to review the strengths and limitations of the study reported in this thesis to assist with considering its academic and scientific merit. This discussion has been arranged to reflect the qualitative and quantitative components of the study and is presented in the sections that follow.

6.4.1 Qualitative component – Studies 1 and 2

This research project has captured the voice of people with dementia and uncovered their future expectations which have previously been largely unknown. There has also been a similar paucity of information on the perspectives of the care partner on this matter. The study reported in this thesis has provided insight into this vital component given the advocacy role that care partners undertake on behalf of the person living with dementia. Care partner advocacy is essential for the person with dementia to sustain their autonomy over the longer term. Study 1 and Study 2 generated new knowledge and highlighted the limited awareness that people with dementia have about their future. This has been a significant finding in that it has raised the need to explore the preparedness of diagnosing physicians to disclose a likely dementia trajectory to people newly diagnosed. The contextual factors that impact the degree to which care partners understand the person with dementia's future expectations have also been highlighted as well as the evolving role of the care partner, reflected in the terminology change from carer to care partner.

A limitation of the studies reported in this thesis is that they are set within an Australian context. More research is required to ascertain how the context of the phenomena under study may vary with different cohorts of participants. For example, the relationship between the person with dementia and their care partner may vary amongst people from a cultural context that is different to Australia and consequently impact the awareness a care partner has about the person's expectations. The degree to which people with dementia and their care partner experience dementia-related stigma may differ from one culture to another impacting how they perceive their condition, the likelihood of them seeking support and the expectations they may have for the future. Exploring these variations in experiences is necessary so that appropriate support can be targeted to all people who are diagnosed while being regardful of their diversity. While this study has uncovered the perspectives of people with dementia and their care partners about experiences and expectations of planning for future care, it also identified the importance of understanding what health professionals feel a person with dementia needs and wants in the future. This aspect was beyond the remit of the study reported in this thesis and is recommended as a focus for future research to build on the new knowledge gained through the present study so that support initiatives can commence from the point of diagnosis.

6.4.2 Quantitative component – Studies 3 and 4

A strength of this research, evident within Study 3, encompassed the development of the Dementia Community Attitudes Questionnaire. As documented in Chapter 5, a rigorous developmental process was undertaken. The questionnaire was piloted by members of the community including both people with dementia and care partners to determine the tool's face validity. Careful consideration was given to the use of language within the tool so that it did not perpetuate dementia-related stigma and aligned with the changing paradigm of dementia support. Study 4 involved the implementation of the Dementia Awareness Raising Forum which provided some insight into how such events can help to positively change the attitudes of people within the community towards people living with dementia. The forum was of a high calibre with expert presenters and proved successful in changing community attitudes towards people living with the condition. The forum included participation by a person with dementia as a presenter which was pivotal in ensuring the lived experience was communicated to attendees. This consumer involvement helped to change attitudes towards people with dementia as it demonstrated to forum attendees their capacity to contribute meaningfully despite their dementia diagnosis.

While the Dementia Community Attitudes Questionnaire is a significant piece of work in helping to change the way people with dementia are perceived by others, it is newly developed and has undergone preliminary psychometric testing only. Further psychometric testing is required to ensure the tool is both valid and reliable and is well worth pursuing given the robust approach taken to its initial development and the need for carefully worded instruments to stymie dementia-related stigma. Implementation of the tool in different settings and contexts is necessary to determine the extent of the questionnaire's suitability. While the Dementia Awareness Raising Forum was shown to be effective in changing community attitudes toward people with dementia there needs to be some consideration that those people in attendance, who were seeking to identify contemporary ways of supporting people with dementia, were more likely to experience greater motivation in changing their mindset about this phenomenon. This also raises the question as to whether forum attendees were a true representation of the general population and the need to test such initiatives across a broader representation of community populations. Another possible limitation was the face-to-face delivery of the forum which might have limited community access. Further work is needed to determine if providing online access would ensure greater community attendance with potential attitude change across a wider cohort of people. Furthermore, more extensive exploration is needed into different types of awareness-raising initiatives to establish the extent to which they can positively shift attitudes towards people living with dementia and help to reduce stigma.

6.5 Implications and Recommendations

A summary of recommendations made across this thesis has been arranged as they apply to the areas of research, education, practice and policy, and are presented in the following sections.

6.5.1 Research

- Findings from the qualitative studies revealed an experience of perceiving reluctance of diagnosing doctors to provide information on what to expect with the condition. This left people with dementia and their care partners feeling unable to adequately anticipate and plan for their future undermining their capacity for sustained autonomy. While findings have placed the spotlight on doctors, research that explores health professionals’ preparedness to talk to people with dementia about what to expect in their future is needed as advance care planning is likely to involve an inter-professional health care team approach. Adequately prepared health professionals will enable newly diagnosed people to start to think about their possible dementia trajectory and commence future care planning as appropriate.

- Findings from Studies 1 and 2, reported in this thesis, uncovered limited awareness on the part of people with dementia and care partners about what to expect in the future. This in turn was found to result in an inadequate dialogue between the person living with the condition and their care partner about planning and support for their future. Continued research exploring early diagnosis is vital so that people diagnosed with dementia have an increased opportunity prior to significant cognitive decline to come to terms with their diagnosis, improve their health literacy and establish measures to ensure self-determination and maintain quality of life. Early diagnosis will support dialogue and planning between the person living with the condition and their care partner and help to strengthen the care partner's role in advocating on their behalf as this becomes necessary.
- People with dementia have disclosed a desire to stay connected to their pre-diagnosis lifestyle, with self-determination being central. It is necessary to evaluate services received by people with dementia to establish whether service providers grant service users the opportunity to indicate the services they need and whether these provide them with the necessary support to maintain their pre-diagnosis quality of life.
- Existing evidence has highlighted that some diagnosing physicians feel there is little that can be done to support people with dementia once they are diagnosed. This has the potential to leave the person with dementia feeling as

though there is little hope of any quality of life in the future. Establishing post-diagnostic support pathways and researching the effectiveness of such support (including reablement interventions) is necessary so that health care professionals can assist them as appropriate to support their ongoing quality of life and self-determination.

- A review of the literature conducted as part of Study 3, reported in this thesis, identified the lack of a suitable tool to measure community attitudes toward people with dementia. This led to the development of the Dementia Community Attitudes Questionnaire used to evaluate the Dementia Awareness Raising Forum conducted as part of this research. Further research to test and further establish the psychometric properties of the questionnaire is essential to confirm that the tool is valid and can reliably measure what it intends to. When these properties have been established, there are multiple lines of enquiry to follow, including whether or not attitude change can be sustained over time.
- The evaluation of the dementia awareness-raising initiative informed the likely usefulness of such events in terms of how feasible they might be and the extent to which they might change community attitudes towards people living with dementia. Further research is required to determine whether different types of awareness-raising initiatives prove more useful in positively shifting community attitudes to people with dementia. Awareness raising is important in reducing dementia-related stigma so that communities are more dementia-friendly and inclusive of people living with the condition.

6.5.2 Education

- As indicated in the previous section, the preparation of health care professionals to manage the diagnosis experience of people with dementia and assist them with advance care planning requires attention. Education initiatives that target the therapeutic nihilism experienced by health care professionals are necessary so that they have the required knowledge and skills to assist people with dementia to uphold their quality of life and maintain self-determination, aligned to participants' needs identified in Study 1, reported in this thesis.
- The desire for self-determination and connection to pre-diagnosis lifestyle as expressed by people with dementia participating in this research study captured their need for social inclusion and community participation. Ongoing education initiatives aimed to reduce dementia-related stigma are therefore required to inform members of the wider community of the capacity of people with dementia to remain engaged with others and contribute to their community according to the trajectory of their condition. Community members need to be made aware of how they can be more inclusive towards people living with dementia and their care partners. This improved inclusivity will allow for relatability and creating dementia-friendly communities will assist people living with the condition to maintain connectedness to their pre-diagnosis lifestyle.
- A person with dementia's desire for self-determination encompasses their sustained independence. Consequently, the role of the care partner needs to continue to evolve beyond meeting the person with dementia's needs to one that supports the individual living with the condition to meet their own needs

with appropriate assistance as necessary. Educating care partners and health professionals about how this evolving role of the care partner is conceptualised within the 21st century is necessary so they can help promote the person with dementia's independence and sustained autonomy.

- People with dementia's desire for connectedness to their pre-diagnosis lifestyle means they require information on how to live with the condition. Education initiatives conducted by health care professionals that inform people with dementia about how they can preserve their health, maintain functional capacity, and engage in advance care planning are therefore necessary as it means they will be better prepared to maintain their self-determination and well-being for as long as possible, remaining autonomous over the longer term. Social inclusion is important to be able to live well with dementia. Providing people with the condition with opportunities to engage with and give back to the wider community will assist with social inclusion. People with dementia should be included in education initiatives as experts on their experience of living with the condition. These interactions demonstrate a person with dementia's functional capacity and ability to contribute to the community while living with the condition which means their desire for self-determination is shared with others.

6.5.3 Clinical practice

- A person with dementia's desire for self-determination does not necessarily change following their experience of cognitive decline as revealed in Study 1 findings. As such implementation of advance care planning with people with dementia and their care partner in clinical practice following receipt of their dementia diagnosis is necessary so they can plan for their future. Engaging in future care planning at this time is pivotal as the person with dementia is more likely to have the cognitive capacity to do so. Increased dialogue between the person with dementia and their care partner can then be encouraged so care partners can adequately advocate for their needs and wants as required, helping to sustain the person's autonomy as this becomes necessary.

- A way for health professionals to assist people with dementia to maintain their continued connection to their pre-diagnosis lifestyle is by facilitating their consumer involvement in service development, planning and evaluation. This will ensure that services are responsive to consumer needs while supporting the meaningful involvement of those living with dementia in service enhancement. Health professionals should implement goal-directed rehabilitation/reablement interventions across the services they provide. Giving people with dementia the opportunity to outline their goals and assisting them to achieve these will support their sustained self-determination.
- Findings from the qualitative studies indicated that dementia-related stigma is evident within our communities and impacts people with dementia's capacity to remain connected to their pre-diagnosis lifestyle. Implementation of the Dementia Community Attitudes Questionnaire (following further testing of its psychometric properties) by health professionals and people working within the dementia support industry will assist with identifying attitudes of people within the community towards people living with the condition. This will allow insight into the degree to which communities are dementia-friendly. This way strategies can be implemented to enhance the social

inclusion of people with dementia, thus helping to uphold their quality of life through connection to the community and their pre-diagnosis lifestyle.

6.5.4 Policy

The World Health Organisation's global action plan on the public health response to dementia 2017-2025 (World Health Organisation, 2017) details the need for ongoing research and innovation necessary to improve the lives of people with dementia. The research reported in this thesis has heeded this call and provided an opportunity for people living with dementia and their care partners to share their experiences and contribute to the generation of evidence to support dementia-related care and support. The following policy recommendations emanate from the included studies.

- Findings from Study 1, conducted as part of this research, highlight that people with dementia value sustained independence and the opportunity for decision-making despite the condition they live with. This knowledge, newly conceptualised within the context of exploring people with dementia's future expectations, should be considered when policies are being developed to support healthcare provision to people living with the condition and their care partners. The review of existing healthcare policies and the development and implementation of new policies should include a focus on strategies and opportunities to increase dementia healthcare consumers' agency. This focus should include contributing to policy development and being able to engage in decision-making around care and support preferences. Such inclusion is critical given that people with dementia and care partners who provided data for this study indicated having limited opportunity to have agency and active participation in care and support decision-making. This argument is further borne out by the integrative literature review which also highlighted the limited inclusion of people with dementia in research intended to inform care provision. These recommendations align with those set out by the recent Royal Commission into Aged Care within Australia (2018) which indicate that older people, which includes most people with dementia, should be provided with care and support that enables them to maintain their independence and decision-making and as such, self-determination. Future policy refinement and development can be steered by existing policy development guidelines, such as, “Supported Decision-Making in Aged Care: A policy development guideline for aged care providers in Australia” (Cognitive Decline Partnership Centre, 2018).

- Findings from Studies 1 and 2, reported in this thesis, identify that people with dementia and their care partners have very little awareness of what to expect and how to plan for their future following receipt of the dementia diagnosis. This newly identified deficit indicates the need for health care policy to include the development and implementation of extensive post-diagnostic pathways of support for people with dementia and their care partners. Such measures are necessary to improve the dementia dyad’s health literacy, that is their ability to understand and use health care information, enabling them to plan for and live well into the future. This recommendation also aligns with the direction set out by the Australian Royal Commission into Aged Care (2018) which, includes the provision of information on dementia and available support networks, access to counselling and education, and assistance with planning for continued independent living.

Post-diagnostic pathways of support have been discussed in this thesis and include, but is not limited to, the strategies of dyadic counselling, goal-directed advance care planning and inter-professional health care team reablement interventions. Establishing such support pathways will guide healthcare professionals on the support that is required by the dementia dyad to help limit their experience of distress and enable them the opportunity to maintain a lifestyle they perceive as meaningful into the future.

- Further policy development is required to ensure that research into issues relevant to people living with dementia must include input from those with the condition and their care partners such as the research detailed within this thesis. Within a broader Australian context, this is supported by Dementia Australia, the Cognitive Decline Partnership Centre and was a focus of the National Health and Medical Research Council’s National Institute for Dementia Research since 2015. However, funding allocation for this initiative has since ceased with the Institute viewed as having fulfilled its remit (2020). This focus needs to remain front of mind for policy developers to ensure that research knowledge dissemination and translation into practice prioritises the importance of the experiential knowledge of people living with dementia and their care partners. Ensuring that the voices of people with dementia are captured and their experiences and expectations for the future are communicated to others is pivotal to safeguarding their wellbeing. Including such detail in clinical practice guidelines will assist healthcare professionals in having knowledge and understanding of what it means for this cohort of people to live well and guide them on how best to support care provision.

- Outcomes for people with dementia from policy implementation intended to improve their quality of life require robust evaluation. Evaluating the participation of people with dementia in the planning of their care and support is necessary to ensure that services provided are in response to their identified needs and to safeguard their self-determination. This recommendation is particularly pertinent in light of the findings from the integrative literature review reported in this thesis that uncovered the limited extent of such outcome evaluation and indicated much work in the area is needed. Furthermore, policy guidelines should include a robust evaluation of initiatives to address dementia-related stigma and attitudes of people within the community towards people living with the condition, given that the findings from Studies 1 and 2 unveiled participants' experience of dementia-related stigma. This evaluation should also include any interim steps in the process of developing such initiatives as this will help determine their effectiveness. It will also assist with identifying further action that may be required to ensure the inclusion of people with dementia within our communities.

6.6 Conclusion

Globally the number of people living with dementia is rising and their visibility within communities is increasing. As such identifying ways in which we can better support people with dementia is critical. Establishing the unique needs of people with the condition is one way in which this can be achieved. People with dementia have disclosed a desire for sustained connection to their pre-diagnosis lifestyle and as such their self-determination on receiving their diagnosis. There are factors however that may hinder this from happening. These include the relationship the person with dementia has with their care partner, dementia-related stigma held by members of the community and by health professionals, and the capacity of people within the community to relate to and offer social inclusion to those diagnosed with the condition. Through the application of the self-determination theory and considering a person-centred approach, health professionals, researchers and policy makers can work towards ensuring people with dementia, with the assistance of their care partner, have sustained autonomy, self-determination, and good quality of life from diagnosis and throughout the trajectory of their condition. Enhancing dementia knowledge of people within the community has been shown to positively change attitudes towards people with the condition. Initiatives such as the Dementia Awareness Raising Forum reported in this thesis can play an essential role in enabling people with dementia to relate to others within the community, enjoy social inclusion and maintain quality of life.

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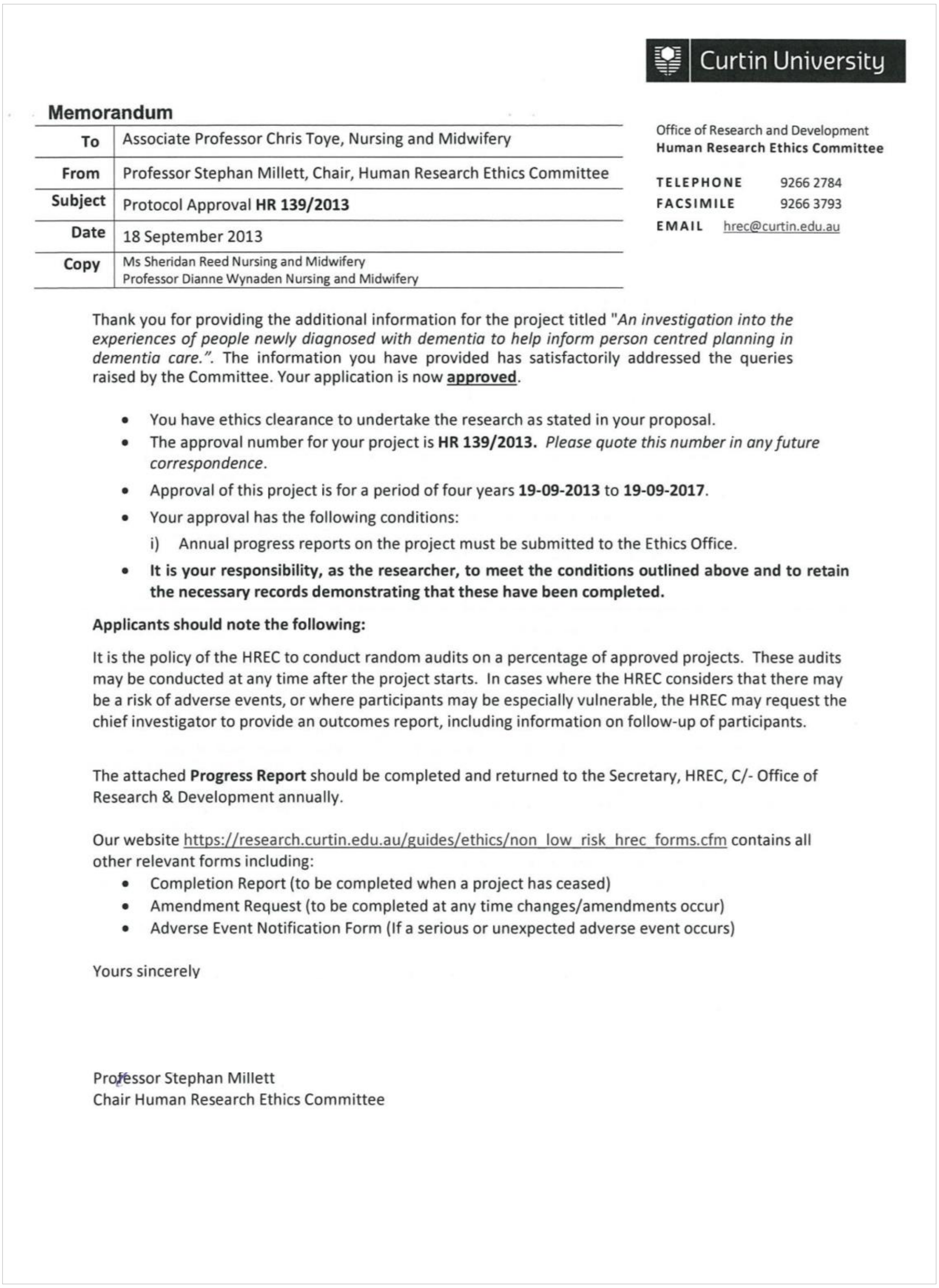
Appendix A

Ethics approval documentation

A.1 Ethics initial approval letter



Curtin University

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Memorandum

To	Associate Professor Chris Toye, Nursing and Midwifery
From	Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval **HR 139/2013**
Date	18 September 2013
Copy	Ms Sheridan Reed Nursing and Midwifery Professor Dianne Wynaden Nursing and Midwifery

Thank you for providing the additional information for the project titled "*An investigation into the experiences of people newly diagnosed with dementia to help inform person centred planning in dementia care.”*. The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 139/2013.** *Please quote this number in any future correspondence*.
- Approval of this project is for a period of four years **19-09-2013** to **19-09-2017**.
- Your approval has the following conditions:
  i) Annual progress reports on the project must be submitted to the Ethics Office.
- **It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.**

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

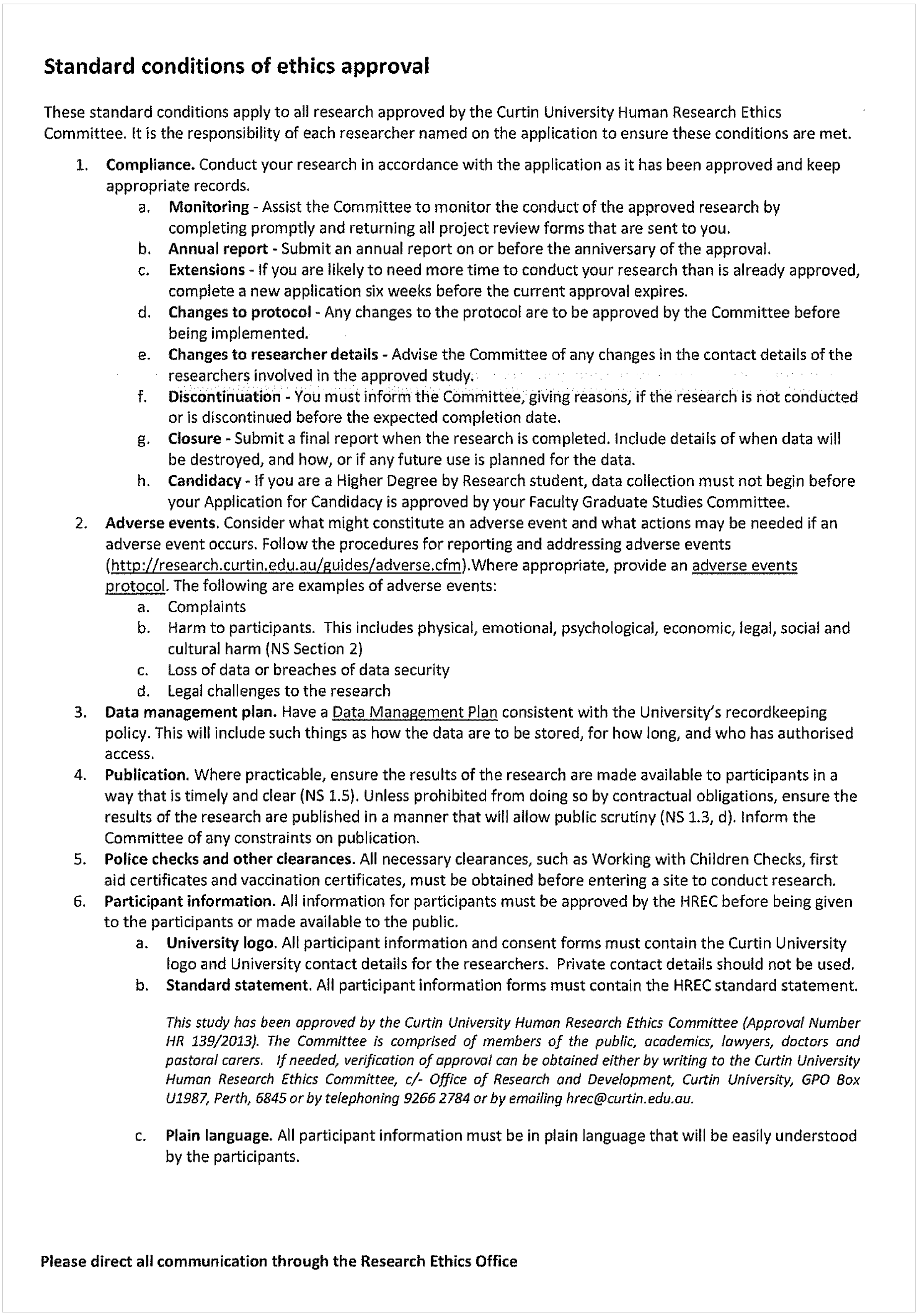
The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:

- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (If a serious or unexpected adverse event occurs)

Yours sincerely

Professor Stephan Millett
Chair Human Research Ethics Committee



Standard conditions of ethics approval

These standard conditions apply to all research approved by the Curtin University Human Research Ethics Committee. It is the responsibility of each researcher named on the application to ensure these conditions are met.

