

School of Occupational Therapy, Social Work, and Speech Pathology

**Identifying and Supporting the Needs of People with Dementia
and Their Families - Strengthening Communication Skills for
Formal Carers**

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**This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University**

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Author's 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.

Human Ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number HR111_2013 dated 7.08.2013 and Approval Number HRE2017-0790 dated 13.11.2017

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Statement of Contributors

As co-authors of the following article:

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We confirm that Claire Morrisby has made the following contribution:

- Conceptualisation and design of research;
- Collection of data;
- Analysis and interpretation of results; and
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Abstract

Supporting people with dementia to remain at home is a complex endeavour. Most people with dementia will require support, generally from family and friends and particularly from spousal carers. However, for a significant proportion, family support is only part of the equation, with additional support required from community services. Diagnostic, assessment, and direct care services need to meet the consumers' expectations of a quality service and provide the types of support needed in an accessible and cost-effective manner. Assistance from external services reduces the risk of people with dementia having to move into residential care earlier and reduces the chance that carers will experience additional stressors that affect their quality of life.

Community services in Western Australia are centred on normative need; that is, community services are developed and based on health professionals' and policy makers' interpretations of what is needed. However, the question of whether these services actually meet the needs of people with dementia and their carers is continually challenged in Australia and other countries. Numerous studies have identified unmet needs in relation to the supports that people with dementia and their carers require to continue living at home. However, limited research has been conducted in Western Australia, which has developed a distinct community services system shaped by workforce retention and development issues, vast geographical differences and the largest forecast increase in dementia in Australia. A key issue is that needs are often broader and more difficult to assess than standardised measures can define. This is because a dementia diagnosis, living context, and complex biographic and personality factors combine to affect the experiences of an individual. To provide a holistic perspective and capture the complexity of living with dementia, the International Classification of

Functioning Disability and Health was chosen as the framework to explore the perceived needs of people with dementia and spousal carers in the Western Australian context.

The central aim of this thesis was to identify the experiences of need among people living with dementia and their spousal carers. The objectives were to explore the personal, environmental, occupational, and participatory needs of people living with dementia and their spousal carers and compare these to the perception of needs among community service providers. A key necessity identified by people with dementia and their carers, and the service providers who support them, was improved communication skills training. Consequently, a training package to support effective communication was developed and its feasibility and acceptability evaluated.

The lived experience of carers and people with dementia cannot be fully appreciated with the use of standardised measures; therefore, Studies one and two utilised a qualitative methodology, interpretive description. Dyadic semi-structured interviews with people living with dementia and their spouses were conducted and thematically analysed. The themes from dyadic interviews were expanded on using two focus groups of spousal carers. Analysis of all data identified that the needs of people with dementia and spousal carers encompassed social systems and environments that provided support, and that also considered occupational and relational aspects of support and care. The identified needs were used to inform semi-structured interviews and focus groups with West Australian service providers, gathering the concurrent perspectives of service providers. Inductive and deductive thematic analysis of the responses of the service providers, in conjunction with those of the people with dementia and spousal carers indicated needs beyond those offered in the current services. Knowledge of

dementia and skilled communication which facilitates relationship-based care was identified as underpinning good community care.

Improvement of the dementia specific communication skills of community support workers has the potential to progress the quality of community services. The current training available and in use, has been demonstrated to lack engagement with limited opportunities for feedback to support learning. In 2015, the Curtin University Empathy Simulator (CUES) was developed to provide real-time feedback and safe, replicated practise in communicating with an older Australian gentleman positioned in a virtual learning environment. The verbal and non-verbal responses of the avatar simulating an older Australian gentleman, were consistent with those of someone with mild to moderate dementia. The CUES embedded communication training package was evaluated in studies three and four for feasibility, suitability and acceptability for community-based support workers with the use of a mixed methods research design incorporating observational data and semi-structured qualitative interviews. The results indicated that participants demonstrated significant improvements in their use of pragmatic communication skills following training, when communicating both with the CUES, and with a person with dementia, and that these results were maintained at two-month follow-up. In addition, participants perceived significant improvements in communication knowledge and satisfaction. However, immediately post training their confidence decreased. This finding was addressed in the qualitative semi-structured interviews which identified how CUES had challenged participants, and reinforced the standards needed to communicate effectively with the individual with dementia. This thesis documents the met and unmet needs experienced by people with dementia and spousal carers living in the community in Western Australia and proposes an innovative approach to improving community services through the implementation of an engaging, communication training program.

Acknowledgements

This project began from my work as a service provider working with people with dementia and carers in the community; thank you for sharing your stories and experiences with me. The wisdom and grace you showed as you ran into bureaucratic blockades while navigating the systems designed to help, and fought for what you needed, inspired me to set out upon this journey. To the people with dementia and carers who took part in interviews, your capacity to share so generously made this project possible. And to the service providers, support workers, students, and volunteers who so patiently and willingly gave the training a go - thank you.

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Dedication

To my grandmothers, Pip and Valmai, whose lives with dementia became quiet; this is in the hope that the future holds more love and laughter and living at home for us all.

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List of Abbreviations

ACAT	Aged Care Assessment Team
AD	Alzheimer's Disease
ADI	Alzheimer's Disease International
AIHW	Australian Institute of Health and Welfare
CANE	Camberwell Assessment of Needs in the Elderly
CareNapD	Care Needs Assessment Pack for Dementia
CHSP	Commonwealth Home Support Packages
COPE	Carers of Older People in Europe
CUES	Curtin University Empathy Simulator
DKAS	Dementia Knowledge Assessment Survey
DVA	Department of Veteran Affairs
FAST	Functional Assessment Staging Tool
HCP	Home Care Packages
HACC	Home and Community Care
ICF	International Classification of Functioning Disability and Health
ID	Interpretive Description
JHDCNA	Johns Hopkins Dementia Care Needs Assessment
SP	Simulated Patient
TRQ	Training Reflective Questionnaire
VD	Vascular Dementia
VHC	Veterans Home Care

VLE	Virtual Learning Environment
VR	Virtual Reality
WA	Western Australia
WHO	World Health Organization

Preface

In my early career, I worked as a respite coordinator in a specialist dementia service, which is not a typical role for occupational therapists, but one where our skills are uniquely suited. In this capacity, I explored the issues that people with dementia and carers have, attempting to understand their priorities, and then I creatively implemented a service to support them, which was all inherently satisfying. However, the services proved to be inflexible, the funding was limited, and the support workers who worked effectively with people with dementia were rare. Eventually these issues and my frustrations in relation to them led me to try a new path.

I started in academia as a lecturer committed to improving the care and support of older people in Western Australia, particularly those with dementia. I accomplished this in part through teaching best practice to my students; however, I remained driven to understand more about the experiences of older people with dementia who lived in the community. This desire saw me commence post-graduate studies in a Master of Philosophy (MPhil) primarily to understand the lived experience of need from the perspectives of spousal carers and people with dementia. As this research progressed, I constantly heard from people with dementia, spousal carers, and services providers how services were refused because they were ‘not right’, carers were uncomfortable with leaving their loved one’s with strangers, and that those living with dementia did not receive adequate support because of a lack of understanding of dementia. There were singular frustrations expressed regarding difficulties in communicating purposefully and meaningfully with someone who has dementia.

At the same time as I was collecting these stories, my students were also concerned about their abilities to communicate with older people and that these concerns increased when the person had dementia. During role-play activities, particularly in the early years of their study, students experienced difficulty

demonstrating accurately the communication deficits that people with dementia experience. I deemed this limited insight an important limitation in developing students' empathy and understanding regarding dementia-specific needs. In searching for solutions, I began working with Janet Beilby and the Speech Pathology team at Curtin University. Janet and her computer software and design team at Citrine Technologies in Atlanta, Georgia, had recently developed a computerised Virtual Learning Environment (VLE) with a simulated avatar who was an older Australian man with dementia – The Curtin University Empathy Simulator (CUES). The verbal and non-verbal utterances of the avatar had been designed specifically to support students to practice and improve their communication skills with people with dementia. Janet had published research showing that the knowledge, skills and confidence of tertiary students could be improved with communication skills training in conjunction with the CUES. Her research also demonstrated significant improvements in empathy for dementia. We knew that using the avatar could assist adult learners in a tertiary education setting, but we were interested in generalising this research to other populations. I wanted to address the need for improved communication skills that I had repeatedly heard expressed by the service providers who I had interviewed in the previous stages of my MPhil research. This opportunity came when my MPhil was in advanced stages but not yet completed, and I was particularly motivated by my desire to explore the use of this innovative augmented reality technology in the training of community carers. As a result, I converted my post-graduate research to a Doctor of Philosophy, was joined by Janet as a new co-supervisor, and I headed down a new, more extensive, and applied research trajectory. This thesis is the culmination of this journey.

Chapter 1 Introduction and Overview of the Thesis

Dementia is a progressive neurological condition that can have significant impact on the lives of people with the condition. It also affects those who care for the person who, in most instances is their spouse. People with dementia prefer to continue living at home in their local communities; however, as the disease progresses and they lose the ability to care for themselves, services and supports are required to remain at home. The quality and acceptability of these services and supports can make a real difference in the ability of carers to continue to meet the needs of the people with dementia for whom they care. An important factor for quality care, is the ability of formal carers to build positive interpersonal relationships; a skill that can be improved through effective communication.

This research aimed to investigate the needs of people with dementia and their spousal carers, and to determine if a gap existed between the needs perceived by service providers compared to those of people with dementia and their carers. A key finding in contemporary literature and an outcome of this research was that the communication skills of formal carers are often not effective in building and maintaining rapport and relationships with people with dementia, which is essential to support engagement in daily living care and meaningful activities. Based on these findings, studies considering the feasibility and acceptability of a communication training package with an integrated virtual learning environment were included. These studies demonstrated the potential for innovative communication training with community-based support workers.

This introductory chapter provides an overview of the four studies undertaken for the purpose of: (i) investigating the needs of people with dementia and their spousal carers; (ii) identifying gaps in community services; (iii) the feasibility of a communication training package for community-based support workers; and, (iv) the acceptability of the communication training package.

1.1 Dementia and its prevalence in Australia

Dementia is a syndrome characterised by progressive neurodegeneration that not only affects memory, but all cognitive functions as the disease progresses (World Health Organization, 2017). More than 100 diseases result in dementia and the most prevalent is Alzheimer's disease, to which 50-70% of all dementias is attributed (WHO, 2017).

Internationally greater than five per cent of the population over the age of 65 years (approximately 47 million people) are currently affected by dementia according to international world health definitions and records (WHO, 2017). The most recently reported prevalence of dementia in the Australian population is estimated to be 447,115 (National Centre for Social and Economic Modelling, 2019). As the current Australian population ages, the prevalence is projected to continue, potentially doubling by 2036 and almost tripling by 2056 (Brown & Hansnata, 2017).

In the absence of an effective prevention, treatment or cure, and given the continuing rise in the prevalence of dementia, necessary and requisite attention has attempted to identify the most effective strategies to support people living with dementia. The National Framework for Action on Dementia 2015-2019 (Australian Government, 2015) was developed as a structured guide for the development and implementation of policies, plans and actions to reduce the risk of developing dementia and improve the outcomes for people with dementia and their support networks. While covering all aspect of care, including prevention, diagnosis, primary, hospital and residential care, a significant focus of the framework is the provision of effective support for people to remain in their own homes.

1.2 Home support

Dementia impacts significantly on an individual's capacity to participate in society and engage across all facets of daily occupation (Bowlby Sifton, 2011; Nygård & Öhman, 2002). Dementia ranges from mild symptoms causing deficits in completing complex tasks of daily living such as difficulty with planning meals or calendar events, through to severe dementia whereby the functional abilities of walking, talking, and swallowing are gradually lost (Sclan & Reisberg, 1992). Impairment in function as a result of dementia is often assessed through formal and informal cognitive testing and the use of measures such as activity of daily living (ADL) and instrumental activity of daily living (IADL) scales (Muò et al., 2005). However, these assessments do not include the important skills of interpersonal communication and relationship building that are critical in ascertaining the impact of dementia and improving the support for people with dementia.

As an individual's ability for independent function declines, their uptake of support from formal and/or informal sources increases (van Exel et al., 2007). It is estimated that 92% of people with dementia in the community receive support from one or more informal carers (Australian Institute of Health and Welfare [AIHW], 2012). Informal carers are people who provide assistance on an ongoing basis to those who have disabilities that limit their ability to care for themselves. Most commonly, co-resident carers (i.e., residing with the person with dementia) are typically a partner or spouse (57%), or son or daughter (36%), and most likely provide 40 or more hours of care per week (AIHW, 2012). By contrast, formal carers, those who are paid or volunteer to work with non-family members are predominantly female (90%) and middle aged (45-54 years). Most frequently, formal carers such as community-based support workers have completed a Certificate III training course for their role, however, this is not mandatory and in most instances is too short to support sufficient development of skills (Palesy et al., 2018).

The decision to care for a person with dementia at home is influenced by various factors: a historical shift towards non-institutionalisation of older people (Egdell et al., 2010); increasing cost of residential care (Low et al., 2011); 'ageing in place' policies (Robinson et al., 2012); and the desire of most people with dementia to remain in their own homes (Polacsek et al., 2020; van der Roest et al., 2009). Familial responsibility and the belief of family carers that care provided by families is more understanding of the person's needs than formal supports are the primary reasons that families provide care (AIHW, 2012). However, the challenges of caregiving such as the carer's fatigue, interrupted sleep, and reduced social support may lead to the acceptance of formal support services. The provision of effective services to people with dementia and their carers in the community delays entry of the person into residential aged care (Alzheimer's Australia, 2011; Gaugler et al., 2005; Samus et al., 2014).

1.3 Using formal services to support people to remain in the community

Government-funded services for people with dementia who are living in the Australian community have faced criticism regarding quality, cost, and accessibility of services (O'Connell et al., 2012; Polacsek et al., 2020; Robinson et al., 2012; Robinson et al., 2005). Current services in Australia designed to support people with dementia and their carers to remain at home include counselling and education, respite, and dementia-specific packages of care (My Aged Care, 2015; Phillipson et al., 2019). A report commissioned by the Department of Health and Ageing found that the responsiveness of community services to the individual needs of people with dementia and their carers was important in assisting people with dementia to remain

in their own homes; “a need for services that meet [carers and people with dementia] needs rather than the needs of the service providers” (Alzheimer's Australia, 2011, p. 8).

Refining and extending Australian services that allow people with dementia to remain at home with the support of informal carers is important (Low et al., 2012). Research has considered what outcomes are needed and the required characteristics carers and providers of community-based, dementia-specific services deem critical. Formal support services need to be flexible with funding for sufficient support hours and the provision of continuity of care with well-trained staff is also a priority (Low et al., 2012). These findings provide an important foundation for the development of services; however, there are gaps in service providers and policy makers' understanding of the needs of the person with dementia (as separate from the needs identified by carers) as well as appreciating how the needs of people with dementia and carers are met by services already in place. Australian research has found that formal services may not be utilised due to lack of knowledge of services, the characteristics of service provision, and a lack of perceived need for services (Brodaty et al., 2005). Informal carers value services provided by well-trained and knowledgeable staff (Low et al., 2012) but access to such staff who are knowledgeable about dementia and are effective in communicating with people with dementia continues to be a challenge in the provision of dementia care in Australia (Polacsek et al., 2020).

1.4 Communication with people with dementia

To appreciate the compromises that dementia imposes on an individual's life, a hallmark consideration is the impact of impaired communication skills over time. Communication is a two-way process in which information, thoughts, feelings, and ideas are expressed and received between two (or more) people (Kourkouta & Papathanasiou, 2014). Dementia progressively affects expressive and receptive components of speech, and communication more holistically due to praxis deficits and impaired non-verbal communication skills (Ripich, 1994). Deficits in attention and working memory, and impairments in syntactic, pragmatic, and semantic language irrevocably alter the abilities of people with dementia to communicate their wants, needs, and desires (Haberstroh et al., 2011). Individuals with dementia often retain some form of communication abilities but these are compromised during the disease progression. For example, the ability to use and understand short, direct sentences and recall long-term memories may remain unimpaired for a period of time (Haberstroh et al., 2011; Machiels et al., 2017). Small et al. (2000) described how communication changes affect the ability of the carer to support a person with dementia, not only in normal conversation but also during activities of daily living; for example, communicating on the telephone, using the bathroom, and finding misplaced items. Petrovsky et al. (2019) reported in their large-scale study with dyads of carers

and people with dementia, that most carers used some forms of communicative frustration, such as feeling the need to scream or yell (55.2%), using a harsh tone (51.6%), or criticising the person for whom they cared (37.2%). These maladapted communication strategies occurred most frequently when carers were experiencing burden or depression, and when the person with dementia demonstrated significantly changed behaviours such as increased agitation or aggression (Petrovsky et al., 2019). Difficulty communicating can lead to an increase in caregiver burden and trigger negative behavioural responses in people with dementia; however, by contrast, the use of supportive strategies by carers can reduce detrimental behaviours and perceived burden (Haberstroh et al., 2011; Liddle et al., 2012).

In addition to family carers, health professionals and staff who provide direct support to people with dementia also experience difficulties in communicating with them. Nursing staff for people with dementia have described the experience of talking to such individuals as “a chicken is talking to a duck” (Chinese proverb), whereby the person with dementia and their nurse are each using a different language (Wang et al., 2013, p. 101). The task-oriented nature of both nursing and caring have been identified as key barriers in promoting meaningful interpersonal communication (Machiels et al., 2017; Wang et al., 2013). Task-oriented care is frequently described as a negative factor in community-based care for people with dementia (Ducharme et al., 2014; Gethin-Jones, 2014; Landmark et al., 2013). Less is known about the experiences of community-based staff who work with people with dementia than their residential care-based counterparts (Elliott et al., 2013) however, communication with people with dementia has been identified as very challenging in this role.

1.5 Supporting effective communication through training

Systematic reviews by Machiels et al. (2017), Eggenberger et al. (2013) and Morris et al. (2018) each identified effective communication training is a critical component in improving care for people with dementia, regardless of the setting in which they are being supported. Evaluative research of training provided to family carers and formal support staff working with people with dementia living in the community has shown that training can be effective in improving communication outcomes and skills (Eggenberger et al., 2013; Morris et al., 2018). In addition, training has demonstrated some improvement in reducing caregiver burden (Morris et al., 2018). Current training programs available in Australia include the multimedia format MESSAGE communication strategies in dementia for formal carers (Conway & Chenery, 2016) which has been found to improve the knowledge and confidence of formal carers’ abilities to communicate with people with dementia. A more commonly referred to training programme for community-

based support workers is the Dementia Care Essentials course (now known as the Dementia essentials course), which includes a training component on effective communication skills (Fleming & FitzGerald, 2009). This broad training aims to promote understanding the impacts of dementia, person-centred care, effective communication, changed behaviours and promoting wellbeing through understanding unmet needs and activities. Evaluation of this popular and large scale training (Dementia Essentials is delivered to thousands of support workers annually) has identified mixed results, with resultant care provided observed as consistent with the recommendations from the training, but no consistent changes (improvement or decline) in depressive symptoms or behavioural concerns in people with dementia being supported (McCarthy, 2012). Research by Lawn et al. (2017) demonstrated how education focused on improving the skills of community-based support workers had the potential to improve the capacity of support workers to identify and respond to complexities in care such as the person's behaviour change and impaired communication. To date, no information is available about the effectiveness of training currently available in Australia improving communication practices in community-based support workers.

Given the limited research in this area, the nature of effective communication training needs to be described. Systematic reviews conducted by Morris et al. (2018) and Eggenberger et al. (2013) have identified that effective training incorporates the following characteristics:

- Includes feedback on participants' performance of communication skills and strategies;
- The inclusion of 'booster' sessions over time to reinforce participant learning;
- Participants are exposed to active learning and engagement strategies such as role play and simulation; and
- Organisational support to reduce barriers to effective communication, such as time restraints and sufficient staff levels.

Relative to these recommendations, the training currently available in Australia is limited in its capacity to provide effective communication training to support formal carers. Limitations include the opportunity to receive feedback on performance and strategies for active engagement during training. Contemporary researchers addressing simulated learning with a training program titled THE VOICE, have demonstrated that the use of live actors who are trained as simulated patients (SP) to provide opportunities for feedback and support active engagement in learning can improve communication skills and confidence for healthcare professionals (O'Brien et al., 2018). Although simulation using SP is recognised as a valuable opportunity to create an engaging learning experience that supports feedback (Lateef, 2010), it remains an expensive proposition. Communication training for pharmacy students including SP

led to higher pass rates but at an estimated cost of USD\$100.93 per student (Gillette et al., 2017). The availability of well-trained SP and the inherent flexibility to provide immediate feedback in a range of settings may limit feasibility when considering the training needs of community-based support workers. The development of simulation alternatives to SP is emerging as an important requirement in dementia training and education (Harder, 2010).

1.6 Virtual learning environments

Virtual learning environments (VLEs) have developed in line with growth in technology (Ducange et al., 2017), and can be used in training where access to real-life situations pose a risk to the student or those around them. In higher education, VLEs have become increasingly popular with a range of experiences offered, from fully immersive three-dimensional environments using virtual reality (VR) headsets, computer generated simulated patients (avatars), to basic level learning platforms such as Moodle or Blackboard (Derboven et al., 2017). Avatar-based VLEs have been found to be motivational and offer specific opportunities for students to engage actively in repeated practising of important learning concepts (Tiago et al., 2016).

The development of avatars specifically designed to support the development of communication skills has increased in the past five years. Communicative interactions with VLE and avatars can create an authentic learning environment, providing the opportunity to develop self-efficacy through repeated exposure to communication simulations, during which mastery experiences and verbal persuasion in the form of feedback (Bandura, 1997; Shorey et al., 2019). The Curtin University Empathy Simulator (CUES) was developed as an original VLE to emulate dementia specific communication impairments (Quail et al., 2016). Originally intended for use with speech pathology students, the CUES has been trialled more broadly with health professionals in educative training in tertiary institutions and with formal dementia carers in residential care (Cartwright et al., 2020). In these settings, CUES has been shown to provide participants with immediate access to consistent, repeatable opportunities to practice communication skills in a safe and repeatable environment (Cartwright et al., 2020; Quail et al., 2016).

1.7 Research aims and objectives

1.7.1 Aim

The initial research aim addressed in Studies one and two was to gain an understanding of the needs of people with dementia and their spousal carers while they are living together at home. Additional aims were to gain an understanding of how these needs change with the progression of dementia, and how these needs are, or could be, better supported by Australian service providers. Other research aims addressed in Studies three and four were to implement and evaluate a communication skills training package, which incorporated an innovative avatar-based virtual learning experience designed for community-based formal carers of people with dementia.

1.7.2 Objectives

1.7.2.1 Study one objectives

- Identify the personal, occupational, environmental, and participatory needs of people with dementia living at home in Western Australia (WA) as well as those of their spousal carers;
- Determine the importance of the needs of people with dementia living at home and those of their spousal carers across the different stages of the disease;

1.7.2.2 Study two objectives

- Explore the current responses of WA community service providers to the needs of people with dementia and their spousal carers at mild-moderate and moderately severe stages of dementia; and
- Identify barriers and enablers to improving responsiveness.

1.7.2.3 Study three objectives

- Evaluate the effectiveness, feasibility, and practicality of an expanded, International Classification of Function and Disability (ICF) based communication skills training package using a computer-generated virtual environment;
- The further objectives were to assess and improve carer confidence, satisfaction, skill, and empathy when communicating with people with dementia.

1.7.2.4 Study four objectives

- Determine the perceived value, acceptability, and relevance of the communication skills training package for community-based formal carers.

1.7.3 Significance

Studies one and two explored the needs of people with dementia who lived at home as well as their carers across the different stages of dementia. The priority of needs relevant to the stage of dementia experienced were established in this research; enabling service providers to identify where services are not meeting such needs as well as potential barriers, enablers or more flexible ways of meeting these designated needs. This research has the potential to inform state and federal governments of the current needs of people with dementia and their carers who are living at home.

Western Australian service providers identified that education to support communication for informal or family carers and community-based formal carers was a high priority need. Specific carer training to support communication was identified as an important intervention in order to support the identified needs by the spousal carers.

Studies three and four evaluated the feasibility and acceptability of a standardised communication skills training package integrated with the CUES. The potential for the program to be utilised on a large scale to improve community-based formal carers' communication skills, knowledge, and confidence when communicating with people with dementia was determined. The ICF (WHO, 2002) underpinned this training because the complexity and uniqueness of communication and language changes that are experienced by people with dementia required an approach with the flexibility, interprofessional relevance, and inclusivity outlined within the ICF (Byrne & Orange, 2005). The communication skills training package, in conjunction with proven, realistic assessment and feedback mechanisms using CUES, was hypothesised to be a safe, standardised, confidential training and a significant development in comparison to standardised options in use. Developing the communication skills of formal carers had a positive impact on their ability to develop and maintain supportive relationships with people with dementia. The potential for broader impacts on quality of life and wellbeing, not only the carers but also for people with dementia, is considered.

1.8 Structure of thesis

This thesis is presented in a hybrid format, with three of the five studies already published. It consists of the following sections and corresponding peer-reviewed publications represented in Figure 1.1.