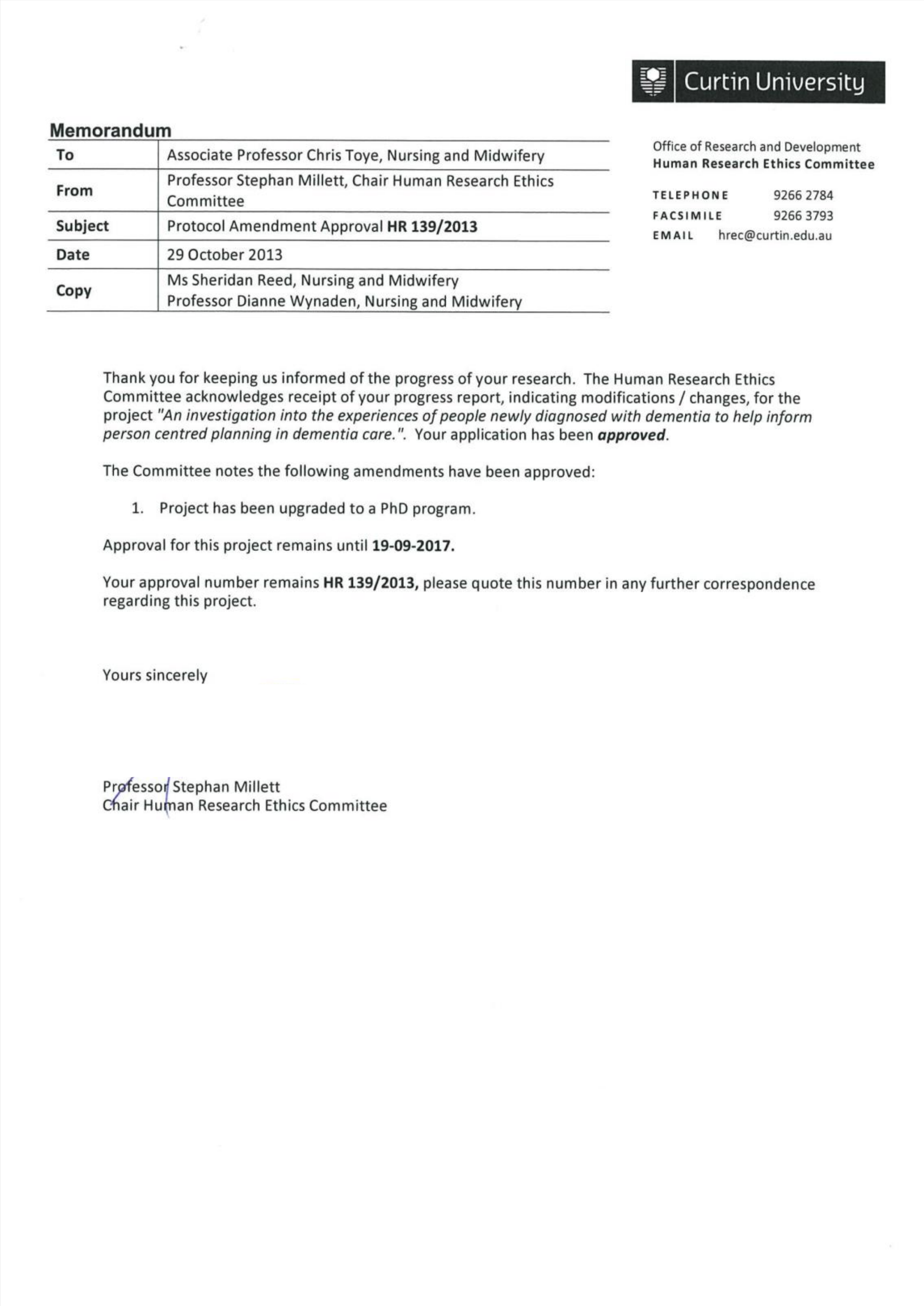
1. **Compliance.** Conduct your research in accordance with the application as it has been approved and keep appropriate records.
    a. **Monitoring** - Assist the Committee to monitor the conduct of the approved research by completing promptly and returning all project review forms that are sent to you.
    b. **Annual report** - Submit an annual report on or before the anniversary of the approval.
    c. **Extensions** - If you are likely to need more time to conduct your research than is already approved, complete a new application six weeks before the current approval expires.
    d. **Changes to protocol** - Any changes to the protocol are to be approved by the Committee before being implemented.
    e. **Changes to researcher details** - Advise the Committee of any changes in the contact details of the researchers involved in the approved study.
    f. **Discontinuation** - You must inform the Committee, giving reasons, if the research is not conducted or is discontinued before the expected completion date.
    g. **Closure** - Submit a final report when the research is completed. Include details of when data will be destroyed, and how, or if any future use is planned for the data.
    h. **Candidacy** - If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
2. **Adverse events.** Consider what might constitute an adverse event and what actions may be needed if an adverse event occurs. Follow the procedures for reporting and addressing adverse events (http://research.curtin.edu.au/guides/adverse.cfm).Where appropriate, provide an adverse events protocol. The following are examples of adverse events:
    a. Complaints
    b. Harm to participants. This includes physical, emotional, psychological, economic, legal, social and cultural harm (NS Section 2)
    c. Loss of data or breaches of data security
    d. Legal challenges to the research
3. **Data management plan.** Have a Data Management Plan consistent with the University's recordkeeping policy. This will include such things as how the data are to be stored, for how long, and who has authorised access.
4. **Publication.** Where practicable, ensure the results of the research are made available to participants in a way that is timely and clear (NS 1.5). Unless prohibited from doing so by contractual obligations, ensure the results of the research are published in a manner that will allow public scrutiny (NS 1.3, d). Inform the Committee of any constraints on publication.
5. **Police checks and other clearances.** All necessary clearances, such as Working with Children Checks, first aid certificates and vaccination certificates, must be obtained before entering a site to conduct research.
6. **Participant information.** All information for participants must be approved by the HREC before being given to the participants or made available to the public.
    a. **University logo.** All participant information and consent forms must contain the Curtin University logo and University contact details for the researchers. Private contact details should not be used.
    b. **Standard statement.** All participant information forms must contain the HREC standard statement.

        This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 139/2013). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

    c. **Plain language.** All participant information must be in plain language that will be easily understood by the participants.

Please direct all communication through the Research Ethics Office

A.2 Upgrade to PhD program



Curtin University

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
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EMAIL hrec@curtin.edu.au

Memorandum

To	Associate Professor Chris Toye, Nursing and Midwifery
From	Professor Stephan Millett, Chair Human Research Ethics Committee
Subject	Protocol Amendment Approval **HR 139/2013**
Date	29 October 2013
Copy	Ms Sheridan Reed, Nursing and Midwifery Professor Dianne Wynaden, Nursing and Midwifery

Thank you for keeping us informed of the progress of your research. The Human Research Ethics Committee acknowledges receipt of your progress report, indicating modifications / changes, for the project *"An investigation into the experiences of people newly diagnosed with dementia to help inform person centred planning in dementia care."*. Your application has been ***approved***.

The Committee notes the following amendments have been approved:

1. Project has been upgraded to a PhD program.

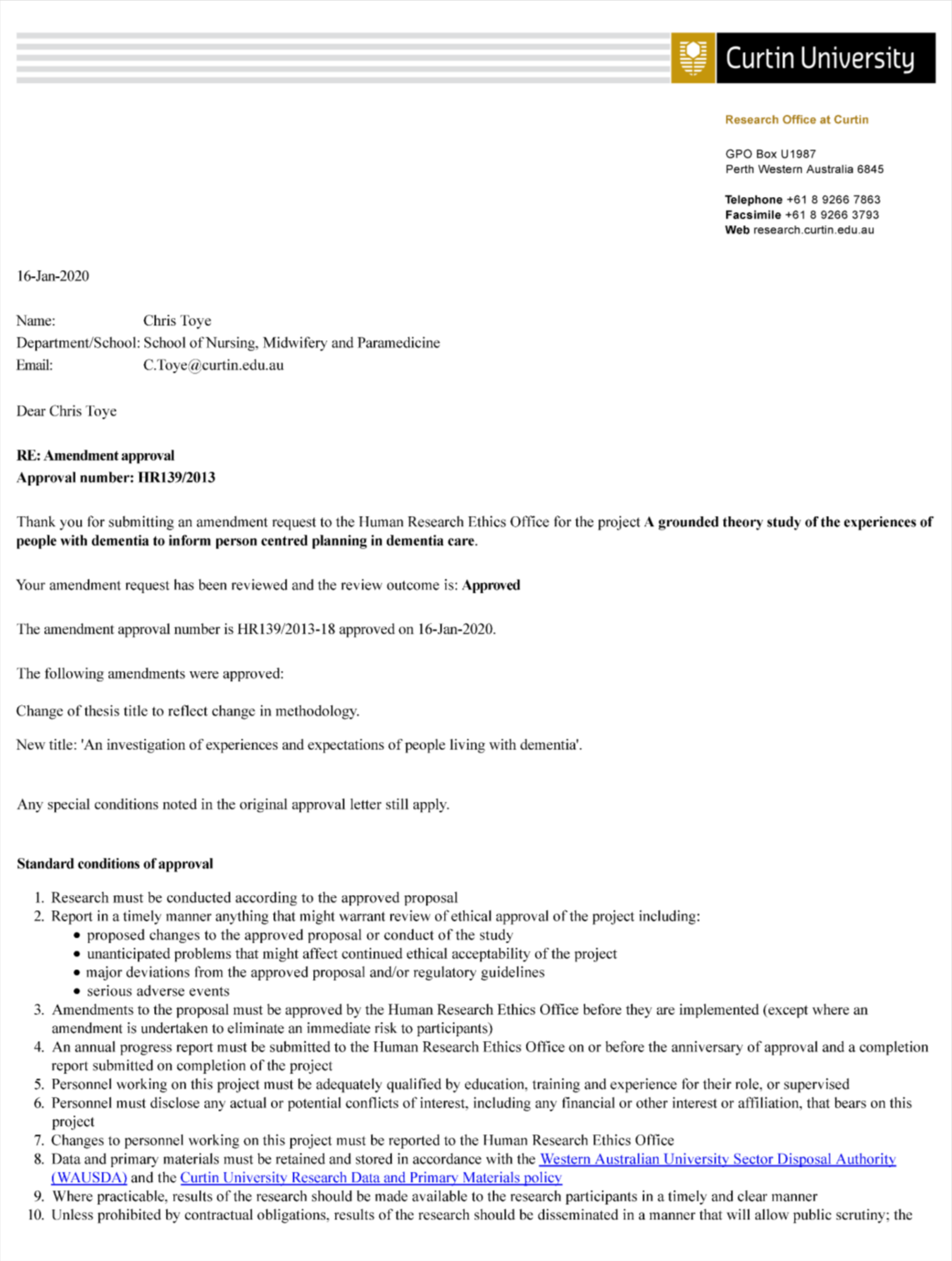
Approval for this project remains until **19-09-2017.**

Your approval number remains **HR 139/2013,** please quote this number in any further correspondence regarding this project.

Yours sincerely

Professor Stephan Millett
Chair Human Research Ethics Committee

A.3 Change to thesis title



Curtin University

Research Office at Curtin

GPO Box U1987
Perth Western Australia 6845

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Web research.curtin.edu.au

16-Jan-2020

Name: Chris Toye
Department/School: School of Nursing, Midwifery and Paramedicine
Email: C.Toye@curtin.edu.au

Dear Chris Toye

RE: Amendment approval
Approval number: HR139/2013

Thank you for submitting an amendment request to the Human Research Ethics Office for the project **A grounded theory study of the experiences of people with dementia to inform person centred planning in dementia care**.

Your amendment request has been reviewed and the review outcome is: **Approved**

The amendment approval number is HR139/2013-18 approved on 16-Jan-2020.

The following amendments were approved:

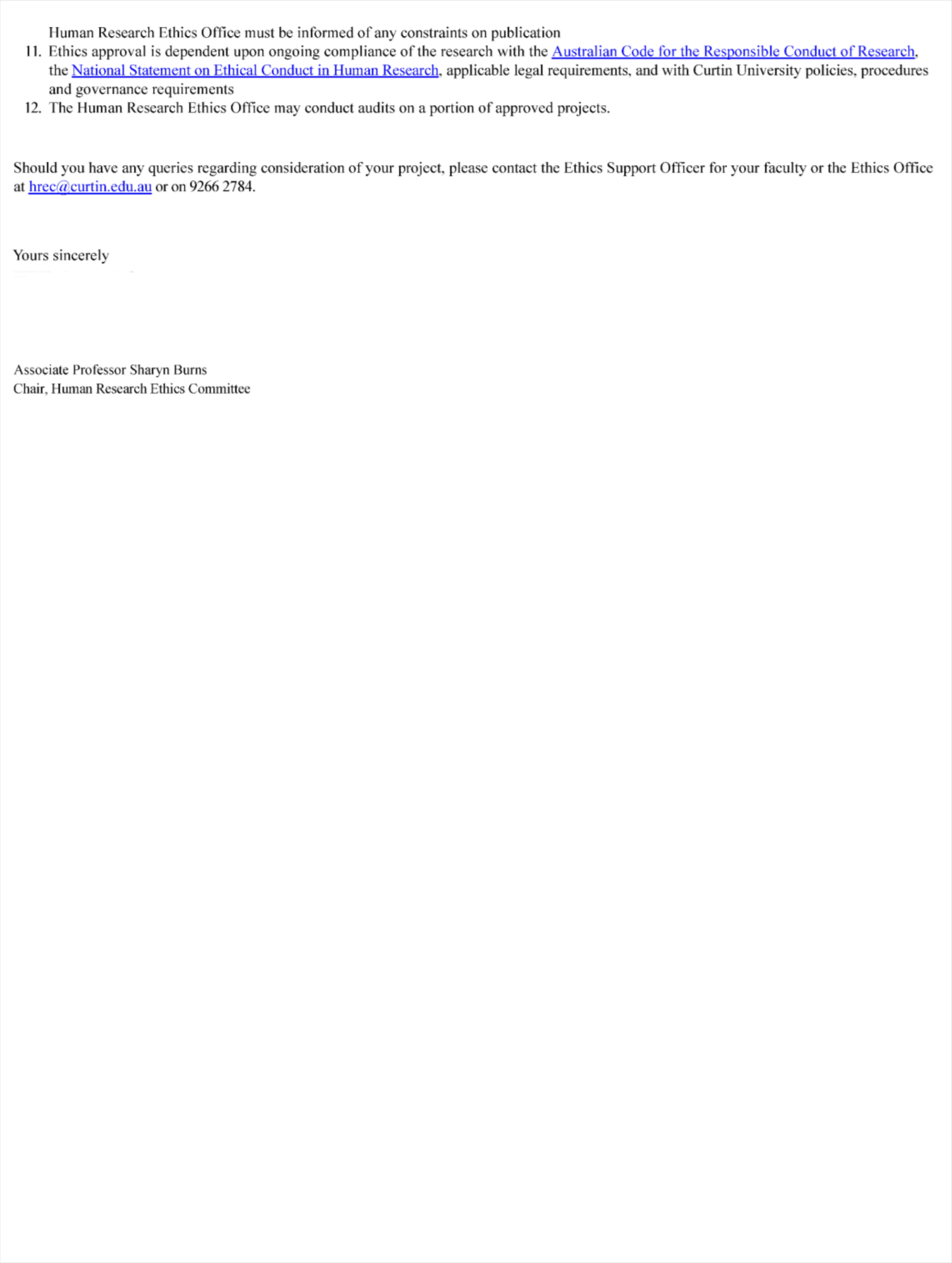
Change of thesis title to reflect change in methodology.

New title: 'An investigation of experiences and expectations of people living with dementia'.

Any special conditions noted in the original approval letter still apply.

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
    - proposed changes to the approved proposal or conduct of the study
    - unanticipated problems that might affect continued ethical acceptability of the project
    - major deviations from the approved proposal and/or regulatory guidelines
    - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the



Human Research Ethics Office must be informed of any constraints on publication

11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Associate Professor Sharyn Burns
Chair, Human Research Ethics Committee

A.4 Annual report acknowledgement

Curtin University

Research Office at Curtin

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28-Jul-2022

Name: Ravani Duggan
Department/School: Curtin School of Nursing
Email: R.Duggan@curtin.edu.au

Dear Ravani Duggan

RE: Annual report acknowledgment
Approval number: HR139/2013

Thank you for submitting an annual report to the Human Research Ethics Office for the project **An investigation of experiences and expectations of people living with dementia**.

The Human Research Ethics Office acknowledges the project is ongoing and approval will remain current until 18-Sep-2023.

Special Condition of Approval Extension.

It is the responsibility of the Chief Investigator to ensure that any activity undertaken under this project adheres to the latest available advice from the Government or the University regarding COVID-19.

Any special conditions noted in the original approval letter still apply.

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
    - proposed changes to the approved proposal or conduct of the study
    - unanticipated problems that might affect continued ethical acceptability of the project
    - major deviations from the HREC approved protocol procedures and/or regulatory guidelines
    - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication
11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Yours sincerely

Professor Sharyn Burns
Chair, Human Research Ethics Committee

Appendix B

Research information sheet for people living with dementia – Study 1

Curtin University
Curtin School of Nursing
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Perth Western Australia 6845

Telephone +61 8 9266 0000
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sheridan.read@postgrad.curtin.edu.au
Web curtin.edu.au

16 February 2021

Curtin University – Curtin School of Nursing

Research Information Sheet

Project Title: A grounded theory study of the experiences of people diagnosed with dementia to inform person centred planning in dementia care.

My name is Sheridan Read. I am a Doctoral of Philosophy (Nursing) student at the Curtin School of Nursing at Curtin University. I am a Registered Nurse who has worked with people living with dementia for over ten years. I am carrying out a study to explore the experience of people newly diagnosed with dementia with the aim of helping service providers to meet the needs of people living with dementia. You may find this study is of benefit to you as it will allow you the opportunity to speak about what is important to you and what you may want in the future. The study will also provide an opportunity for you to impact on how community services can benefit others.