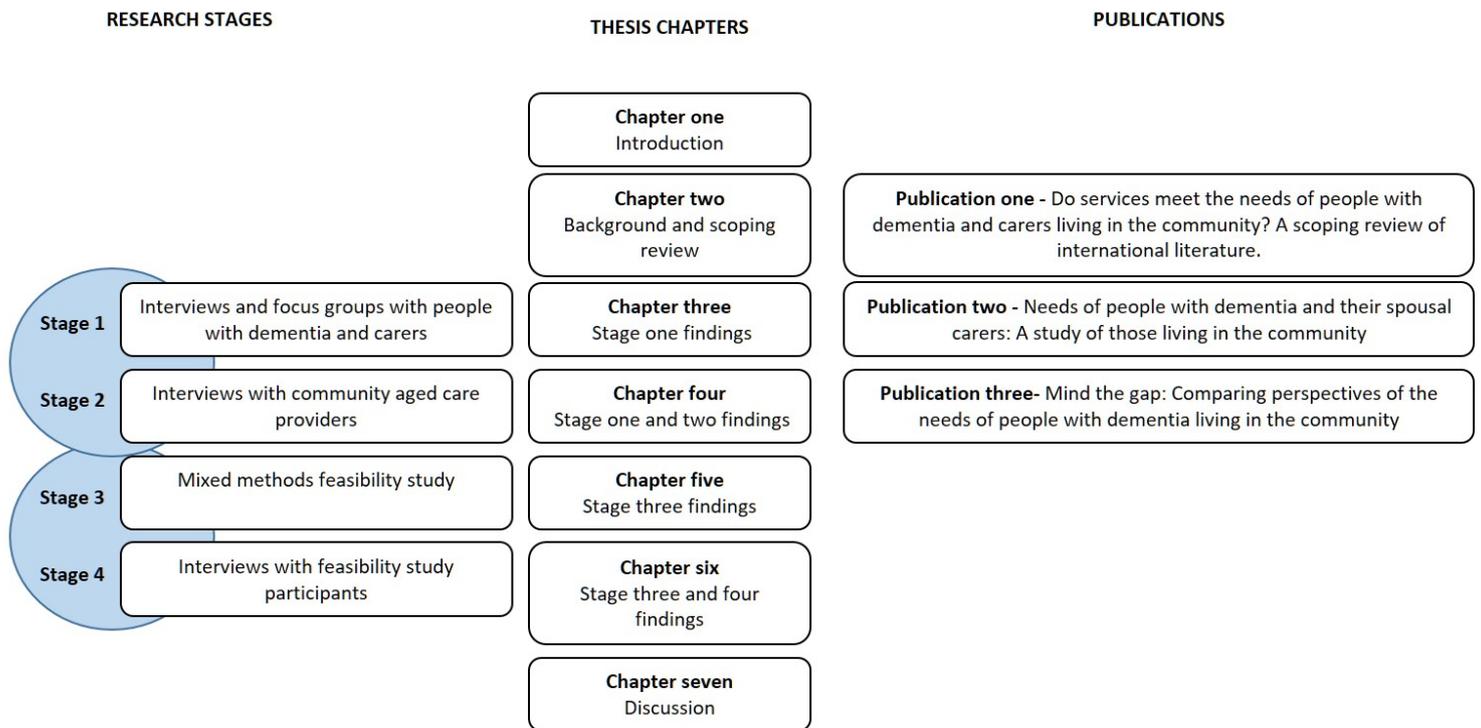


Figure 1-1 Structure of thesis

1.8.1 Introduction and overview

The current chapter provides an overview of the aims and objectives of this research, the thesis structure and a summary of the subsequent chapters.

1.8.2 Background (chapter two)

A scoping review of the literature was conducted to ascertain the existing understanding of need amongst people with dementia and carers living in the community, and their experience of support services. The scoping review methodology was an appropriate approach due to the broad question. The scoping review undertaken and subsequently published identified that people with dementia and their carers have a broad range of needs that are not effectively measured using quantitative assessments exclusively, and that services are an important source of support that currently have significant gaps and restrictions in their ability to meet the broad ranging needs of people with dementia and carers. A peer reviewed publication is included in this chapter, representing the work completed:

Morrisby, C., Joosten, A., & Ciccarelli, M. (2018). Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. *International Psychogeriatrics*, 30(1), 5-14. <https://doi.org/10.1017/S1041610217001491>

1.8.3 Study 1 results (chapter three)

The objectives of this chapter were to explore the personal, occupational, environmental, and participatory needs of people with dementia living at home along with those of their spousal carers in WA. Additionally, the chapter sought to determine the importance of the needs of people with dementia living at home and their spousal carers across the different stages of the disease. In order to obtain these insights, qualitative methodology using interpretive description (ID) was utilised. ID is commonly used in health research, as it respects and details the lived experience of those with an illness or disease.

Dyads of spousal carers and people with dementia living in the West Australian community were interviewed to explore the needs experienced by both groups following the diagnosis of dementia. The interviews considered a broad range of needs including personal, environmental, participatory and occupational as grounded in the ICF. Focus groups of carers were conducted to provide a richer description of experiences to refine and contrast the needs of the person and carers as the disease progresses. These findings are expanded on in study two. A peer reviewed publication is included, representing and highlighting findings from stage one:

Morrisby, C., Joosten, A., & Ciccarelli, M. (2019). Needs of people with dementia and their spousal carers: A study of those living in the community. *Australasian Journal on Ageing*, 38(2), e43-e49 <https://doi.org/doi:10.1111/ajag.12609>

1.8.4 Study 2 results (chapter four)

This chapter sought to develop the findings from study one, by exploring the responses of WA community service providers to the needs of people with dementia and their spousal carers at mild-moderate and moderately severe stages of dementia. Furthermore, barriers and enablers to improving responsiveness were identified. This study continued the use of ID methodology, utilising and basing probe questions on the results from study one. A semi-structured interview pro forma was developed for use with service providers who work with people with dementia living in the WA community.

Interviews were completed with a range of WA service providers to explore their perceptions of what is required by people with dementia and their spousal carers. The results of these interviews were considered both independently and in comparison with the needs previously identified by people with dementia and their spousal carers. The use of both deductive and inductive thematic analysis provided a multi-layered understanding of the lived experience of dementia. A peer-reviewed publication is included, representing and highlighting findings from study two:

Morrisby, C., Joosten, A., & Ciccarelli, M. Mind the gap: Comparing perspectives of service providers to the needs of people with dementia living in the community. Submitted to *Dementia: The International Journal of Social Research and Practice*. Accepted for publication on July 10th, 2020 (in press).

1.8.5 Study 3 results (chapter five)

The research undertaken in this thesis identified the need for an improved communication training programme for community-based support workers. As a result, the next body of research devised a novel training program utilising the demonstrated benefits of the virtual reality environment of the Curtin University Empathy Simulator (CUES). This training was implemented with staff and volunteers in community-based older adult social centres and was evaluated using a mixed-methods pre-post study design. Data were collected which elucidated both the objective and the perceived effects and benefits of the training embedded with the CUES.

A mixed methods approach, in which quantitative data based on measurements of the participants' pragmatic communication skills were analysed in conjunction with qualitative data pertaining to the satisfaction and feasibility of the training. Mixed methodologies are commonly used in evaluation of training as they provide the opportunity to test, and to evaluate the potential feasibility of training (Palinkas & Cooper, 2017). The quantitative and qualitative results supported the investigation of both the effect of the training and the feasibility of the training in this context. This study has been prepared for submission to a peer-reviewed journal.

1.8.6 Study 4 results (chapter six)

Study four evaluated the experiences and perceived benefits of the VLE technology (CUES) embedded in an innovative communication training programme. A qualitative phenomenological approach was used to explore the experiences of participating in the training, and the knowledge gained and perceived benefits of the communication strategies in this novel integrated programme. The results evaluated the perceived value, acceptability, and relevance of the communication skills training package for formal carers. Qualitative phenomenological approaches were used as they are considered suitable for elucidating the experiences of participants in the pragmatics and practicalities of implementing communication strategies with people with dementia (McWilliam, 2010). Semi-structured interviews were conducted with participants from study three, to evaluate their experiences following their return to work. Thematic analysis of the data from this study also expounded the findings of study three (Palinkas & Cooper, 2017). This study has been prepared for peer-reviewed publication submission.

1.8.7 Discussion (chapter seven)

This chapter aimed to synthesise the findings from each study and ultimately present the relevance of the findings in the context of contemporary research into training and support for individuals living with dementia and their carers. The future implications of this research are considered, including the recommendations regarding the use of CUES in health care worker communication training and the ultimate necessary improvement of services for people living with dementia in the community. Both the strengths and limitations of this research are also considered.

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Chapter 2 Background and Scoping Review

2.1 Introduction

It is acknowledged in the literature that remaining at home is desirable for most people with dementia; however, people with dementia and their carers may require support to achieve this goal. Internationally, the experiences of people with dementia living in the community vary considerably; particularly with respect to the complexities of supports and services available to support people with dementia and their carers. These different experiences are a result of diverse models of community-based support, access to information, assessment services, and funding of service provision. A thorough understanding of the individual needs of people with dementia and their carers is required to support the people effectively. The measurement and understanding of need is a complex proposition with any population, but especially so for people with dementia who may have limitations in understanding the challenges and barriers they experience as a result of their dementia. The information in this chapter presents an overview of the common experiences of met and unmet need of people with dementia and their carers. The chapter also highlights the limited knowledge regarding needs of this population within the specific context of Western Australia (WA). In addition, the complexities of measuring need and the perspectives of people with dementia are described.

The findings of publication one and the subsequent four stages of this research assisted with the exploration and identification of needs experienced by people with dementia and their spousal carers, and their experiences of support while living in the community. As the research progressed, it became evident that people living with dementia and their spousal carers perceived the needs of people with dementia differently to service providers, leaving the potential for gaps in support provision. This research also identified the development of communication competency of community-based support workers as a priority need.

2.2 Supporting people living with dementia

The gold standard of care for people with dementia in most countries is the provision of person-centred care (Brooker, 2003; Hobson, 2019). There are multiple models of person-centred care that commonly view the person as central to care delivery and adopt the perspective that the environment and relationships should empower and not disempower the person. Valuing the person with dementia and their carers; treating people with dementia as Individuals; considering

the Perspectives of the person with dementia; and, providing a positive Social environment, the VIPS framework is a common model of person-centred care (Brooker, 2003). These principles, which form the foundation of effective support services are however, difficult to enact and define (Brooker, 2003; Edvardsson et al., 2008). An extension of person-centred care is the understanding of the person through thorough exploration of needs experienced by people with dementia and their carers. For services to be person-centred, they must address the needs of this population and be flexible to the needs expressed at an individual level (Hobson, 2019).

2.3 Perception of need

Need has been defined “as a state where help, or more help, with specific difficulties is seen to be required by the care professional making the assessment, taking into account the views of the person assessed or of their advocate” (McWalter et al., 1994, p. 217). Need is an important basis for the development and allocation of supports for people of all ages; particularly older adults (Bergmark et al., 2000; Meaney et al., 2005). The assessment of need is a difficult proposition as it is often not well conceptualised (McWalter et al., 1994). Bradshaw’s (2005) described need across four domains:

1. Normative need: as identified by experts such as doctors or health professionals, as well as policymakers
2. Felt need: the wants and desires that are subjectively experienced
3. Expressed need: felt needs that are translated into action; for instance, seeking services
4. Comparative need: application of normative or expressed needs to a different population to promote equity.

The experience of need may encompass all four domains; however in some cases, such as for those who are in receipt of services, differentiation between the domains is important to determine the relationships between the different domains/needs (Bradshaw, 2005). For instance, Stirling et al. (2010) found that the felt need of carers of people with dementia (identified by carers themselves) and the number of services they accepted was significantly correlated; however, normative need (as defined by professionals and researchers) was not as strong a predictor of service acceptance. The differentiation and assessment of need has the potential to highlight gaps where services and supports may not be effectively supporting people with dementia and their carers, with the implications for increasing opportunities to provide person-centred care.

2.4 International services for people with dementia and carers

The development of services to support people with dementia and their carers to remain at home in their communities has been a central focus of international health advisory bodies including the World Health Organization (WHO) and Alzheimer's Disease International (ADI). Given the increasing prevalence and incidence of dementia in association with global ageing, the cost-effective support of people with dementia is a critical issue (WHO, 2017). Based on multiple metrics, keeping people at home is considered a positive outcome, as this environment meets the desires of people with dementia and their carers (Rapaport et al., 2020) and represents a smaller financial burden on the individual and State than out-of-home care (AIHW, 2019). Alzheimer's Disease International promotes social and health care that is continuous, integrated, and holistic in its approach to supporting people with dementia (Prince et al., 2016). The empowerment of people with dementia and their carers, and provision of equitable access to services are considered critical (WHO, 2017), and are enacted through seven action areas in the 'Global Action Plan on the Public Health Response to Dementia'. The action areas cover risk reduction, research, awareness and education, support for people with dementia and carers, information systems, and research. These action areas are enacted in respective countries through frameworks for dementia care or national dementia action plans (ADI, 2017) whereby 32 countries worldwide have published these documents including the United Kingdom, Canada, Australia, Japan, South Korea, Indonesia, and the Netherlands (Cahill, 2020). Since the move towards a human-rights based ideological approach as described in the 'Global Action Plan on the Public Health Response to Dementia' (WHO, 2017), national action plans have begun to re-frame care for people with dementia as personalised rather than generic, empowering rather than clinical, and person-centred rather than restrictive (Cahill, 2020). While all seven action points are important to improve the care of people with dementia at national and international levels, the relevant priority action areas for people living with dementia and their carers are:

- Action 2: awareness and friendliness,
- Action 4: diagnosis, treatment care and support
- Action 5: support for dementia carers

(Cahill, 2020; WHO, 2017)

These areas encompass the experiences of the journey with dementia; from diagnosis to end of life. International research on the services, supports, and experiences of health care among people living with dementia has identified that there may be ongoing difficulties in implementing person-centred care based on the needs experienced by people living with dementia. For instance, Ireland's National Dementia Strategy was found not to contain guidance to support the re-configuration of services towards a person-centred approach (Department of Health, 2014; Hennelly & O'Shea, 2017). To effectively re-configure supports to be person-centred, further research into the needs of people with dementia and their carers is required to facilitate and improve the quality of services.

2.5 Australian services for people with dementia and carers

The Australian National Framework for Action on Dementia 2015-2019 is aligned to the WHO global action plan and has guided the development and implementation of public awareness, services, supports, healthcare, and research since its introduction (Australian Government, 2015). The framework sets an international benchmark for satisfying the WHO global action targets including early diagnosis and participation in the global dementia observatory (ADI, 2018). However, issues such as a traditional focus on dementia within a medical frame of reference may have limited by the implementation of the Australian National Framework in regards to providing effective support to people currently living with dementia, as has been experienced elsewhere (Cahill, 2020; Hennelly & O'Shea, 2017). Research by Phillipson et al. (2019) identified that reforms to simplify access to assessment, information, and community services have not been effective in supporting carers and people with dementia to access acceptable service options. This has occurred despite a 73% increase in Australian Government funding for assessment and information services in 2013-14 and 2018-19 (AIHW, 2019). Without effective access to assessment and information services, the unmet need for respite and community-based supports identified by Phillipson et al. (2019) is unlikely to be resolved, resulting in gaps in the implementation of the National Framework for Action on Dementia 2015-2019.

2.6 Publication one – ‘Do services meet the needs of people with dementia and carers living in the community? A scoping review of international literature.’

Understanding how need is conceptualised by service providers, policy makers, carers and people with dementia is essential to effectively respond to needs and unmet needs of people with dementia and their carers so that people can remain at home/in the community. The aim of the first publication of this thesis was to present a scoping review that identified the met and unmet needs of people with dementia and carers internationally. It was also aimed at discussing the potential gaps and strengths that exist in the services available to people with dementia in the international community.

The literature was also examined to determine whose perspective/information was reported in the literature. Particular consideration was paid to the criteria used for the inclusion of the perspectives of people with dementia. The inclusion of the voice of people with dementia is acknowledged as a critical component of all dementia research and planning, “Nothing about us, without us” (Swaffer, 2015). The findings of this scoping review informed the subsequent stages of the thesis to support the further exploration of need amongst West Australian spousal carers and people with dementia.

Inclusion in the thesis as a PDF copy has been approved by the Publisher, License number: 4845111063368.

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REVIEW

Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature

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ABSTRACT

Background: Providing effective support to the increasing number of people with dementia to remain at home is a challenge for families, health professionals, service providers, and governments worldwide. The aim of this paper was to summarize and disseminate the current international research evidence on the met and unmet needs of people with dementia and their carers, to inform researchers and policy-makers.

Method: A scoping review methodology was used to guide a search of studies published between 2004 and 2015 using specified search terms; 27 studies relevant to the aim were included. A constant comparison approach was used to thematically analyze the data.

Results: Holistic needs encompassing basic human survival, medical, financial, and social needs were experienced by people with dementia and carers, regardless of country or methodology used to collect data. A gap was identified frequently between what was needed and the supports that were received; this gap encompassed quantity, quality, and flexibility of services underpinned by service delivery models.

Conclusion: The needs of people with dementia and their carers were diverse and not always effectively met by the services designed to support them. Recommendations are offered to service providers, policy-makers, and researchers to support more effective service provision tailored to meet the needs of people with dementia and their carers while they are living in the community.

Key words: dementia, community, carers, aged care, services

Background

The decision to care for a person with dementia at home is influenced by a range of factors including a historical shift towards the non-institutionalization of older people (Egdell *et al.*, 2010); the increasing cost of residential care (Low *et al.*, 2011); aging in place policies (Robinson *et al.*, 2012); and the desire of most people with dementia to remain in their own homes (van Der Roest *et al.*, 2009). The provision of services to people with dementia and their carers in the community delays entry into residential aged care (Gaugler *et al.*, 2005).

Dementia is a neurocognitive disorder that interferes with the person's ability to independently

complete everyday tasks such as shopping, cooking, or dressing (American Psychiatric Association, 2013). Over time, people with dementia require assistance with complex and eventually basic activities of daily living (Seeher *et al.*, 2011). As the individual's capacity for independent function declines, the uptake of support from either formal or informal sources increases (van Exel *et al.*, 2007). Informal carers (who are not service providers or volunteers) are those who provide assistance on an ongoing basis to those whom have disabilities that limit their ability for independent self-care (Australian Institute of Health and Welfare, 2012).

A broad range of supports and services for people with dementia and their informal carers are described in the international research literature including nursing care, personal care (or home care), domestic assistance (or home help), allied health, and various respite care models (Cantegreil-Kallen *et al.*, 2006; Kelly and Williams,

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2007; Raivio *et al.*, 2007; Forbes *et al.*, 2008; Roelands *et al.*, 2008; Wolfs *et al.*, 2010; Casado and Lee, 2012; Lim *et al.*, 2012; Department of Social Services, 2015). Support services are not uniformly defined in the literature; for example, in Australia there are six service types that could be classified as respite for carers (Department of Social Services, 2015). Respite incorporates short-term care in residential care settings (as provided in Australia (Department of Social Services, 2015), Finland (Raivio *et al.*, 2007), and the Netherlands (Wolfs *et al.*, 2010)), through to individual social support providing carers with a respite break (as provided in the United Kingdom (National Health Service, 2015) and Australia (Department of Social Services, 2015)). Education for carers was described in literature for four countries: Singapore (Lim *et al.*, 2012), France (Cantegreil-Kallen *et al.*, 2006), the Netherlands (Wolfs *et al.*, 2010), and Australia (Department of Social Services, 2015). Education may have been available in other countries; however, it was not described as a government-funded service. This highlighted the broad range of services available to people with dementia and their carers, but there are gaps between the met and unmet care needs of people with dementia and their carers (Forbes *et al.*, 2008; Freyne *et al.*, 2010; Landmark *et al.*, 2013).

A number of studies have identified the experience of people with dementia and carers when accessing services in various countries. van der Roest *et al.* (2007) identified that while people with dementia have needs, it has been difficult to gather accurate information because they do not always clearly express their wants and needs. The association between carers' felt need (as identified by carers) and the number of services they accept is significant; while normative need (as defined by professionals and researchers) is not as strong a predictor of service acceptance (Bradshaw, 1994; Stirling *et al.*, 2010). Furthermore, Cheston *et al.* (2000) highlighted the importance of understanding the views of people with dementia and their carers as key stakeholders to services with the potential to respond to those needs. Understanding what is needed by people with dementia and their carers to support continuing to live in the community has been recognized as an area of research that needs further development (Seeher *et al.*, 2011). The purpose of this scoping review was to summarize and disseminate what is known internationally about the identified care needs of people with dementia and their informal carers living in the community, and if there are common gaps in the services available to meet their needs.

Method

The methodology used in this scoping review has been described by Arksey and O'Malley (2005) as a five-stage iterative and ad hoc process in which inclusion and exclusion criteria are developed to ensure that the scope of included literature is broad and the aims of the review are met. This review aims to summarize and disseminate the current international research evidence on the met and unmet needs of people with dementia and their carers, to inform researchers and policy-makers. A scoping review is particularly appropriate due to the breadth of the research question and limited availability of randomized controlled trials on this issue (Levac *et al.*, 2010).

Stage 1: identifying the research question

The research question guiding this review was "What is currently known from existing peer-reviewed literature about the needs of people with dementia living in the community; the needs of their carers; and whether the available services meet the needs of the person with dementia and their carer?" A broad approach was used to gather all relevant studies, including those using qualitative, quantitative, and mixed methodologies.

Stage 2: identifying relevant studies

A search of five databases (Medline, CINAHL, Science Direct, SCOPUS, and PsycInfo) and Google Scholar was performed. Saturation was apparent as no additional studies were identified. Reference lists of included studies were hand searched to locate any other relevant studies. Original research studies published in English between 2004 and 2015 to reflect contemporary care contexts, which focused on the needs of people with dementia and/or their carers living in the community were considered. Multiple papers based on the same dataset were included only once and studies that focused solely on non-continuing pilot care services were excluded. Services included any type of respite, education, support groups, assistance with daily care tasks, counseling, or other support.

The term "need" is complex and has many connotations. Bradshaw (1994) identified four types of need (normative, expressed, felt, and comparative) that are still widely referred to.

The following search terms were used (all fields):

dementia OR Alzheimer's AND
 home OR community dwelling NOT residential care
 OR long term care OR nursing home AND
 spouse OR caregiver OR family AND
 service OR utilization OR non-utilization AND

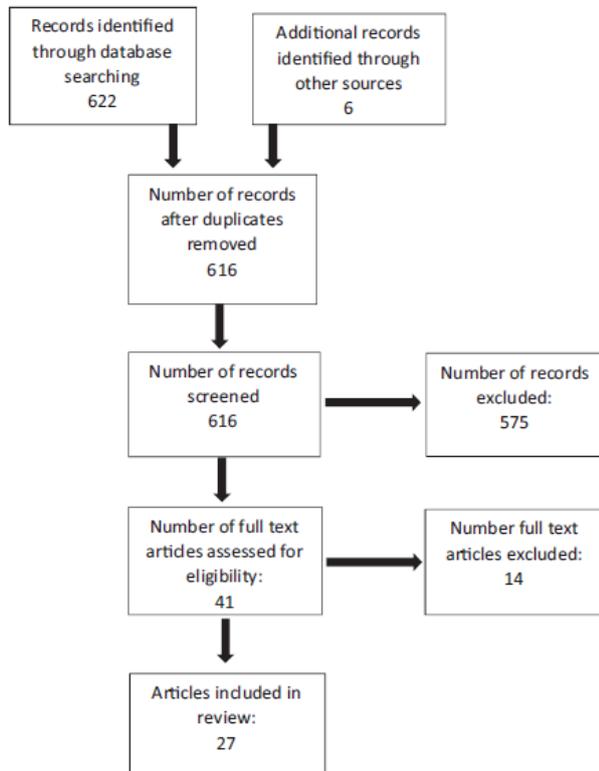


Figure 1. Flow diagram of study selection.

need OR demand OR preference OR expectation
AND
evaluat* OR satisf* OR response OR reaction

Stage 3: study selection

The search process initially identified a large number of studies, given the broad search terms used; for example, the term “caregiver” is inclusive of many types of care roles and dementia has many etiologies. Study titles and where necessary abstracts were reviewed for fit to the inclusion criteria. Studies were included if participants had any form or stage of dementia and the focus was on informal caregiving. Studies referring to caring for people with dementia in residential or nursing home care were excluded. The first author initially located 622 studies; titles were checked for relevance and duplicates removed, resulting in 41 potentially relevant articles. Abstracts of studies were checked to ensure they met the inclusion criteria; ineligible studies were excluded reducing the total to 21 studies. Hand searching reference lists identified six more studies resulting in a final total of 27 studies included in this review (see Figure 1).

Stage 4: charting the data

The 27 studies were read and data on authors, year, location, study population, aims, outcomes,

and conclusions were collated. Critical appraisal of the quality of the articles was not completed as that is not required in a scoping review (Arksey and O’Malley, 2005); although, limitations of included studies were considered in the discussion of the status of current literature.

Stage 5: collating, summarizing and reporting the results

Data related to authors, location, and methodology of studies were collated to understand the scope of the available literature.

Publication year and location of research

The majority of studies were from the United Kingdom (UK; $n = 6$) and Australia ($n = 5$); the USA, Canada, and the Netherlands each produced three studies; Finland two studies; and Norway, Hong Kong, Sweden, Germany, and South Korea each produced one study. There was an upwards trend in the number of relevant publications from 2009 until 2013, before falling to only two publications in 2014.

Type of research

Of the 27 studies included, an equal number of studies ($n = 11$) utilized either a mixed methods or a qualitative approach, including participatory action research and critical ethnography. Five studies were purely cross-sectional in design.

Participants

There were 5,069 carers (4,618 in quantitative studies), 2,089 people with dementia (1,796 in quantitative studies), and 54 other respondents (such as care workers and other health professionals) in the included studies. Six studies specified the type of dementia (younger onset ($n = 2$), Alzheimer’s disease (AD) and Vascular Dementia (VD) ($n = 1$), and AD only ($n = 3$)). Participants were generally recruited via agencies from which they had received services or been assessed ($n = 18$); were consecutively referred from services or care agencies ($n = 3$); or were randomly selected from databases of those known to have a diagnosis of dementia ($n = 3$).

Measures used

The outcome measure of need most commonly used in the mixed methods research was the Camberwell Assessment of Needs in the Elderly (CANE) ($n = 4$). Other measures used included the Care Needs Assessment Pack for Dementia (CareNapD), the COPE index, and the Johns Hopkins Dementia Care Needs Assessment (JHDCNA)

Table 1. Results for studies using CANE: PWD

NEEDS	VAN DER ROEST <i>ET AL.</i> (2009), N = 236			MIRANDA-CASTILLO <i>ET AL.</i> (2013), N = 152			COMBINED AVERAGES OF NEEDS, N = 388		
	MET %	UNMET %	TOTAL %	MET %	UNMET %	TOTAL %	AVERAGE MET %	AVERAGE UNMET %	AVERAGE TOTAL %
Food	90	0.8	90.8	75.7	0	75.0	82.9	0.4	82.9
Looking after home	69	0.9	69.9	67.6	0.9	68.5	68.3	0.9	69.2
Memory	46.9	10.2	57.1	71.3	2.8	74.1	59.1	6.5	65.6
Money	51.4	1.4	52.8	54.6	0	54.6	53.0	0.7	53.7
Physical Health	41.8	0.4	42.2	47.2	4.6	50.9	44.5	2.5	46.6
Drugs	26.3	0.4	26.7	47.7	1.9	49.1	37.0	1.2	37.9
Mobility	39.8	0.9	40.7	25.9	1.9	27.8	32.9	1.4	34.2
Eyesight/hearing	24.9	3.6	28.5	28.7	10.2	38.9	26.8	6.9	33.7
Self-care	31.6	0.4	32	33.3	0	33.3	32.5	0.2	32.7
Daytime activities	24.8	4.4	29.2	18.5	13.1	31.5	21.7	8.8	30.3
Psychological distress	12.1	4.9	17	15.7	18.5	34.3	13.9	11.7	25.6
Information	5	9.9	14.9	9.3	12	21.3	7.2	11	18.1
Company	12.5	5.4	17.9	7.4	10.2	17.6	10.0	7.8	17.7
Continence	13.8	1.8	15.6	13.9	0.9	14.8	13.9	1.4	15.2
Benefits	12.2	1.8	14	9.3	0	9.3	10.8	0.9	11.6
Accommodation	7.8	0.9	8.7	5.6	4.6	10.2	6.7	2.8	9.4
Accidental self-harm	4.5	0.9	5.4	7.4	2.8	10.2	6.0	1.9	7.8
Intimate relationships	3.2	3.2	6.4	2.8	2.8	5.6	3.0	3	6.0
Psychotic symptoms	1.8	0.9	2.7	5.6	2.8	8.3	3.7	1.9	5.5
Deliberate self-harm	2.2	1.8	4	0.9	4.6	5.6	1.6	3.2	4.8
Behavior	1.3	1.3	2.6	2.8	0	2.8	2.1	0.7	2.7
Abuse/neglect	1.3	0	1.3	1.9	1.9	3.7	1.6	1	2.5
Alcohol	0.9	0.4	1.3	1.9	0	1.9	1.4	0.2	1.6
Caring for another	0.9	0	0.9	0	0	0.0	0.5	0	0.5

($n = 1$) with which a skilled clinician rates needs as met or unmet based on observation and interview. Of the four studies that used CANE, only two reported full data from people with dementia (see Table 1).

Results

Identified needs and unmet needs

Based on the CANE, people with dementia reported on average a high number of needs in the areas of food (82.9%), looking after the home (69.2%), memory (65.6%), money (53.3%), and physical health (46.6%) (see Table 1). People with dementia reported fewer unmet needs, with the most common being psychological distress (11.7%), information (11%), daytime activities (8.8%), company (7.8%), eyesight/hearing (6.9%), and memory (6.5%).

In the four studies using carer proxy reports of the needs of people with dementia (Table 2), the most commonly reported needs related to memory (89.3%), looking after the home (89.2%), money (87.7%), food (78.3%), self-care activities (74.6%),

and daytime activities (73.9%). Carer proxy reports indicated that people with dementia had unmet needs in the following key areas: daytime activities (29.3%), company (22.3%), psychological distress (19.2%), memory (19.1%), and eyesight/hearing (14.6%).

Chung (2006) reported that self-care activities (such as daily routines, dressing, and bathing) were also high-priority needs. Unmet needs were reported in areas such as social interaction, issues with memory, and emotional control. High levels of unmet care needs were reported in the areas of home and personal safety (91.7%), allied health and general medical care (67.7%), meaningful activities and activities of daily living (61.4%), and legal assistance (48%) (Hughes *et al.* (2014).

Only one qualitative study (Mountain and Craig, 2012) reported identified needs of people with dementia that included information tailored to them, and support services (including meaningful activities) that are accessible and promote independence. In summary, the most commonly reported unmet needs were related to meaningful activity, social company and social opportunities, and information.

Table 2. Carer proxy reports

	VAN DER ROEST <i>ET AL. (2009)</i>			MIRANDA-CASTILLO <i>ET AL. (2013)</i>			FREYNE <i>ET AL. (2010)^a</i>	BAKKER <i>ET AL., (2014)^b</i>	AVERAGES ACROSS STUDIES		
	MET %	UNMET %	TOTAL %	MET %	UNMET %	TOTAL %	TOTAL %	UNMET %	TOTAL MET%	TOTAL UNMET%	TOTAL %
Abuse/neglect	6.2	1.6	7.8	9.3	1.9	11.2			7.8	1.8	9.6
Accidental self-harm	26.8	5.6	32.4	23.1	10.2	33.3			25.0	7.9	32.9
Accommodation	20.6	5.9	26.5	8.3	8.3	16.6			14.5	7.1	21.6
Alcohol	3.7	1.9	5.6	2.8	2.8	5.6	15		3.3	2.4	5.7
Behavior	11.2	4.7	15.9	6.5	4.6	11.1			8.9	4.7	13.6
Benefits	13.7	5.3	19	4.6	0.9	5.5			9.2	3.1	12.3
Caring for another	1.6	0.6	2.2	0	0	0.0			0.8	0.3	1.1
Company	23.4	13.1	36.5	14.8	31.5	46.3		37.8	19.1	22.3	41.4
Continence	29	8.7	37.7	21.3	5.6	26.9			25.2	7.2	32.4
Daytime activities	49.8	16	65.8	32.4	42.6	75.0	95	45.5	41.1	29.3	70.4
Deliberate self-harm	2.2	0	2.2	2.8	5.6	8.4			2.5	2.8	5.3
Drugs	44.9	3.1	48	73.1	4.6	77.7			59.0	3.9	62.9
Eyesight/ hearing	34.4	8.8	43.2	32.4	20.4	52.8		37.3	33.4	14.6	48
Food	77.9	3.4	81.3	85	2.8	87.8			81.5	3.1	84.6
Information	15	8.7	23.7	22.2	11.1	33.3			18.6	9.9	28.5
Intimate relationships	4.7	3.4	8.1	3.7	6.5	10.2	22.5		4.2	5	9.2
Looking after home	85.7	6.9	92.6	86.1	0.9	87.0			85.9	3.9	89.8
Memory	54.7	32.5	87.2	94.4	5.6	100.0	100	23	74.6	19.1	93.7
Mobility	49.5	6.9	56.4	38	5.6	43.6			43.8	6.3	50.1
Money	80.1	5.9	86	80.6	0.9	81.5	97.5		80.4	3.4	83.8
Physical health	58.6	2.2	60.8	66.7	4.6	71.3			62.7	3.4	66.1
Psychological distress	23.4	8.7	32.1	22.2	29.6	51.8	92.5		22.8	19.2	42
Psychotic symptoms	11.8	8.1	19.9	9.3	5.6	14.9			10.6	6.9	17.5
Self-care	62.3	5.9	68.2	57.4	5.6	63.0	92.5		59.9	5.8	65.7

^aIncomplete data provided; missing data excluded in calculation of averages.

^bReported unmet needs only, excluded from calculation of averages.

Thematic analysis of qualitative themes and quantitative results

An inductive thematic analysis of the results included in the qualitative and mixed methods studies (Corbin and Strauss, 2008) using constant comparison approach revealed five key areas of need: information, availability, barriers to services, personalization of services, and peer support. Two of the researchers independently analyzed the qualitative results and then discussed, resolved discrepancies, and agreed on the themes.

Availability of services for people with dementia

Six of the 11 qualitative studies identified that services were not adequately available (Grenade and Walker, 2005; Forbes *et al.*, 2008; Raivio *et al.*, 2011; Mountain and Craig, 2012; Ward-

Griffin *et al.*, 2012; Ducharme *et al.*, 2014). Carers in Ireland reported dissatisfaction with services available to support daytime activities and the need for services to support completion of self-care activities and home maintenance (Freyne *et al.*, 2010). Raivio *et al.* (2007) noted that further support (i.e. additional need for the same services) was an issue for between 16.1% and 30.8% of Finnish carers. Problems with availability of formal services (both initial and to supplement previously established services) in Canada were reportedly due to financial prioritization of available services according to perceived needs (Ward-Griffin *et al.*, 2012; Ducharme *et al.*, 2014). The time available to provide care was associated with the ability to provide outcome-focused or relationship-focused care, the key components of personalized services (Grenade and Walker, 2005; Gethin-Jones, 2014).

The timing of services was a factor in receiving the right support along the continuum of dementia. Four qualitative and one quantitative study identified this as an issue (Chung, 2006; Raivio *et al.*, 2011; Mountain and Craig, 2012; Ward-Griffin *et al.*, 2012; Ducharme *et al.*, 2014), and included a lack of ongoing assessment of care needs to adapt to changes in function (Ward-Griffin *et al.*, 2012), and a lack of referral to support services appropriate for early stage dementia (Mountain and Craig, 2012).

Personalized services

Services that provided trusting relationships, choice and control, and focused on the goals of the person with dementia (or carer) were highly regarded by people with dementia and carers. Ward-Griffin *et al.* (2012) in Canada stated: “When formal care services were provided in a standardized and regimented way, they were often described as inadequate and substandard” (p. 6). In their qualitative studies, Raivio *et al.* (2007) and Grenade and Walker (2005) found that carers required adequately tailored or personalized care to meet the needs of families of people with dementia, and this led to improvements in sense of independence and confidence among people with dementia. People with dementia and carers reported that control and autonomy were valued and important features of services that met their needs (Grenade and Walker, 2005; Rothera *et al.*, 2008; Raivio *et al.*, 2011; Landmark *et al.*, 2013; Gethin-Jones, 2014). When services were not flexible and personalized this contributed to non-use of services (Brodaty *et al.*, 2005). Landmark *et al.* (2013), Gethin-Jones (2014), and Ducharme *et al.* (2014) identified the need for services in to be person-centered or outcome-focused rather than task-oriented because families were concerned by the lack of social contact provided during home care visits. This is a particularly crucial recommendation given the high number of unmet needs regarding social interaction as reported by people with dementia and their carer proxies.

Barriers to effective services

Key barriers to effective service provision were identified as cost, geographic location, lack of flexibility, fragmentation of services, and a lack of expertise or knowledge among health professionals (Forbes *et al.*, 2008; Rothera *et al.*, 2008; Raivio *et al.*, 2011; Mountain and Craig, 2012; O’Connell *et al.*, 2012; Ward-Griffin *et al.*, 2012; Landmark *et al.*, 2013; Ducharme *et al.*, 2014; Gethin-Jones, 2014). Fragmentation of services because of changes in frontline staff and systemic

communication breakdowns negatively affected the quality of services received by people with dementia and their carers (Ward-Griffin *et al.*, 2012). Wolfs *et al.* (2010) found that more than 70% (177) of carers in the Netherlands were satisfied with services provided through a case management system because it supported quality communication and consistency of providers. A lack of knowledge or expertise among health professionals affects access to relevant services and may also impact on the ability of carers to continue supporting people with dementia in the community. This was identified as an issue in three qualitative studies (Forbes *et al.*, 2008; Hain *et al.*, 2010; Raivio *et al.*, 2011).

Education and information

Commonly reported needs for carers and people with dementia included information regarding future expectations as a carer for a people with dementia, services available, or education for practical skills in caring such as communication (Raivio *et al.*, 2007; Forbes *et al.*, 2008; van Der Roest *et al.*, 2009; Alwin *et al.*, 2010; Freyne *et al.*, 2010; Wolfs *et al.*, 2010; Raivio *et al.*, 2011; Mountain and Craig, 2012; Robinson *et al.*, 2012; Ducharme *et al.*, 2014; Hughes *et al.*, 2014). Carers in Sweden identified receiving information about dementia as a priority with 70% (77) reporting this as met (Alwin *et al.*, 2010). In contrast, Freyne *et al.* (2010) found that 52.5% (21) of carers had a need for information with more than half not having this need met. Similarly, 64.3% (158) of carers in an American study reported a need for dementia education, and 24.8% (61) reported an unmet need for education on practical caring skills (Hughes *et al.*, 2014). People with dementia indicated that there was a lack of information or education designed for them, and that resources were predominantly aimed towards carers (Mountain and Craig, 2012).

Knowledge of available services was a key need for carers in Germany (Graessel *et al.*, 2011) and Finland (Raivio *et al.*, 2007; Raivio *et al.*, 2011); some services (i.e. home nursing) were well known but carers experienced difficulty locating additional services. Carers in the USA (Hain *et al.*, 2010) and the United Kingdom (Rothera *et al.*, 2008) experienced difficulties in identifying sources of guidance or advice about what to expect in the future. This was also identified by Robinson *et al.* (2012) who found that Australian carers were often overwhelmed by the “maze of information out there” (p. 205).

Peer support for carers and people with dementia

Carers and people with dementia across countries reported a need for peer or emotional support; a finding that was similar in qualitative and quantitative studies. Over one-third (34.9%) of American caregivers stated that their need for emotional support was unmet (Hughes *et al.*, 2014). Opportunities to discuss challenges faced in caregiving were very important to 70% (77) of Swedish carers (Alwin *et al.*, 2010). Positive social interactions and affectionate support were considered by South Korean carers to be more helpful than information or emotional support to reduce psychological burden associated with caregiving (Han *et al.*, 2014). Carers in the United Kingdom had a need for support groups that focused on proactive strategies and coping mechanisms and not just talking (Mountain and Craig, 2012). Sharing past and present experiences with other carers provided emotional support, encouraged carers to share coping strategies, and helped carers to develop problem-solving skills (Rothera *et al.*, 2008; Greenwood *et al.*, 2013). People with dementia reported their need for support groups that provide peer support and emotional release (Greenwood *et al.*, 2013), as well as having a support group separate to those for their carers (Mountain and Craig, 2012). The continuation of social contact was a key need for 63% (20) Canadian people with dementia in a study by Ducharme *et al.* (2014).

A fear of the future due to lack of predictability or normalcy, the need for hope, and the need to learn to cope with changes in family relationships was reported by carers in Sweden (Alwin *et al.*, 2010), the USA (Hain *et al.*, 2010), Norway (Landmark *et al.*, 2013), and the United Kingdom (Mountain and Craig, 2012). Freyne *et al.* (2010) reported the needs identified by carers included adequate sleep and ways to encourage service use by people with dementia. No information was available to confirm if available services addressed the needs reported by Freyne *et al.* (2010).

Discussion

This scoping review investigated the research literature reporting the needs of people with dementia and their carers, and the responsiveness of community services to those needs. As the quality of the included studies was not established, the data are considered a representative view of the current state of the research. Common met and unmet needs for people with dementia and their carers reflected a shared experience

across countries, regardless of different models of service. Although the findings of the 27 studies focused on community-based carers and people with dementia across 12 countries, differences in study methodologies, quality of services, and social policy between countries limited the conclusions that can be drawn.

Measurement and identification of need is a difficult task with data collection and methodology influencing the conclusions of each study. Studies using quantitative outcome measures (e.g. CANE, CareNapD, and JHDCNA) focused more on survival and basic daily needs. The spectrum of met and unmet needs also incorporates needs that are not effectively met; however, this subset of needs was not well expressed in the findings of the quantitative studies in this review. Qualitative studies for people with dementia and their carers focused on the lived experience of dementia, even when exploring the same needs as the quantitative studies; for example, memory, activity, and social company. Diverse findings between qualitative and quantitative studies provided support for using both research approaches to measure outcomes (McCabe *et al.*, 2016). Using measures that quantify need in conjunction with rich descriptions from people with dementia, carers, health professionals, and service providers, better revealed the extent of needs and how well they were responded to, the importance of individualized care, and contextual factors.

Self-reports from people with dementia, as opposed to proxy reports by carers, affected how needs were measured (Moyle *et al.*, 2012). Voices of people with dementia were included in only two of 11 quantitative studies (van Der Roest *et al.*, 2009; Miranda-Castillo *et al.*, 2013). The exclusion of the perspectives of people with dementia in research was acknowledged (McKeown *et al.*, 2010); however, given the insights obtained from people with dementia, the value of including their perspectives to understand their needs is unquestionable. Disparities between perceptions of needs among people with dementia and their carers, and the perceptions of health professionals, create a challenge for researchers and service providers. Understanding the generic needs of people with dementia and their carers is important for generic service development and planning (Beeber *et al.*, 2008). However, by understanding *specific* needs of people with dementia and their carers as individuals or families, providers can take a client-centered approach to service delivery (Rothera *et al.*, 2008; Raivio *et al.*, 2011). Understanding the felt or perceived needs of carers was a better measure of service need than standardized measures of caregiver burden

or functional status of the people with dementia (Roelands *et al.*, 2008; Stirling *et al.*, 2010).

Difficulties among carers in recognizing their own needs or those of the people with dementia were frequently identified as a reason for not accessing available services. The impact of this on service utilization has been documented in the literature (Brodady *et al.*, 2005; Wolfs *et al.*, 2010; Robinson *et al.*, 2012); however, this scoping review also highlighted this gap and the importance for service providers to understand the perspectives of people with dementia. Although the literature indicated that basic needs such as food, security, and housing for people with dementia were met, it was not clear who met these needs. Forbes *et al.* (2008) raised the concern that meeting needs was generally the responsibility of family and other informal carers, and the exhaustible nature of these informal supports needs to be addressed. From this perspective, it is also crucial to understand the needs of carers, separate to those of people with dementia (Steiner *et al.*, 2016).

The methodological quality of included studies limited the validity of the findings of this scoping review. Data reported in two quantitative studies were incomplete (Freyne *et al.*, 2010; Bakker *et al.*, 2014) and the inconsistency in outcome measures used and the diverse dimensions of need that were identified limited the comparison of findings across studies. For example, only one study addressed needs related to sleep strategies, relationship support, and support in service utilization (Hughes *et al.*, 2014). The methodological limitations of the included studies resulted in a gap in the evidence reported across studies. While all included studies investigated the needs of people with dementia and carers living in the community, some only focused on the experience of carers utilizing specific services, thereby creating a potential bias wherein some needs were perceived as more important than others.

When qualitative data were collected solely on the needs of people with dementia it was from dyads (the person with dementia and their carer) rather than only from the people with dementia. This may explain why only one study, which included the views of people with dementia, described maintenance of meaningful roles as an identified need (Mountain and Craig, 2012). Study samples ranged in size from 10 carers (Mountain and Craig, 2012) to 731 dyadic pairs (Han *et al.*, 2014). Typically, studies using a qualitative methodology had small, purposive samples selected from active service users who provided rich, detailed information based on their personal experiences as per the aims of qualitative research.

In conclusion, the needs identified by carers and people with dementia encompassed social, emotional, personal, and physical needs. Most commonly identified needs were meaningful activity, social company and social opportunities, and information or education; and many study participants reported the inadequacy of formal services in meeting these needs. Carers in all studies in this review had concerns about the quality of available services, particularly with regard to responsiveness and flexibility. High levels of satisfaction with services were influenced by those that had a strong focus on empowering people with dementia and their carers. Service delivery methods and models perceived by carers as insufficient were related to those that were not sufficiently responsive and flexible to the holistic needs of carers and people with dementia. Providing people with dementia and their carers with greater control, choice, support to make decisions, and guidance to navigate through the complex health and welfare systems is needed.

Implications for practice and future directions

It is important for various stakeholders to acknowledge the holistic nature of needs and include the voices of people with dementia and their carers. Health professionals working with this population must recognize that timeliness and flexibility are key elements of effective services and that trust and rapport among formal services, people with dementia, and families are crucial to building strong relationships.

Policy-makers, funding bodies, and service providers have a clear remit to develop services that focus on choice, continuity, and certainty. Allocation of funds and services should be individualized to respond to the perceived needs of people with dementia and their carers, empower their ongoing education and access to information, and provide consistent access to health professionals. Current service delivery models are considered to be fragmented, disempowering, and confusing – leading to negative health and quality of life outcomes for people with dementia and carers.

Researchers have a responsibility to meet the challenge of actively including the views of people with dementia; their contribution is invaluable to help others to understand their needs. Although the studies included in this scoping review used both quantitative and qualitative methodologies to collect data about the needs of people with dementia and their carers, the flexibility in design of the qualitative studies allowed the capture of

rich data that supports the holistic investigation and analysis of needs.

Conflict of interest declaration

None.

Description of authors' roles

C. Morrisby designed the scoping review, collected and analyzed the data, and wrote the paper. A. Joosten assisted with study design, data analysis, and wrote the paper. M. Ciccarelli confirmed data analysis and wrote the paper.

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Chapter 3 Study One

3.1 Introduction

The findings of the scoping review (Chapter two) identified that the needs of people with dementia and their carers world-wide were not currently met by contemporary services. The needs of people with dementia and carers identified in the scoping review were diverse, and the standardised surveys implemented in cross-sectional study designs were not always able to capture the depth and diversity of the participants' experiences. Studies that used mixed-methodologies and qualitative approaches enabled a deeper understanding of the lived experience of need, and the ability of services designed to support people with dementia and their carers to meet these needs. One article from WA (Grenade & Walker, 2005) emphasised the gap in the knowledge of the needs of the population within the Western Australian context.

In considering the needs of carers, the scoping review identified spousal relationships and intimacy as an area of unmet need. Given co-resident carers are most commonly spouses or partners (AIHW, 2012), a specific focus on the needs experienced by this group of carers is warranted. This is further supported by Wadham et al. (2016), Robinson et al. (2005) and Egilstrod et al. (2019) who found that understanding the needs of spousal carers may contribute to developing more effective interventions to support community dwelling people with dementia. Furthermore, the scoping review highlighted the importance of including people with dementia as participants in, rather than subjects of, research. This has been consistently reiterated in the literature as a critical feature of research into needs to emphasise the authentic voice of people with dementia in contrast to the perspective of carers and health professionals (Braun et al., 2009 ; Brooke, 2019; Moyle et al., 2012; Rivett, 2017).

Based on the findings that people with dementia needed to be included in research about them, study one was developed to identify the needs of people with dementia and their spousal carers in WA. Given the breadth of needs previously identified in the scoping review, a framework to support the holistic identification of needs was required. The ICF framework (WHO, 2002) was identified as capable of identifying the needs of people with dementia and carers; it considers the impact of dementia within the complex interaction of environment, activity, and participation (Muò et al., 2005). As such, the personal, environmental, participatory, and occupational needs of people with dementia and spousal carers were investigated in this study using qualitative methods of inductive enquiry.

3.2 Publication two - Needs of people with dementia and their spousal carers: A study of those living in the community

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Needs of people with dementia and their spousal carers: A study of those living in the community

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Objective: To identify care and support needs, as reported by people with dementia and their spousal carers living in the community in metropolitan Western Australia.

Methods: An interpretive description approach was utilised. Semi-structured interviews were conducted with 10 dyads of spousal carers and people with dementia. Comparative analysis was used to develop themes regarding need, which were reviewed using two focus groups of spousal carers.

Results: Three major themes were developed through analysis of data from the interviews and were refined by the focus groups: (a) environmental enablers to support care; (b) strong caring relationships; and (c) adaptation of daily life roles.

Conclusions: As dementia progresses, continued support to maintain participation in meaningful activity is needed. Strong caring relationships, knowledge and an understanding of dementia among health professionals, service providers and family members were key to maintaining support for the needs of people with dementia and their spousal carers.

KEYWORDS

community, dementia, health services, spousal carers

1 | INTRODUCTION

Dementia in Australia is rising in prevalence; an estimated 354 000 Australians were living with the disease in 2016.¹ Of these, 70% lived in the community and relied on 200 000 informal carers for support. Co-resident carers (residing with the person with dementia) were typically a partner or spouse (57%), or son or daughter (36%), and most likely provided 40 or more hours of care per week.²

Given the proportion of spousal carers, understanding the dyadic relationship of carer and person with dementia is critical for developing and providing effective interventions and services.³ With changes in intimacy, identity and perceived value reported differently by the carer and the person with dementia, transitioning from roles as “husband and wife” to “carer and person with dementia” can be challenging for both partners.³ Australian aged care policies and systems depend on informal carers such as spouses, even though it is acknowledged that spousal caring is highly intensive.⁴ Recent legislative changes towards consumer-directed aged care may provide greater flexibility and person-centredness

in the delivery of care for people with dementia.⁵ However, consumer-directed care places responsibility on carers to choose the “right” level of support for consumers, potentially creating conflict within spousal relationships.⁴ This raises questions as to how the needs of people with dementia and their spouses are understood.

In existing research literature, participatory, occupational, personal and environmental needs of people with dementia and their carers have been used as the basis for needs assessment.⁶ This categorisation of needs reflects the International Classification of Functioning, Disability and Health (ICF) framework by using common terms such as participation, environment and person.⁷ A broad understanding of need and unmet need is critical; research indicates that increased unmet need correlates with a greater likelihood of entry to residential care and higher rates of morbidity.⁸

Contemporary Australian research literature reporting the needs of people with dementia and their carers has considered a broad range of caring situations and focused on carers’ experiences.⁹ Views of people with dementia are commonly not included in research; however,

inclusion of people with dementia in qualitative research is important in developing personalised and responsive services.^{3,10} Research concerning dementia and services in the Australian context has focussed on experiences of carers who use services and reasons for service use (or non-use) but has not explored how the needs of carers and the people with dementia change as dementia progresses.¹¹⁻¹³ A broader discussion of needs experienced by people with dementia and their carers, respectively, is required to develop services and systems that will benefit those living in the community.¹⁴ This study aimed to identify self-reported needs of people in various stages of dementia and their spousal carers living at home in Western Australia across the course of the disease.