Your participation is voluntary, and you may withdraw at any time, your access to services at Alzheimer's Australia WA will not be affected. Please feel free to discuss this research with your family or doctor. If you agree to take part in this study, information will be collected in an interview with me, which will last approximately 40 minutes. The interview will be recorded and typed up by me. My supervisors and I will be the only people who will have access to the interview data. Any publications or reports resulting from the study will not use your name, your confidentiality will be maintained, and findings will be presented as group findings. If you have any questions or require any further information please don't hesitate to contact me via email, sheridan.read@postgrad.curtin.edu.au. My supervisors are also contactable (and you can make telephone contact with me via them); they are Associate Professor Chris Toye on 92661756 or via email c.toye@curtin.edu.au and Professor Dianne Wynaden on 92662203 or d.wynaden@curtin.edu.au.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 139/2013). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

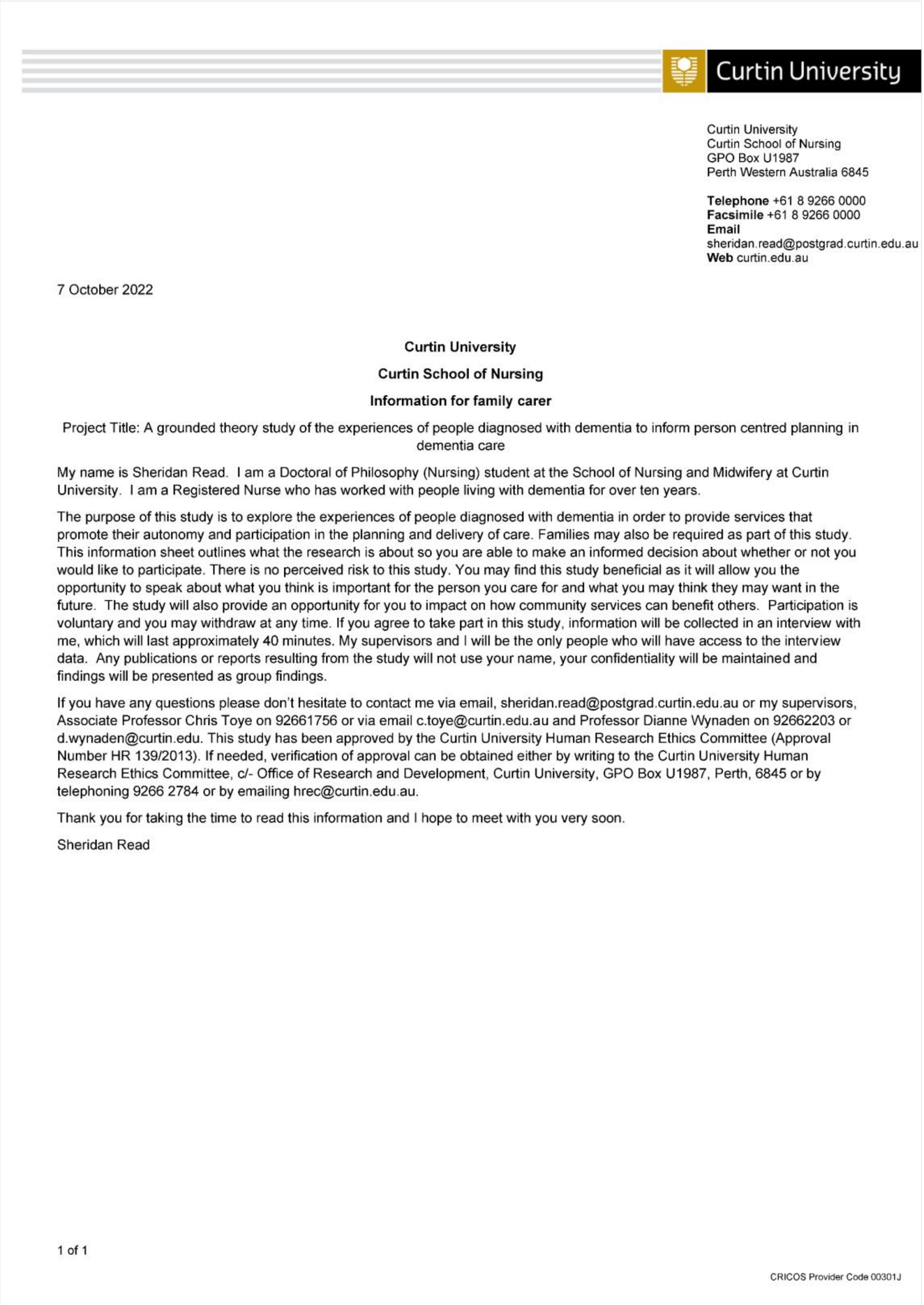
Thank you for taking the time to read this information.

Sheridan Read

CRICOS Provider Code 00301J

Appendix C

Research information sheet for family carer – Study 2



Curtin University

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7 October 2022

Curtin University

Curtin School of Nursing

Information for family carer

Project Title: A grounded theory study of the experiences of people diagnosed with dementia to inform person centred planning in dementia care

My name is Sheridan Read. I am a Doctoral of Philosophy (Nursing) student at the School of Nursing and Midwifery at Curtin University. I am a Registered Nurse who has worked with people living with dementia for over ten years.

The purpose of this study is to explore the experiences of people diagnosed with dementia in order to provide services that promote their autonomy and participation in the planning and delivery of care. Families may also be required as part of this study. This information sheet outlines what the research is about so you are able to make an informed decision about whether or not you would like to participate. There is no perceived risk to this study. You may find this study beneficial as it will allow you the opportunity to speak about what you think is important for the person you care for and what you may think they may want in the future. The study will also provide an opportunity for you to impact on how community services can benefit others. Participation is voluntary and you may withdraw at any time. If you agree to take part in this study, information will be collected in an interview with me, which will last approximately 40 minutes. My supervisors and I will be the only people who will have access to the interview data. Any publications or reports resulting from the study will not use your name, your confidentiality will be maintained and findings will be presented as group findings.

If you have any questions please don't hesitate to contact me via email, sheridan.read@postgrad.curtin.edu.au or my supervisors, Associate Professor Chris Toye on 92661756 or via email c.toye@curtin.edu.au and Professor Dianne Wynaden on 92662203 or d.wynaden@curtin.edu. This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 139/2013). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Thank you for taking the time to read this information and I hope to meet with you very soon.

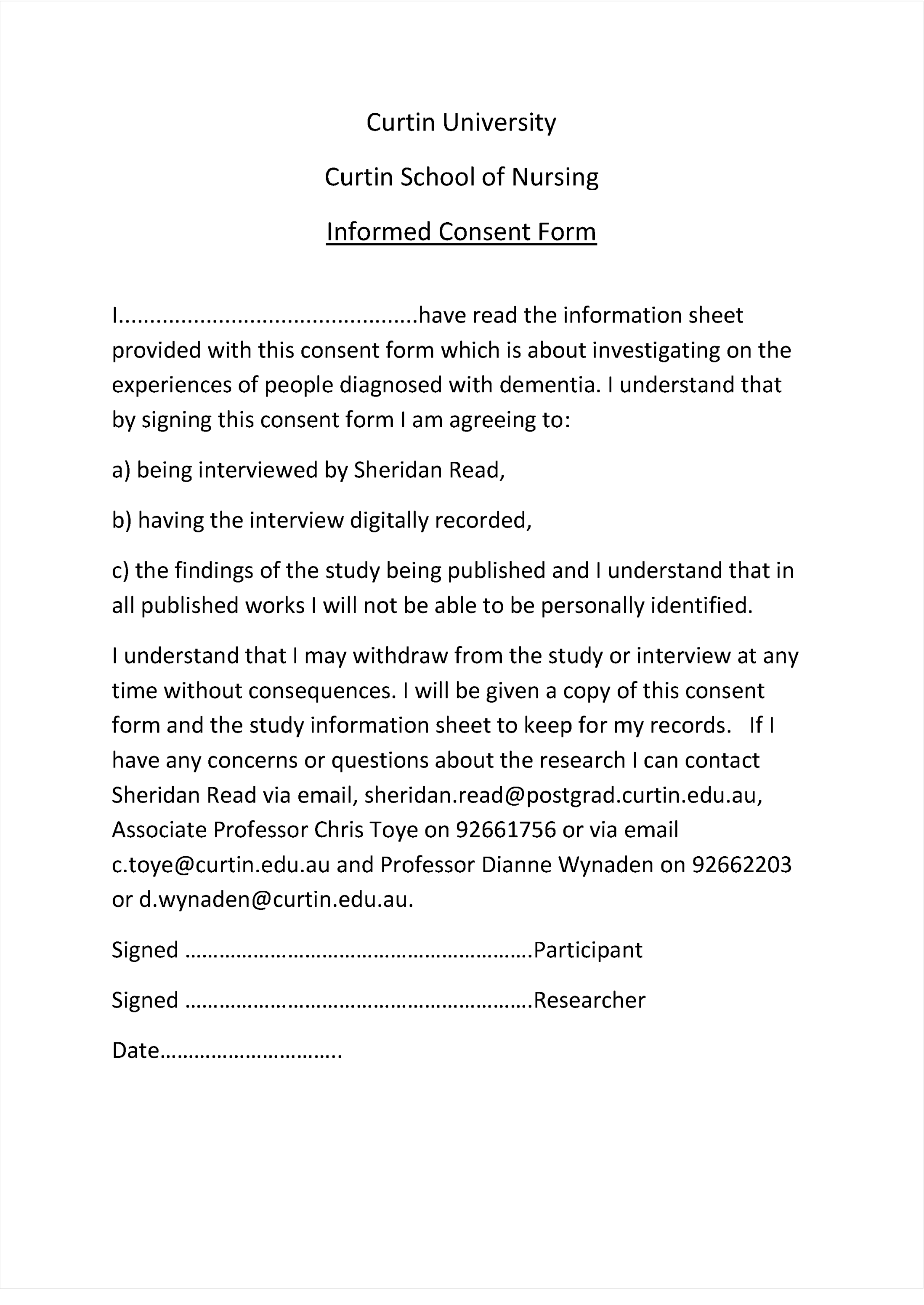
Sheridan Read

1 of 1

CRICOS Provider Code 00301J

Appendix D

Participant informed consent form – Study 1 and 2



Curtin University

Curtin School of Nursing

<u>Informed Consent Form</u>

I...have read the information sheet provided with this consent form which is about investigating on the experiences of people diagnosed with dementia. I understand that by signing this consent form I am agreeing to:

a) being interviewed by Sheridan Read,

b) having the interview digitally recorded,

c) the findings of the study being published and I understand that in all published works I will not be able to be personally identified.

I understand that I may withdraw from the study or interview at any time without consequences. I will be given a copy of this consent form and the study information sheet to keep for my records. If I have any concerns or questions about the research I can contact Sheridan Read via email, sheridan.read@postgrad.curtin.edu.au, Associate Professor Chris Toye on 92661756 or via email c.toye@curtin.edu.au and Professor Dianne Wynaden on 92662203 or d.wynaden@curtin.edu.au.

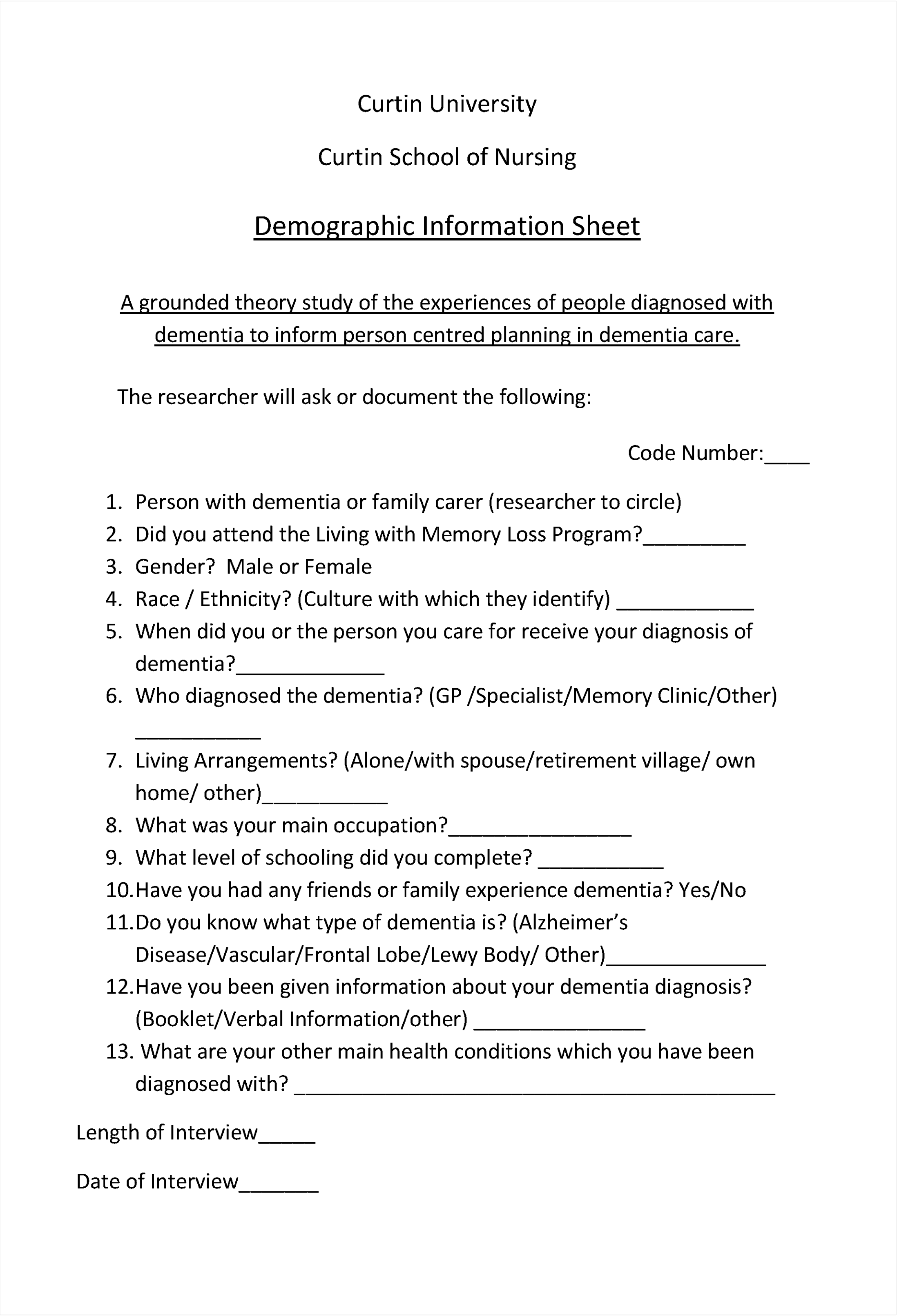
Signed ……………………………………………………Participant

Signed ……………………………………………………Researcher

Date…………………………..

Appendix E

Demographic information sheet – Study 1



Curtin University

Curtin School of Nursing

Demographic Information Sheet

A grounded theory study of the experiences of people diagnosed with dementia to inform person centred planning in dementia care.

The researcher will ask or document the following:

Code Number:____

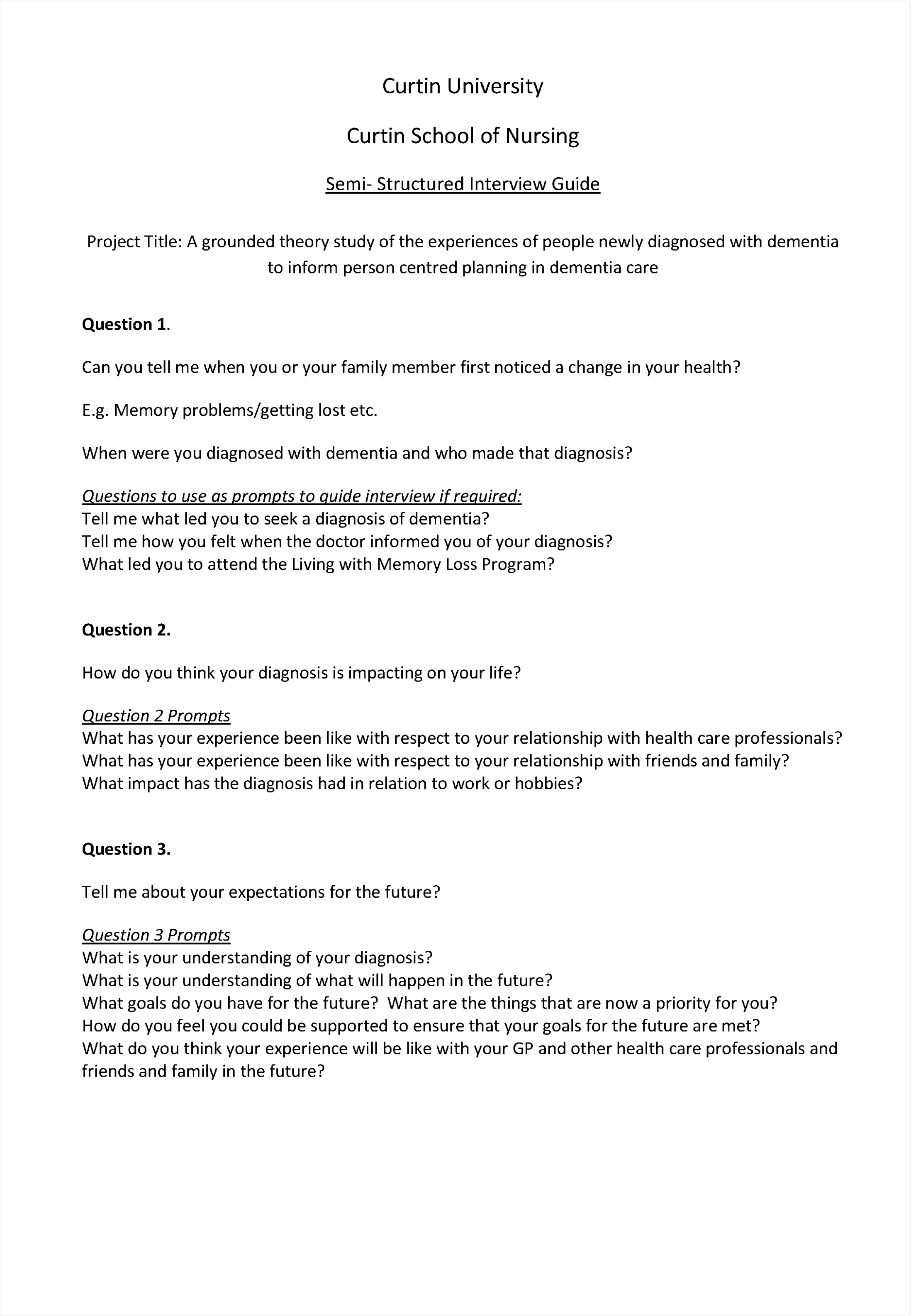
1. Person with dementia or family carer (researcher to circle)
2. Did you attend the Living with Memory Loss Program?_________
3. Gender? Male or Female
4. Race / Ethnicity? (Culture with which they identify) ____________
5. When did you or the person you care for receive your diagnosis of dementia?_____________
6. Who diagnosed the dementia? (GP /Specialist/Memory Clinic/Other) ___________
7. Living Arrangements? (Alone/with spouse/retirement village/ own home/ other)___________
8. What was your main occupation?________________
9. What level of schooling did you complete? ___________
10. Have you had any friends or family experience dementia? Yes/No
11. Do you know what type of dementia is? (Alzheimer's Disease/Vascular/Frontal Lobe/Lewy Body/ Other)______________
12. Have you been given information about your dementia diagnosis? (Booklet/Verbal Information/other) _______________
13. What are your other main health conditions which you have been diagnosed with? ____

Length of Interview_____

Date of Interview_______

Appendix F

Semi-structured interview guide for people with dementia – Study 1



Curtin University

Curtin School of Nursing

Semi- Structured Interview Guide

Project Title: A grounded theory study of the experiences of people newly diagnosed with dementia to inform person centred planning in dementia care

Question 1.

Can you tell me when you or your family member first noticed a change in your health?

E.g. Memory problems/getting lost etc.

When were you diagnosed with dementia and who made that diagnosis?

Questions to use as prompts to guide interview if required:
Tell me what led you to seek a diagnosis of dementia?
Tell me how you felt when the doctor informed you of your diagnosis?
What led you to attend the Living with Memory Loss Program?

Question 2.

How do you think your diagnosis is impacting on your life?

Question 2 Prompts
What has your experience been like with respect to your relationship with health care professionals?
What has your experience been like with respect to your relationship with friends and family?
What impact has the diagnosis had in relation to work or hobbies?