2 | METHODS

Interpretive description is a qualitative methodology aimed at generating knowledge that is relevant in clinical contexts such as health. It was used as a co-constructive approach to explore experiences of spousal carers and people with dementia.¹⁵ Interpretive description recognises the impact of shared experience and acknowledges the contextual and constructed nature of ill health.¹⁵ This project was approved by the University Human Research Ethics Committee (HR111/2013).

2.1 | Participants

Purposive sampling was used to recruit people experiencing different stages of dementia, and their spousal carers, across metropolitan Perth. Staff from community care organisations managed initial contact with prospective participants, providing information about the study and the researchers' contact details. People diagnosed with dementia, living in the community and being cared for by a spouse willing to be interviewed were eligible. Thirteen couples contacted the researchers. Of these, one carer withdrew to prevent potential distress of the person with dementia; one couple was unable to participate for personal reasons; and one couple was ineligible due to an unconfirmed dementia diagnosis. All participants provided signed informed consent. Prior to interview, the Functional Assessment Staging (FAST)¹⁶ was administered to identify functional performance indicators to classify each person's level of dementia. The FAST has good reliability and validity, and takes less than 2 minutes to administer.¹⁷ Participants' dementia levels ranged from 4 to 6.4, with a median of 5, indicating moderate dementia (see Table 1). Of the 10 couples interviewed, three participants with dementia responded articulately. Four participants with dementia provided explanatory comments relevant to the questions. Two participants with dementia had limited

Policy Impact

Needs of spousal carers and people with dementia are related to the environment, participation in meaningful daily life roles and positive relationships. These needs are beyond the current scope of available formal support services. When planning and delivering services to people with dementia and their spousal carers, service providers and policy-makers should consider the unique nature of spousal relationships within the context of progressive dementia, particularly during the transition to consumer or carer-driven care.

expressive communication and made few contributions to the interview. One carer asked to be interviewed alone because they felt their spouse did not have sufficient insight to discuss their experience of dementia.

2.2 | Interview

The interview schedule was devised with reference to the ICF. The interviews explored person and contextual factors, ensuring needs related to participation in desired everyday activities and roles were identified and discussed (see Table 2). Participatory needs refer to engagement in social situations, reciprocity and a sense of control.¹⁸ Occupational needs include engagement in paid or voluntary roles, or a sense of independence in carrying out activities of daily

TABLE 1 Spousal interview participants

	FAST	Person with dementia pseudonym	Age	Carer pseudonym	Age
	6b	Allen	70	Jenny	69
	5	Melanie	73	Paul	74
	5	Penelope	83	Ned	90
	4	Jason	65	Veronica	63
	6d	Ben	81	Jackie	79
	5	Ryan	84	Jill	68
	6c	Joanne	73	James	75
	6a	Sarah	80	Fred	81
	6a	Perry	73	Elsie	75
	5	Tim	72	Anne	63
Median FAST score	5	Average age	75	Average age	74

FAST, functional assessment staging.

TABLE 2 Examples of interview questions (for both person with dementia and carer)

Can you describe what has happened since you were aware that you (or the person you care for) had or might have dementia?
Since being diagnosed with dementia have you had opportunities to provide care or support to others?
Has your daily routine changed? And if so, how?
Do you have any assistance from family or friends?
Has there been any change in how you feel about yourself?

living.¹⁹ Personal needs encompass feelings of security, self-esteem, acceptance, spirituality, and health or other factors that may affect how dementia or caring is experienced by the individual.^{7,20} Environmental needs focus on physical, social and attitudinal enablers or barriers that exist for a person with dementia or their carer.⁷ A pilot interview with a person with younger-onset dementia and their carer was completed to refine the interview guide.

The first author, an occupational therapist with 5 years' experience in interviewing and assessing the care needs of people with dementia and their carers in the community, was contacted by participants to arrange a home visit. Ten semi-structured interviews (average duration: 65 minutes) were conducted in participants' homes. Participants described their journeys with dementia, from diagnosis to their current situation, and considered their future needs. Initially, the first three interviews were transcribed verbatim and analysed using continuous inductive analysis to identify the main themes.¹⁵ Data collection continued until no new themes were identified. All transcripts and field notes were analysed by the first and second authors to identify themes of common experiences between interviewees; respective needs of people with dementia and their carers were identified from these themes. Participants' names were changed to preserve anonymity. Themes developed from interviews were used to guide questions used in two focus groups with carers.

2.3 | Focus groups

Two focus groups (average duration: 120 minutes) with the spousal carers of people with dementia were conducted to obtain a more complete description of needs identified during the dyadic interviews. All carers interviewed in dyadic interviews were invited to participate in focus groups, only three were available. The remainder ($n = 7$) were recruited via advocacy organisations and service providers in metropolitan Perth. Focus groups provided the opportunity for member checking, triangulation of data and identifying congruence between themes from dyadic interviews with the experiences of spousal carers.²¹ The focus groups were audio-recorded and transcribed verbatim. Transcripts of the focus groups were analysed manually by the first and second authors.

2.4 | Analysis

Ten interviews with participants with dementia and their spousal carers, followed by two focus groups with carers, obtained a rich description of the needs of people with dementia and their spousal carers. Data were analysed using a six-stage thematic analysis²² that allowed for flexibility and an inductive approach based on the obtained data.

3 | RESULTS

3.1 | Thematic analysis

Three themes, focused on the needs of the participants, were developed from analysis of the interviews and focus groups. These were as follows: (a) environmental enablers to support care; (b) strong caring relationships; and (c) adaptation of life roles. How participants experienced these needs was dependent on the current stage of dementia.

3.1.1 | Theme 1: Environmental enablers to support care

A social environment that is supportive and well educated

Social support was needed at three levels—family, friends and broader social networks. Family support was considered important for participants at all stages of dementia. Family support played a role in encouraging three carers and people with dementia to engage with formal services, particularly in the moderate to late stages:

Well, mostly you get pushed into it from the children, you know. (Paul*, carer)

Family members' knowledge and understanding of dementia and its effects varied considerably and lessened as families became geographically separated. When family lacked knowledge of dementia, particularly in the later stages, the carers felt less able to rely on their support:

There are family members who have just backed right away as if to say, "Well, I don't want to know about it". (Anne*, carer)

Participants believed social support from friends was needed, particularly in the moderate to late stages of the disease. Carers in interviews and focus groups identified that contact with friends provided a sounding board, a sense of normality and continuation of important social roles. Specific social groups for people with dementia and their carers were particularly valued for their role in allowing couples to socialise:

They've got people there, the same as what they are or similar to what they are. And we've got people that we can talk to and communicate with. So, to me that's a real asset. (Jill*, carer)

Knowledge and understanding of dementia among broader social networks, such as work colleagues, were described as a need at all stages of the disease. Many participants reported limited knowledge of dementia among others, or felt there was a stigma attached to the syndrome:

She had friends in work, and we had quite a lot of friends, but when she was diagnosed with Alzheimer's ...her friends all went the other way. They thought it was something they could catch. (James*, carer)

One person with early-stage dementia preferred not to disclose their diagnosis and instead initially told acquaintances they had a diagnosis of Parkinson's disease.

Institutional support that is timely, effective and affordable

Formal community services, such as respite care or domestic assistance, assessment and diagnosis, and financial support options, are considered institutional. These services and supports are governed by federal- and state-based policies.

A key need reported by participants, particularly in the moderate to late stages of dementia, was access to quality services that met their needs. This included strong, ongoing relationships with service providers. Carers felt that service providers rotated staff to reduce attachments to clients, thereby damaging opportunities to build trust with specific staff and increasing the likelihood of non-individualised care:

They [service providers] give them different placings, which I object to because when you get used to somebody, they know exactly what to do. (Ned*, carer)

Individualised care was needed to meet the needs of the carer *and* the person with dementia. Carers used services less when regular support workers were unavailable; they cancelled services when the activities provided were repetitive or replicated the couple's current activities.

The process of applying for and receiving services was experienced as complex, and services lacked understanding of people with dementia. Individually and jointly, carers identified that there were too many assessments, that there was a lack of communication between service providers, and that assessors did not understand dementia effectively. When describing being assessed for services, one carer stated:

She just took everything that [person with dementia] answered and forgot me. (Carer, focus group)

Many participants identified unmet needs during the process, from diagnosis to ongoing care. People with dementia and their carers identified a lack of empathy from health professionals and inconsistency in the care provided; for example inadequate referral to support services. Allen, a person with dementia, commented on his experience of diagnosis: "some people don't care [referring to memory clinic]." Three participants resorted to private health services to get the quality of care they sought. Another couple accessed both public and private health services, opting to continue in the public system. Participants' discussion on quality of care referred to the timeliness of receiving appointments, perceived accuracy of diagnosis, and the number of services or supports to which they were referred. Carers of people with late-stage dementia had concerns about the amount of support received in the community or processes of looking for permanent care. Cost became a concern for carers in the moderate to late stages when additional support services became necessary:

He's [at] day clubs three times a week. If he was going to day club and I was on a package one week would cost \$360. (Carer, focus group)

There were variations in participants' financial situations; two people had younger-onset dementia and had been forced into premature retirement; others were self-funded retirees or were recipients of partial or full aged and/or veterans' pensions. Those who accessed government welfare through Centrelink reported generally good service; however, some had concerns about lengthy application processing times affecting their availability to care for their spouse:

I can't go down to Centrelink without a time-frame, and be there for three hours. (Carer, focus group)

A safe home and community

Participants discussed the importance of suitable environments to facilitate the person with dementia remaining at home. This issue particularly affected carers; participants in focus groups and individual interviews identified factors such as familiarity with surroundings, proximity of social support, safety and access to services as reasons for wanting to remain living in their respective communities:

I selected on four criteria, if I can remember them. One was hospitals, or medical. Second was public transport. And security... shopping. (Carer, focus group)

These enabling factors were offset by the financial status and perceived ability of the carers to maintain the home into the future.

3.1.2 | Theme 2: Developing and maintaining strong caring relationships

Strong caring relationships between spouses were the culmination of many years of partnership. All carers expressed a commitment to provide support to their partner. Participants with early- to moderate-stage dementia expressed their commitment to the spousal relationship:

I like to hop in and help and do what I can do.
Make it easier for her to do what she's got to do.
We're both great mates for each other, I think,
too... This is me, I do the best I can that way.
(Perry*, person with dementia)

People with early-stage dementia and their carers recognised that love, humour, patience and tolerance were key attitudes when it came to supporting each other through the disease process:

I think the greatest thing that anyone can give is understanding, I think it's love,... you can see [husband]'s down, and you say, 'Come on, let's have a hug,' you know, so you have a hug, even though your heart's breaking because you can see... you can see the road ahead, where he can't see that.
(Anne*, carer)

Having time to relax and reflect, developing coping strategies and getting support from other carers were important for maintaining a strong caring relationship. Carers, particularly those in the focus groups, identified needing to take responsibility for looking after themselves. This included accessing education about dementia (via Internet resources or community services), asking for help and making decisions that benefitted them; for example when to access support services. Reflecting on their previous experiences in caring was of great help in preparing for the future. There was wide variation among carers regarding who provided the best support—family, long-term friends and new friendships with other carers were all identified as being important.

3.1.3 | Theme 3: The future of daily life for people with dementia and their carers

Engaging in everyday activities such as driving, leisure and home maintenance was an ongoing need of people with dementia and their carers. Changes in function, holding a

drivers' licence and work were of specific concern to people with dementia (and their carers) at all stages:

He [neurologist] said you have to let the transport people know, which I did. Mind you, within 10 days there was someone on our doorstep wanting the licence, which was a bit rude I thought. (Jason*, person with dementia)

Participants at all stages also recognised the need to participate in daily activities and roles to maintain feelings of self-worth, for example helping with household tasks or actively being a grandparent:

One of them he says, Nonno, you always teach me things. This was quite a while ago. I used to say, what would you like to do? And we'd go out the back here and we'd get a bit of wood or pipes or something and they'd love to do that, it was good... It was great for me and it was also great for him too. (Allen*, person with dementia)

Maintenance of important roles required support from carers and, at times, support services. Over the course of the disease, changes in roles needed to be managed. Participants (particularly in the earlier stages) reported that they needed to work in partnership to continue roles or develop new roles:

I said to my husband when it first started, 'No one's going to come along and pick us up. We've got to work together as a team to get through this,' and luckily he's happy to do that so far.
(Carer, focus group)

4 | DISCUSSION

This study identified a holistic range of needs for spousal carers and people with dementia at different stages of the disease. Understanding the needs of people with dementia and their carers will assist in ensuring service provision is effective and relevant.⁸ People with dementia and their carers utilised services to support them to remain living at home and to improve quality of life; this is difficult to achieve without quality services. A lack of quality services reportedly leads to earlier admission to residential care.⁸

Community services were a frequent cause of both frustration and salvation among participants. In general, participants were grateful for the support they received; however, they recognised serious downfalls in institutional supports. Carers in this study identified reasons why they did not use services, and low utilisation was due, in part, to services not

meeting their expectations for quality, relationship-based care, a finding consistent with previous studies.^{11,12,23,24} Participants were more likely to use services when services were positive, and family, friends and health professionals provided the right information at the right time.²⁵

Knowledge about dementia for carers, extended family and the community was consistently identified as a need. Health professionals were perceived to be lacking knowledge and understanding about dementia, confirming the findings of previous studies.^{14,26} Participants found that dementia stigma affected their ability and willingness to receive support from family and friends, and education was needed as a key strategy for reducing the impact of stigma.²⁷

Needing to adapt and change daily activities and roles within the context of a spousal relationship with disease progression was identified previously as a complex process of loss¹⁴ and was a concern for participants in the current study. Many participants recognised that maintaining valuable roles, such as grandparenting or helping the person with dementia to complete useful tasks around the home, helped maintain their quality of life. Providing professional support to tailor communication and develop supportive environments for carers of people with dementia resulted in adaptation of roles, but may increase caregiver burden.²⁸

Participants in this project were recruited from service providers so they had some experience in accessing community services. This may have resulted in a selection bias, although it did provide them with relevant information to share regarding navigating support systems.

Although carers in focus groups were asked to consider the needs of their spouses, differences exist in the perceived subjective states of carers and people with dementia.²⁹ This was evident in the focus groups with carers, which centred on needs related to changing relationships and progressing dementia, rather than their partners' broader needs. For example, there was greater focus on changes in spousal relationships and needing to continually adapt their roles as spouse and carer. A strength and contribution of this study was the inclusion of people with dementia and their carers, and this study highlights that further research including the perspectives of people with dementia is needed.¹⁸

Needs of spousal carers and people with dementia are related to the environment, participation in meaningful daily life roles and positive relationships. Meeting these needs is beyond the current scope of available formal support services. When planning and delivering services to people with dementia and their spousal carers, service providers and policymakers should consider the unique nature of spousal relationships within the context of progressive dementia, particularly during the transition to consumer or carer-driven care.

5 | CONCLUSIONS

The relationship between spousal carers and people with dementia requires tailored support, particularly with regard to their environment, engaging in occupations and maintaining relationships. The needs of people with dementia and their spousal carers change as the disease progresses, typically requiring additional tangible formal support. People with dementia and their carers need supportive environments in which to live. Stigma experienced by people with dementia continues to cause access barriers to formal services and informal supports. Serious limitations in the structure, process and underpinning purposes of community support services were identified by people with dementia and their carers. Formal support services in the community need further refinement to better meet the needs of this population.

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Chapter 4 Study Two

4.1 Introduction

The findings from Study One (Chapter three) indicated that people with dementia and their spousal carers living in the WA community experienced clearly defined unmet needs. These concerns related to available services, their social environment, the maintenance of their community relationships, and their engagement in meaningful occupations. These needs changed as the dementia progressed, particularly in relation to the types of services and supports they required, and the costs of receiving adequate and appropriate care. While the quality of care was deemed generally positive, a number of issues were raised including the consistency of support workers that enabled relationship-based care, the timing of the introduction of services, and the support or encouragement from family and friends enabling access of such services. Unmet needs that were not recognised within the purview of services by the participants included safe environments, strong caring relationships, and adaptation of different occupational roles. International literature has demonstrated how services may be capable of supporting people with dementia to address these needs; for instance, with interventions that support relationship development through life story work (Ingersoll-Dayton et al., 2013) and the improvement of quality of life through adaptation of occupations (McLaren et al., 2013).

People with dementia who receive effective and supportive dementia services enter residential care at a slower rate than those who do not (Gaugler et al., 2005). Furthermore, such services contribute to improving relationships and overall quality of life by reducing carer stress and promoting continued independence (Gaugler et al., 2005; Rapaport et al., 2020) Hence, in combination with the now known unmet needs of WA service recipients it was deemed important to understand the barriers to and limitations of services from the perspective of the service providers. In addition, understanding what service providers perceive as being necessary for people with dementia and spousal carers provides insight into the normative need being applied to this population (Bradshaw, 2005). The perspectives of service providers offer insight into the systemic response to supporting people with dementia and spousal carers along their journey living with dementia (Danaher & Gallan, 2016; Ward-Griffin et al., 2012).

Study Two aimed to explore the current responses of community service providers in Western Australia to the needs of people with dementia and their spousal carers during the mild-moderate and moderately severe stages of dementia. Further, it aimed to identify the barriers and enablers to improving services. Interpretive Description (Hunt, 2009) was used to identify needs, with a hybrid inductive-deductive analysis used to and draw comparisons between the responses of participants in Study one and Study two.

4.2 Publication three - Comparing perspectives of service providers to the needs of people with dementia living in the community

Inclusion in the thesis of the accepted manuscript is approved under the Green Open Access agreement from Sage Publishing.

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Details of this arrangement can be found in Appendix C SAGE's Author Archiving and Re-Use Guidelines, official acceptance of this article can be found in Appendix D.

Abstract

Introduction: Research with West Australians with dementia and their carers living in the community identified that they have a diverse range of needs. However, little is known about the needs of people with dementia and their carers from the perspectives of service providers who provide formal support. This study aimed to investigate the needs of people with dementia and their carers living in the community from the perspectives of service providers and compare this to service recipients.

Method: This interpretive descriptive study used focus groups to collect qualitative data from service providers (N=10). Data were analysed using a hybrid inductive-deductive approach to compare the needs identified by service providers to those identified by people with dementia and their carers.

Results: Three major themes were identified: (i) services and supports required by people with dementia and their carers should be flexible, tailored, and equitable; (ii) building capacity to support carers and people with dementia; and (iii) systems designed to care were fragmented and difficult to navigate. Service providers prioritise needs that are limited to their current capacity to provide in contrast to the holistic needs of people with dementia and their carers.

Conclusion: There was poor alignment between the perceived needs of people with dementia and their carers and the needs prioritised by service providers in the West Australian community. This gap may reduce the ability of services to effectively support people with dementia to remain living in the community.

4.3 Background

The prevalence of dementia among Australians is estimated to be 447,115 (National Centre for Social and Economic Modelling, 2019). Future projections indicate the prevalence will potentially double by 2036 and almost triple by 2056 (Brown & Hansnata, 2017). A range of services are available for people with dementia living in the community in Western Australia under three separate funding systems: the Commonwealth Home Support Programme (CHSP); Home Care Packages (HCP); and Veterans' Home Care (VHC) (Productivity Commission, 2018). These systems provide funds for direct community services such as domestic assistance and respite, assessment, information about service pathways and care strategies, residential respite, and ongoing coordination of care for individuals and their families (Productivity Commission, 2018).

Alzheimer's Australia's report into consumer engagement in the aged care reform process highlighted, "a need for services that meet [carer and people with dementia] needs rather than the needs of the service providers" (Alzheimer's Australia, 2011, p. 8). Needs related to services designed to support people with dementia living in the community include services that focus on the person - not the task, have open communication, and are accessible (Grenade & Walker, 2005; Raivio et al., 2011; Ward-Griffin et al., 2012). Highly desirable characteristics of dementia care services, such as availability of hours, continuity of services, and affordability of services are determined by funding models (Phillipson & Jones, 2011; Raivio et al., 2011). That said, the attitudes of service providers and policy makers have been described as "inconsiderate behaviour, especially taking into account that these caregivers are elderly, stressed, and unable to defend themselves" (Raivio et al., 2011, p. 6).

Few studies have evaluated services for people with dementia and their carers living in the community in Western Australia (WA). Downes (2013), Hancock and Jarvis (2005) and Grenade and Walker (2005) evaluated services and programs provided in the WA community and found pockets of good practice. More broadly, access to respite in Australia is limited by inflexibility and inaccessibility of services, and concerns regarding the wellbeing or safety of the person with dementia (Tang et al., 2011). To understand the experience of accessing and using community services, the authors conducted qualitative research with people with dementia and their spousal carers in WA. Three themes identified that people with dementia and their spousal carers needed: an enabling environment (including social, institutional and physical); to develop and maintain strong caring relationships; and to plan ways to maintain their daily life.

Service providers have a unique perspective (Danaher & Gallan, 2016) when addressing the needs of people living with dementia in the community because their purpose is to provide relevant services designed based on population needs (Ward-Griffin et al., 2012). Service providers are limited in the type and number of support services they are able to implement, by a lack of flexibility to accommodate the needs of a heterogeneous population (Ward-Griffin et al., 2012) or ineffective assessment of the needs perceived by people living with dementia (Stirling et al., 2010). It is important to explore the unique perspectives of service providers to understand systemic responses to the needs of people with dementia and their carers. The aim of this study was to explore the responses of community service providers to the needs of people with dementia and their carers, and to identify barriers and enablers to improving service providers' responsiveness.

4.4 Methods

4.4.1 Study design

This study utilised a qualitative interpretive description method (Hunt, 2009) to explore the perspectives of service providers in the same community, building on a previous study of people with dementia and spousal carers (Morrisby et al., 2019). Interpretive description was used as a co-constructive approach to first identify the needs of people with dementia and their spousal carers living in the community and then those of service providers. Interpretive description recognises the impact of shared experience and acknowledges the contextual and constructed nature of ill-health (Thorne et al., 1997). Ten spousal couples of carer and person with dementia participated in dyadic, semi-structured qualitative interviews. Participants in the previous study were purposively sampled to identify the needs of people with dementia and their spousal carers at different stages of the progression of dementia. Interviews were audio-recorded, and transcripts analysed using qualitative thematic analysis (Braun & Clarke, 2006) to identify provisional themes. These themes were refined using two focus groups of spousal carers (N=10). Three themes were identified: (i) environmental enablers to support care; (ii) strong caring relationships; and (iii) adaptation of life roles (Morrisby et al., 2019). These themes were used to develop a semi-structured interview guide for use with WA service providers within the same community of metropolitan Perth, WA. This study was approved by the Curtin University Human Research Ethics Committee (HR111/2013).

4.4.2 Participants

The study was advertised via email to dementia assessment agencies and direct dementia care providers in metropolitan Perth, WA. Health professionals were eligible to participate if they were: currently working with people with dementia living in the community in WA; and were responsible for assessment, service provision or support for people with dementia. Health professionals who worked primarily in residential aged care services were excluded. Participants responded via email and provided signed informed consent prior to participating in interviews, all respondents met the inclusion criteria. All participants (N=10) were female and from a range of backgrounds including three care coordinators, two occupational therapists, two social workers, two registered nurses, and one counsellor. Participants were employed by four service providers and worked in various roles, including day-therapy unit work, assessment services, memory clinic, respite provider, counselling, and education.

4.4.3 Procedure

The interview schedule was based on the key needs previously identified by people with dementia and their spousal carers (See Figure 4.1) (Morrisby et al., 2019). Semi-structured interviews were conducted with participants at their place of employment. The interviewer (first author) has five years' experience working in community services for older adults. Participants were interviewed individually, in dyads, or in small groups of no more than four people based on the number of respondents from each organisation. Variation in interview styles occurred due to the types of pragmatic issues discussed by (Lambert & Loiselle, 2008); however, the impact of context and shared experience is of principle interest within interpretive description, and as such, the data collection procedure supported the methodology. Each interview lasted approximately 60 minutes, and all interviews were audio-recorded and transcribed verbatim. Observational field notes were made during the interview process and were included in the analysis.

Figure 4-1 Semi-structured interview guide

In your experience, what services do you think people with dementia need whilst they are living at home?	Prompts: stage of dementia, family support, other services, age, environment, occupations. Are there any gaps in the services to meeting those needs?
In your experience, what services do you think spousal carers of people with dementia need whilst they are living at home?	Prompts: stage of dementia, family support, other services, age, environment, occupations. Are there any gaps in the services to meeting those needs?
Are there any needs that people with dementia or their carers have described about the diagnosis process?	
In your experience, what are some reasons people with dementia or carers do not accept services or assistance?	
What constitutes a good service?	Prompts: Good relationship with coordinator and ongoing relationship carer worker; Trust; Flexibility; Involve the people with dementia's needs/wishes; Affordable;

	Not stressful.
How do people find out about your services?	
What would it take to address any gaps (to meet the needs) that you might have identified?	

4.4.4 Data analysis

Data were analysed using a hybrid inductive-deductive approach, based on Braun and Clarke’s six-stage thematic analysis, and in combination with Crabtree and Miller’s *a priori* code manual strategy (Crabtree & Miller, 2012). Inductive analysis was completed by the first author prior to the deductive analysis to reduce the impact of prior knowledge on this process (Braun & Clarke, 2006).