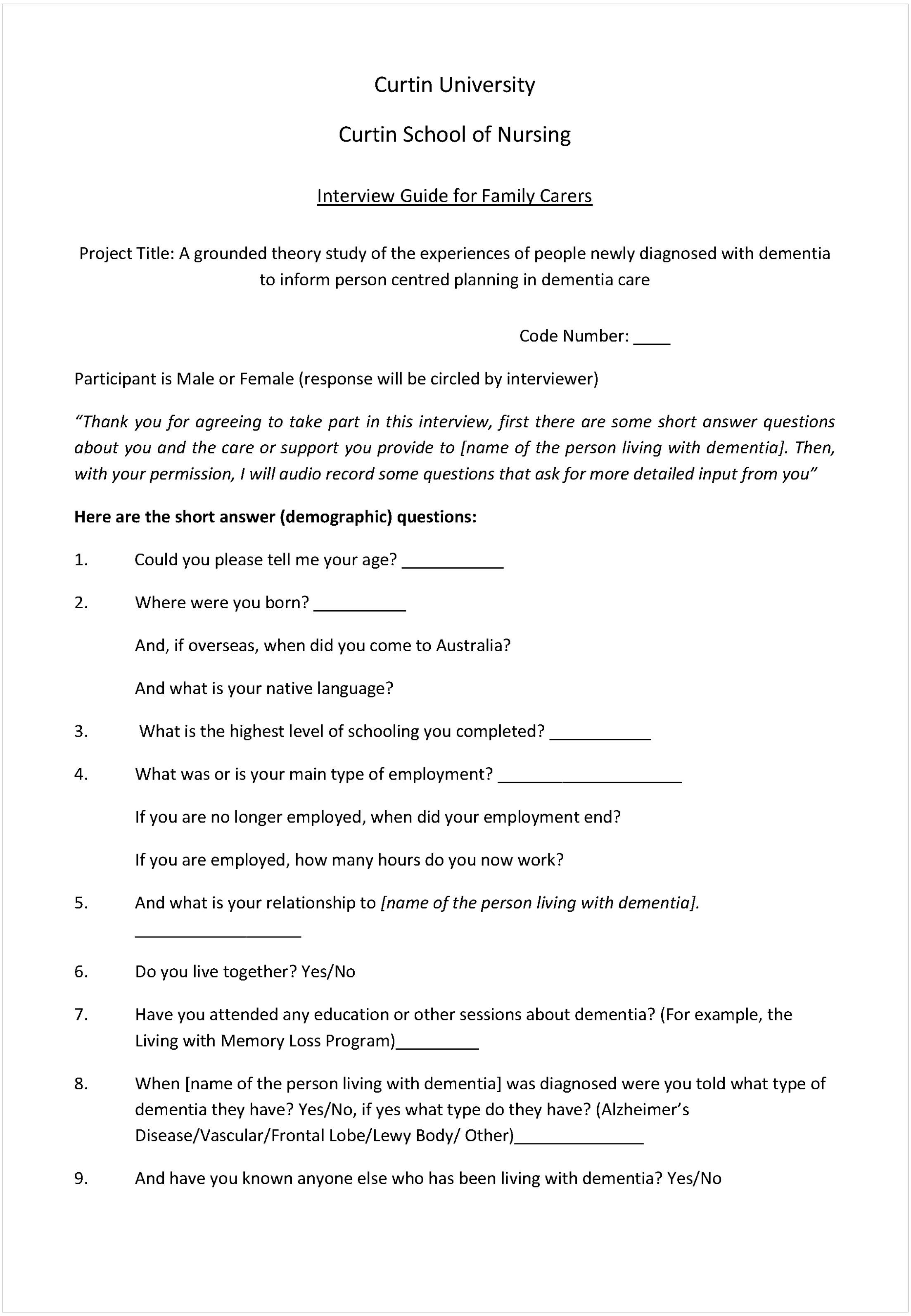
Question 3.

Tell me about your expectations for the future?

Question 3 Prompts
What is your understanding of your diagnosis?
What is your understanding of what will happen in the future?
What goals do you have for the future? What are the things that are now a priority for you?
How do you feel you could be supported to ensure that your goals for the future are met?
What do you think your experience will be like with your GP and other health care professionals and friends and family in the future?

Appendix G

Semi-structured interview guide for care partners – Study 2



Curtin University

Curtin School of Nursing

Interview Guide for Family Carers

Project Title: A grounded theory study of the experiences of people newly diagnosed with dementia to inform person centred planning in dementia care

Code Number: ____

Participant is Male or Female (response will be circled by interviewer)

"Thank you for agreeing to take part in this interview, first there are some short answer questions about you and the care or support you provide to [name of the person living with dementia]. Then, with your permission, I will audio record some questions that ask for more detailed input from you"

Here are the short answer (demographic) questions:

1. Could you please tell me your age? ___________

2. Where were you born? __________

   And, if overseas, when did you come to Australia?

   And what is your native language?

3. What is the highest level of schooling you completed? ___________

4. What was or is your main type of employment? ____________________

   If you are no longer employed, when did your employment end?

   If you are employed, how many hours do you now work?

5. And what is your relationship to *[name of the person living with dementia].*
   ____

6. Do you live together? Yes/No

7. Have you attended any education or other sessions about dementia? (For example, the Living with Memory Loss Program)_________

8. When [name of the person living with dementia] was diagnosed were you told what type of dementia they have? Yes/No, if yes what type do they have? (Alzheimer's Disease/Vascular/Frontal Lobe/Lewy Body/ Other)______________

9. And have you known anyone else who has been living with dementia? Yes/No

Now here are the longer questions that relate to how you perceive [name's] experiences of living with dementia and expectations for the future

1. First, so I can better understand your perspective, please tell me what you understand of [name's] diagnosis?

   Prompts: What might happen over time / care or support needs?

Now I would like you to think about [name's] experiences and expectations

2. Please can you tell me about what you understand of [name's] experiences around the time when a diagnosis was sought?

3. What did [name] say they understood about the diagnosis?

4. Please tell me what [name] has said is important to him/her in the future?

5. Please tell me about any plans that [name] has made for the future?

6. What conversation would you like to have with [name] which would make the journey ahead easier for you if you were able to?

7. As you move forward what are the choices that you may have to make together?

8. What are the difficulties that you may face together moving forward?

9. What support do you think you both might need moving forward?

10. Tell me about the impact of this diagnosis on you both?

11 Is anything else you would like to say about [names] experiences or expectations?

Length of Interview_____

Date of Interview_______

Appendix H

Information sheet and consent form for expert reference group – Review of the Dementia Community Attitudes Questionnaire – Study 3

Curtin University

INFORMATION SHEET AND CONSENT FORM
QUESTIONNAIRE PANEL REVIEW

A research study is being carried out at Curtin University that aims to uncover the experiences and expectations of people living with dementia so that services and support can better respond to their needs.

The final study component involves the dissemination of study findings and other information about dementia to members of the local community during a dementia awareness raising forum involving collaboration between the researcher, the Curtin Ageing Research Network, and Alzheimer's WA.

Curtin University, School of Nursing, Midwifery and Paramedicine - Study Investigators:

Ms Sheridan Read, PhD Candidate,

Associate Professor Christine Toye, Older Persons' Health Care (Supervisor)

Professor Dianne Wynaden, Professor of Mental Health (Supervisor)

What is this study component about?

The aim of this study component is to increase, within the local community, awareness and understanding of what it means to be living with a dementia diagnosis today and how a person diagnosed with dementia can be supported to maintain the best possible quality of life. To measure whether or not this aim has been achieved, we are seeking to measure changes in attitudes towards people living with dementia, in community members, from before to after attendance at the dementia awareness raising forum.

Importantly, attendees at the forum may include people living with dementia and/or their families. The wording of the questionnaire merits consideration of this context. None of the existing questionnaires we have found are suitable. We have therefore undertaken the following steps to provide a new questionnaire: a) review of existing scales evaluating attitudes towards people living with dementia b) identification of validated domains that need to be addressed c) identification of any potentially useful items used in these questionnaires. The final questionnaire will include approximately 10 items addressing these domains, drawing upon previously developed items and/or developing new items as appropriate.

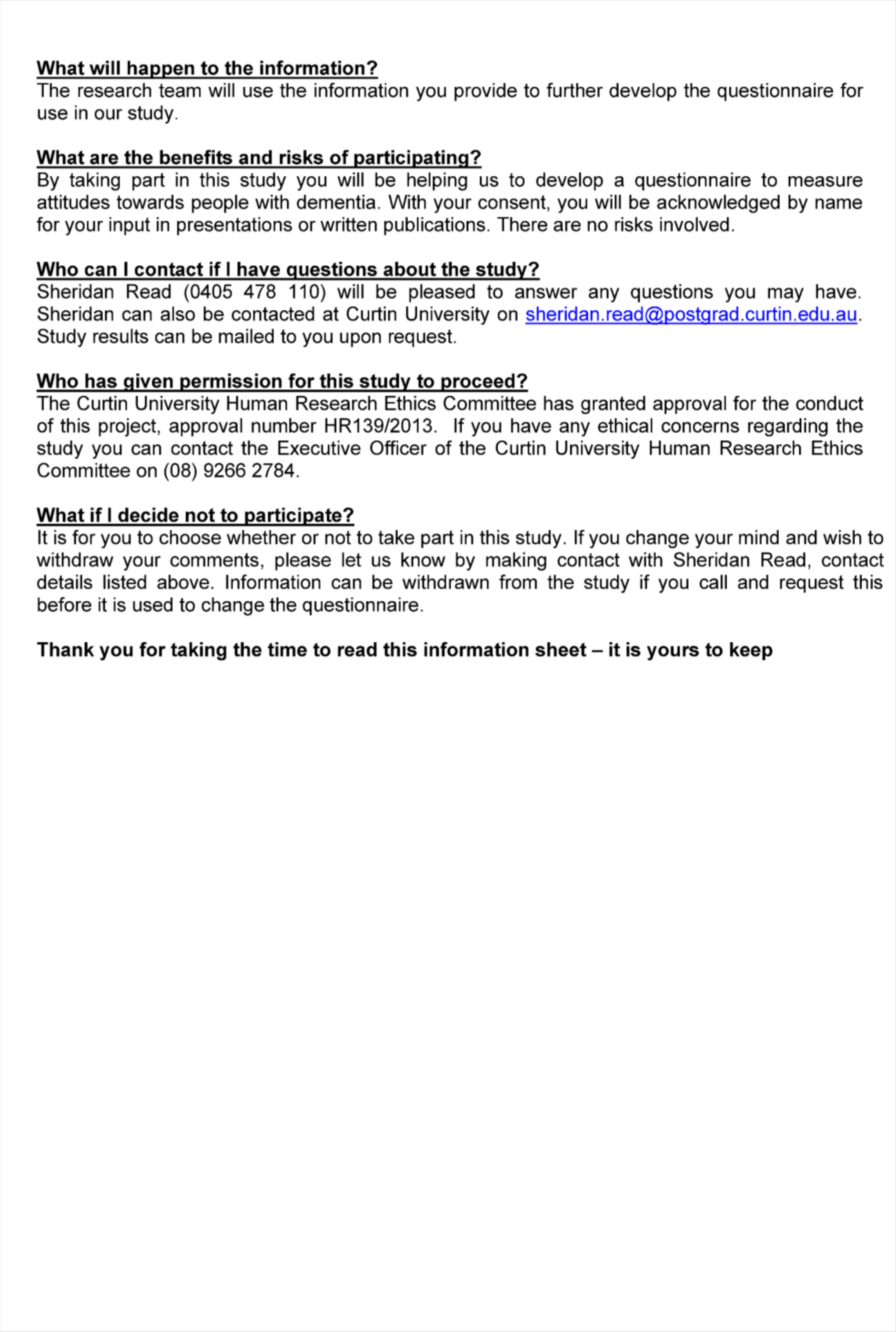
We are now requesting that you review the draft questionnaire using the attached form so that it can be reviewed accordingly.

Why is this study suitable to me?

As a person with special relevant expertise, you have been identified as a person who can contribute to this study by reviewing the questionnaire.

What will my participation involve?

If you decide to take part, you should fill in the consent form and respond to the questions about questionnaire items using the forms provided. Responses will be kept securely at Curtin University for at least 7 years after publication.



What will happen to the information?

The research team will use the information you provide to further develop the questionnaire for use in our study.

What are the benefits and risks of participating?

By taking part in this study you will be helping us to develop a questionnaire to measure attitudes towards people with dementia. With your consent, you will be acknowledged by name for your input in presentations or written publications. There are no risks involved.

Who can I contact if I have questions about the study?

Sheridan Read (0405 478 110) will be pleased to answer any questions you may have. Sheridan can also be contacted at Curtin University on sheridan.read@postgrad.curtin.edu.au. Study results can be mailed to you upon request.

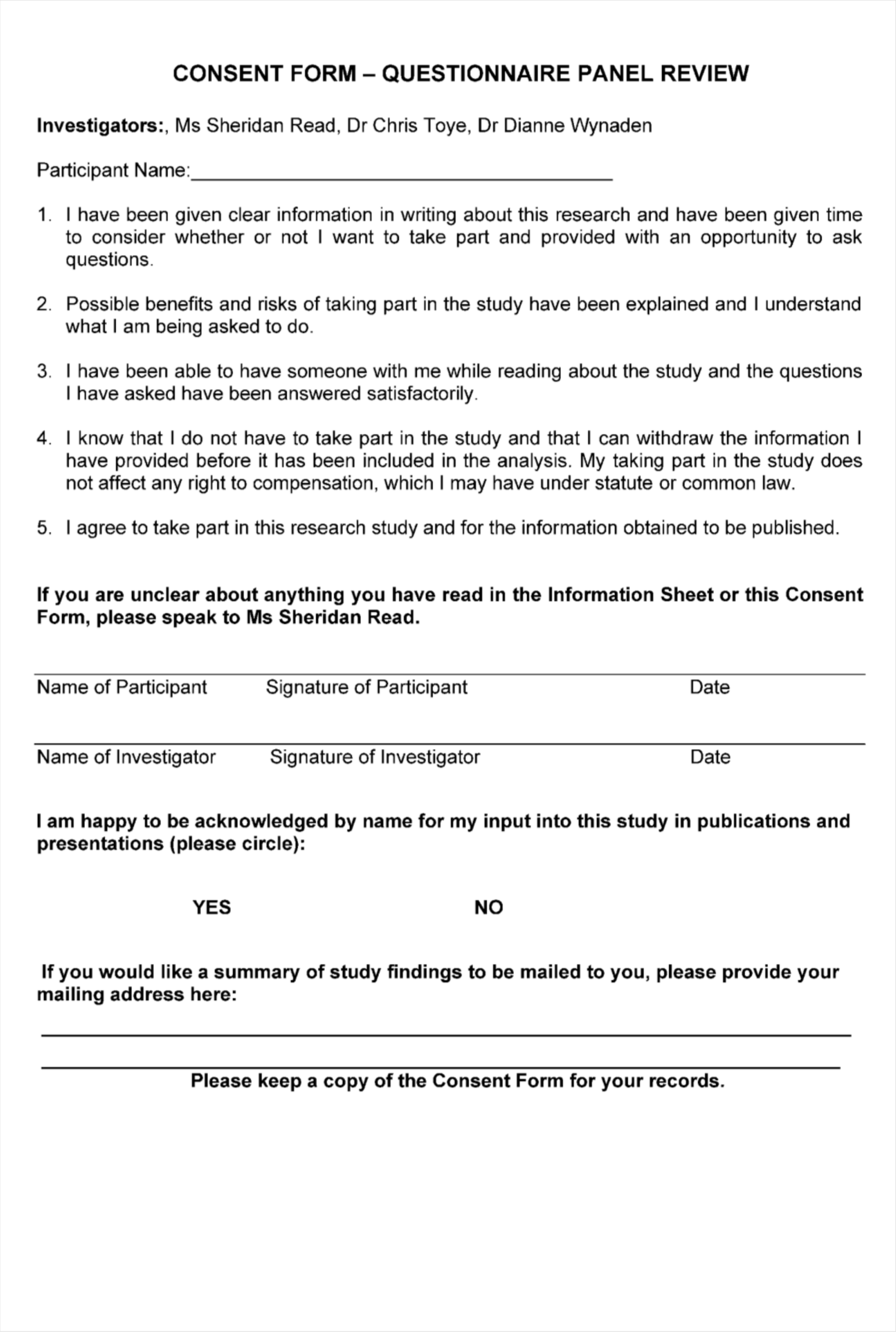
Who has given permission for this study to proceed?

The Curtin University Human Research Ethics Committee has granted approval for the conduct of this project, approval number HR139/2013. If you have any ethical concerns regarding the study you can contact the Executive Officer of the Curtin University Human Research Ethics Committee on (08) 9266 2784.

What if I decide not to participate?

It is for you to choose whether or not to take part in this study. If you change your mind and wish to withdraw your comments, please let us know by making contact with Sheridan Read, contact details listed above. Information can be withdrawn from the study if you call and request this before it is used to change the questionnaire.

Thank you for taking the time to read this information sheet – it is yours to keep



CONSENT FORM – QUESTIONNAIRE PANEL REVIEW

Investigators:, Ms Sheridan Read, Dr Chris Toye, Dr Dianne Wynaden

Participant Name:____

1. I have been given clear information in writing about this research and have been given time to consider whether or not I want to take part and provided with an opportunity to ask questions.
2. Possible benefits and risks of taking part in the study have been explained and I understand what I am being asked to do.
3. I have been able to have someone with me while reading about the study and the questions I have asked have been answered satisfactorily.
4. I know that I do not have to take part in the study and that I can withdraw the information I have provided before it has been included in the analysis. My taking part in the study does not affect any right to compensation, which I may have under statute or common law.
5. I agree to take part in this research study and for the information obtained to be published.

If you are unclear about anything you have read in the Information Sheet or this Consent Form, please speak to Ms Sheridan Read.

____

Name of Participant   Signature of Participant   Date

____

Name of Investigator   Signature of Investigator   Date

I am happy to be acknowledged by name for my input into this study in publications and presentations (please circle):

YES   **NO**

If you would like a summary of study findings to be mailed to you, please provide your mailing address here:

____

____

Please keep a copy of the Consent Form for your records.

Appendix I

Expert Reference Group review form for development of the Dementia Community Attitudes Questionnaire – Study 3

REVIEW OF QUESTIONNAIRE – ATTITUDES AND DEMENTIA STUDY

This questionnaire has been developed for use with members of the community to assess their attitude toward people with dementia, as explained in the study information sheet. Questionnaire items are presented in the following pages, with spaces for you to indicate any need for change. Please can you address the following issues?

1. *Clarity.*

Please read each item and indicate in Column A if it is Unclear (U). If it is unclear, please note the suggested changes below the item.

2. *Content Validity.*

- Please indicate in Column B if the item does not fit with the purpose of the tool by writing NF
- In Column C please write R if the item is redundant. If "R" is written, please write the number of the corresponding item beside that letter, in the column headed "No".

3. *Apparent internal consistency reliability*

Please review the grouping and the order of the items and indicate on the lines provided, if you believe that there is a need for a change in grouping or ordering.

4. *Response options and scoring*

Please review the response options and scoring system. Please indicate on the lines provided, any need for change.

5. *Overall adequacy of the tool*

Please indicate any important omissions that should be addressed on the lines provided.

Thank you very much for using your experience to assist us in this way

Questionnaire.

Newly developed Dementia Community Attitudes Questionnaire

Items in Part One	**A** **Unclear (U)**	**B** **Does not fit (NF)**	**C** **REDUNDANT**	**No.**
1. I have some understanding of what it would be like to live with dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
2. I recognise that symptoms of dementia extend beyond memory loss Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
3. There are a range of treatments that can reduce symptoms related to dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
4. Medication is the only treatment that can reduce symptoms of dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
5. There are strategies that can help people with dementia manage their lives Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
6. Memory aids are the only strategies that can help people with dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
7. We all have the potential to improve the lives of people living with dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
8. Supporting independence is one way to help a person living with dementia Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				

Items in Part One	A Unclear (U)	B Does not fit (NF)	C	
			REDUNDANT	No.
9. If a person has dementia they need assistance all the time Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
10. People with dementia contribute a lot to our communities Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
11. People with dementia have the right to take part in discussions about their future Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				
12. Obtaining a diagnosis of dementia can empower that person to plan for the future Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree ☐				

Comments/Suggestions re grouping or ordering of items

……

Comments/Suggestions regarding any need for change to response options or the scoring system

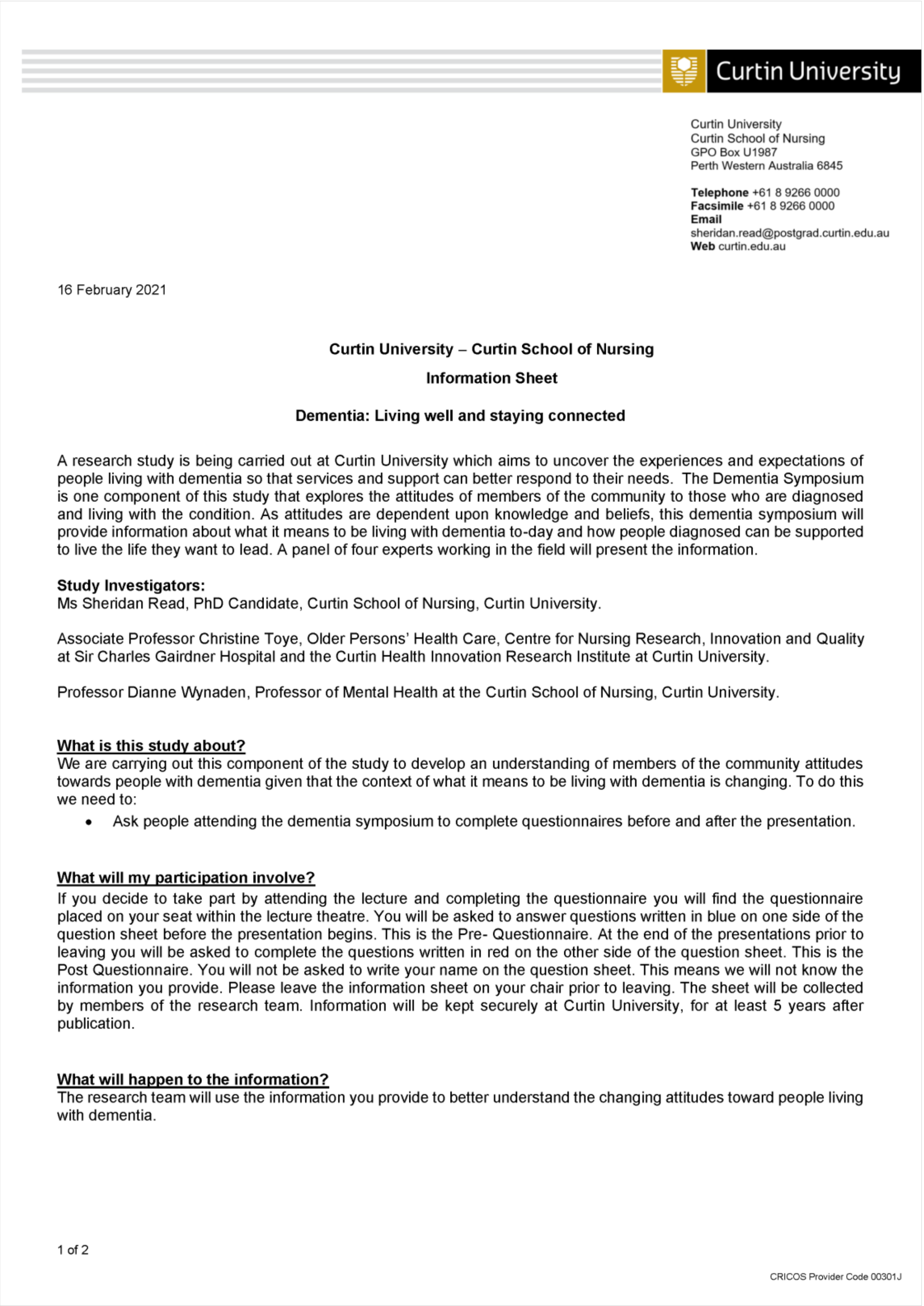
……

Please indicate any important omissions

……

Appendix J

Research information sheet for Dementia Symposium attendees – Study 4



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16 February 2021

Curtin University – Curtin School of Nursing

Information Sheet

Dementia: Living well and staying connected

A research study is being carried out at Curtin University which aims to uncover the experiences and expectations of people living with dementia so that services and support can better respond to their needs. The Dementia Symposium is one component of this study that explores the attitudes of members of the community to those who are diagnosed and living with the condition. As attitudes are dependent upon knowledge and beliefs, this dementia symposium will provide information about what it means to be living with dementia to-day and how people diagnosed can be supported to live the life they want to lead. A panel of four experts working in the field will present the information.

Study Investigators:
Ms Sheridan Read, PhD Candidate, Curtin School of Nursing, Curtin University.

Associate Professor Christine Toye, Older Persons' Health Care, Centre for Nursing Research, Innovation and Quality at Sir Charles Gairdner Hospital and the Curtin Health Innovation Research Institute at Curtin University.

Professor Dianne Wynaden, Professor of Mental Health at the Curtin School of Nursing, Curtin University.

What is this study about?

We are carrying out this component of the study to develop an understanding of members of the community attitudes towards people with dementia given that the context of what it means to be living with dementia is changing. To do this we need to:

- Ask people attending the dementia symposium to complete questionnaires before and after the presentation.

What will my participation involve?

If you decide to take part by attending the lecture and completing the questionnaire you will find the questionnaire placed on your seat within the lecture theatre. You will be asked to answer questions written in blue on one side of the question sheet before the presentation begins. This is the Pre- Questionnaire. At the end of the presentations prior to leaving you will be asked to complete the questions written in red on the other side of the question sheet. This is the Post Questionnaire. You will not be asked to write your name on the question sheet. This means we will not know the information you provide. Please leave the information sheet on your chair prior to leaving. The sheet will be collected by members of the research team. Information will be kept securely at Curtin University, for at least 5 years after publication.

What will happen to the information?

The research team will use the information you provide to better understand the changing attitudes toward people living with dementia.

What are the benefits and risks of participating?

By taking part in this study you will gain a greater awareness and understanding of what it means to be living with dementia plus how supporting a person with dementia can help to maintain their quality of life. By completing the questionnaire you will be helping us to develop an understanding of the changing attitudes towards people living with dementia which will help to identify what further work in this area is required into the future.

The information you provide may be included in presentations or written publications but the information you provide will be non-identifiable meaning that the information will not be linked to you in anyway.

It is unlikely that you will experience any distress or have any concerns throughout or following the presentations. However if you do, please contact Alzheimer's WA on 1300 66 77 88 as they have a counselling service that you will be able to access.

Who can I contact if I have questions about the symposium?

Sheridan Read (0405 478 110) will be pleased to answer any questions you may have.

Who has given permission for this study to proceed?

The Curtin University Human Research Ethics Committee has granted approval for the conduct of this project, approval number HR139/2013. If you have any ethical concerns regarding the study you can contact the Executive Officer of the Curtin University Human Research Ethics Committee on (08) 9266 1792.

What if I decide not to participate?

It is for you to choose whether or not to take part in this study. Participation is voluntary and there will be no negative consequences for you if you decide not to take part.

Thank you for taking the time to read this information sheet – it is yours to keep.

Appendix K

Authorisation to reproduce Publication 1 – Study 1 (Chapter 3)

Experiences and expectations of living with dementia: A qualitative study

Author: Sheridan T. Read,Christine Toye,Dianne Wynaden
Publication: Collegian: Journal of the Royal College of Nursing Australia
Publisher: Elsevier
Date: October 2017

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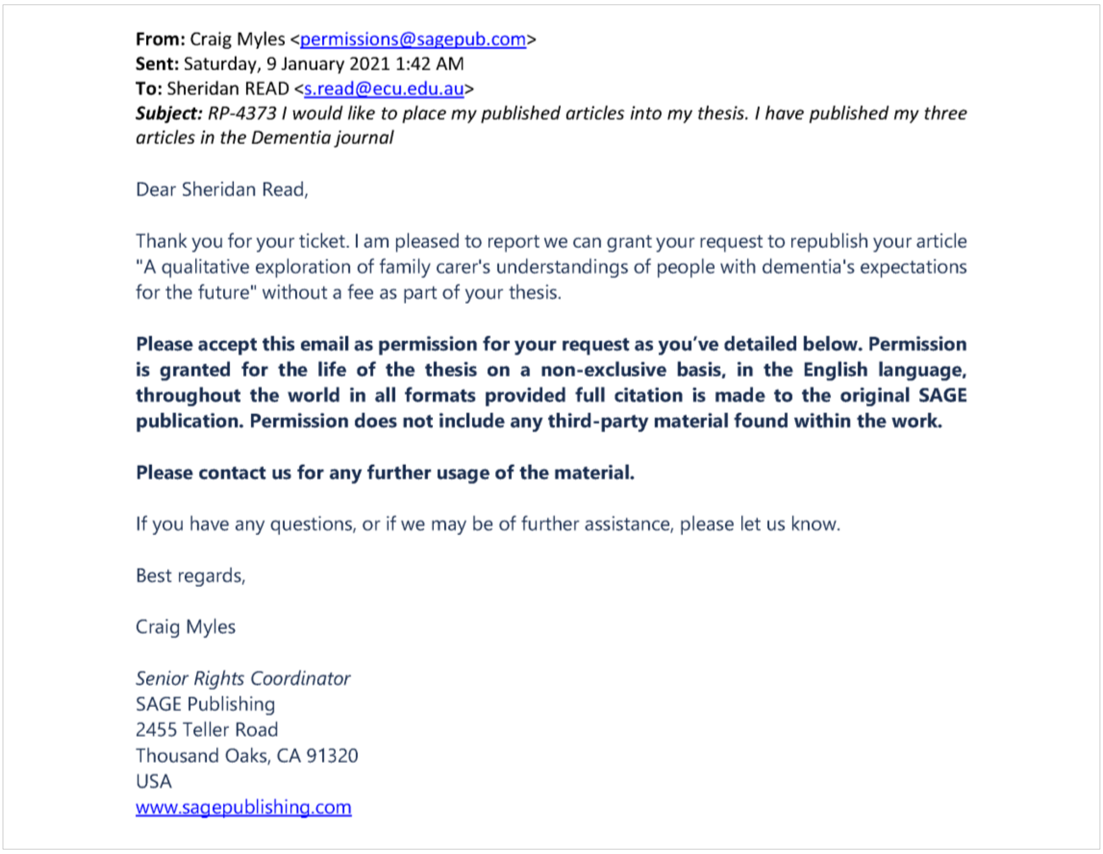
Appendix L

Permission to reproduce Publication 2 – Study 2 (Chapter 3)



From: Craig Myles <permissions@sagepub.com>
Sent: Saturday, 9 January 2021 1:42 AM
To: Sheridan READ <s.read@ecu.edu.au>
Subject: *RP-4373 I would like to place my published articles into my thesis. I have published my three articles in the Dementia journal*

Dear Sheridan Read,

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Craig Myles

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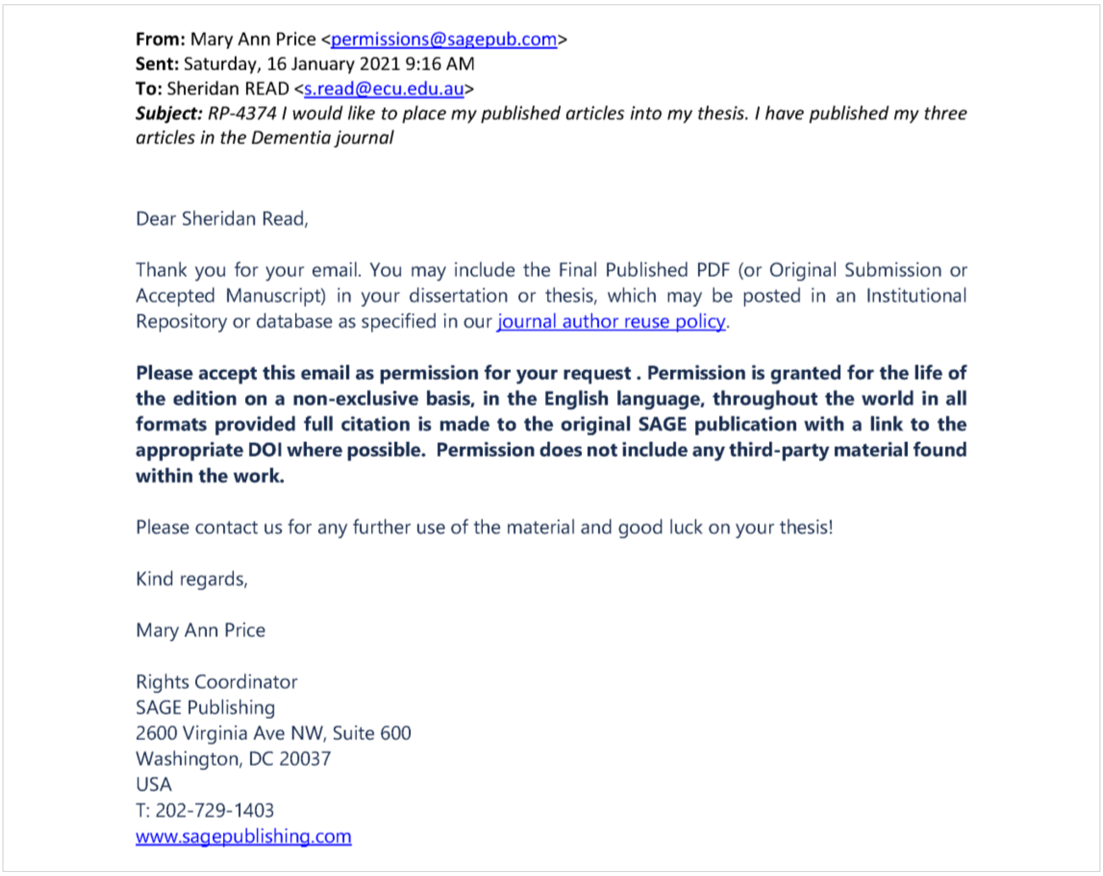
Appendix M

Permission to reproduce Publication 3 (Chapter 4)



From: Mary Ann Price <permissions@sagepub.com>
Sent: Saturday, 16 January 2021 9:16 AM
To: Sheridan READ <s.read@ecu.edu.au>
Subject: *RP-4374 I would like to place my published articles into my thesis. I have published my three articles in the Dementia journal*

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Appendix N

Additional (top up) Literature Review – Excluded articles

	Article	**Excluded at title and abstract screen**	**Excluded at full text review**	**Reason**
1.	Birchley, G., Jones, K., Huxtable, R., Dixon, J., Kitzinger, J., & Clare, L. (2016). Dying well with reduced agency: A scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty. *BMC Medical Ethics*, *17*(1), 46. https://doi.org/http://dx.doi.org/10.1186/s12910-016-0129-x		**X**	Did not report either a qualitative study or a quantitative study or a systematic review.
2.	Bosisio, F., & Barazzetti, G. (2020). Advanced care planning: Promoting autonomy in caring for people with dementia. *American Journal of Bioethics*, *20*(8), 93-95. https://doi.org/10.1080/15265161.2020.1781958	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
3.	Bryant, J., Turon, H., Waller, A., Freund, M., Mansfield, E., & Sanson-Fisher, R. (2018). Effectiveness of interventions to increase participation in advance care planning for people with a diagnosis of dementia: A systematic review. *Palliative Medicine*, *33*(3), 262-273. https://doi.org/http://dx.doi.org/10.1177/0269216318801750		**X**	Did not include papers reporting studies that have recruited people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
4.	Prater, L. C., Wickizer, T., & Bose-Brill, S. (2019). Examining age inequalities in operationalised components of advance care planning: Truncation of the ACP process with age. *Journal of Pain and Symptom Management*, *57*(4). https://doi.org/10.1016/j.jpainsymman.2018.12.338	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
5. Cardona-Morrell, M., Benfatti-Olivato, G., Jansen, J., Turner, R. M., Fajardo-Pulido, D., & Hillman, K. (2017). A systematic review of effectiveness of decision aids to assist older patients at the end of life. *Patient Educ Couns*, *100*(3), 425-435. https://doi.org/10.1016/j.pec.2016.10.007		**X**	Did not include papers reporting studies that have recruited people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
6. Carter, G., McLaughlin, D., Kernohan, W. G., Hudson, P., Clarke, M., Froggatt, K., Passmore, P., & Brazil, K. The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing*, *74*(7), 1595-1604. https://doi.org/10.1111/jan.13576	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
7. Choi, S., Kim, M., & McDonough, I. M. (2018). Do older adults with Alzheimer's disease engage in estate planning and advance care planning preparation? Aging *Ment Health*, *23*(7), 872-879. https://doi.org/10.1080/13607863.2018.1461192	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
8. Cipriani, G., & Di Fiorino, M. (2019). Euthanasia and other end of life in patients suffering from dementia. *Legal Medicine*, *40*, 54-59. https://doi.org/10.1016/j.legalmed.2019.07.007	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
9. Clarfield, A. M., Dwolatzky, T., Brill, S., Press, Y., Glick, S., Shvartzman, P., & Doron, I. (2020). Israel ad hoc COVID-19 committee: Guidelines for care of older persons during a pandemic. *Journal of the American Geriatrics Society*, *68*(7), 1370-1375. https://doi.org/10.1111/jgs.16554	**X**		Did not investigate the participation of people with dementia in the planning of their care and or support throughout the dementia journey.
10. Eastman, P., Ko, D., & Le, B. H. (2020). Challenges in advance care planning: The interface between explicit instructional directives and palliative care. *Medical Journal of Australia*, *213*(2), 67-68 https://doi.org/10.5694/mja2.50653	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
11. Garcia-Ptacek, S., Eriksdotter, M., Dahlrup, B., Edlund, A. K., & Wijk, H. (2019). The caregiving phenomenon and caregiver participation in dementia. *Scandinavian Journal of Caring Sciences*, *33*(2), 255-265. https://doi.org/10.1111/scs.12627	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
12. Goering, S. (2020). "Why should adamancy of an uninformed view give moral weight?". *American Journal of Bioethics*, *20*(8), 78-79. https://doi.org/10.1080/15265161.2020.1781956	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
13. Harrison, K. L., Allison, T. A., Garrett, S. B., Thompson, N., Sudore, R. L., & Ritchie, C. S. (2020). Hospice staff perspectives on caring for people with dementia: A multisite, multi stakeholder study. *Journal of Palliative Medicine*, *23*(8), 1013-1020. https://doi.org/10.1089/jpm.2019.0565	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
14. Hérault, É., Bravo, G., & Trottier, L. (2018). Advance directives for research: How do they compare with surrogates' predictions of older adults' preferences? *IRB: Ethics & Human Research*, *40*(5), 11-19. https://doi.org/10.1002/eahr.405002	**X**		Did not explore the participation of people with dementia in the planning of their care and support throughout the dementia trajectory.
15. Huang, H. L., Lu, W. R., Liu, C. L., & Chang, H. J. Advance care planning information intervention for persons with mild dementia and their family caregivers: Impact on end-of-life care decision conflicts. *PLoS ONE*, *15*(10), e0240684. https://doi.org/10.1371/journal.pone.0240684	**X**		Study was not conducted in either Australia, NZ, UK, Ireland, USA, Canada, and Western Europe.
16. Ibrahim, J. E., MacPhail, A., Winbolt, M., & Grano, P. (2016). Limitation of care orders in patients with a diagnosis of dementia. *Resuscitation*, *98*, 118-124. https://doi.org/10.1016/j.resuscitation.2015.03.014	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
17. Jox, R. J. (2020). Living will versus will to live? How to navigate through complex decisions for persons with dementia. *American Journal of Bioethics*, *20*(8), 85-87. https://doi.org/10.1080/15265161.2020.1781966	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
18. Kolva, E., Rosenfeld, B., & Saracino, R. (2018). Assessing the decision-making capacity of terminally ill patients with cancer. *Am J Geriatr Psychiatry*, *26*(5), 523-531. https://doi.org/10.1016/j.jagp.2017.11.012	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
19. Lee, J. J. Y., Thompson, C. L., Shaik, M. A., Wan, E., Chen, C. L. H., & Dong, Y. H. (2018). Service use, advance planning and lifestyle changes following cognitive screening in primary healthcare in Singapore. *International Psychogeriatrics, 30*(1), 139-145. https://doi.org/10.1017/S1041610217001971	**X**		Study was not conducted in either Australia, NZ, UK, Ireland, USA, Canada or Western Europe.
20. Levi, B. H., Simmons, Z., Hanna, C., Brothers, A., Lehman, E., Farace, E., Bain, M., Stewart, R., & Green, M. J. (2017). Advance care planning for patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 18*(5-6), 388-396. https://doi.org/10.1080/21678421.2017.1285317	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
21. Lyreskog, D. M., Karlawish, J., & Nagel, S. K. (2020). Where do you end, and I begin? How relationships confound advance directives in the care of persons living with dementia. *American Journal of Bioethics, 20*(8), 83-85. https://doi.org/10.1080/15265161.2020.1781967	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
22. McCreedy, E., Loomer, L., Palmer, J. A., Mitchell, S. L., Volandes, A., & Mor, V. (2018). Representation in the care planning process for nursing home residents with dementia. *Journal of the American Medical Directors Association, 19*(5), 415-421. https://doi.org/10.1016/j.jamda.2018.01.004	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
23. Menzel, P. T. (2017, Winter2017). Voluntarily stopping eating and drinking: A normative comparison with refusing lifesaving treatment and advance directives. *Journal of Law, Medicine & Ethics, 45*(4), 634-646. https://doi.org/10.1177/1073110517750602	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
24. Moore, N., Detering, K. M., Low, T., Nolte, L., Fraser, S., & Sellars, M. (2019, Oct). Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: An Australian interview study. *Bmj Open*, *9*(10), Article e032638. https://doi.org/10.1136/bmjopen-2019-032638	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
25. Murray, L., Butow, P. N., White, K., Kiernan, M. C., D'Abrew, N., & Herz, H. (2016). Advance care planning in motor neuron disease: A qualitative study of caregiver perspectives. *Palliative Medicine*, *30*(5), 471-478. https://doi.org/10.1177/0269216315613902	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
26. Prater, L. C., Wickizer, T., & Bose-Brill, S. (2019). Examining age inequalities in operationalized components of advance care planning: Truncation of the ACP process with age. *Journal of Pain and Symptom Management*, *57*(4), 731-737. https://doi.org/10.1016/j.jpainsymman.2018.12.338	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
27. Read, S. T., Toye, C., & Wynaden, D. (2020). The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia*, *19*(3), 691-707. https://doi.org/10.1177/1471301218784806	**X**		This paper was retrieved during the search but was excluded given that it was the original review.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
28. Ries, N., Thompson, K., & Lowe, M. (2017). Including people with dementia in research: An analysis of Australian ethical and legal rules and recommendations for reform. *Journal of Bioethical Inquiry, 14*(3), 359-374. https://doi.org/10.1007/s11673-017-9794-9	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
29. Romøren, M., Pedersen, R., & Førde, R. (2016). How do nursing home doctors involve patients and next of kin in end-of-life decisions? A qualitative study from Norway. *BMC Med Ethics, 17*(4), 5-5. https://doi.org/10.1186/s12910-016-0088-2	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
30. Sævareid, T. J. L., Lillemoen, L., Thoresen, L., Førde, R., Gjerberg, E., & Pedersen, R. (2018). Implementing advance care planning in nursing homes – study protocol of a cluster-randomized clinical trial. *BMC Geriatr, 18*(1), 180-180. https://doi.org/10.1186/s12877-018-0869-1		**X**	Did not report either a qualitative study or a quantitative study or a systematic review.
31. Sævareid, T. J. L., Thoresen, L., Gjerberg, E., Lillemoen, L., & Pedersen, R. (2019). Improved patient participation through advance care planning in nursing homes—A cluster randomized clinical trial. *Patient Educ Couns, 102*(12), 2183-2191. https://doi.org/10.1016/j.pec.2019.06.001		**X**	Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
32. Schoene-Seifert, B., Uerpmann, A. L., Gerß, J., & Herr, D. (2016). Advance (Meta-) Directives for patients with dementia who appear content: Learning from a nationwide survey. *Journal of the American Medical Directors Association, 17*(4), 294-299. https://doi.org/10.1016/j.jamda.2016.01.014		**X**	Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.