Transcriptions were managed using NVivo (QSR International, Version 11). The first few interviews were analysed using continuous, inductive analysis to identify the main themes (Hunt, 2009). Themes were cross-checked with field notes for confirmation or consideration of alternative interpretations. Data collection continued until saturation of themes had been achieved. The first and third authors reviewed transcripts line by line and identified statements relevant to the study aim. Eighteen basic codes were identified and organised into three global themes (see Figure 4.2). Analysis was a continuous iterative process throughout data collection to allow successive interviews to saturate themes. Early interviews were re-analysed to ensure developed codes were upheld (Braun & Clarke, 2006). A deductive approach was then used to enable comparison of the service providers’ perspectives with the needs identified by people with dementia and their spousal carers (Morrisby et al., 2019). Themes previously developed from interviews with spousal carers and people with dementia were developed into a code book (see Figure 4.3 for an example), which defined the theme and described how to know when the theme occurred (Fereday & Muir-Cochrane, 2006).

Figure 4-2 Initial codes and final themes

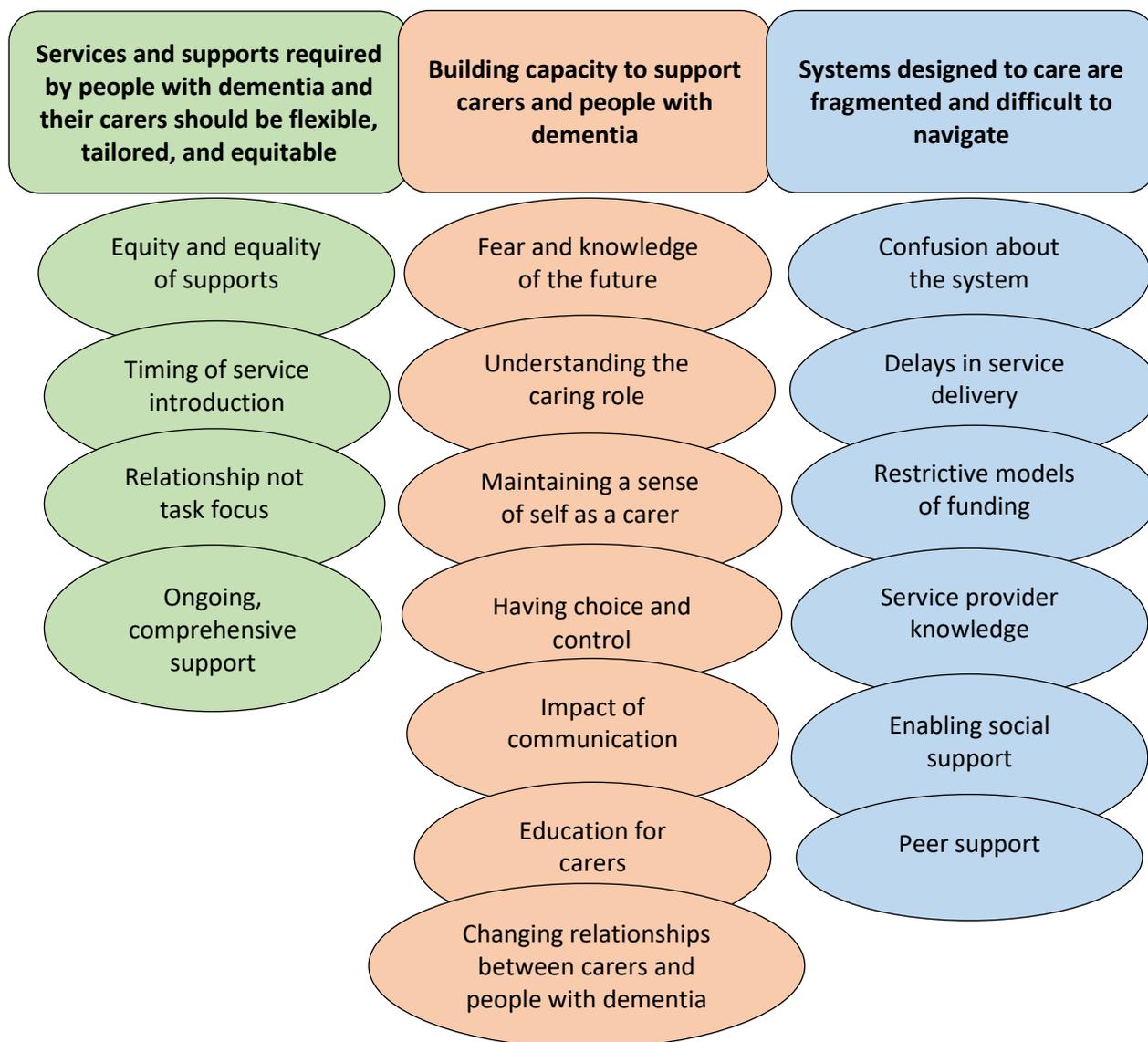


Figure 4-3 Codebook examples

Code 1.1	Label	Environmental enablers to support care: A social environment that is supportive and well educated.
	Definition	Social environment that spans three levels - family, friends, and broader social networks (acquaintances or work colleagues), which has accurate knowledge of dementia and is capable of providing emotional or practical support.
	Description	Provision (or lack) of support to a person with dementia or carer from non-institutional sources.
Code 1.2	Label	Environmental enablers to support care: Institutional support that is timely, effective, and affordable.
	Definition	Institutional support includes formal services, access to health care, and financial services.

	Description	Provision (or lack) of support from institutions designed to maintain a person with dementia and/or their spousal carer to remain living in the community.
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4.5 Results

4.5.1 Inductive analysis

Three major themes were identified from the interview data: (i) services and supports required by people with dementia and their carers should be flexible, tailored, and equitable; (ii) building capacity to support carers and people with dementia; and (iii) systems designed to care are fragmented and difficult to navigate.

4.5.1.1 Services and supports required by people with dementia and their carers should be tailored, flexible, and equitable

Service providers identified respite as the most common type of service need. In-home respite was seen to provide people with dementia with opportunities to: engage meaningfully in occupations that were relevant to them; continue a community activity, like shopping or socialising with others; and develop new skills, *“Or even, like they go to the Men's Shed, but they want to go to the Men's Shed, not because that's what's scheduled for that day”*.

(Participant 4)

Participants believed carers and people with dementia had a need for access to comprehensive and ongoing support mechanisms to help them navigate the complexities of caring for people with dementia and accessing services. The need to tailor services as the disease progressed was identified as an important issue. Eight participants identified the timing of services and development of strong caring relationships were underpinned by effective, ongoing, and comprehensive support that was generally referred to as a case management approach. These issues were described by one case manager (also known as a key worker): *“it could almost be, like, a distant monitoring-type system. Like, somehow flagging more involvement from the relative services or systems around as things change for people and getting them linked in with those”* (Participant 7). Participants identified a lack of ongoing support for people with dementia and their carers, limited knowledge about services, and breakdowns in communication between services resulted in consumers not transitioning effectively between service types.

Participants perceived the names of service types held significance for people with dementia and their carers. For instance, participants identified that ‘personal care’ for instance was perceived as labelling dependence; more so than ‘social support’. The timing and type of the service first offered was considered very important. Introducing respite or social support first was preferable as it was considered less intimate or confronting than personal care. Participants reported learning this from past experiences when a service or formal assessment had been introduced too early, which resulted in the person with dementia or carer rejecting the service:

I've had a client [person with dementia] just recently try respite for the first time. He did a three-day respite, which was very hard for her [carer], and she was a mess beforehand. He had a fine time, it was fine, but when he came out he was like, "Yeah, I'd rather be with you." So now she doesn't want to do it again, even though it's beneficial [for her]".
(Participant 5)

Participants identified respite as a core service for carers, more so than home cleaning or personal care, because respite provided carers the opportunity to have a break from their carer role and participate in their own meaningful occupations. As people with dementia experience a greater number of physical needs over time, packaged funds were devoted exclusively for personal care, other self-care tasks, or home cleaning. This resulted in insufficient funding to support ongoing engagement of people with dementia in meaningful activities, with some providers stating that it was expected that carers would assume this role.

Flexibility was a core feature that facilitated people with dementia and carers to use respite services. Depending on the type of respite, this flexibility included availability of specific days or times, and the ability to book services at late notice. Participants articulated concerns about the paucity of short-term or overnight respite services. Three participants stated that it was very difficult to locate or book short-term respite services (i.e., 2-3 days), and that many facilities that formerly provided overnight respite were being closed. Additionally, participants noted that support previously available to assist carers to arrange funding and booking of residential respite had become limited, and now was restricted to only providing funding. Participants reported that no official services were available to replace this booking service and that carers now had to assume this additional responsibility.

All participants identified flexible and personalised or tailored care was easiest to provide when the service delivery model focussed on relationships rather than discrete tasks. This was best facilitated by having consistent staff working with each person with dementia:

Some organisations do it better than others, but one of the biggest issues with families is that they have problems getting consistent care workers, and for people with dementia, the vast majority of them benefit from having consistent care workers who they're able to build up a rapport with, who they begin to trust, who get to know them ...the other family member isn't having to explain everything each time a service happens, to start things up again. (Participant 2)

Equity of access to quality assessment and community services was a concern raised by five participants. Service providers were concerned that it was just someone's 'good fortune' that determined if the medical specialist and general practitioners (GP) that were involved in the diagnostic process were experienced and understood dementia. This 'good fortune' affected the timing and accuracy of diagnosis; to whom referrals (if any) were made; and access to medication or clinical trials for people with dementia.

Participants gave a critical summary of the variability in services, policies, and procedures they were aware of in the WA community. For instance, some organisations used volunteers effectively to increase the number of service hours provided, which made their services better able to meet the needs of people with dementia and carers. This was also summarised by participants' comments related to organisational policies, such as mandatory staff rotation between clients:

I think that's part of the challenge is that, you could have two people who are fairly similar in progression of their dementia and their needs, for instance, if you go to one service provider you might get this, if you go to another service provider you might get this. And it's trying to navigate the quality or equity. (Participant 9)

4.5.1.2 Building capacity to support carers and people with dementia

Participants commonly identified how carers, people with dementia, and the general public had a limited understanding of dementia. This was attributed to stigma about dementia, lack of available education, and fear of what might happen because of the diagnosis.

Probably the biggest thing is, is there a knowledge deficit about dementia? Because many people feel as though ... 'Mum's doing this on purpose'. So, then I start thinking, well, we need to improve. If it was some exotic disease, we'd be on the internet, Googling, what is it about dementia? (Participant 1)

Lack of knowledge and understanding about dementia, and the services and supports available, affected the ability of people with dementia and their carers to seek help when necessary. This led to delays in accessing services; over-reliance on external support/services; and at times, inappropriate admission to residential care or hospital. Lack of knowledge was also identified as a cause of fear and uncertainty for people with dementia and carers. Participants identified that some people with dementia and their families did not plan appropriately or responsibly for the future (e.g. no wills or arrangements pertaining to guardianship and enduring powers of attorney).

Participants perceived that the control and sense of power people with dementia and their carers experienced were reduced by the systems designed to support them. Participants believed that people with dementia faced continued loss or restriction of choice in how they lived their lives, and this was, at times, a result of how services were delivered:

[Participant speaking from the perspective of a person with dementia] I mean, I've got dementia so I'm not sure about what's happening anyway, in any way shape or form with myself, and I don't know what this means to me about having a person visit me, you know, 'Am I going to like this person? Are they ...because they're going to take away some of my independence' (Participant 3)

Participants identified the critical role carers had in developing coping strategies that impacted independence, and choice and control of the person with dementia.

I'll go out and say, "So how's things going?" and they're like, "Oh, it's great. He still does the dishes. Yeah. He does it slower and it's not quite as great, but he still does the dishes. He still can do the washing machine. It's great. I'm happy. Everything's fine.' (Participant 4)

Effective and ineffective coping strategies were identified as developing organically with the progression of dementia; however, ineffective coping strategies were linked to early admission to residential care.

The attitudes of carers and people with dementia shaped the spousal relationship. Four participants reported that some carers managed well the transition of identity and role but believed that others could no longer view the spousal relationship as reciprocal, and instead became a carer and a person with dementia. This was evident when carers introduced themselves, “*when they stop referring to themselves as, "Oh hi, I'm Bob," but, "I'm so-and-so's carer"* (Participant 4). Issues were also identified in the maintenance and adaptation of relationships; particularly spousal, but also other care relationships. Intimacy, role boundaries, and reciprocity of love and affection affected the quality of the relationship, as well as the ability of the carer to continue providing support. Participants recognised that the carer’s fear of failing the person with dementia led to their feelings of guilt; particularly related to accepting services.

Participants reported wide variation in the nature of support provided by extended families and community supports such as neighbours and friends. Service providers reported this informal support was highly inconsistent because of different employment patterns among carers (e.g. full-time vs. retired); changing family structures; and lack of knowledge and understanding of dementia in the general community.

Appropriate communication skills were identified as essential to support a person with dementia in the community. Service providers recognised the difficulties and fears experienced by people with dementia and their carers in communicating needs to one another; particularly around difficult topics such as accepting services,

Another area that we peddle a lot of is communication strategies, the road rules for communication, just to use as a springboard to their own ideas, but to know they're on the right track. And then, often that is the conduit into getting other things done. Oh, well, that worked well, then I'll try this. And then, that communication strategies often do get respite booked (Participant 1)

Participants strongly recommended education about communication strategies for carers and people with dementia and identified that some carers coped by relying on service providers to deliver information to the person with dementia, in the belief that their professional communication skills and overall knowledge was superior to their own.

4.5.1.3 Systems designed to care are fragmented and difficult to navigate

Difficulty accessing appropriate services, limited knowledge and expertise of service providers, and a highly complex system of care were identified as major sources of frustration and harm for people with dementia, their carers, and service providers.

Participants expressed frustration that lack of funding limited services that could be delivered and thereby restricted their ability to meet the needs of people with dementia and carers. An inability to follow-up effectively, to provide services to clients across broader geographic area, and to provide holistic services from within the one organisation were identified as frustrations and restrictions in the delivery of quality care. Participants reported that the primary focus of services needed to be on personal hygiene or managing medications for people with dementia and limited funding restricted access to meaningful activities that might improve quality of life.

The development of services that reduce the complexity of support systems for people with dementia and carers was a key issue reported by eight participants. Service providers had a long list of ideal supports and services that could be offered; however, funding restrictions and attitudinal beliefs amongst health professionals created persistent barriers:

I even had that too, from a very well-known [medical] consultant, you know, I said, 'Look, there's lots of things that we could introduce for this person, strategies.' [The consultant said] "Well, what's the point? The condition's going to change anyway'. I said, 'Yes, but they're in the early phases,' I said, 'We could be working with them and their family on their calendar systems, a whole manner of [options]'. (Participant 7)

Education of carers on an 'as needed' basis was not possible due to limitations in time frames for service delivery, *"I mean, we could try to provide education in that context, but that's not the context that we're there for... difficult when we're only there for an hour, and you know, we're trying to review their entire function, you know?" (Participant 7)*

Participants recognised the contribution of families in providing care as another reason why people with dementia and their carers may not pay for additional formal support services, *"But very often, people don't want to spend money if they don't really feel that there's a need to. So, you're overcoming a few different barriers to try and achieve that". (Participant 2)*

Participants were forthright about the lack of knowledge of dementia among professionals and support workers:

A lack of training, lack of knowledge as well. Like even some of the support workers that I've got for some of my guys through different organisations; they're wonderful, absolutely wonderful people, but their awareness of, I guess, the difficulties that someone with dementia faces is just ... it's not enough. You need more than just an understanding, "Oh well, this person has dementia." You need to know.... (Participant 1)

The aged care services system in Australia at the time of this study was in transition from packaged care determined by the service provider, towards more flexible, consumer directed care (CDC) packages. This transition of systems was perceived as difficult to navigate for services providers and referrers, as well as for people with dementia and their carers. Service providers were uncertain of their ability to refer to key agencies such as the Aged Care Assessment Team (ACAT):

“I think, sometimes, they have a feeling that they can’t refer people to us, that it has to go through the GP. Sometimes I just think ... like, I’ve spoken to a service provider recently, and they said, ‘We’ve been trying for months to get this referral to ACAT,’ and I’m thinking, ‘why didn’t you ring ACAT?’” (Participant 9)

4.5.2 Deductive analysis

Three themes of need identified from the data obtained from people with dementia and spousal carers were: (i) environmental enablers to support care; (ii) strong caring relationships; and (iii) adaptation of life roles by spousal carers and people with dementia, to which service providers responded (reference removed for peer review process). Participants in the current study focussed primarily on institutional support in comparison to all other themes combined (see Table 1).

Table 4-1 Cross-case analysis of service provider data with needs identified by people with dementia and spousal carers

Themes	Participant number										Total	
	1	2	3	4	5	6	7	8	9	10		
Environment												
<i>Social environment that is supportive and well-educated</i>	3	2	1	5	2	3	6	6	9	2	39	
<i>Institutional support that is timely, effective and affordable</i>	26	28	16	41	11	31	28	24	26	14	245	
<i>A safe home and community</i>	3	0	0	4	0	1	3	4	3	1	19	
Developing and maintaining strong, caring relationships	1	3	3	16	4	9	2	5	5	1	49	
The future of daily life for people with dementia and carers	3	1	3	9	2	4	3	1	1	1	28	
Total	36	34	23	75	19	48	42	40	44	19	380	

4.5.2.1 Environment

A social environment that is supportive and well-educated

This theme was described in terms of supportive available and expectations on families to fill the gaps: *“I know there are carer groups out there but it’s quite a daunting experience, you’d probably want to do that with somebody else. You would have done that with your wife or husband and now there’s nobody to do that with. You’ve got to do it yourself, so they don’t, that’s what we tend to find”* (Participant 10). Knowledge about dementia within social networks, including family and social support for carers, were each mentioned by only two participants. Stigma about dementia was described once; however, that was in relation to people accessing support services from Alzheimer’s WA (due to the name being specific to Alzheimer’s and not inclusive of all forms of dementia).

Institutional support that is timely, effective and affordable

All participants described barriers to service provision and areas where services needed to improve. Service providers required a broad range of education to equip them to support people throughout the dementia continuum; for instance, developing a basic understanding of dementia through to manual handling techniques and communication strategies: *“Some people, you can tell the difference between those who have accessed information, and those who have attended anything that’s formal education. Not a lot of the carers I see have accessed formal education”* (Participant 1). A similar range of education needs was suggested for health professionals, GPs, care coordinators, and assessors, with a particular focus on maintaining contemporary knowledge of services and supports.

Limitations in the pathways that people with dementia could follow to access to services was identified as a need by most participants. Participants reported inconsistent pathways to care, which meant that some people with dementia and their carers only accessed services in a crisis, and there was unnecessary confusion for many carers. *“I guess some of these people that we see, they don’t go to the GP very often, or some of them don’t even have a GP, so they kind of just ... fall through the cracks”* (Participant 8). The importance of timing when introducing services was discussed, *“you either get them way too early and they don’t want a bar of you [want nothing to do with the service] ... Too late and they’re in crisis and they need it now”* (Participant 4).

Participants identified that carers experienced barriers to accessing services due to the complicated structure of the care services system:

I was talking to a gentleman the other day and he said, 'Oh, it is just so nice to be able to speak to somebody about everything that's bothering me.' He said, 'You know, I've tried this organisation, and they could tell me this, but not that, and they told me to phone so-and-so, who could tell me that, but not this, and they told me to phone another organisation' (Participant 1)

The cost of services was a further challenge to accessing the appropriate level of services, and carers often did not have sufficient information about fee waivers.

A safe home and community

Four service providers expressed their desire to do more to promote a supportive physical environment at home. Two participants who talked about the Dementia Enabling Environment Project, saw the need to make the home environment more accessible; e.g. signage, lighting, and visual access. However, limited funding constrained the role of occupational therapy in environmental modification to improve function as described by Participant 6

In my role I want to be able to go out into someone's home and say, 'Yeah, you do need a raised toilet seat.' ... and then follow that through, so it's not just me going, 'I'll give someone a call and then they'll call, and then they'll call you, and someone will come out and see you'.

4.5.2.2 Developing and maintaining strong, caring relationships

Planning respite and providing education and counselling to informal carers about the need to access services in a planned way were identified by most participants as being important to supporting people with dementia and carers to maintain strong relationships. Participants described conflicting demands when meeting the needs of people with dementia and of their carers, particularly when working with spousal carers:

We allow them the opportunity to discuss things separately, because often, you know, we see the person with the spouse, but we need to make sure that we can separate at some stage, so they can really talk openly about what's going on. (Participant 7)

Spousal intimacy was identified as a need by two participants. Participants considered their role was to promote stronger relationships between carers and people with dementia and support other formal care providers to consider the impact of caring on spousal relationships.

4.5.2.3 The future of daily life for people with dementia and carers

All participants recognised a need to provide opportunities for people with dementia to engage and participate in socially valued life roles. *“For some people, they just want to be able to go to the local shop, and have a coffee ...And if they look in the shop, they’ll be able to buy a gift for a grandchild, all those sorts of things. They don’t want to sit and play bingo.”* (Participant 7). Participants identified the importance of implementing services to support carers’ needs to engage in other meaningful activities, such as looking after grandchildren. Two participants identified the important part of their role included supporting carers and people with dementia to develop skills to work together, and to adapt to changes in functional performance related to the progression of dementia.

4.6 Discussion

This study identified that service providers have a narrower perspective of what is needed by people with dementia and spousal carers living in the WA community than those living with dementia. Service providers reported that restrictions in funding and service types affected the amount and scope of support they could provide. Knowledge, accessibility, and availability of education for all stakeholders was essential for meeting the needs of people with dementia and their carers.

Service providers’ abilities to assess accurately and without bias the needs of people with dementia and spousal carers is challenging (Bangerter et al., 2017). Research by Miranda-Castillo et al. (2013) identified the importance of people with dementia feeling as though their needs were respectfully being understood and met. The findings of the current study indicate that there is a gap in the ability of service providers to consider the holistic needs of people with dementia, potentially leading to negative experiences in interactions with health care professionals (von Kutzleben et al., 2012).

Fragmented dementia care services is a global issue (Prince et al., 2016; Ward-Griffin et al., 2012), and a case management approach was a common recommendation of all service providers interviewed in the current study. The Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016) recommended that all people with dementia should be supported by a consistent care manager or coordinator from the time of initial diagnosis. There should also be coordination and integration of referrals, transitions in care, and communication between all agencies. Care or case coordination that empowers carers and people with dementia “to optimally fulfil” their needs (Wolfs et al., 2010, p. 1011) was deemed by participants to be lacking in WA services. A case management

approach to delivery of dementia services has recognised benefits such as improving function, more appropriate use of medication, increased utilisation of community services, and reduced rates of admission to residential care (Low et al., 2011).

Limited knowledge about dementia, insufficient services available, ineffective communication strategies, and other practical considerations, such as environmental housing design and procedures for manual handling were consistently described by carers, people with dementia, and service providers (Morrisby et al., 2019). Education was frequently discussed as a method to improve knowledge and the quality of life of people with dementia and their carers (Bruen, 2005). The Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016) recommend that effective communication training is provided to people with dementia and their carers reinforces this finding. According to the National Framework for Action on Dementia 2015-2019 (Australian Government, 2015), assessment through Aged Care Assessment Services or other Commonwealth Home Support Program services should also trigger access to information, education, and counselling. This has the potential to empower carers, while improving quality of life for the person with dementia and delaying their entry into residential care (Brodaty et al., 1997).

The majority of the participants interviewed in this study regarded flexibility of available services to meet the individualised needs of people with dementia and their carers to be a significant gap in service provision. The participants identified that it is very important for consumers to have choice and control over the nature and timing of support they accessed. Participants' chief concerns about care were that it should be based on relationships and meaningful engagement, as opposed to being task driven. This is made increasingly difficult by inconsistent staffing, an issue frequently experienced at an international level (Forbes et al., 2008; O'Connell et al., 2012; Phillipson & Jones, 2011). The Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016) stated that "interventions should include consistency of care staff" (p. 13). Community support workers interviewed by (Elliott et al., 2013), identified that having stability and consistency within long-term relationships with people with dementia contributed to their positivity and happiness about their caring roles. The service providers regarded the move to the CDC model in 2017 as positive. Increases in consumer satisfaction overall for people with dementia or carers receiving services in the CDC model; however, there is no evidence for improvements on clinical outcomes (Low et al., 2011).

Stigma, negative beliefs, and generalised fear of being diagnosed with dementia exist internationally (ADI, 2019) and among the Australian general population (Phillipson et al., 2012). Service providers in this study described how these factors affected the support available to people with dementia and their carers. Programs designed to reduce stigma, encourage timely diagnosis, and improve treatment and access to community-based care are required urgently (ADI, 2019; Phillipson et al., 2012). In conjunction with education about dementia for the general public, important and priority needs include greater awareness among health professionals of potential treatments, the availability of community services and supports, and the benefits of early and accurate diagnosis by GPs (Aminzadeh et al., 2012; Bruen, 2005; Phillipson et al., 2015). However, these needs require change and leadership at a national level and adequate funding to support the time required to realistically assess and monitor people living with dementia (Aminzadeh et al., 2012).

The results of this study indicate that services for people with dementia in Western Australia are limited by a focus on tangible supports that meet basic care needs, especially as the disease progresses. From the perspective of service providers, services and supports may be improved through greater education of the community and health professionals about dementia, implementation of clinical practice guidelines, and the development of ongoing, comprehensive, and consistent support. Recent changes to funding of community services may have the opposite effect through further separation of diagnosing dementia, assessment for services and service provision. Greater continuity will require changes to policy and funding models to create a less fragmented approach to the care and support for people with dementia in this community.