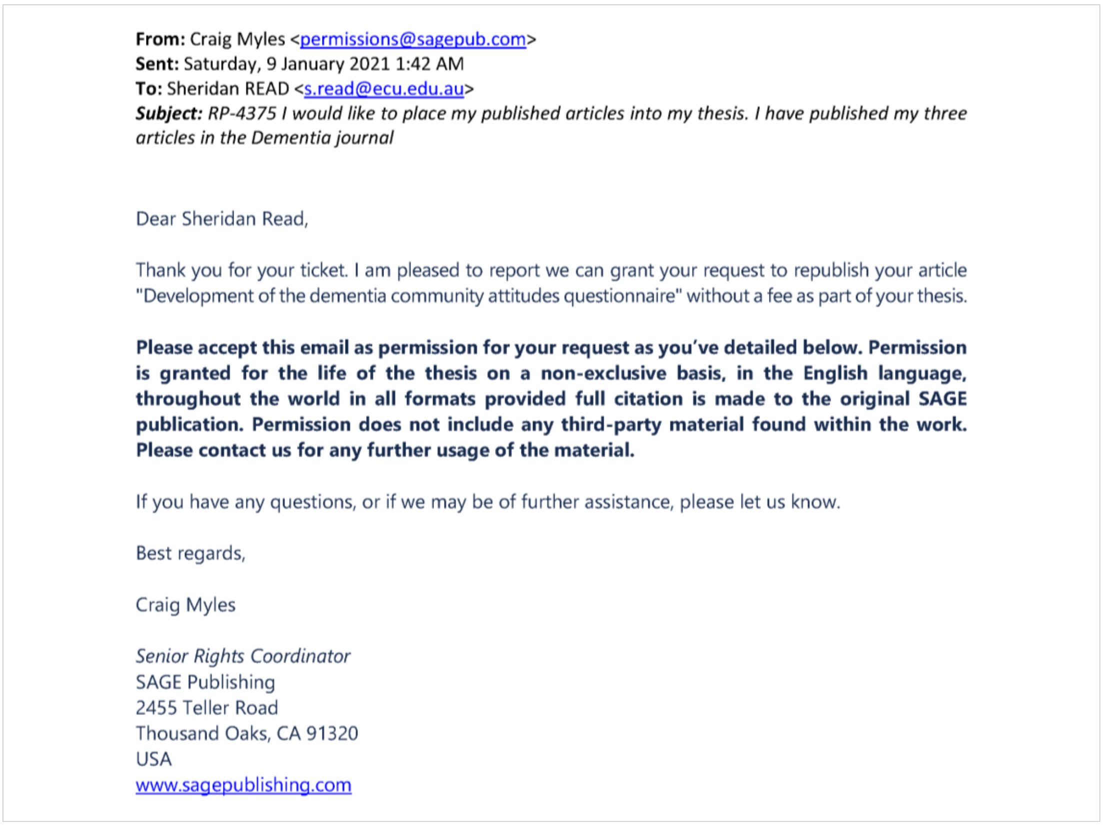
Article	Excluded at title and abstract screen	Excluded at full text review	Reason
33. Schwartz, D. B., Pavic-Zabinski, K., & Tull, K. (2019). Role of the nutrition support clinician on a hospital bioethics committee. *Nutrition in Clinical Practice, 34*(6), 869-880. https://doi.org/10.1002/ncp.10378	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
34. Sinclair, J. B., Oyebode, J. R., & Owens, R. G. (2016). Consensus views on advance care planning for dementia: A Delphi study. *Health & Social Care in the Community*, *24*(2), 165-174. https://doi.org/10.1111/hsc.12191	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
35. Song, M.-K., Ward, S. E., Hepburn, K., Paul, S., Shah, R. C., & Morhardt, D. J. (2018). SPIRIT advance care planning intervention in early stage dementias: An NIH stage I behavioural intervention development trial. *Contemp Clin Trials*, *71*, 55-62. https://doi.org/10.1016/j.cct.2018.06.005	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
36. Steinbock, B., & Menzel, P. T. (2018). Advance directives for refusing life-sustaining treatment in Dementia. *Hastings Center Report*, *48*, S75-S79. https://doi.org/10.1002/hast.919	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
37. Thomas, K., Giles, L., Stobbart-Rowlands, M., & Keating, A. (2017). P-270 Improving eolc at home provided by domiciliary teams using the gsf domiciliary care programme. *BMJ Supportive & Palliative Care*, *7*(Suppl 2), A106. https://doi.org/10.1136/bmjspcare-2017-hospice.295	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.

Article	Excluded at title and abstract screen	Excluded at full text review	Reason
38. Van Rickstal, R., De Vleminck, A., Aldridge, M. D., Morrison, S. R., Koopmans, R. T., van der Steen, J. T., Engelborghs, S., & Van den Block, L. (2019). Limited engagement in, yet clear preferences for advance care planning in young-onset dementia: An exploratory interview-study with family caregivers. *Palliative Medicine*, *33*(9), 1166-1175. https://doi.org/10.1177/0269216319864777	**X**		Did not include people with dementia with the capacity to verbally articulate their care and support preferences as research participants.
39. Walsh, E. (2020). Cognitive transformation, dementia, and the moral weight of advance directives. American *Journal of Bioethics*, *20*(8), 54-64. https://doi.org/10.1080/15265161.2020.1781955	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
40. Widdershoven, G., Janssens, R., & Voskes, Y. (2020). Beyond precedent autonomy and current preferences: A narrative perspective on advance directives in dementia care. *American Journal of Bioethics*, *20*(8), 104-106. https://doi.org/10.1080/15265161.2020.1781969	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.
41. Wright, J. L., Jaggard, P. M., Holahan, T., Ethics Subcommittee, A., & Soc Post-Acute Long-Term, C. (2019, Nov). Stopping eating and drinking by advance directives (SED by AD) in assisted living and nursing homes. *Journal of the American Medical Directors Association*, *20*(11), 1362-1366. https://doi.org/10.1016/j.jamda.2019.07.026	**X**		Did not report either a qualitative study or a quantitative study or a systematic review.

Note: Paper written by Read, S. T., Toye, C., & Wynaden, D. (2020). The participation of people with dementia in the planning of their care and support: An integrative literature review. Dementia (14713012), 19(3), 691-707. was retrieved during the search but was excluded given that it was the original review article.

Appendix O

Permission to reproduce Publication 4 – Study 3 (Chapter 5)



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Appendix P

Dementia Awareness Raising Forum briefing document – Study 4

CURTIN UNIVERSITY- DEMENTIA AWARENESS RAISING FORUM

PRESENTER AND FACILITATOR BRIEFING DOCUMENT

PROJECT TITLE	Dementia: Living Well, Staying Connected
CONTACT PERSON	Sheridan Read – 0405 478 110
PROJECT AUTHORS	1. Sheridan T. Read. RN (BNurs) PhD Candidate. 2. Christine Toye RN PhD 3. Dianne Wynaden RN MHN PhD

BACKGROUND AND RATIONALE

The way an individual experiences dementia, will partly be determined by their social environment and the attitudes of those people with whom they associate (Cheston, Hancock, & White, 2016). Historically, dementia has been seen from a biomedical viewpoint with the assumption that a person diagnosed would be dependent upon others to ensure their needs are met (Edvardsson, Winblad, & Sandman, 2008). This perception about a person with dementia's lack of independence creates an expectation about the support they may require and often results in the premature loss of a person's decision making autonomy (Cheston et al., 2016; Read, Toye, & Wynaden, 2016). Furthermore, people diagnosed with dementia often report a nihilistic attitude from health professionals in regard to their treatment and support options (Read et al., 2016; Swaffer, 2015).

Advances in treatment and support however mean that there is an increasing array of options for people with dementia in how they choose to live their life. In addition, the introduction of an individualised and goal oriented reablement approach means that a person's independence and function is maximised for as long as possible. Through the implementation of various interventions, including but not limited to, use of assistive technology and environmental adaptations (Brims & Oliver, 2018; Hadjri, Rooney, & Faith, 2015; Poulos et al., 2017), people are more able to stay connected to their pre-diagnosis lifestyle (Read et al., 2016; Swaffer, 2014). Contemporaneous to the rise in advances in treatment and support is the rise in dementia's consumer movement, and the number of people diagnosed speaking out to ensure that they and others living with the condition are included in decisions which affect their lives (Dementia Alliance International, 2016). Ensuring a human rights based approach and introducing strategies that enable people living with dementia's contribution to society requires a shift in people's attitudes about what it means to live with the condition (Dementia Alliance International, 2016; Marshall & Tibbs, 2006; World Health Organisation, 2015).

People's attitudes to dementia are dependent on their knowledge and beliefs regarding the condition which subsequently impacts upon how they respond to people who are diagnosed

(Breckler, 1984; Staples & Killian, 2012). The increasing numbers of people diagnosed and the shift toward earlier diagnosis means that people with dementia are more consistently visible to others in the community and therefore a broader community understanding of what it means to be living with the condition is required. Whilst people with dementia sometimes report that they are often passive receivers of care, and often provided with little opportunity to live a life of any meaning following their diagnosis, health professionals have increasing knowledge about advancing treatment and support options which will impact on support people are offered into the future. Translating this new knowledge surrounding the changing landscape of living with dementia, and detailing the consumer voice to members of the community is required through forums such as public lectures and media campaigns. Communicating how people with dementia can live well, will assist in reducing dementia related stigma and means that members of our community will have an increased understanding of how people with dementia can be supported to maintain their quality of life following their diagnosis.

PROJECT AIMS / OBJECTIVES

Aim:
To increase, within the local community, awareness and understanding of what it means to be living with a dementia diagnosis within the current context and how best a person diagnosed can be supported to maintain their quality of life.

Objectives:

1. To instigate a community seminar (promoted as a Curtin Ageing Research Network event and to be Co- Badged with Alzheimer's WA) designed to increase awareness and understanding about the changing context of what it means to be living with dementia plus how supporting a person with dementia can help to maintain their quality of life. The public lecture will be a facilitated event and the information presented to attendees via a panel of four experts working in the field.

2. Conduct a brief evaluation of the extent to which attitudes to people living with dementia has been influenced by the seminar. Attendees will be asked to complete the questionnaire at two time intervals, both before and after the forum.

PROJECT DETAILS

Event Date: 2nd October 2019

Event Address: Curtin University.
Kent Street
Bentley WA 6102

Curtin University Lecture Theatre: Elizabeth Jolley Lecture Theatre, Building 210

Scheduled timing of the event:

The duration of the facilitated event will be approximately 2 hours long.

- Participant arrival time of approximately 5.30pm for drinks/afternoon tea and registration.
- The lecture to commence at approximately 6pm. Attendees asked to complete pre-questionnaire (Time 1 data collection).
- The lecture to conclude at approximately 7.20pm following presentation of four panel members plus question and answer time. Participants then asked to complete the post questionnaire (Time 2 Data collection) and leave at 7.30pm.

Facilitator briefing:

The facilitator will be provided with an oral briefing by Sheridan Read (and supervisor or alternative staff members as appropriate) approximately one week prior to the event and a written script detailing the event proceedings and requirements. **The facilitator will be asked to attend the event at approximately 5pm (to be confirmed)** to meet with the panel members, at which time the facilitator will be given an opportunity to ask any questions to each of the panel members. Panel members and facilitator will be provided with drinks and afternoon tea at this time.

Panel members:

The lecture presentation will be conducted by a panel of four prominent speakers with expertise in the field.

Presentations, 7 to 8 minutes in duration, are to proceed as follows:

- Speaker 1, to detail the dementia human rights movement.
- Speaker 2, new knowledge in early diagnosis and advances in a range of treatment and support options.
- Speaker 3, the expectations of people living with dementia.
- Speaker 4, new initiatives in living well with dementia and how we as a community can break down the stigma of living with dementia.

Presenters are to detail the changing landscape of living well with dementia within their specialty area, past, present and future. Presenters to email presentations in advance, 1 week prior to the event to sheridan.read@postgrad.curtin.edu.au, power point slide size 16:9. In addition presenters to bring back up copies of slides on a USB to the event. Curtin IT personnel will be in attendance at the event to assist with audio and visual requirements.

Sheridan Read will liaise with and brief selected panel members intermittently as required in the lead up to the event, and ensure there is no presentation content duplicated between presenters. **Panel members to arrive at the event at approximately 5pm (to be confirmed)** to meet with facilitator and to be further briefed on proceedings as required. Panel members to be provided with a written script detailing event proceedings and requirements approximately one week prior to the event.

.

References

Breckler, S. J. (1984). Empircal Validation of Affect , Behaviour and Cognition as distinct components of Attitude. *Journal of Psychology and Social Psychology, 47*(6), 1191-1205.

Brims, L., & Oliver, K. (2018). Effectiveness of assistive technology in improving the safety of people with dementia: a systematic review and meta-analysis. *Aging & Mental Health*, 1-10. doi:10.1080/13607863.2018.1455805

Cheston, R., Hancock, J., & White, P. (2016). A cross-sectional investigation of public attitudes toward dementia in Bristol and South Gloucestershire using the approaches to dementia questionnaire. *28*(10), 1717-1724. doi:10.1017/S1041610216000843

Dementia Alliance International. (2016). *The Human Rights of People Living with Dementia: from Rhetoric to Reality*. Retrieved from

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: Current status and ways forward. *Lancet Neurology, 7*, 362-367.

Hadjri, K., Rooney, C., & Faith, V. (2015). Housing Choices and Care Home Design for People With Dementia. *HERD: Health Environments Research & Design Journal, 8*(3), 80-95. doi:10.1177/1937586715573740

Marshall, M., & Tibbs, M. (2006). *Social Work and People with Dementia*. United Kingdom: The Policy Press.

Plichta, S. B., & Kelvin, E. (2013). *Munro's Statistical Methods for Health Care Research*. Philadelphia: U.S.A.: Lippincott Williams & Wilkins.

Poulos, C. J., Bayer, A., Beaupre, L., Clare, L., Poulos, R. G., Wang, R. H., . . . McGilton, K. S. (2017). A comprehensive approach to reablement in dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 3*(3), 450-458. doi:https://doi.org/10.1016/j.trci.2017.06.005

Read, S. T., Toye, C., & Wynaden, D. (2016). Experiences and expectations of living with dementia: A qualitative study. *Collegian, 24*(5), 427-432. doi:http://doi.org/10.1016/j.colegn.2016.09.003

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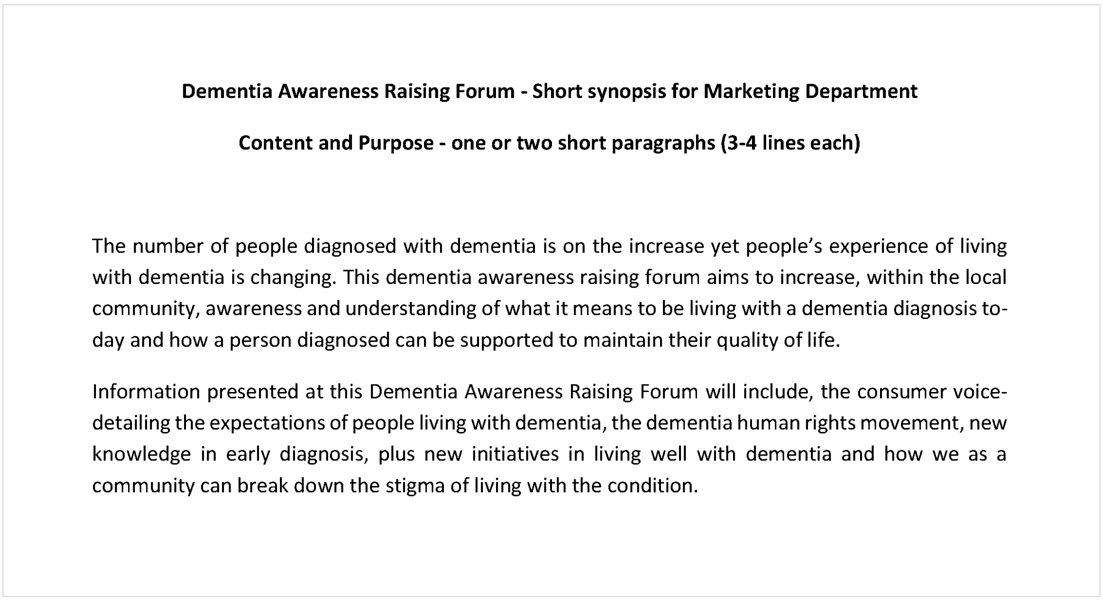
Swaffer, K. (2014). Reinvesting in a life is the best prescription. . *Australian Journal of Dementia Care, 3*(6), 31-32. Retrieved from http://journalofdementiacare.com/reinvesting-in-life-is-the-best-prescription/

Swaffer, K. (2015). Dementia and prescribed disengagement. *Dementia, 14*(1), 3-6. doi:10.1177/1471301214548136

World Health Organisation. (2015). *Ensuring a human rights based approach for people living with dementia*. Retrieved from http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf.

Appendix Q

Dementia Awareness Raising Forum synopsis – Study 4



Dementia Awareness Raising Forum - Short synopsis for Marketing Department

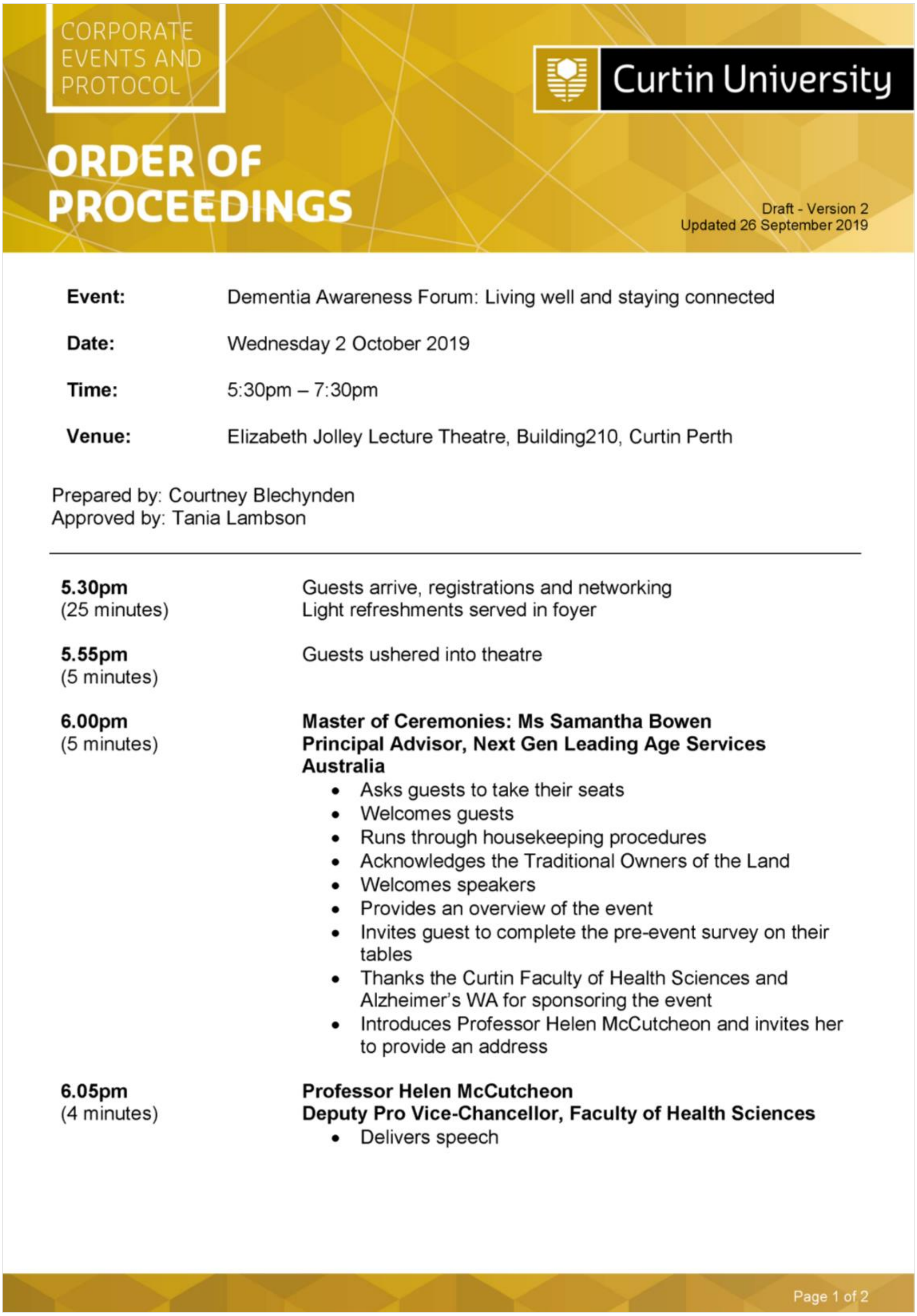
Content and Purpose - one or two short paragraphs (3-4 lines each)

The number of people diagnosed with dementia is on the increase yet people's experience of living with dementia is changing. This dementia awareness raising forum aims to increase, within the local community, awareness and understanding of what it means to be living with a dementia diagnosis today and how a person diagnosed can be supported to maintain their quality of life.