4.6.1 Strengths and limitations

Data saturation was achieved despite the small number of service providers. The purposive recruitment of participants employed in service organisations supporting people with dementia may not be representative of the total population; however, these informants provided significant insight into the research questions. The iterative approach of using deductive and inductive analyses supported the testing and comparison of perspectives of service recipients with service providers. This study was completed in the midst of a significant transition towards CDC and further research is recommended to determine if this service delivery model has improved the experiences of people with dementia and carers in accessing services.

4.7 Conclusion

There is a gap between the focus of service delivery among service providers and the holistic needs of people with dementia and their spousal carers. This disconnect may limit the ability of service providers to respond to the needs expressed by their clients. Identified challenges pertaining to flexibility and provision of relationship-based services were congruent between service providers and people with dementia and their carers. Education and training for health professionals, support workers, and families can improve outcomes for people living with dementia; however, the availability and implementation of this training requires further financial support by the Australian Government.

4.8 References

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Chapter 5 Study Three

5.1 Introduction

Limited formal support for managing changes in relationships and the inability to effectively assess for holistic need were key differences that emerged between the different stakeholder groups from Studies one and two. The contrast in perception of need indicated that gaps exist in the services provided to people living with dementia and their spousal carers living in the community. In combination with findings such as those from the Low et al. (2015) study, that access to services are not consistently based on need, and strong recommendations that services be based on need (Guideline Adaptation Committee, 2016), indicate that this is an area of further research.

The scoping review and Studies one and two demonstrated multiple congruent findings regarding the needs of people with dementia and spousal carers, and the opportunities that existed to provide improved care. Service providers were acutely aware that limitations existed in the services available to people with dementia and carers. In particular, there were issues highlighted pertaining to consistency of care and support, and the provision of care by people who are knowledgeable and skilful in working with people with dementia. Inconsistent knowledge and understanding of dementia within community support workers, care coordinators, health professionals, and the general population was seen as a significant barrier to accessing quality services. Additionally, participants described the language and communication used to support the implementation and continuation of services as foundational to the potential success of community support. Effective communication with people with dementia is an underpinning characteristic of relationship-based care (Eggenberger et al., 2013; Morris et al., 2018; Polacsek et al., 2020). Caregiver competence in communication has been shown to improve through the provision of specialised training, leading to improved care delivery (Garrod et al., 2019). Based on the findings of Studies one and two, the training of people who work with people with dementia in improved and effective communication skills was identified as a priority.

Education and training for community support workers in communication skills is an area warranting further research and evaluation. In a review of the key dementia training course available to community support workers that covers communication, McCarthy (2012) found inconclusive evidence regarding the impact of such training. Furthermore, funding for the education and training of community-based support workers in Australia has been in decline since 2012 (AIHW, 2019). Further research is warranted regarding the effectiveness of available training for community-based support workers (Goh et al., 2018); however, systematic reviews

have found that training interventions can be effective in improving communication skills (Eggenberger et al., 2013; Morris et al., 2018). Further to this, a recent review by Morris et al. (2018) identified a successful communication training evaluation which focussed on community-based support worker knowledge of dementia and communication strategies; however, the recommendation was that communication outcomes needed to more effectively evaluated.

Evidence that training to support effective communication can have a positive impact on the quality of life of people with dementia has been equivocal (Haberstroh et al., 2011; Morris et al., 2018). Goh et al. (2018) found that education or training for community support workers would benefit from less didactic educational approaches and greater utilisation of strong theoretical frameworks or pedagogical approaches. These recommendations were also common to the communication-specific studies (Eggenberger et al., 2013; Morris et al., 2018), which were found to have limited use of engaging teaching strategies or feedback that are known to improve educational outcomes.

These factors endorse the importance of an engaging, effective communication training to improve retention of knowledge and communication with people with dementia. The Curtin University Empathy Simulator (CUES) provided an opportunity to address this gap. Study three aimed to evaluate an expanded communication skills training package that was based on the International Classification of Function and Disability (ICF) and incorporated a computer-generated virtual learning environment (the CUES). The feasibility and acceptability of this training on quality of communication between community-based carers and people with dementia was evaluated.

5.2 Research methods

Studies three and four used an explanatory sequential mixed methods approach (Maxwell et al., 2015) to evaluate the preliminary effectiveness of communication training with an embedded CUES interaction, as well as the feasibility of this training. Using a pre-post design, Study three (presented in Chapter five) collected objective observations and self-reported subjective data from participants before, during, and immediately after the training, and at a two-month follow-up. The objective of Study four (presented in Chapter six) was to evaluate the experiences and perceived effect of using the VLE-facilitated training on the communication skills demonstrated in a communicative dyad with the CUES avatar and also with people with dementia. The Study four objective was addressed using a qualitative phenomenological approach (Maxwell et al., 2015).

5.3 From virtual reality to reality: Training to improve communication with people with dementia

5.3.1 Abstract

Objective: This study investigated the feasibility of a communication training program plus a Virtual Learning Environment (VLE) for community support workers who work with people with dementia. Secondly, this study aimed to determine the impact of the training on community support workers' use of communication strategies when communicating in a dyad with a person with dementia.

Methods: A prospective mixed-methods design was used to test the feasibility and effectiveness of the training package with embedded VLE (the Curtin University Empathy Simulator [CUES]), using a pre-post study design. Twenty-four support workers, volunteers and students, recruited from six community day centres participated in the communication training. Participants interacted with CUES and received feedback, attended a 2-hour training session and a second interaction with CUES with feedback; self-rating scales were completed before and after training. Video-recorded observations of participants communicating with a person with dementia were conducted pre and post training, and at two-month follow up.

Result: Participants' (N=24) use of specific communication strategies with the virtual avatar and with people with dementia improved significantly following the communication training session ($p \leq 0.001$). This improvement remained significant compared to baseline at two months post-training. Participants' self-rated knowledge and satisfaction in communication with people with dementia improved significantly ($p \leq 0.001$); however, participants' confidence decreased significantly.

Conclusion: Dementia specific communication training with embedded VLE was effective in improving use of communication strategies for community care workers. CUES provided an immediate and safe environment for deliberate practise and skill development.

Keywords: dementia, support workers, training, virtual learning environment

5.3.2 Introduction

Dementias due to diseases such as Alzheimer's disease, are typically progressive neurological conditions that cause a gradual decline of cognitive functions (World Health Organization, 2017). A significant increase in the number of people diagnosed with some form of dementia in Western Australia (WA) from 25,177 in 2012 to 57,000 people is expected by the year 2040 (Deloitte Access Economics, 2011). Dementia impacts significantly on an individual's capacity to participate in society and engage in all facets of daily occupation (Bowly Sifton, 2011; Nygård & Öhman, 2002). Mild dementia can cause deficits in completing tasks of daily living such as planning meals or future events, and progressively affects the ability to mobilise, communicate, and swallow (Sclan & Reisberg, 1992). As the individual's independent function declines, the uptake of support from either formal or informal sources increases (van Exel et al., 2007). Given the growing population of people with dementia and increasing demand on community services, developing the capacity of this workforce is important for worker retention and quality of care for the client and their family (Lawn et al., 2017). Dementia-specific education of formal carers who work with people with dementia has improved outcomes in relation to person-centred care (Elliott et al., 2012) and may build capacity in staff to manage the increasingly complex job demands (Elliott et al., 2013). However, a lack of mandatory training, and inconsistency of training offered by different providers has resulted in community support workers having gaps in the areas of communication, knowledge of dementia, and managing behavioural and psychological symptoms of dementia (Palesy et al., 2018).

Eggenberger et al. (2013) identified that communication training interventions in community and residential care settings develop and improve the wellbeing and quality of life for people with dementia. Positive communication is acknowledged as a key skill for supporting people with dementia. Clinical practice guidelines for working with people with dementia in Australia (Guideline Adaptation Committee, 2016) recommend communication education for formal and informal carers; however, there are limited programs available, particularly for informal carers (Liddle et al., 2012). Communication training for formal carers of people with dementia in Australia is provided by the Dementia Essentials course (Fleming & FitzGerald, 2009). This 3-day course covers five key outcomes including developing person-centred care through verbal and non-verbal communication. A post-training evaluation of Dementia Essentials (previously known as Dementia Care Essentials) identified mixed improvements in care provided, and the experiences of being cared for among people with dementia in residential and community care settings. However, without organisational changes to support staff in delivering person-centred care, the training did not produce a significant change in the quality of care provided (McCarthy, 2012).

More specific communication training has been trialled in Australia. A DVD-based training package was developed for formal and informal carers of people with dementia (Smith et al., 2011). This package utilised a knowledge-translation framework to develop and deliver strategies for improving communication. Conway and Chenery (2016) evaluated a didactic, video-based communication training package (MESSAGE: Maximise, Expression, Simple, Support, Assist, Get, Encourage) and found that training increased knowledge, self-efficacy, and preparedness for the provision of care for formal carers in the community. A study by Liddle et al. (2012) investigated the effects of the same training package on person with dementia and carer dyads and found that the training significantly enhanced knowledge, potentially reduced disruptive behaviours, and improved perceptions of the caring role. These evaluations did not observe the communication exchange with a person with dementia; however, the authors recommended this as a focus of future research (Conway & Chenery, 2016; Liddle et al., 2012). Whilst these studies reported that formal carers accepted the DVD format of the MESSAGE training well, recent trends in tertiary health education may facilitate greater improvements in knowledge retention and transfer of skills.

Embedding learning through immediate assessment and feedback in an authentic, repeatable, simulated scenario has become increasingly important in the education of tertiary students studying health sciences. Lateef (2010) found that simulation supported students to develop strong links between conceptual or theoretical information and application within situational contexts. A review of high-fidelity simulation-based training techniques showed they increased the clinical skills of tertiary health students in a majority of included studies when compared to traditional lectures or computer-based programs (Harder, 2010). Available virtual learning environments for communication, such as the Curtin University Empathy Simulator (CUES) have been shown to develop communication skills through an immersive virtual learning environment (VLE) by simulating a person with dementia during real-time conversation. The CUES has been shown to develop knowledge, confidence, and improved level of communication skills for speech pathology students (Quail et al., 2016). The communication VLE used within this training package, was also suitable for formal carers in residential care (Cartwright et al., 2020), and provided participants with immediate access to a repeatable, consistent opportunity to practise and develop competence in a low-risk environment. This study aimed to investigate the feasibility of a communication training program incorporating CUES as a VLE for community support workers who work with people with dementia. Secondly, this study aimed to determine the impact of the training on community support workers use of communication strategies when communicating in a dyad with a person with dementia.

5.3.3 Method

5.3.3.1 Design

The implementation of the CUES VLE with community-based support workers is a novel approach to communication skills training. Therefore, the feasibility and effectiveness of dementia specific communication training with the CUES is important to establish (Eldridge, et al., 2016). Feasibility studies are required to determine the usability of measures and in this case, the structure and content of the communication training package. Due to the heterogeneity of the population of community-based support workers and the limited number of participants available for recruitment, a pre-post study design was utilised. The Curtin University Human Research Ethics Committee provided approval for this study (HRE2017-0790).

5.3.3.2 Participants

Participants were recruited from a not-for-profit community aged care provider in Perth, Western Australia. The community care provider has seven social centres across metropolitan and regional centres, up to 150km from Perth Western Australia. The social centres provide centre-based respite care to a mixed clientele of older adults, many of whom experience dementia, who live at home, independently or with support from family and formal carers. The social centres focus on social integration and promoting quality of life and are staffed by paid and volunteer support workers as well as students completing studies in community care. Centre coordinators attended an information session regarding the training and all centre coordinators agreed to participate. At study commencement, six of the seven centres were able to participate (a single centre withdrew due to ongoing staffing challenges). Staff at each centre were invited by the centre coordinator to voluntarily participate in the study. Inclusion criteria for staff were that they had direct contact with at least one person with dementia, were able to communicate in English, and were employed by the organisation. Volunteers and students on placement were included if they had direct contact with at least one person with dementia, were able to communicate in English, and were training with a registered training organisation (for example, completing Certificate IV in Community Services) or had completed volunteer induction with the organisation. Two staff members, both centre managers, consented and completed initial observations however did not complete the training due to other work commitments. Signed informed consent was obtained from all participants prior to commencement of the training.

5.3.3.3 Communication training package

The communication training package was designed to be portable and implemented within the spaces available in community day centres. The flexibility of the training package enabled clients to remain on-site during the training session.

Face-to-face training

The complexity and individuality of communication and language changes experienced by people with dementia requires an approach with flexibility, interprofessional relevance, and inclusivity which can be implemented using the International Classification of Function and Disability Framework (ICF; World Health Organization, 2002). The ICF promotes recognition that communication barriers may be an outcome of dementia but that the barriers can be mediated by environmental factors, and expressed as a person's performance within the context of activity (Byrne & Orange, 2005). To support the effective use of pragmatic communication components suitable for people with dementia, the FOCUSED (face-to-face, orientation, continuity, unsticking, structure, exchange, direct) communication strategies (Ripich et al., 1995) and Empathic Curiosity (McEvoy & Plant, 2014) were employed. These communication strategies have demonstrated efficacy in improving communication between carers and people with dementia (Ripich et al., 2000). Conway and Chenery (2016) suggest that training that incorporates empathic curiosity supports greater understanding of the emotional concerns and needs of people with dementia, and the underpinning purpose of their behaviour/s. The strategies were presented to participants in a small group training session, which included discussion of communication principles and role-play of different approaches to communication with each other during the training.

Virtual Learning Environment

An innovative intervention designed to increase the efficacy of learning communication strategies with people with dementia using a VLE (CUES) was developed. The VLE included a simulated person with dementia named Jim seated in a clinic room (see Figure 5.5.1). The training allowed participants to immediately apply the communication principles learned, in a safe and confidential environment (Quail et al., 2016), drawing on the principle of deliberate practice (Ericsson, 2004). The effectiveness of this reinforced training had not previously been evaluated objectively and the feasibility of using it to train formal carers was not yet determined. The CUES communication VLE utilised in this training was originally developed to support pre-service health professionals to improve their communication skills before clinical placements (Quail et al., 2016). In this study, the CUES provided operator-controlled real-time responses to communication from a participant. The two CUES operators (the first and second authors) completed training together and utilised a conversation guide to provide a similar communication experience for each participant. A brief background regarding the simulated avatar 'Jim' was provided, with instruction to the participants that they were to speak with Jim as a new client to the centre, and investigate his social history, and past and present interests. Following the conversation (of 5-7 minutes duration), each participant received verbal feedback from the CUES operator on key effective pragmatic communication components present in their communication as well as areas requiring further development. These pragmatic components included the quality of their introductions, ability to maintain topics and respectful turn taking.



Figure 5-5-1 Curtin University Empathy Simulator

The Curtin University Empathy Simulator (Image credit: J. Beilby, Curtin University & J. Spitalnick, Citrine Technologies)

The communication training package incorporated a face-to-face small group training session, bookended by two individual sessions with CUES. The communication training package was delivered onsite at the social centres, each session taking approximately three hours with between five and eight participants. Staff from two centres participated in each session and the session was run twice in one day to facilitate the participation of all staff at one centre.

5.3.3.4 Measures

(1) FOCUSED/empathy observational checklist

Observations of typical conversations at five time points between either (i) participant and a person with dementia, or (ii) participant and the VLE, were recorded and scored (see Figure 5.2). The observational checklist was based on the FOCUSED communication strategies (Ripich et al., 1995) and empathic curiosity (McEvoy & Plant, 2014). The observation checklist identified the use of 35 specific observable communication strategies such as non-verbal communication and validation of the reality of the person with dementia. Participants were given standardised conversation prompts to ensure there was sufficient content in the short conversations (approximately 5-7 minutes duration) for analysis. Each observation was video recorded using an action camera (Zoom Q2N Handy Recorder) while the participant communicated with a person with dementia in the setting where their interactions at the social centre typically occurred. Persons with dementia, who were regular attendees of the social centre, gave assent to be video recorded for the purposes of evaluating the participant's communication skills. The researcher was present in the room during each observation to ensure that the video captured the verbal and non-verbal communication of the participant. Communication behaviours were rated on a 3-point scale; not observed (0), observed up to 50% of the time as appropriate (1), observed most of the time as appropriate (2), with a total maximum score of 70. The first and last authors completed the ratings; the second rater was blinded to the point in time that each observation was recorded. Interrater reliability was established between the raters on a randomised sample of 10% of the recorded observations. A two-way mixed interclass correlation co-efficient (ICC) was computed using SPSS version 26; an ICC of .979 was achieved, indicating excellent interrater reliability (Koo & Li, 2016).

(2) Dementia Knowledge Assessment Scale

The Dementia Knowledge Assessment Scale (DKAS) was used to provide a measure of carers' knowledge of dementia before the intervention and is valid for use with a range of health professionals (Annear, Toye, McInerney, et al., 2015; Annear, Toye, Eccleston, et al., 2015). The DKAS contains a brief demographic survey including the carer's gender, age, and educational background. Participants completed the DKAS prior to completing the communication training (see Figure 5.2).

(3) *Training reflection questionnaire (TRQ)*

The Training Reflection Questionnaire (TRQ) asks participants to retrospectively rate their knowledge, satisfaction, and confidence in communicating with people with dementia prior to interacting with CUES as well as following the second CUES interaction. The TRQ was originally developed by Quail et al. (2016) for use with speech pathology students; it has since retrospectively been validated for use (Robinson et al., 2018) to avoid a “response-shift bias” (Sullivan & Haley, 2009, p. 352). The questionnaire consists of 32 self-rated items about participants’ knowledge, confidence, and satisfaction with their communication skills. Responses are marked on a semantic differential scale; the TRQ was completed immediately following the second interaction with CUES (see Figure 5.2).

Timeline	1-2 weeks pre training (n=20)	Training (n=24)*	1-2 weeks post training (n=20)	2 months post training (n=12)^
Condition	Communicating with person with dementia	Communicating with avatar (pre/post)	Communicating with person with dementia	Communicating with person with dementia
Measures	FOCUSED/Empathic curiosity observational checklist	DKAS Training Reflection Questionnaire FOCUSED/Empathic curiosity observational checklist	FOCUSED/Empathic curiosity observational checklist	FOCUSED/Empathic curiosity observational checklist
* Additional staff were present on the day of the training session and elected to participate ^ 8 participants were unavailable for follow-up due to ` leave [2], changed roles [2] or having left the organisation [4]				

Figure 5-2 Timeline of measures

5.3.3.5 Data Analysis

All data were analysed using SPSS (version 26). The FOCUSED/empathic curiosity observational checklists generated a total score (with a possible maximum of 70) for each observation; mean differences for paired observations i.e. before and after training were analysed. Data were tested for normality using the Kolmogorov-Smirnov test. Non-parametric data were analysed using the Wilcoxon-Signed Rank test to identify any changes in utilisation of communication strategies after training. The TRQ questionnaire responses were grouped into knowledge, confidence, and satisfaction domains. The Wilcoxon-Signed Rank test was used to determine the change in participants’ perceptions of their performance in these domains, before and after training. Effect size was calculated using Pearson’s correlation co-efficient (r). Results from the DKAS were calculated (with a possible maximum of 54) and participants median scores compared between those with and without formal training. Correlation between participants’ DKAS and FOCUSED/empathic curiosity observational checklist scores was established using Pearson’s correlation coefficient to identify if prior general dementia knowledge was related to utilisation of communication strategies. A significance level of $p \leq .05$ was used for all statistical tests.

5.3.4 Results

This study recruited a total of 24 participants with diverse cultural and language backgrounds (see Table 5.1). Fifteen of the 24 participants stated they had completed formal training about dementia, with a mean (SD) training duration of 3.4 (3.4) days. Two participants had completed training over longer durations (8 weeks and 12 months; respectively); however, no details were provided regarding the type of training or level of qualification of this training. Participants had worked with people with dementia for a mean (SD) of 9.2 years (8.4 years).

Table 5-1 Participant demographics

Age	Gender n (%)		Country of origin n (%)		English as a first language n (%)		Primary role at facility n (%)		
Mean	55	Female	21 (87.5%)	Australia	13 (54%)	Yes	22 (92%)	Professional Care worker / Activity Assistant	13 (54%)
SD	9	Male	3 (12.5%)	England	3 (12.5%)	No	2 (8%)	Volunteer	7 (29%)
Min	28			New Zealand	2 (8%)			Other health care worker (including manager)	2 (8%)
Max	67			South Africa	2 (8%)			Other	2 (8%)
				Republic of South Korea	1 (4%)				
				Spain	1 (4%)				
				Sri Lanka	1 (4%)				
				Uruguay	1 (4%)				

Participants' use of specific communication strategies with the virtual avatar and with people with dementia were evaluated following the communication training session. Participants' (n=24) communication when interacting with the avatar after training ((median (IQR) observations score = 55.5 (46.75 - 56.25) improved significantly compared to baseline before the training (median (IQR) 44 (32.25 - 44); $z = 4.288$, $p \leq .001$, $r=0.88$). Participants (n = 20) also significantly improved in their communication strategies when speaking with a person with dementia following the training session (median (IQR) communication observations score = 56.5 (52.5 - 63) compared to baseline (median (IQR) score = 39 (35.75- 42.25), $z = 3.92$, $p \leq .001$, $r=0.88$).

When compared to their baseline observed communication with a person with dementia, participants (n=12) who were available for follow-up at two months post-training still demonstrated a significant increase in their use of communication strategies with a person with dementia (Mdn = 50.5) compared to prior to training (Mdn = 39, $z = -3.18$, $p = 0.002$, $r = -0.88$). Participants demonstrated a reduced utilisation of communication strategies with a median of 50.5 (46.75; 56.5) when compared to immediately following the training session median of 6.5 (52.5; 63), $z = -2.02$, $p = 0.037$, $r = -0.60$.

The group median (IQR) score on the DKAS was 36 (16.5) out of a possible maximum score of 54. Participants who had received formal training about dementia scored higher on the DKAS (Mdn (IQR) = 40 (36- 48.5)) compared to participants who had had no formal training (Mdn (IQR) = 28 (22- 30)) $U = 14$, $z = -3.2$, $p = .001$, $r = -0.65$. There was no significant correlation between participants' knowledge of dementia (based on DKAS scores) and their use of communication strategies before the intervention ($r_{(23)} = .107$, $p = .617$) or after the intervention ($r_{(23)} = .090$, $p = .677$). However, the small sample size may mean this test is underpowered to detect an association.

The results from the TRQ (see Table 2) suggest that participants' (N=24) perceived knowledge of how to communicate with people with dementia (Mdn=3), and their satisfaction in communicating with people with dementia (Mdn = 2.24) prior to training improved significantly after the training (Mdn= 3.71 and 4; respectively). However, participants' overall confidence in communicating with people with dementia declined significantly after training (Mdn = 3.79) compared to baseline (Mdn = 4.07; $p < .001$).

Table 5-2 Participants' perceived Knowledge, Skills, & Confidence in communicating with people with dementia

	Pre- training Median (IQR)	Post- training Median (IQR)	Test Statistic	Standard Error	Standardized Test Statistic	Asymptotic Sig.(2-sided test)	Effect size (<i>r</i>)
Knowledge (N=24)	3 (1.9)	3.71 (1.33)	210	26.782	3.921	≤.001	0.8
Satisfaction (N=24)	2.24 (1.75)	4 (1.08)	267.5	32.74	3.955	≤.001	0.81
Confidence (N=24)	4.07 (1.07)	3.79 (1.42)	5.5	24.797	-3.609	≤.001	0.74

5.3.5 Discussion

Virtual learning environments such as the CUES are an emerging technological advancement in training community-based aged care workers. In this study, community support workers completed a 3-hour training session within their usual work environment. Interactions with the CUES provided participants an opportunity for deliberate practise (Ericsson, 2004) and to receive feedback on their performance of pragmatic communication components. Face-to-face training with a robust theoretical base was delivered in an interactive and engaging small group format. Participants significantly improved their use of communication strategies following the training with the embedded VLE when observed communicating with the CUES and, most importantly, with people with dementia. This improvement in communication from before to after the VLE training remained significant at the 2-month follow-up. Participants in this study perceived that communication training with an embedded VLE significantly increased their knowledge and satisfaction in communicating with people with dementia.

Consistent with the findings of Liddle et al. (2012) and Conway and Chenery (2016), training in communication skills can immediately improve support workers' knowledge and satisfaction in communicating with people living with dementia. The inclusion of the CUES strengthened this training program through embedding theoretical learning with deliberate practise (Ericsson, 2004). As identified by Cartwright et al. (2020), Quail et al. (2016), and Robinson et al. (2018), the CUES VLE provided community-based support workers the opportunity to directly apply the skills taught during training in a safe customisable, and repeatable scenario. Communication training that includes active participation and is based on practical skills was identified by

Morris et al. (2018) as more likely to be effective than traditional didactic training. While simulated patients and VLEs are now relatively common in the tertiary education of student health professionals (Harder, 2010), this study is the first to investigate the use of VLE to support communication skills development in community support workers in the aged care setting.

Effective communication strategies enable community support workers to understand better the viewpoints of people with dementia and support the enhanced feelings of control among this population (Eggenberger et al., 2013). The opportunity to learn more about dementia is regarded positively by care workers (Eggenberger et al., 2013) and may increase their satisfaction with their role (Elliott et al., 2012; Lawn et al., 2017). The inclusion of VLE within training provides a viable and effective option for improving perceived knowledge and satisfaction, *and* actual performance. In their recent review, Morris et al. (2018) identified few studies that reported the outcome of the training on performance of specific communication strategies; Conway and Chenery (2016) recommended that future studies should measure staff performance. The current study has demonstrated the feasibility and preliminary effectiveness of communication training with an embedded VLE with community support workers demonstrating significantly improved communication skills when interacting with the CUES and with people with dementia.