Information presented at this Dementia Awareness Raising Forum will include, the consumer voice-detailing the expectations of people living with dementia, the dementia human rights movement, new knowledge in early diagnosis, plus new initiatives in living well with dementia and how we as a community can break down the stigma of living with the condition.

Appendix R

Dementia Awareness Raising Forum order of proceedings document – Study 4



CORPORATE
EVENTS AND
PROTOCOL

Curtin University

ORDER OF PROCEEDINGS

Draft - Version 2
Updated 26 September 2019

Event:	Dementia Awareness Forum: Living well and staying connected
Date:	Wednesday 2 October 2019
Time:	5:30pm – 7:30pm
Venue:	Elizabeth Jolley Lecture Theatre, Building210, Curtin Perth

Prepared by: Courtney Blechynden
Approved by: Tania Lambson

5.30pm
(25 minutes)

Guests arrive, registrations and networking
Light refreshments served in foyer

5.55pm
(5 minutes)

Guests ushered into theatre

6.00pm
(5 minutes)

Master of Ceremonies: Ms Samantha Bowen
Principal Advisor, Next Gen Leading Age Services Australia

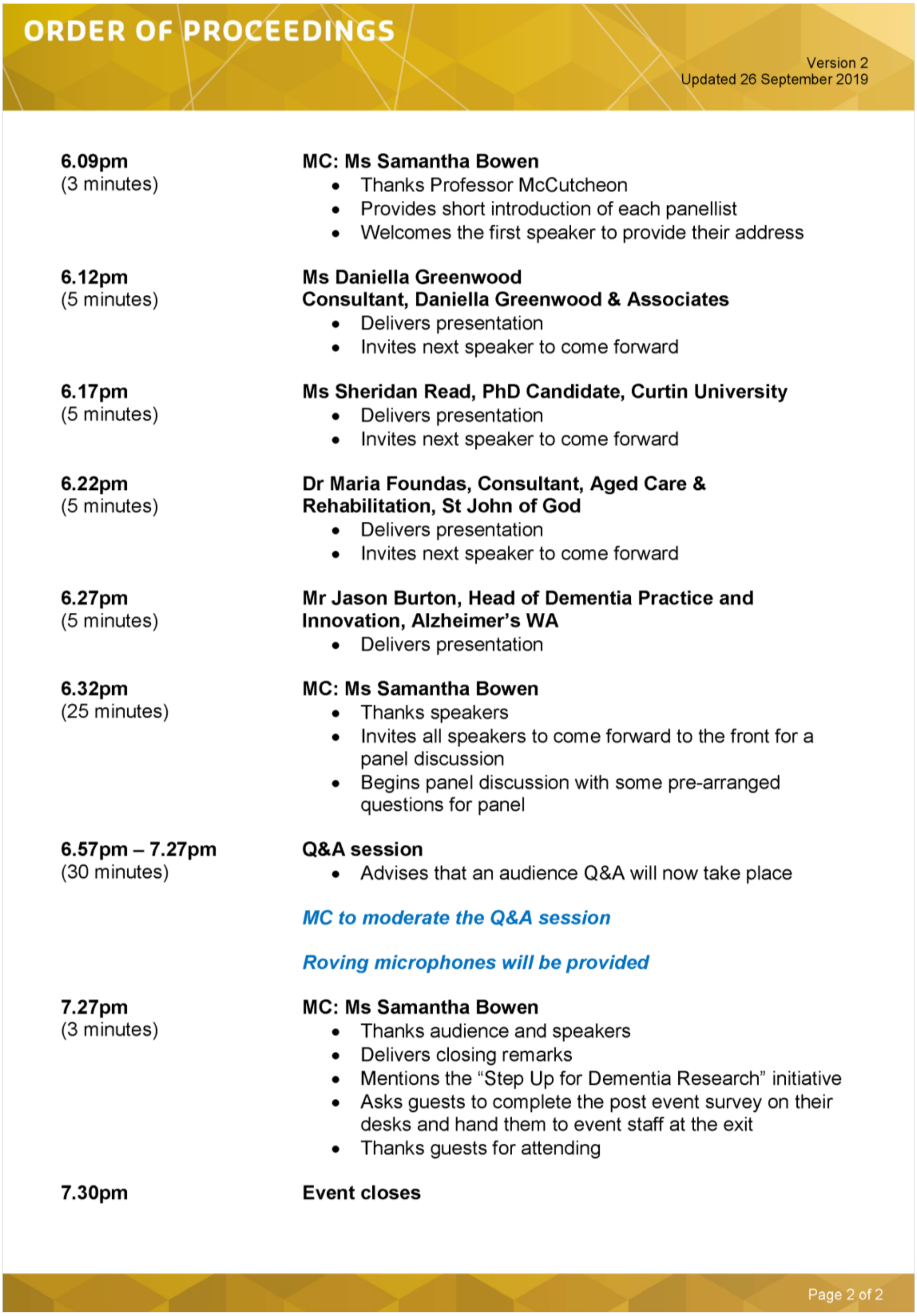
- Asks guests to take their seats
- Welcomes guests
- Runs through housekeeping procedures
- Acknowledges the Traditional Owners of the Land
- Welcomes speakers
- Provides an overview of the event
- Invites guest to complete the pre-event survey on their tables
- Thanks the Curtin Faculty of Health Sciences and Alzheimer's WA for sponsoring the event
- Introduces Professor Helen McCutcheon and invites her to provide an address

6.05pm
(4 minutes)

Professor Helen McCutcheon
Deputy Pro Vice-Chancellor, Faculty of Health Sciences

- Delivers speech

Page 1 of 2



ORDER OF PROCEEDINGS

Version 2
Updated 26 September 2019

6.09pm (3 minutes)	**MC: Ms Samantha Bowen** • Thanks Professor McCutcheon • Provides short introduction of each panellist • Welcomes the first speaker to provide their address
6.12pm (5 minutes)	**Ms Daniella Greenwood** **Consultant, Daniella Greenwood & Associates** • Delivers presentation • Invites next speaker to come forward
6.17pm (5 minutes)	**Ms Sheridan Read, PhD Candidate, Curtin University** • Delivers presentation • Invites next speaker to come forward
6.22pm (5 minutes)	**Dr Maria Foundas, Consultant, Aged Care & Rehabilitation, St John of God** • Delivers presentation • Invites next speaker to come forward
6.27pm (5 minutes)	**Mr Jason Burton, Head of Dementia Practice and Innovation, Alzheimer's WA** • Delivers presentation
6.32pm (25 minutes)	**MC: Ms Samantha Bowen** • Thanks speakers • Invites all speakers to come forward to the front for a panel discussion • Begins panel discussion with some pre-arranged questions for panel
6.57pm – 7.27pm (30 minutes)	**Q&A session** • Advises that an audience Q&A will now take place ***MC to moderate the Q&A session*** ***Roving microphones will be provided***
7.27pm (3 minutes)	**MC: Ms Samantha Bowen** • Thanks audience and speakers • Delivers closing remarks • Mentions the "Step Up for Dementia Research" initiative • Asks guests to complete the post event survey on their desks and hand them to event staff at the exit • Thanks guests for attending
7.30pm	**Event closes**

Appendix S

Dementia Awareness Raising Forum speaker biographies – Study 4

Dementia Awareness Raising Forum

Dementia: Living Well Staying Connected

Speaker Biographies

Speaker 1 – Daniella Greenwood

Daniella is a consultant, published author and keynote speaker working internationally alongside organisations, government, individuals and service-providers in the creation and implementation of initiatives that focus on relational and human rights-based approaches for people living with dementia.

Speaker 2 – Sheridan Read

Sheridan is a PhD candidate in the School of Nursing, Midwifery and Paramedicine at Curtin University. She has a keen interest in advocating for people living with dementia and has worked in the field for over 20 years. Her PhD topic explores person centred planning in dementia care from the perspectives of people living with dementia and their care partners. Sheridan has worked on numerous projects which aimed to enhance the quality of life of people living with dementia. Sheridan is the student representative on the WA Division of the Australian Association of Gerontology and is also a part of the Australian Hartford Consortium in Nursing Care of Older People.

Speaker 3 – Dr Maria Foundas

Dr Maria Foundas graduated with Honours from the University of Western Australia in 1996 and obtained her Fellowship with the Royal Australasian College of Physicians (RACP) in 2008 (subspecialty Geriatric Medicine). Dr Foundas also completed a Masters of Public Health (with Distinction) through Curtin University. Currently employed by St John of God Healthcare (both at the Midland and Mount Lawley sites), Dr Foundas has largely focused on the specialised area of inpatient Aged Care Rehabilitation and Restorative Care over the last decade. In addition, Dr Foundas has long been involved with Education, both as a Facilitator for the RACP Supervisor Development Program and the teaching of medical students.

Speaker 4 – Jason Burton

Jason Burton originally trained as a Mental Health Nurse in the UK. He has specialised in working with people with dementia for nearly 30 years, both in the U.K. and in Australia. After immigrating to Australia, Jason took up a position with Alzheimer's WA and in his role as Head of Dementia Practice and Innovation he leads the organisations focus on developing innovative dementia care philosophy and practice, research and establishing evidence based services and emerging sector partnerships. Jason has a strong background in developing contemporary enabling environments for people with dementia through dementia design and implementing person centred approaches.

Appendix T

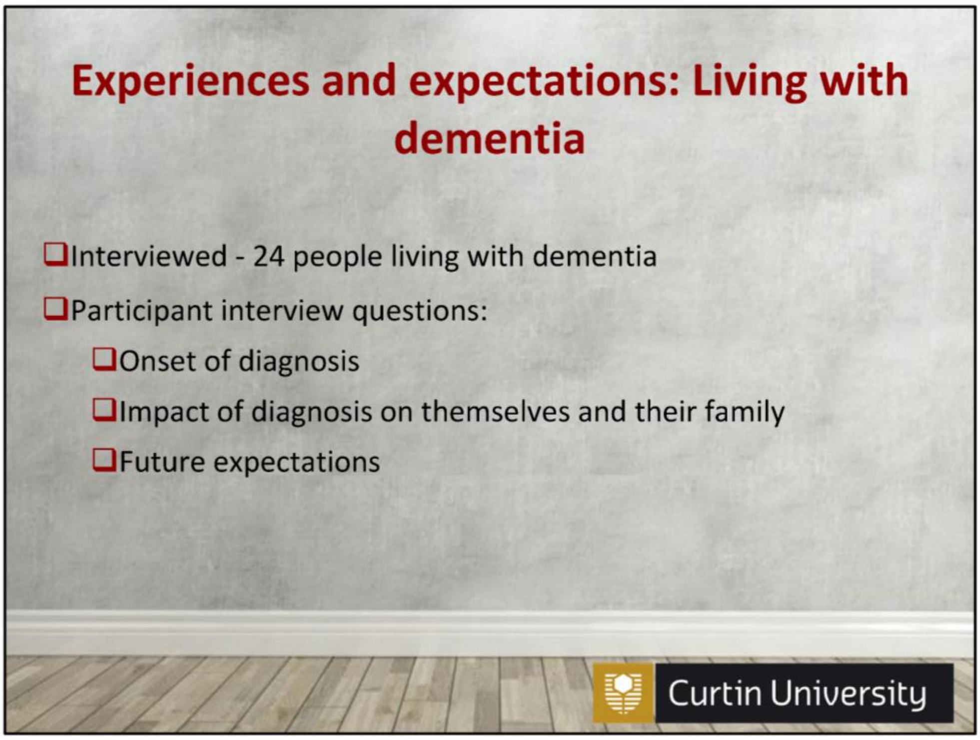
Dementia Awareness Raising Forum panel discussion script – Study 4

Sam:	*[introduces facilitated panel discussion]* Now that we have heard from our 4 excellent speakers, we are going to move onto a panel discussion. Sheridan, we heard from Dennis Frost during your presentation, he clearly articulated some of his experiences living with dementia and talked about some of his newly acquired advocacy roles, does Dennis represent most people living with dementia?
Sheridan:	Many thanks Sam, no, very few people living with dementia have the capacity to be able to advocate as extensively as Dennis does. People with dementia can give back and stay connected to the community in many ways. To help people understand what it is like to live with dementia and provide the consumer experience people with dementia are encouraged to participate in research if they wish to.
Sam:	I imagine that not all people will want to be give back to the community. What other ways can we help to preserve a person's quality of life?
Sheridan:	Again, this is about collaboration and how providers and the interdisciplinary team work together using a reablement or restorative approach to assist people with dementia to maintain functional capacity and social independence. What's most important is to help a person with dementia work towards their own personal goals, if goals are more meaningful and relevant to the individual, they are more likely to be achieved. So, for a person with dementia restorative goals may be more focused on memory and planning, for eg. trying to remember recent events, manage how to reuse the stove, or relearn how to catch a bus which will help to maintain independence and social connectedness
Sam:	Is there much evidence proving the effectiveness of a reablement approach for people with dementia?
Sheridan:	Evidence for a reablement approach for people with dementia is still limited, there is a US based COPE study which stands for Care of persons with dementia in their environment and a community based occupational therapy program in the Netherlands – these programs are largely driven by OT with the COPE study have a small nursing component as well. There is an Australian led study, the I-Harp study which has a much greater interdisciplinary component and is now underway helping to build the evidence base in this area.
Sam:	Dr Foundas, Sheridan has talked a bit about how we can maintain functional capacity in people with dementia, I imagine that the decline a person with dementia experiences may not solely be caused by the neurodegenerative nature of dementia. What other conditions may be contributing to the functional decline a person with dementia experiences?
Dr Foundas:	*[Responds]*
Sam:	Dr Foundas – in the work that you do how might you and your team help to restore function and independence in people with dementia? I was also wondering if you might be able to comment on the benefits of exercise in improving cognition in people with dementia?
Dr Foundas:	*[Responds]*
Sam:	Daniella now to you, I was wondering if you could provide some commentary around the stigma of dementia and how that impacts on people with dementia being able to live well?
Daniella:	*[Responds]*

Sam:	Jason – Dr Foundas spoke to us about other conditions that may contribute to functional decline in people with dementia, could you possibly comment on ways in which we can enhance the physical and social environment to improve a person with dementia ‘s independence and quality of life?
Jason:	*[Responds]*
Sam:	Jason, in what ways can members of our community support people living with dementia?
Jason:	*[Responds]*

Appendix U

Dementia Awareness Raising Forum – Sheridan Read – PowerPoint slides – Study 4



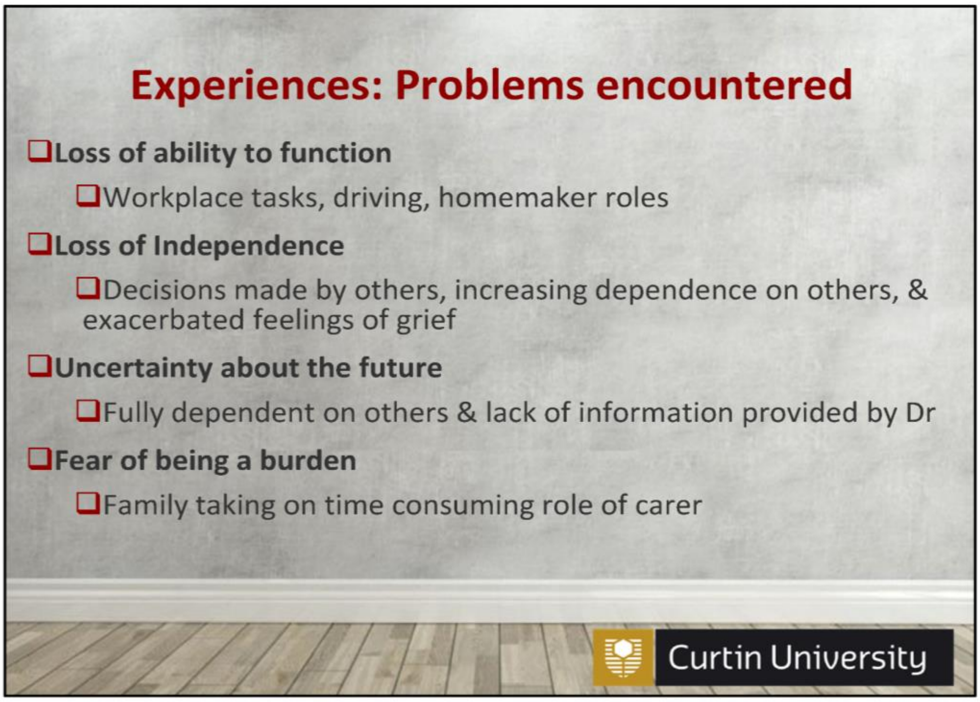
Experiences and expectations: Living with dementia

- ❑Interviewed - 24 people living with dementia
- ❑Participant interview questions:
  - ❑Onset of diagnosis
  - ❑Impact of diagnosis on themselves and their family
  - ❑Future expectations

Curtin University

Good evening everyone,

Many thanks for joining us at our dementia awareness raising forum, many thanks to Daniella, In 2013 as part of my PhD study, it was with absolute pleasure that I began to interview people in our community who were living with dementia,
Participant interview questions focused on the experiences for the person with dementia, from the onset of their diagnosis, the impact of the diagnosis on themselves and their family and the person's future expectations.



Experiences: Problems encountered

- ☐ **Loss of ability to function**
    - ☐ Workplace tasks, driving, homemaker roles
- ☐ **Loss of Independence**
    - ☐ Decisions made by others, increasing dependence on others, & exacerbated feelings of grief
- ☐ **Uncertainty about the future**
    - ☐ Fully dependent on others & lack of information provided by Dr
- ☐ **Fear of being a burden**
    - ☐ Family taking on time consuming role of carer

People with dementia, who participated in my study, spoke to me about a range of problems that they encountered in their day to day life which came about because of their diagnosis. These problems often resulted from a:

Loss of ability to Function as they use to – People spoke of a sudden inability to carry out workplace related tasks.

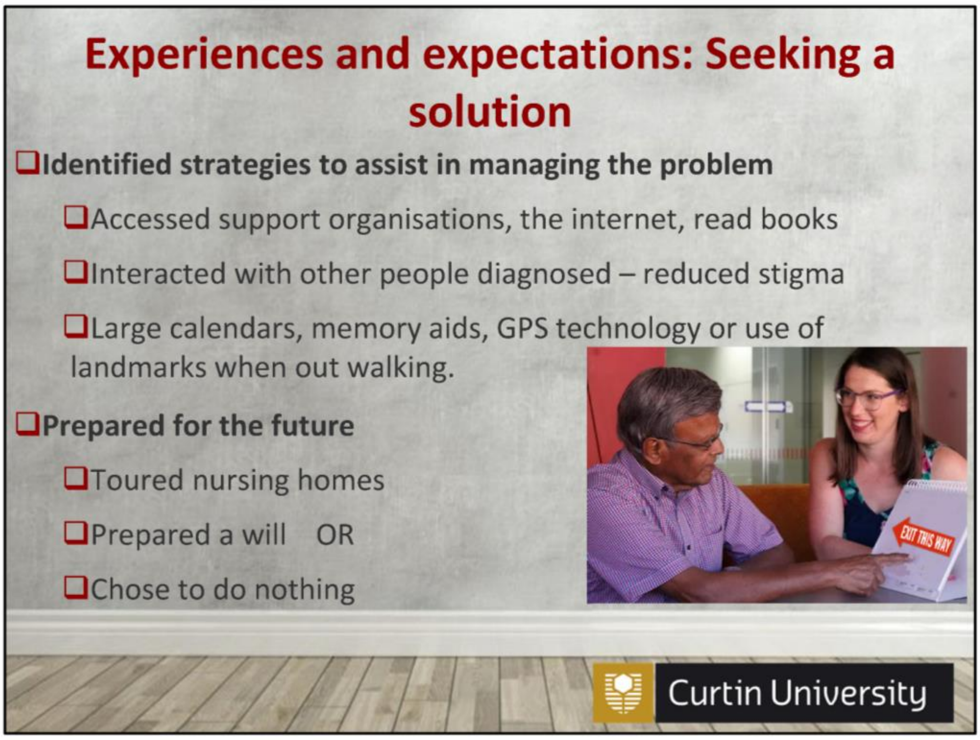
- Reduced ability to drive a motor vehicle
  and complete house hold tasks - doing the shopping or caring for grandchildren.

Loss of Independence – Participants spoke of a loss of independence in particular with decision making and reported that often decisions were made on their behalf by other people that led to a loss of self esteem and confidence. Participant experience of stigma intensified their loss of independence – they reported feeling devalued as people just assumed that they lacked decision making capacity.