The majority of care workers in Australia are community-based, have low levels of job permanency, and work in an industry that lacks regulation of training requirements (Elliott et al., 2012; Palesy et al., 2018). These factors combined with limited time and availability of suitable work coverage affect the access to, and uptake of training to build capacity in this workforce (Elliott et al., 2013). The training package including the CUES system that was used in the current study is portable, flexible, and able to accommodate groups of up to 15 people in a three-hour training session. One single session for communication training is considered less effective than programs with multiple sessions (Eggenberger et al., 2013), this extended delivery of training may not be feasible for support workers in the current Australian work context. Importantly, the flexible and repeatable nature of the CUES provides the opportunity for flexible refresher sessions within the workplace.

This study recruited a heterogeneous participant group comprised of paid support workers, volunteers, and students with diverse knowledge, training, and experience in dementia care. All participants reported that the communication training they received in this study had a positive impact on their knowledge and satisfaction in communicating with people with dementia. Prior training did not affect participants' improvements in using relevant and appropriate communication strategies following the training. This finding suggests that specialised communication training is necessary to improve communication with people with dementia.

Literature in the fields of dementia and communication training have identified the need for a supportive organisational culture and the support of management in facilitating ongoing professional development (Eggenberger et al., 2013; McCarthy, 2012; Morris et al., 2018). The partner organisation in the current study was supportive of their workers participating in the training; however, ongoing feedback and continuing support following the training as recommended by Eggenberger et al. (2013) was not possible within this project. Future studies should include a follow-up or refresher training within a more robust, randomised controlled study design incorporating a control group with no formal training with longitudinal follow-up over time.

Despite significant increases after the training in participants' self-rated knowledge and satisfaction when communicating with a person with dementia, their confidence decreased significantly. This finding is in contrast with those of studies that have previously investigated the effect of simulation training on confidence in a range of skills including communication (Harder, 2010). The reduced confidence in the current study may have been due in part to differences between the CUES VLE (an Australian Caucasian retired male with a farming background) and the people with dementia attending the day centres who were from a broad range of cultural and social backgrounds. Greater knowledge perceived by the participants of the importance of communication with people with dementia may have resulted in them having a more informed perception of the quality of their communication skills with this population. Participants in this study completed the TRQ immediately following the second interaction with the CUES, and because of this timing, participants may not have been able to determine if they could incorporate the skills and the knowledge they had just gained from the training into the real-world context. Bandura's self-efficacy theory (Bandura, 1997), and in particular the *mastery* experience, proposes that individuals build upon initial experiences and observations to develop resilience in managing challenges or setbacks. The timing of completing the TRQ prior to returning to communicating with people with dementia may explain this phenomenon in relation to the confidence with communication of the participants in the current study. Future studies are recommended to repeat the TRQ following return to the workplace to provide greater clarity of the cause of the reduced confidence.

5.3.5.1 Limitations and future implications

The effect sizes found in this study were generally large, between 0.6 and 0.88; however, the small sample size reduces the sensitivity to detect significant changes. Further research is recommended with a larger sample size and the use of a control group to replicate these preliminary results and determine the clinical validity of communication training with embedded the CUES for the complexities of communicating with people with dementia. In addition, comparisons between communication training with and without the CUES training

should be compared. Another recommendation is to replicate this study across different work settings and contexts. Future research should control for personal factors that may affect participants' performance, such as prior communication skills training and education, gender, length of work experience and specific vocational roles; factors that were not feasible to control for with this sample of 24. The Clinical Practice Guidelines and Principles for Care of People with Dementia recommend that communication training be provided to families and informal carers of people with dementia (Guideline Adaptation Committee, 2016), so, a strong recommendation would be to extend the Dementia specific communication training with the CUES training to family members and informal carers and evaluate its benefit to their interactions with people with dementia.

5.3.6 Conclusion

Dementia-specific communication training with an embedded VLE was effective in improving self-rated and assessor-rated performance in the use of communication strategies by community care workers. Current training options for improving communication skills within the Australian context are most commonly those provided by the Dementia Essentials course and bespoke offerings from individual care providers. Training using the CUES is flexible, portable, and effective in developing communication skills at the workplace, reducing time away from work for support workers. VLE has been used primarily to develop communication skills among higher education students, but the findings of this study show that can also be an effective learning tool for community support workers, while providing an immediate and safe environment for deliberate practice and skill development.

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Chapter 6 Study Four

6.1 Background

The results of Study three (Chapter five) indicated that the communication training package incorporating the CUES had a significant and positive effect on participants' observed implementation of pragmatic communication strategies when conversing with the CUES avatar and with people with dementia. Study three demonstrated that the training is possible and feasible to implement within this context and can produce improvements in communication skills. Perceived positive gains in participants' knowledge and satisfaction were established, as was a decrease in confidence. The mechanisms by which these changes occurred, particularly regarding the decrease in confidence, were difficult to determine through the exclusive use of quantitative methodology. The application of strategies and skills learnt during the training within a workplace context may ultimately necessitate changes in organisational policy and procedures (Kirkpatrick & Kirkpatrick, 2006); therefore, understanding the experiences of participants in their application of the training within their respective workplaces was important to ascertain. Study four investigated this perceived value, acceptability, and relevance of the communication skills training package for community-based formal carers of people with dementia.

6.2 Communicating with people with dementia: Is virtual simulation training suitable for community support workers?

6.2.1 Introduction

With a current estimated 50 million people living with dementia internationally (Alzheimer's Disease International, 2019) and a prevalence of 459,000 in Australia that is projected to grow to 1,076,000 by 2058 (Dementia Australia., 2018), developing the capacity of services to provide effective support to people with dementia has become increasingly important (Palesy et al., 2018). Much of the research on effective care provision has focused on improving care in residential and hospital settings (Surr et al., 2019); however, people with dementia articulate a definite preference to stay in their homes and remain in their communities rather than move to residential care (Polacsek et al., 2020; van der Roest et al., 2009). As their dementia progresses, people living with the disease inevitably experience increasing levels of disability (Seeher et al., 2011). This inevitable functional decline often necessitates increased informal support from family and friends and increased reliance on formal support services in order for the person to remain at home (Phillipson et al., 2019).

Formal support services in Australia are available through a single gateway service called “My Aged Care”, which provides access, information, and advice through two main programs; The Commonwealth Home Support Program and Home Care Packages (My Aged Care, 2015; Phillipson et al., 2019). These services provide a range of assistance with home care tasks such as cleaning and shopping, personal care, social support, and respite. Respite and social support are considered some of the key unmet needs and deemed to be a priority for family carers of people with dementia in Australia who are cared for in their own homes, in a day centre, or in residential care (Brodaty et al., 2005; Phillipson et al., 2014).

Despite the availability of respite services, uptake by people with dementia has traditionally been low due to a range of factors including lack of knowledge about services, the prohibitive cost of services, and concerns about the quality of the available care (Morrisby et al., 2019; Phillipson et al., 2014; Stockwell-Smith et al., 2010). The quality of community care has improved by satisfactory funding to attract and train support staff in effective dementia care (Low et al., 2012), access to services at the right time and in the right place (Morrisby et al., 2019), and shared decision making and control for family carers (Stockwell-Smith et al., 2010). Ultimately, all of these considerations underpin and support person-centred care.

Person-centred care considers the holistic experience of the person with dementia and extends beyond the diagnosis of dementia to incorporate personality, biography, and social psychology, within the context of their physical and social environments (Hobson, 2019; Low et al., 2012). Person-centred community care can be facilitated through appropriate dementia-specific training and education (Elliott et al., 2012). Facilitating person-centred care through interpersonal communication supports the continuity of self and development of staff knowledge of the person's history, experiences, and preferences. Person-centred care is also achieved by being 'present' with the person and prioritising the person instead of the task, and, supporting success during care activities by using skilled, effective, and positive communication strategies (Conway & Chenery, 2016; Edvardsson et al., 2010).

Communication training has been shown to improve the quality of life and wellbeing of people living with dementia in community and residential care settings (Eggenberger et al., 2013). In Australia, communication training is provided to formal carers, including community-based support workers through the Dementia Essentials course (previously known as Dementia Care Essentials) as a component of the person-centred care approach taught within the course (Fleming & FitzGerald, 2009). In a review of Dementia Care Essentials, McCarthy (2012) identified that people with dementia did not consistently experience improved care after their support carers had received training, and that organisational changes were required for training to have a significant effect on lasting quality of care. An education initiative trialled in Australia was a video-based training package for formal carers that utilised a knowledge-translation framework (Conway & Chenery, 2016; Liddle et al., 2012; Smith et al., 2011). The video-based training increased knowledge, self-efficacy, and preparedness for the provision of care among formal carers in the community. Whilst the video format was reported as being well tolerated by participants (Conway & Chenery, 2016), a review of communication training by Morris et al. (2018) indicated that group format training incorporating active participation and support in developing skills was more effective than traditional didactic training, such as used in a video-based format.

High-fidelity virtual reality simulations are new interactive learning contexts that contemporary research has demonstrated are more effective in supporting development of a range of clinical skills when compared to traditional education methods, such as lectures or computer-based programs (Lateef, 2010). Embedding learning through repeatable, authentic, and safe opportunities for practise and feedback using a virtual learning environment (VLE) improved perceived knowledge, confidence, and skills for communicating with people with dementia among tertiary education students (Quail et al., 2016). The Curtin University Empathy Simulator (CUES) is a VLE designed specifically to support the development of communication skills with people with dementia through enabling real-time communication between participants and a virtual person with dementia. Using the CUES as a training tool has been

found to be effective in supporting speech pathology students develop greater knowledge, satisfaction, and confidence in communicating with people with dementia (Cartwright et al., 2020; Quail et al., 2016; Robinson et al., 2018). Broad-based application generating increased knowledge about appropriateness and audience suitability of this training, however, is warranted.

6.2.1.1 Study context

The communication training package embedded with the CUES used in this study was developed as a flexible, three-hour course delivered on-site in community day centres across metropolitan and regional Western Australia. The training included two individual sessions with the CUES for each participant, and an interactive, small group workshop component that provided information about the causes, signs, and symptoms of dementia, and specific targeted communication strategies (see Figure 6.1).



Figure 6-1 Curtin University Empathy Simulator

The Curtin University Empathy Simulator (Image credit: J. Beilby, Curtin University & J. Spitalnick, Citrine Technologies)

All participants completed the small-group training workshop that highlighted communication strategies framed on a variety of effective pragmatic discourse skills including introducing and maintaining topics, eye contact, body language and turn taking. The training workshop content was aligned with the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2002) participation and engagement priorities. The philosophy

behind the training was to support greater understanding of the complex interaction between disease, personal characteristics, and the environment, and how these come together during participation in activities of daily living. In hallmark research, Byrne and Orange (2005) identified that the ICF, as an underpinning framework in dementia education, would be effective in addressing communication impairment in a holistic and comprehensive manner. The key communication strategies used in the current study were the FOCUSED (face-to-face, orientation, continuity, unsticking, structure, exchange, direct) communication strategies (Ripich et al., 1995) and Empathic Curiosity (McEvoy & Plant, 2014) strategies. Both strategies are effective in improving communication between people with dementia and their carers (Ripich et al., 2000). Empathic curiosity, in particular, supports carers to understand the needs and emotional concerns of people with dementia and therefore, to understand the purpose that underpins their myriad of behavioural responses (Conway & Chenery, 2016).

FOCUSED strategies (Ripich et al., 1995)	
F	Face to face: face the person with dementia directly; attract the person's attention before talking; introduce yourself; use the person's name during conversation; and maintain eye contact, give the person your full attention.
O	Orientation: repeat key words several times; repeat sentences, exactly when clarification is sought; and give the person time to comprehend and respond.
C	Continuity: continue the same topic for as long as possible; provide reminders of the topic; round off each topic; and prepare the person if a new topic is introduced.
U	Unsticking: suggest the word they are looking for; repeat their sentence using the correct word; and seek clarification if you haven't understood by asking, "Do you mean...?" or "I think what you are saying is..."
S	Structure: provide simple choices (no more than two at a time) and require a yes or no answer rather than recall of specific memories or information

E	Exchange: begin conversations with pleasant, interesting, and familiar topics; ask questions or raise topics of conversation that you know the person enjoys; and share something about yourself to engage the person in conversation
D	Direct: use short sentences, gestures, pictures, facial expression, and other prompts to reinforce what you say; provide clear reference to what you are speaking about – for example, use real names for people and objects rather than words like “it”, “she” or “them”.
Empathic curiosity (McEvoy & Plant, 2014)	<ol style="list-style-type: none"> 1. Ask short and open questions in the present tense 2. Identify emotional cues 3. Control the pace 4. Explore metaphoric language

Figure 6-2 Communication strategies

Virtual Learning Environment

Virtual learning environments provide the opportunity to apply knowledge in safe, repeatable, and realistic simulations (Cartwright et al., 2020). The Curtin University Empathy Simulator (CUES) was the VLE used in this study. ‘Jim’, is an avatar of an older, retired Australian dairy farmer who has dementia and was presented to participants on a television screen large enough and at the correct height to display Jim as a life size person seated in a realistic clinic room in front of the participant (see Figure 2). Jim had 77 responses (verbal and non-verbal) controlled in real-time by an operator sitting outside of the participant’s field of view, so as to increase the participant’s immersion in the experience.

Previous foundational research by the authors demonstrated positive and significant improvements in pre- and post-knowledge, and satisfaction among community support workers when communicating with people with dementia. In particular, participants significantly increased their use of communication strategies following the training when communicating with the CUES avatar and with people with dementia. In addition, these positive results were maintained at two months follow-up. It is noteworthy that although participants’ self-perceived knowledge and satisfaction in communicating with people with dementia improved significantly; they also reported that their confidence decreased significantly over this training experience. This disparity highlighted the need for an in-depth investigation of the perceptions

of the community support workers after they completed the communication skills training embedded with the CUES.

Evaluation of training is necessary to determine effectiveness and generalisation of training benefits (Beeber et al., 2008; Surr et al., 2019), and to guide future training development (Garrod et al., 2019). Communication is complex and fundamental to the formulation of important interpersonal relationships for people with dementia and their carers (Morris et al., 2018). It was important for us to understand the perceptions and experiences of participants in this study after they undertook this novel and innovative training programme including strengths or challenges that may impact the implementation of future large scale studies (Eldridge et al., 2016). Using a qualitative approach to understand individuals' experiences of communicating with people with dementia offered the advantage of exploring the human phenomena of contemporary health care delivery (McWilliam, 2010). This study aimed to determine the perceived feasibility, acceptability and effectiveness of the CUES communication training from the perspectives of community support workers who completed the training as part of their role in supporting people with dementia.

6.2.2 Method

6.2.2.1 Participants

A subset of 12 participants were recruited by convenience sampling from a cohort (N= 24) drawn from six community-based social centres for older adults in the metropolitan Perth, Western Australia and regional centres within 100Km of Perth. Participants were those who remained available at the designated sites at two-month follow-up and were drawn from the larger sample of 24 who completed the initial communication training (Study three). Inclusion criteria for staff were that they: (a) had direct and regular contact with at least one person with dementia, (b) were able to communicate fluently in English (as ascertained by informal conversation with the researcher), and (c) were employed by the organisation. Volunteers and students on placement were included if they: (a) had direct contact with at least one person with dementia, (b) were able to communicate in English, and (c) were training with a registered training organisation (for example completing Certificate III in Community Services), or had completed volunteer induction with the organisation. Participants in the current study consisted of 11 female and one male and were aged between 28 to 64 years (see Table 6.1 for additional participant information). Although 12 participants were interviewed, the final four interviews resulted in no new themes being identified and saturation was deemed satisfactory (Guest et al., 2006).

Table 6-1 Demographics of interview participants

Age Mean(SD) (Min-Max)	Gender n (%)	Country of origin n (%)	English as a first language n (%)	Primary role at facility n (%)
54(11) (28-64)	Female 11 (91.6%)	Australia 7 (58%)	Yes 12 (100%)	Professional care worker / Activity assistant 6 (50%)
	Male 1 (8.3%)	England 1 (8.3%)		Volunteer 5 (42%)
		New Zealand 2 (17%)		Other 1 (8%)
		Sri Lanka 1 (8.3%)		
		Uruguay 1 (8.3%)		

6.2.2.2 Procedure

Ethics approval was obtained for this study through the University Human Research Ethics Committee. All participants completed and signed an informed consent prior to commencing the training session. Individual, semi-structured interviews were conducted with participants at approximately two-months following completion of the training, at a time and location convenient to them. The interviews were completed in the social centre (usually the social room or manager’s office) and were up to 30 minutes in duration. Each interview was digitally recorded and transcribed verbatim by the researcher. The semi-structured interview guide (see Figure 6.3) based on the ICF principles was constructed to explore the impact and feasibility of the training broadly, with semi-structured probe questions used to refine and clarify the participants’ responses. The interview guide was responsively adapted following the first two interviews to demonstrate respect for the participants’ experiences and responsibilities. Introductory questions about participants’ general experiences of working with people with dementia were included.

Can you describe your experiences working with people with dementia?	
Regarding the training session:	
Please describe your experience with the avatar	<ul style="list-style-type: none"> ○ What did you think was positive? ○ What did you think was negative?
What did you think about the content of the training session?	<ul style="list-style-type: none"> ○ Was it new information? ○ Was it engaging? ○ Did the content help you to develop skills to communicate with Jim (or people with dementia you work with)?
Regarding communication with a person with dementia:	
Do you feel like there has been any change in the way you communicate with people with dementia?	<p>For example:</p> <ul style="list-style-type: none"> ○ Ability to engage person in activities ○ Understanding dementia and communication changes ○ Understanding behaviour changes ○ Any changes made to the environment to support communication? ○ Change with relationship with person with dementia?
Any other comments or feedback?	

Figure 6-3 Semi-structured interview guide

6.2.2.3 Data analysis

Qualitative analysis was completed inductively using NVivo 12 (QSR International, 2020) following Braun and Clarke's (2019) six-stage reflexive thematic analysis process. Analysis was completed by two authors; the first author, a final year doctoral student and occupational therapist specialising in aged care and dementia, and the third author, an experienced qualitative researcher and occupational therapist. Reflection and field notes completed at the time of interviews and throughout analysis helped confirm findings were related to the data. The first author maintained a reflective journal throughout data collection and analysis to manage the research process and to make visible the non-linear process of research (Ortlipp, 2008). An audit trail of this process was kept to maintain dependability; transferability of the findings was addressed by providing rich description of participants and context. Transcripts were initially read, then re-read as they were transferred to NVivo. Initial codes were generated by the first and third authors, and potential themes were developed and then reviewed collaboratively by all authors before being fully defined to reach a shared consensus of themes supporting credibility. The major themes were then re-examined to identify relevant sub-themes and extracts were finally selected from the original transcripts and agreed by consensus.

6.2.3 Results

Three major themes, each with subthemes, were developed through the data analysis process. These major themes were (1) Participants' perceptions of the training, (2) gaps and opportunities in communication training, and (3) barriers to effective communication.

6.2.3.1 Major theme 1. Participants' perceptions of the training

Participants expressed their perceptions of the training, particularly the experience of speaking with the CUES and how they had translated their learning into their practice. A strong perception was articulated regarding the positive communication with the CUES and the subsequent skills that were learned. This major theme was identified by 11 of the 12 participants, indicating a perceived overall benefit of the training program by participants. One participant identified no significant gain from receiving the training.

6.2.3.1.1.1 Subtheme 1.1 Positive discomfort

The majority of participants reported concurrent emotions about communicating with the CUES. Their emotions were positive yet uncomfortable at times. Participants generally described the CUES as realistic; albeit, some discomfort or disconnection was identified as a result of the simulated environment in which they communicated with the avatar. The experience of communicating with the CUES was generally regarded as positive:

“I found him [Jim the avatar] confronting in that I thought I knew how to handle him but I didn’t, because he wasn’t having a bar of what I was trying to say and that made me sit back and think, well, maybe I need to reassess the way I was doing things.” Participant 22

The opportunity to apply knowledge immediately and receive feedback was regarded positively by participants. Approximately one-third of participants reported feeling safe to experiment with using the communication strategies they had just learned. The training session allowed participants to trial FOCUSED strategies such as direct questioning, which facilitated more effective responses in the communication exchange with the CUES. The feedback provided to participants was through their interaction with the CUES and direct feedback from the CUES operator. Several participants identified that feedback was not a usual component of training and that it added an element of interest and value that resulted in changes in how they communicated:

“It’s very good to get the feedback to say, well, you did this but you could have done it this way ... because we do tend to get into what we think’s right but when someone observes you, you think, my goodness, did I really do that or did I say that?” Participant 13

Two participants recognised that one of the key positives of a training package that included the CUES was the ability to practise communication strategies without the possibility of causing harm to a real person. Participants were able to trial strategies safely, “Like any interview, it’s always very difficult. So, I think with Jim, you feel that. At least you can do no harm.”
Participant 23

6.2.3.1.1.2 Sub theme 1.2 Translating skills into practice

Participants reflected on how they had implemented communication strategies learned in the training into their practice. At two months after the training, the majority of participants reported that they regularly implemented the FOCUSED strategies into their practice. Specifically, they provided people with dementia with additional time to respond during conversation, “Just to slow down... we’ve got to stop because that’s not in their best interests.” (*Participant 13*). Participants were also more confident in supporting a person with dementia to make decisions for themselves, “Maybe they’ve just got the two choices rather than five because it just, like, totally confuses them,” (*Participant 23*); and to be more direct and simplify the questions or information (*Participants 1 and 18*). Positive outcomes of the training were reported including supporting people to share their stories and opinions more fully by maintaining the topic (*Participant 17*) and using active listening (*Participant 26*). Participants reported an increase in approaching interpersonal communication with empathy and supporting the person to lead the conversation more, “Instead of them doing what I want, maybe I do what they want and follow, instead of always leading.” (*Participant 22*). Two participants, who perceived that they did not need training, reported that they felt the training had not changed their practice.

6.2.3.2 Major theme 2. Gaps and opportunities in communication training

Staff and volunteers identified the importance of receiving ongoing feedback and reinforcement of training outcomes. Tailoring training to the identified specific needs of participants was considered important by the participants. In addition, there was recognition by participants that families and informal carers would also benefit from this training.

6.2.3.2.1.1 Sub theme 2.1 The importance of ongoing training and feedback

Three participants were emphatic in their support of the VLE being available for integrated training. The VLE was perceived as a novel alternative from traditional training that typically used presentation slides. Furthermore, recommendations by participants for repeated opportunities for training within the context of the social centre were highlighted,

“But it’s like all training, Claire, it’s in the moment and it sinks in and they [workers at the centre] think about it for a little while, but then it gets a little bit more distant and a little bit more distant, until somebody jolts their memory or something jolts their memory...Like a three-monthly chat with Jim [the avatar]...as part of their annual training or their quarterly training.” Participant 12

Two participants outlined the importance of the individualised learning with the CUES because this required participants to actively engage and talk with the CUES in the training. In comparison to previous training experiences, these participants reported being unable to be passive in the learning process.

6.2.3.2.1.2 Subtheme 2.2 Tailoring training to meet specific needs

Nine participants spoke about the need for more dementia education. For some participants, the training offered in this research study was their first dementia-specific training. Three participants identified that they needed more advanced training specifically regarding the use of communication strategies as part of their management of responsive behaviours,

“Also, talking about really refocusing the communication training at times to supporting people with more severe behavioural needs because the feeling was that she could ... or that the staff here could manage people in the earlier stages of dementia without behaviour but then as the behaviours progressed then this was becoming much more of a challenge.” Participant 14

The majority of participants strongly recommended training that included general knowledge about dementia and communication strategies for staff and volunteers who were new to working in dementia care. The training offered in this study was generally deemed by participants to be appropriate for people new to working with people with dementia.

6.2.3.2.1.3 Subtheme 2.3 Families and informal carers

Several participants were concerned about the abilities of families and informal carers to cope with caring for people with dementia after observing negative communications by them, “the way they spoke to him, rudely and abruptly, made me feel a little bit sad for him” (*Participant 17*). Two participants specifically identified the need for communication training to be available to family carers of people with dementia and that training incorporating the CUES would be appropriate for them.

6.2.3.3 Major theme 3. Barriers to implementing effective communication strategies

Obstacles to implementing effective communication skills and strategies were identified by one-third of the participants. Key barriers included the increasing severity of dementia in clients accessing the service and logistical changes in staffing levels and personnel in the service.

6.2.3.3.1.1 Subtheme 3.1 Changing demographics

Four participants reported that the social centres were experiencing an increase in attendance of clients with significant communication and functional disabilities associated with dementia. This was further discussed by two participants who explained that institutional changes have resulted in integrated services for people without significant cognitive impairment, as well as those with cognitive impairment. Participants described how addressing the needs of people with *and* without dementia made it challenging for staff to provide equitable support: “Then all of a sudden when you’ve got a high-care dementia client, it actually upsets the whole apple cart with all the other clients” (*Participant 14*). While some participants from one social centre described the clients as being generally supportive of one another, two participants identified issues with a lack of support or tolerance from clients without cognitive impairment towards those with dementia,

“You come out of the office sometimes and you look around and the person living with dementia is just aimlessly wandering and not included in the same game because the people with cognitive abilities ...are not very forgiving.” Participant 12

6.2.3.3.1.2 Subtheme 3.2 Changes in staffing

Reductions in funding support for organisations, due largely to changes in national models of aged care funding, were identified as having a flow-on effect on the opportunities and abilities of the participants to spend time communicating with clients in ways that supported interpersonal communication. Participants reported decreased staffing levels had resulted in fewer staff working directly with clients, with a greater reliance on volunteers,

“It’s been a little bit more difficult because we have two with higher needs and probably with the staffing restraints, it’s certainly more expected that that’s what a staff member would do, rather than a volunteer.” Participant 23

Several volunteers highlighted the particular challenges they experienced because of not having had formal training in dementia care. They had limited understanding of dementia, which affected their confidence to support people with dementia. The costs to the organisation associated with providing traditional training were acknowledged, as were the benefits of the current training with the CUES.