Uncertainty about the future -
Once diagnosed participants reported moving into a period of uncertainty and questioned how long it would take before they became fully dependent on others. Participants spoke about a lack of information provided to them from the doctor about the progressive nature of the condition – and because of this were unable to articulate what their future support needs might be

Fear of being a burden

Participants also reported a fear of being a burden on family and whilst participants discussed moving into residential care as an option, to avoid being a burden, some viewed this negatively, reporting their view that residential care environments are too restrictive and often risk averse meaning that people with dementia are often denied opportunities to do as they wish for fear of their safety



Experiences and expectations: Seeking a solution

- **Identified strategies to assist in managing the problem**
  - Accessed support organisations, the internet, read books
  - Interacted with other people diagnosed – reduced stigma
  - Large calendars, memory aids, GPS technology or use of landmarks when out walking.
- **Prepared for the future**
  - Toured nursing homes
  - Prepared a will OR
  - Chose to do nothing

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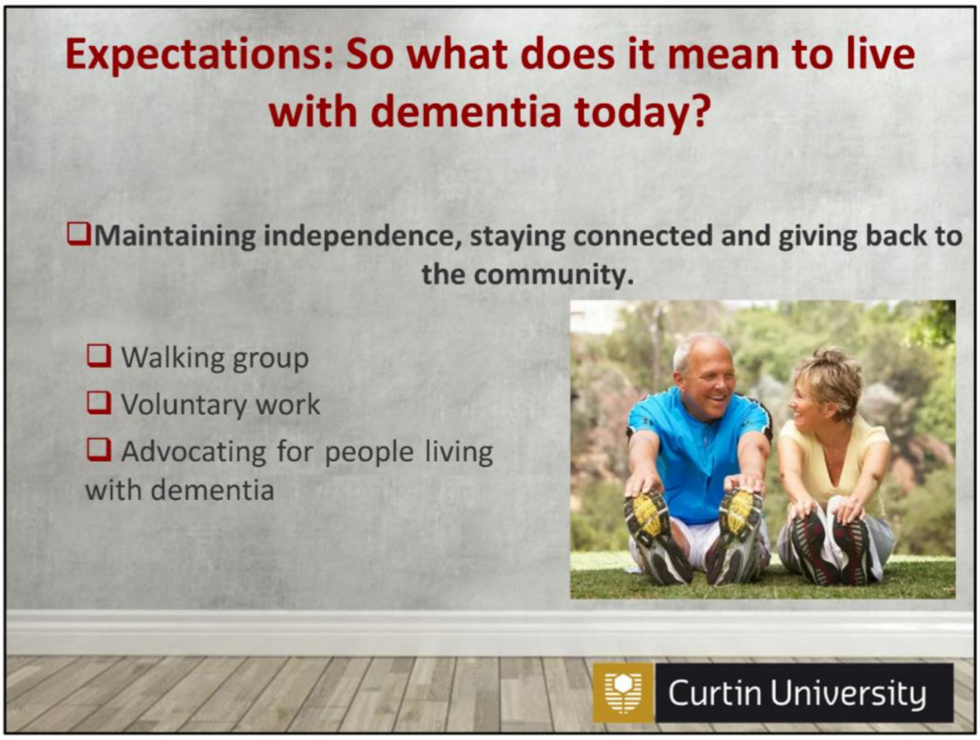
People participating in this study identified a range of strategies to assist in managing the problem.

Accessed support organisations, the internet, read books
Interacted with other people diagnosed with the condition which reduced their feelings of social isolation.
They looked to maintain independence – with use of calendars, memory aids, or GPS technology when out walking.

As participants came to terms with their diagnosis they began to prepare for their future - what became clear was the degree to which participants valued their autonomy – some toured NH's to decide on where they might like to live into the future and organised their will yet others chose to do nothing and left decision making to the family



Expectations: So what does it mean to live with dementia today?

☐ **Maintaining independence, staying connected and giving back to the community.**

- ☐ Walking group
- ☐ Voluntary work
- ☐ Advocating for people living with dementia

Within my study participants indicated a desire to maintain independence and to stay connected to their pre-diagnosis lifestyle into the future.
Some reported wanting to:

Get back into the walking group that they had once had
Take up voluntary work or less taxing work roles
Take up advocacy roles to advocate for themselves and others living with dementia

For this to occur there is a need to limit the stigma of dementia so that people diagnosed are accepted, have the confidence to seek an early diagnosis and the support that encourages their continued engagement in society.

Do these findings account for all people living with dementia?....

☐ How can we assist people with dementia plan for their future?

☐ Implementing a range of strategies for decision making and the use of advance care plans

☐ Increasing evidence –supported decision making policy guidelines – Cognitive Decline Partnership Centre (2018)

☐ The role of the care partner - not to be underestimated

But is this what all people living with dementia want?

We need to remember that within my study I spoke to just 24 people with dementia whose experiences and expectations varied.
We need to remember to celebrate uniqueness and to not judge each other based on what we have heard from others – to truly discover a person's experiences and assist them to lead the life of their choosing we need to speak with the person.

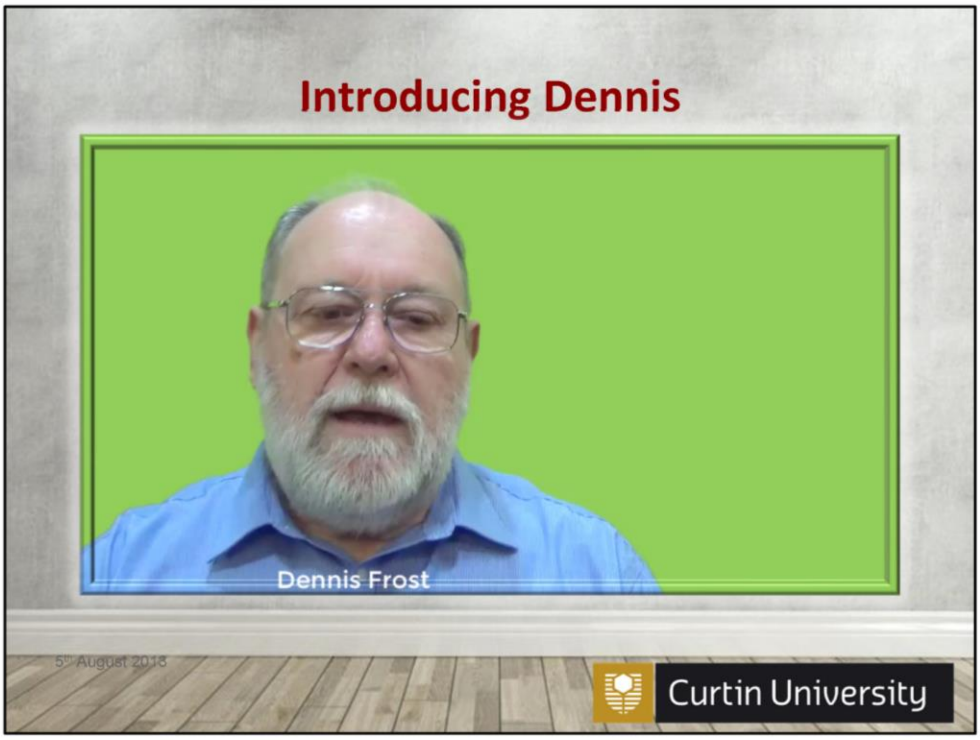
So how do we assist people with dementia with this when they may have experienced a decline in their decision making autonomy?

How can we help people with dementia overcome the stigma of the condition and understand what living with dementia means?

Do we offer adequate counselling to people following their diagnosis? Do we encourage people with dementia to discuss what it is that they feel they will need into the future. Implementing advance care plans for example may help to preserve the autonomy of the person diagnosed and their quality of life when capacity to make and communicate decisions becomes impaired.

Conversations between the care partner and PWD surrounding future support requirements are to be encouraged to ensure the autonomy of the person with dementia is upheld and care partners can accurately advocate on behalf of the person when they need to do so. With this raises the question-

How can we better support care partners to assist the person diagnosed with their future decision making?
There are a range of strategies that can assist a person with their decision making for as long as possible such as implementing use of a suitable environment at a suitable time, involving trusted friends and family and implementing use of communication tools – people with dementia and their care partner need to be educated on the implementation of such strategies to ensure the decision making autonomy of the person with dementia for as long as possible.



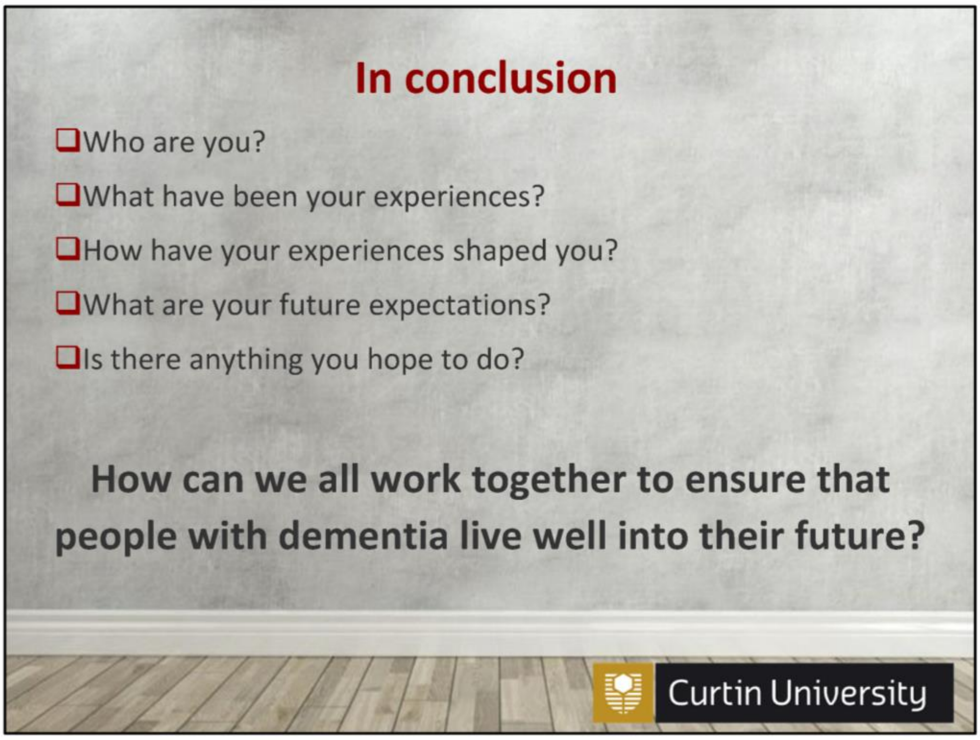
Introducing Dennis

Dennis Frost

5th August 2018

Curtin University

I would now like to introduce to you a person with dementia who assisted me with my study – he will talk to you about his experiences



In conclusion

☐Who are you?

☐What have been your experiences?

☐How have your experiences shaped you?

☐What are your future expectations?

☐Is there anything you hope to do?

How can we all work together to ensure that people with dementia live well into their future?

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As my presentation comes to a close can I ask you to consider:
Who are you? – PWD, care partner, community member, person working within the dementia support industry
What have been your experiences?
How have your experiences shaped you?
What are your future expectations?
Is there anything you hope to do?
Most importantly how can we all work together more effectively to ensure that people with dementia live well into their future

This cannot rest with just one or two people but will take a collaborative effort from all of us within our community – and now to help us on our journey it is with great pleasure that I introduce to you Dr Maria Foundas.

Contact details

Sheridan Read

Email: Sheridan.read@postgrad.curtin.edu.au

Mobile Contact: 0405 478 110

Put this at the end of speaker 4 presentation

Appendix V

Dementia Communities Attitude Questionnaire – Study 3 and 4

This questionnaire was used at the forum in its presented format.

FORUM: LIVING WELL AND STAYING CONNECTED

Thank you for attending the *Living Well and Staying Connected Forum* at Curtin University. We appreciate the time you have taken to come here. We also request that you complete the attached two questionnaires. Your responses will help us determine the outcomes of the forum for those who attended.

PROCEDURE FOR COMPLETING QUESTIONNAIRES

STEP 1: PRE-FORUM QUESTIONNAIRE

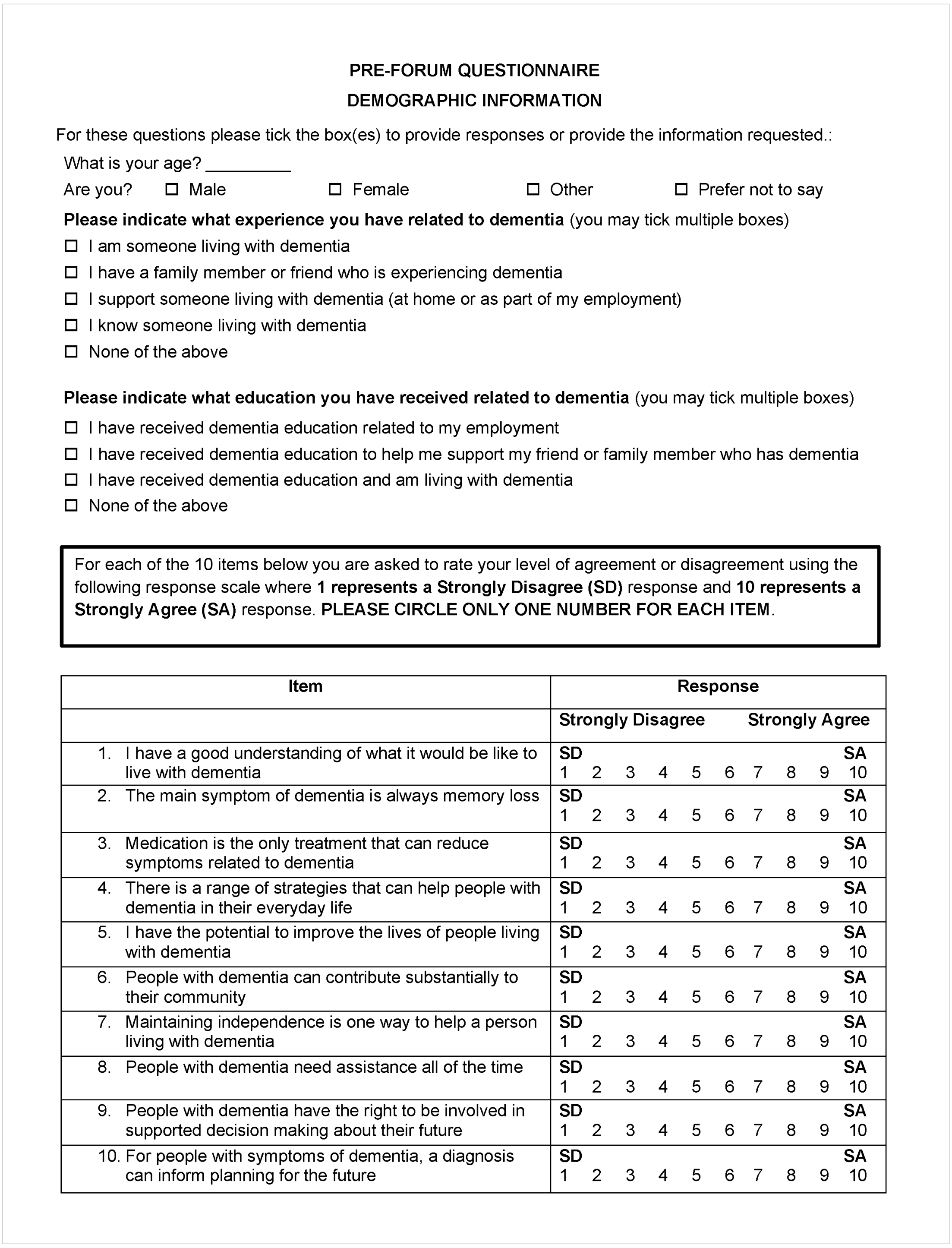
The Pre-Forum Questionnaire is written in **BLACK and** should be answered **BEFORE** the forum begins. This Pre-Forum Questionnaire also includes a few questions to provide the organisers with an overview of who has responded.

STEP 2: POST-FORUM QUESTIONNAIRE

The Post-Forum questionnaire is written in **RED** and is on the other side of the sheet of paper. The Post-Forum Questionnaire should be completed **AFTER** the forum has finished but before you depart.

STEP 3: COMPLETED QUESTIONNAIRE

Please place the completed questionnaires in the box provided as you leave this evening.



PRE-FORUM QUESTIONNAIRE
DEMOGRAPHIC INFORMATION

For these questions please tick the box(es) to provide responses or provide the information requested.:

What is your age? _________

Are you? ☐ Male ☐ Female ☐ Other ☐ Prefer not to say

Please indicate what experience you have related to dementia (you may tick multiple boxes)

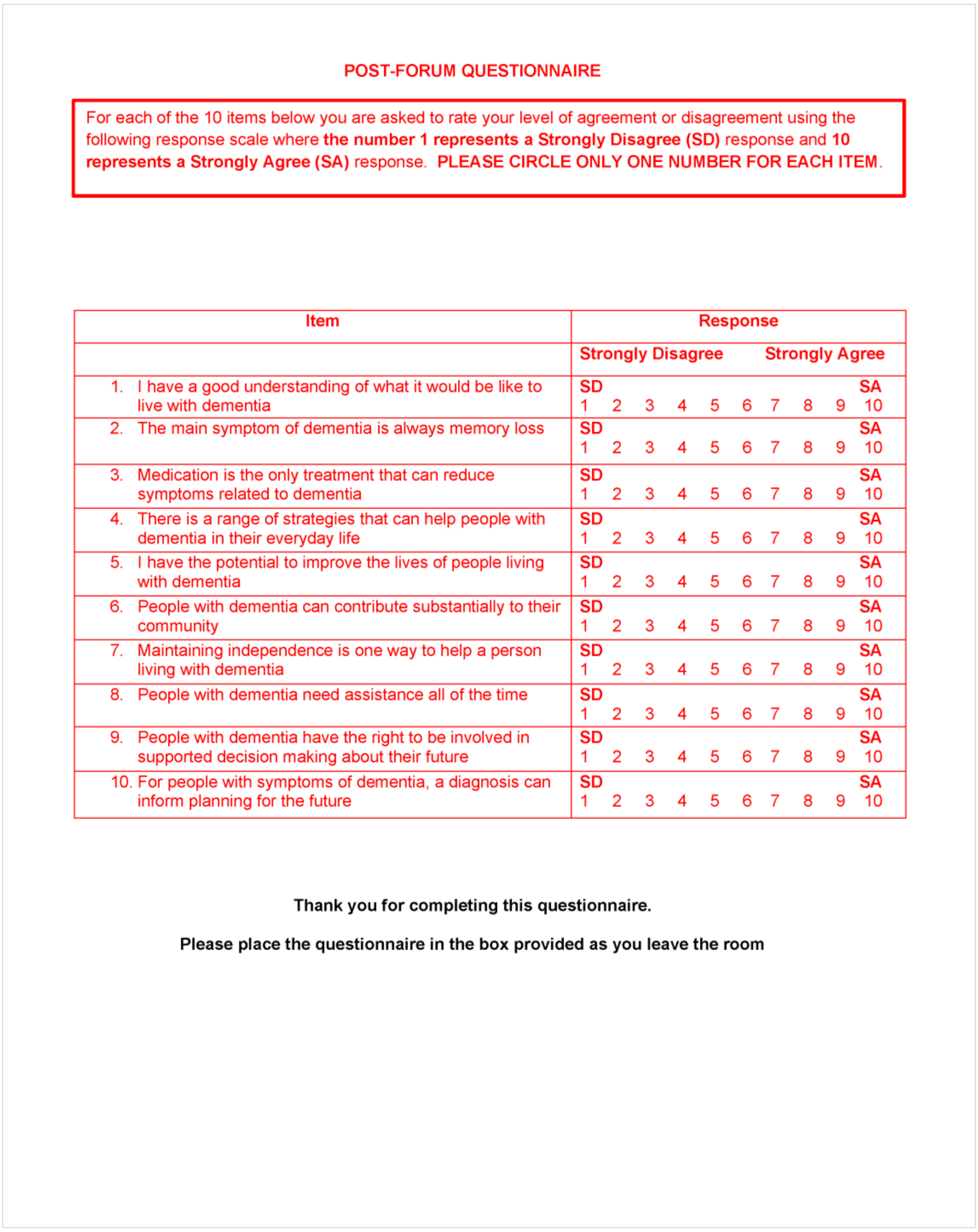
☐ I am someone living with dementia
☐ I have a family member or friend who is experiencing dementia
☐ I support someone living with dementia (at home or as part of my employment)
☐ I know someone living with dementia
☐ None of the above

Please indicate what education you have received related to dementia (you may tick multiple boxes)

☐ I have received dementia education related to my employment
☐ I have received dementia education to help me support my friend or family member who has dementia
☐ I have received dementia education and am living with dementia
☐ None of the above

For each of the 10 items below you are asked to rate your level of agreement or disagreement using the following response scale where **1 represents a Strongly Disagree (SD)** response and **10 represents a Strongly Agree (SA)** response. **PLEASE CIRCLE ONLY ONE NUMBER FOR EACH ITEM**.

Item	**Response**
	Strongly Disagree Strongly Agree
1. I have a good understanding of what it would be like to live with dementia	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
2. The main symptom of dementia is always memory loss	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
3. Medication is the only treatment that can reduce symptoms related to dementia	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
4. There is a range of strategies that can help people with dementia in their everyday life	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
5. I have the potential to improve the lives of people living with dementia	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
6. People with dementia can contribute substantially to their community	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
7. Maintaining independence is one way to help a person living with dementia	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
8. People with dementia need assistance all of the time	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
9. People with dementia have the right to be involved in supported decision making about their future	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
10. For people with symptoms of dementia, a diagnosis can inform planning for the future	**SD** **SA** 1 2 3 4 5 6 7 8 9 10



POST-FORUM QUESTIONNAIRE

For each of the 10 items below you are asked to rate your level of agreement or disagreement using the following response scale where **the number 1 represents a Strongly Disagree (SD)** response and **10 represents a Strongly Agree (SA)** response. **PLEASE CIRCLE ONLY ONE NUMBER FOR EACH ITEM**.

Item	**Response**
	Strongly Disagree Strongly Agree
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6. People with dementia can contribute substantially to their community	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
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9. People with dementia have the right to be involved in supported decision making about their future	**SD** **SA** 1 2 3 4 5 6 7 8 9 10
10. For people with symptoms of dementia, a diagnosis can inform planning for the future	**SD** **SA** 1 2 3 4 5 6 7 8 9 10

Thank you for completing this questionnaire.

Please place the questionnaire in the box provided as you leave the room