“The training has given me confidence definitely so that’s the main thing. In fact, I’ve got a friend who’s got a mother who’s got quite bad dementia in a nursing home and the friend went away for five weeks, so I volunteered to go over and take her out and do some things with her. Now, I wouldn’t have done that if I hadn’t had that bit of training.”

Participant 1

6.2.4 Discussion

This study explored the perceptions of community-based support workers towards the feasibility and acceptability of a communication skills training program with an embedded VLE. The insights shared by participants during semi-structured interviews indicated that although talking to an avatar was a new and at times uncomfortable experience, most reflected how they had integrated the principles of the training into practice. Participants highlighted the importance of having active engagement with the VLE as part of training and identified other stakeholders to whom the training may be extended in the future. Finally, it was apparent that training remains only one part of the solution for building capacity for effective interpersonal communication; the pressures of less funding for staff, an increased use of volunteers, and the increase in the number and needs of clients in later stages of dementia affect all aspects of ongoing dementia care and management.

Participants described the CUES as a novel component of the training and was considered an acceptable and positive inclusion in training carers in dementia-specific communication strategies. Participants who had previously completed dementia-specific training believed the inclusion of the CUES was an improvement over standard training for two key reasons: it required and facilitated active engagement; and it provided an opportunity for feedback on individual participants’ communication skills. In light of the literature review by Morris et al. (2018) that identified the importance of active participation to support the development of communication skills was identified, embedding VLE is acknowledged as an effective strategy to provide repeatable deliberate communication practice (Ericsson, 2004; Lateef, 2010) in a personalised and dynamic manner (Wonggom et al., 2019). The opportunity to receive feedback on performance during training is generally limited within training currently available to Australian community-based support workers. Most training is delivered with more traditional methods such as didactic lecture delivery, group discussions and role-play (Elliott et al., 2012). As was recognised by participants in this study, receiving feedback on performance was critical for the development of their communication skills. Effective feedback cycles, in which learners receive iterative feedback on their developing skills improves student learning (Boud & Molloy, 2013).

The repeated exposure to the CUES supported the identification, development and evaluation of skills through feedback. One participant with management experience suggested that the CUES should be used to provide ongoing feedback and review of communication strategies as a regular component of staff development. This concept is well supported by Morris et al. (2018) and Eggenberger et al. (2013) who identified that communication training should be offered over time and include periodic refresher sessions. Because the CUES is flexible, adaptable, and easily transportable, it is ideally suited to support ongoing and intermittent training; however, further research is needed to evaluate effectiveness of this approach to training. Participants found that their ability to apply the communication strategies consistently was limited by factors outside of their control such as staffing constraints and changes in the demographic profiles of clients attending the social centres. Numerous studies have identified that stand-alone training without organisational support is not sufficient to achieve and maintain improvements following training (Eggenberger et al., 2013; McCarthy, 2012; Surr et al., 2019). Specific organisational barriers such as access to feedback (Surr et al., 2019) can be addressed using the CUES; however, organisational factors such as policy changes to align care more to a person-centred care model (McCarthy, 2012) are beyond the scope of this intervention.

The communication training using the CUES facilitated application of communication strategies in participants' everyday work. Objective measures, as reported in Chapter five, demonstrated significant changes in participants' observable communication behaviours with the CUES and people with dementia immediately following the VLE training. Evaluation of the effect of the training through the perceived implementation of communication strategies into everyday practice by participants was deemed to be very important. Kirkpatrick's model of training evaluation (Kirkpatrick & Kirkpatrick, 2006) determines impact through participants' reactions to the training (level 1 change), their learning of skills (level 2 change), their ability to change their behaviour in the workplace (level 3 change), and changes in organisational performance (level 4 change). The current study demonstrated level three changes in participants' behaviours in practice following the communication training. Further investigation of changes in organisational benefits of this training are required, and increased rates of participation of managerial staff in future studies is recommended. Importantly, this qualitative evaluation identified broader benefits of the training in developing knowledge of dementia and the value of embedding the CUES as an innovative addition in the training. Challenges experienced by participants when working with people with dementia included the impact of client demographics and staffing constraints. Qualitative evaluation provides greater insights into the non-causal links between training evaluation and implementation of training into practice (Bates, 2004). Further evaluation of this communication training is needed to determine the impact of improved communication on the quality of life and experiences of the people with dementia who receive care services in social centres.

6.2.4.1 Participant recommendations for future development of the training

This study identified that participants who received the communication training using the CUES considered it effective in improving their use of pragmatic communication strategies and feasible to implement with community carers. However, the participants identified potential areas for development of the communication training including increasing the complexity of the training and expanding access to the training to family carers of people with dementia. The current training protocol was developed to address basic communication strategies based on available literature regarding the general training needs of carers (Conway & Chenery, 2016; Elliott et al., 2012; Guideline Adaptation Committee, 2016). Participants reported that the basic nature of the training was effective for support workers or volunteers who were new to caring for people with dementia or those with limited previous training. While the Australian government has increased spending on community-based services by 34% over the last five years, there has been a 62% decrease in spending on workforce and service improvements including training (Australian Institute of Health and Welfare, 2019). Poor access to quality training has the potential to increase staff turnover (Palesy et al., 2018), which may lead to reductions in quality of care. Therefore, the implementation of effective communication training should be a high priority. Three participants identified that communication training, including the CUES training used in this study, could be adapted to address advanced dementia communication needs and interventions, such as responding to challenging behaviours.

Participants in this study believed access to support, education about dementia, and training in dementia-specific communication strategies were also important and relevant for family and informal carers of people with dementia. This correlates strongly with the findings of previous research (Morris et al., 2018; Morrisby et al., 2019; van der Roest et al., 2009) investigating the needs of family carers. A review by Morris et al. (2018) found that caregiver training is effective in increasing knowledge and communication, particularly when supported through active learning. Training incorporating the CUES is flexible and adaptable to the needs of individual participants and requires active engagement of participants that is key to facilitating knowledge and skill development. Future development and evaluation of communication training incorporating the CUES specifically to support informal and family carers is warranted.

6.2.4.2 Limitations

This qualitative evaluation occurred two-months after participants had received the communication training with the CUES. Only half the participants who received the communication training with the CUES were available for inclusion in this follow-up study.

Participants that received the training but who were not available to participate in the interviews were students who had been in the social centre as part of training in their respective courses, staff at the social centres who were on annual leave at the time of the interviews, those who had moved into different roles in their organisation, or were no longer employed by the organisation.

While the demographic profile of the participants in this study are similar to those of community support workers reported in other studies (King et al., 2013), as with all qualitative research, the findings of this study are not generalisable beyond the study sample because of the contextual nature of the participants' personal experiences of the communication training with the CUES (Sandelowski, 2015).

While the findings of the qualitative evaluation of the communication training using the CUES are positive, additional research using robust mixed-methods approaches is required to validate the results in other populations providing support to people with dementia.

A small number of participants identified that the discomfort they felt during the study was due to being videorecorded during their communication session with the CUES, and not because of the training per se. The videorecording of training attendees is not required in practice conditions that are not in a research context. This would likely minimise perceived experiences of discomfort during training when delivered as part of organisational practices.

6.2.5 Conclusion

This study identified that participants perceived communication training with the CUES embedded to be acceptable, feasible to complete with community support workers, and led to improvements in their use of effective communication strategies to support people with dementia. Virtual learning environments such as the CUES support active engagement in training and provide valuable real-time feedback to participants. The CUES provided opportunity to personalise learning and respond to needs of individual trainees and is appropriate to support future dementia-specific training initiatives. This study identified further evaluation of this training is needed through controlled experimental studies, and that the training should be trialled and evaluated for use with family carers of people with dementia.

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Chapter 7 Discussion

7.1 Discussion of findings

There are 459,000 people with dementia living in Australia in 2020, and this population is estimated to rise to approximately 1,076,000 people by 2058 (Dementia Australia., 2018). The majority of people with dementia live at home, with 45% receiving support from informal and formal support services, or formal support services only (Brown & Hansnata, 2017). Nine per cent of people with dementia receive no support and 46% receive support only from informal carers such as family members; particularly spouses or children (Brown & Hansnata, 2017). In 2020, an estimated 215,517 carers will be needed in the community, the majority of whom are family members; this is forecast to rise to 255,812 by 2025 (Brown & Hansnata, 2017).

Understanding the needs of carers, and the needs of people with dementia are keys to providing support that is relevant, acceptable, and effective in maintaining quality of life and engagement for people with dementia and their carers. Understanding the needs of the recipients of support provides policy makers the opportunity to develop responsive services. An important part of providing responsive services is developing a skilled workforce to supplement the large informal carer base. The current gold-standard training for community-based support workers are pivotal in assisting informal carers to continue their care; however, the effectiveness of the current gold-standard training is neither clear nor well supported by current evidence. The research reported in this thesis identified the needs of people with dementia and their carers; addressed communication skills as a key element of need in relationship-based care; and built on innovative health workforce training solutions to develop an effective and replicable training that improved the communication skills of community-based support workers when supporting people with dementia.

The foundation of this research is the needs of people with dementia and their spousal carers living in the community in Western Australia. The International Classification of Functioning, Disability, and Health (ICF: WHO, 2002) was the framework used to identify the

holistic and psychosocial needs of this population. The research reported in this thesis considered the perceived needs of spousal carers and people with dementia and compared them to the needs of the same population as perceived by service providers in Western Australia. The salient similarities and gaps between providers and recipients' perspectives were identified. The abilities of community-based support workers to communicate effectively with people with dementia was identified as a critical gap. The research used a mixed methods approach to investigate the feasibility, acceptability, and effectiveness of a novel dementia-specific communication training package that included a virtual learning environment (VLE) to support the development of communication skills in carers of people with dementia.

Dementia affects all facets of a person's life; from their ability to retrieve a loved one's name and facts about them, through to completing basic self-care activities. The effect of these fundamental but critical changes in ability necessitates gradual increases in support for people living with dementia (Nygård & Öhman, 2002). Chapter Two in this thesis was a scoping review of international literature on the needs of people with dementia and carers. The review identified that the needs of people with dementia and their carers were holistic and individualised. Particular emphasis was placed on the need for people with dementia and their carers to have access to meaningful activity, opportunities for socialisation, and education regarding practical caregiving skills such as communication. Another identified need was access to information tailored specifically to the needs of the person with dementia. Commonly used assessment tools to determine needs — the Camberwell Assessment of Need for the Elderly (CANE) and the Care Needs Assessment Pack for Dementia (CARENAP-D) — focused on needs related to survival or basic care. The quality of life and functional needs were rarely measured with people with dementia in existing studies; rather, the focus was on by-proxy measurement of need by family carers or health professionals. Qualitative studies reported in the literature provided rich descriptions of the person's lived experience. The nature of qualitative research methodologies used generally enhanced opportunities for people living with dementia to participate actively in research about them. The inclusion of people with dementia in research is key to understanding their lived experience of dementia and their specific, practical,

important daily life needs (Murphy et al., 2015). An important contribution of this thesis is the voice of people living with dementia, heard through their interviews. That voice clearly portrayed the desire for more autonomy in life decisions and that the often-reported finding that formal services needed to be flexible and timely in their delivery, was key to this autonomy. National and international literature has identified that the complexity of formal services provided through health and welfare systems requires support to ensure choice and control for service users.

The key findings from the scoping review (Chapter Two) highlighted the importance of understanding the needs of people with dementia and their carers living in the Western Australian community. This formed the basis for Study One (Chapter Three) that addressed the personal, environmental, occupational, and participatory needs of people with dementia and their spousal carers across the continuum of dementia. The needs of people with dementia and their spousal carers were investigated using qualitative interpretive description that included interviews based on the framework of the ICF (World Health Organization, 2002). The ICF framework was used to identify impairment in people with dementia (Muò et al., 2005) because it is appropriate to guide evaluation of peoples' experiences, in particular interpersonal relationships, communication, and engagement in activities (Cerniauskaite et al., 2011).

People with dementia and their spousal carers who participated in the research in Study One identified needs that were holistic, with a strong focus on service systems, social systems, and environments that supported their ability to remain living at home. Congruent with the findings of the scoping review, participants in Study One identified fragmented pathways and inconsistent access Western Australian community services and information. Services typically addressed basic tasks of daily care only, with little to no acknowledgment of the need for the person with dementia to have meaningful engagement in activities or relationships. Services and supports that focused on relationships and were able to respond to the individual needs of people with dementia and carers as they progressed through dementia were highly valued. Carers and some people with dementia were grateful for their access to services and supports, but also frustrated by the effort required to initiate services and/or ensure the standard of care

they expected from these services. These findings in the Western Australian context confirmed those of national Australian research — that difficulties and inadequacies in accessing and receiving effective care were ongoing and experienced by carers across the nation (Phillipson et al., 2019; Polacsek et al., 2020).

The nature of social support for carers and people with dementia was highly variable and highly influenced by the education and knowledge of family and friends, and the geographical distance between people with dementia and their families. Support and encouragement of family were often the prompts for people with dementia and their spousal carers to access services and supports; however, this support was limited when families were geographically separated or when the family had limited knowledge of dementia. Community understanding of dementia has improved but continues to be an acknowledged area of ongoing need (ADI, 2019). In Study Two, service providers were interviewed, identifying gaps between the needs perceived by spousal carers and the people with dementia for whom they care and implications for the way services and supports are accessed. They also identified the variability of knowledge about dementia within the broader community. In Study One, several people with dementia and carers described how previously close friends withdrew their support due to fear and a lack of understanding of dementia.

Study One identified how the needs perceived by people with dementia and their spousal carers were not consistently aligned. As found in the scoping review and highlighted by Moyle et al. (2012), the ability of carers to identify with and understand the subjective experiences of people with dementia were biased by their own circumstances. For example, carers tended to focus on their own coping strategies and how they might adapt within their relationship as the dementia progressed. The complexity of relationships between spousal couples was highlighted, as the nature of their relationship in combination with their management of dementia changed over time. Carers in Study One described caring as their “duty” and as a representation of their love for their partner, while people with dementia expressed their desire and need to work with and support their carer; although this was affected

by insight into their functional limitations. These findings are critical for understanding and appreciating the breadth of the impact of dementia on the relationship. In addition, the findings highlight the importance of having access to supports that will enable people with dementia to be cared for at home by their spousal carers.

Chapter Four (Study Two) reported on the perceived gap between needs and services and supports. This gap promotes negative interactions between people with dementia, carers, and health professionals across international health care systems as identified by von Kutzleben et al. (2012). The gap between the needs perceived by service providers in Western Australia and the people in receipt of their care services is believed to have a significant effect on the availability, access, and effectiveness of overall care provision. There was some alignment in perspectives of service providers interviewed in Study Two and the spousal dyads interviewed in Study One; primarily in relation to the quality of services available in the community. Both groups perceived barriers to services included inconsistencies in the pathways to access care, cost of services, and limited access to education (e.g. effective training of health professionals and support workers in communication skills and dementia).

Major themes discussed by spousal carers and people with dementia that were not considered by service providers included recognising and supporting spousal intimacy for people with dementia and their spousal carers. A second major theme that developed from interviews with people with dementia and their carers that was not well recognised by service providers pertained to supporting couples to adapt to their changing capacities. While the service providers recognised that carers' attitudes and beliefs about caring affected the quality of their support of the person with dementia, the reciprocal nature of caring was not acknowledged. Prior research also identified that the impact of caring on a spousal relationship is not well understood (Braun et al., 2009 ; Cash et al., 2013). Previous research proposed that interventions for people with dementia and their spousal carers needed to target specific needs (Wadham et al., 2016). The majority of service providers interviewed in Study Two failed to acknowledge the impact of stigma and the lack of knowledge about dementia, and the subsequent effects on social support from social networks and family. This gap indicated there

were limitations in the understanding and full appreciation of the lived experience of dementia and associated demands on their carers.

The interviews with service providers in Study Two offered insights into the normative need (Bradshaw, 2005) of clients within the Western Australian community and focussed primarily on the elements of successful services for people with dementia. These factors for success were consistent with those reported in Australian and international communities of service providers as highlighted in the scoping review (Chapter Two). The service providers also discussed the importance of building the capacity of those living with dementia to address systemic issues in care systems and ultimately provide support for overall quality of life. Knowledge of dementia, and the ability to communicate effectively was highlighted specifically by service providers as key to providing effective care for people with dementia. They explained that building knowledge about dementia was considered important for carers, health professionals, and formal carers as effective communication by carers facilitated engagement in meaningful activity and reduced behaviours of concern when working with people with dementia. Elliott et al. (2012) supported the importance of effective communication and emphasised that although communication training can lead to improvements in care, there is a lack of evidence-based education interventions for community-based staff.

The findings of Study Two (Chapter Four) informed Study Three (Chapter Five); a feasibility study of a dementia-specific communication training package using a novel and innovative virtual learning environment (VLE). Study Three determined that community-based support workers demonstrated significant improvements in their use of pragmatic communication strategies after completing a three-hour training, which included interactions with the Curtin University Empathy Simulator (CUES; see Chapter Five for further details). The communication strategies taught were evidence-based and included skills such as conversational turn taking; providing additional time to respond, and the use of effective, focused, and direct questioning strategies. The support workers demonstrated improvements in these skills when communicating with an avatar of a gentleman with dementia in the virtual learning environment and when communicating with people with dementia in real-life practise. Improvements in

communication remained significant and durable two months after the communication training. An important finding was that the CUES was an authentic and valid simulation, representative of communicating with a person with dementia. Each participant's individual communication skills were consistent and similar when they communicated with the CUES and with a person with dementia in the pre-training phase. The community support workers self-rated improvements in their knowledge and satisfaction in communicating with people with dementia following the training session; however, their perceived confidence with their communication skills decreased after training. This finding may be a result of the CUES highlighting to participants the actual gap in their skills, as opposed to only having a perceived ability to apply knowledge from training into practice (Kruger & Dunning, 1999). This finding also aligns with the concept of mastery as proposed by Bandura (1997), whereby the CUES supported participants to identify gaps in their communication performance that were subsequently able to be addressed on their return to the workplace. As identified in Study Four, participants' described that their confidence in communicating with people with dementia had increased following their return to the workplace.

Study Four (Chapter Six) utilised a qualitative approach to explore the experiences of community-based support workers who completed the communication training with the CUES, and subsequently returned to their workplace. The findings from Study Three and Study Four confirmed the communication training with the CUES was feasible to deliver in the workplace; acceptable to the participants; and, had a positive impact on practice for individual participants. This finding indicates that the communication training package was highly successful and beneficial for the support workers, as per the Kirkpatrick model of training evaluation (Kirkpatrick & Kirkpatrick, 2006). The most advanced stage of the Kirkpatrick model, stage four, considers the impact of training on organisational change (Kirkpatrick & Kirkpatrick, 2006). Several participants from Study Four raised concerns regarding the impact of organisational policies on their ability to implement the new beneficial communication strategies. These voiced concerns implied that level four changes in organisational policy (as described in the Kirkpatrick model) required further development and support to ensure that the

training can be effectively implemented at the dementia care organisation where they worked. Several studies of other dementia training programs (McCarthy, 2012; Morris et al., 2018) identified the need for organisational change to support the ongoing implementation and change necessary for effective dementia communication and care.

The qualitative methodology used in Study Four provided participants the opportunity to identify and discuss how their confidence had increased after they were able to apply and use the learning gained from the training session with the people who dementia they support. This finding was in contrast to the finding of Study Three, in which participants reported a decrease in their confidence in communicating with people with dementia following the training. Study Four ultimately highlighted the beneficial nature of the CUES as a novel and innovative experience for the study participants. Embedding the CUES, an avatar based in a virtual clinical environment, into the training for community-based support workers represents a significant advancement in engaging and authentic preparation. While evidence exists for the utilisation of emerging technologies such as the CUES to support simulation in the education of pre-service health professionals (Quail et al., 2016) and formal carers in residential care settings (Cartwright et al., 2020), the wider implementation of this technology has not yet been reported. The findings of Study Four draws attention to the implications of the lack of funding and innovation applied to the education of the very essential, but poorly supported, workforce of community support workers. Australian aged care funding reports indicate that spending on workforce training has decreased in the seven years since 2012-13 (Australian Institute of Health and Welfare, 2019) and that significant gaps remain in the ongoing training of the community-based health workforce (Elliott et al., 2012; Polacsek et al., 2020).

CUES was a novel and educative challenge for most participants and the support workers perceived the overall training to be valuable. Participants reported that the embedded VLE provided a low risk opportunity for them to practise their interactive pragmatic communication skills. Participants welcomed receiving feedback about their communication skills; no other dementia training program has included the opportunity to receive individual feedback as a key component. Participants recognised the flexibility, repeatability, and

scalability of the CUES as factors that enhanced the training experience and its usefulness and relevance for follow-up training. The CUES is appropriate to support ongoing training and implementation of enhanced pragmatic communication skills among support workers in their workplace, and can be used in the future development of specific targeted skills including topic maintenance and conversational turn-taking skills for managing complex and challenging communication scenarios with people with dementia.

7.2 Strengths & limitations

7.2.1 Paper 1

The scoping review explored need from the perspectives of people with dementia and their carers, and if these needs were met or unmet. The scoping review used the methodological framework for scoping reviews proposed by Arksey and O'Malley (2005). This method used a five stage, iterative, and ad hoc process that supported the inclusion of a broad range of literature to explore the overarching aim. The scoping review method does not require evaluation of the quality of the included research articles; however, was selected because of the discursive nature of the literature in this area of inquiry (Levac et al., 2010). The lack of evaluation of quality of papers within the scoping review does ultimately limit the strength of the conclusions drawn from the review, although the review did acknowledge and report the limitations of the research designs of the included articles. These included limitations pertaining to the validity of the studies' reported findings due to incomplete data, inconsistency in conceptualisation of need, limited range of outcome measures, and restricted diversity in the needs identified, all of which culminated in restrictions in comparison of the studies.

Comparisons of the findings of the reviewed studies were limited by the diversity of each country's health care system and differences in cultural attitudes towards caring and dementia. Data from the studies included in the scoping review were drawn from 11 countries that had services and supports for people living with dementia. Service systems varied greatly between and within countries; for instance, Canada manages health and social care at the county and

province levels, resulting in disparities in the support available to people with dementia depending on their geographical location (Forbes et al., 2008).

A strength of the scoping review was the breadth of research data gathered over 11 years from 5609 carers and 2089 people with a lived experience of dementia living in 11 countries including Taiwan, USA, the Netherlands, and Australia, which had a broad range of systems of care for people with dementia and their carers. Culminating in providing an extensive overview of needs, both met and unmet. The inclusion of both qualitative and quantitative methods provided insight into the narratives regarding why needs were considered met or unmet and the critical factors that impacted on service acceptability. Arksey and O'Malley (2005) and Levac et al. (2010) recommended including a final stage of consultation with stakeholders to review the results to determine relevance to the local context. This was not completed formally as part of the scoping review process; however, the results of the scoping review were used to inform the development of Studies One and Two, in which people with dementia, carers and service providers were subsequently interviewed about their perceptions of need. The scoping review proved pivotal in building the foundation and direction for the subsequent ensuing investigations undertaken in this thesis.

7.2.2 Paper 2

Study One (Chapter Three) aimed to investigate the needs of people with dementia and their spousal carers living in the Western Australian community. It utilised interpretive description; a methodology developed to support clinical understanding of need in practice (Thorne et al., 1997). Interpretive description is uniquely suited to healthcare research as it examines “a clinical phenomenon with the goal of identifying themes and patterns among subjective perspectives, while also accounting for variations between individuals” (Hunt, 2009, p. 1285). As a methodology, the use of interpretive description in Study Two proved efficacious in exploring the lived experience of dementia and using a co-constructive approach within the contextual, and constructed nature of dementia.

The use of the ICF as a framework for the semi-structured interviews with participants in Study One was another strength of the research in this thesis. The scoping review had highlighted that needs of people with dementia and carers were broad, and the ICF expanded the scope of the interviews to consider the participants' full experiences of living with dementia, such as social and occupational aspects of care. Needs assessments that are commonly used are based on activities of daily living (Muò et al. (2005), but these do not effectively capture the impact of dementia on interpersonal relationships, communication, or a broad range of meaningful activities.

The inclusion of the personal and consumer insights of people with lived experience of dementia was also a significant strength in this research. As previously highlighted, understanding dementia from the perspectives of those with lived experience is critical to validate people with dementia and promote person-centred care (Murphy et al., 2015). One limitation of Study One was that the perspectives of people with dementia were not highlighted, but rather subsumed into the results of the spousal dyads; this has the potential to diminish the importance and uniqueness of the perspectives of the individuals with dementia (McKillop & Wilkinson, 2004; Murphy et al., 2015). People with dementia and their carers were recruited into the Study One via referral from individuals known to service providers. This sampling method limited the study to the perspectives of people who are in receipt of care or support services; the perspectives of those not receiving formal services were not included.

7.2.3 Paper 3

Study Two (Chapter Four) expanded the research conducted in Study One through examination of the needs of people with dementia and spousal carers from the perspectives of service providers in Western Australia . A key strength of Study Two was the use of deductive coding of qualitative data from service provider and comparison of the data to themes generated by people with dementia and carers. Reflective journaling by the researcher also contributed to the rigour of the study. Additional strategies, such as member checking by the service providers, may have been valuable in increasing the rigour and trustworthiness of this study; however, due to the mixed data collection methods (individual interviews and focus groups) it was difficult to

summarise individual contributions to the data. Furthermore, there was a limited number of participants available to participate in Study Two, likely due to recent changes in service delivery models. Greater consideration regarding the changing progression of needs as dementia advances may have been elicited had there been more and varied participants from different areas of service provision. The fact that Studies One and Two occurred in the midst of a national change towards a consumer-directed care model of service delivery limits the ongoing applicability of results, particularly those regarding the nature and quality of services. However, key findings such as the limited shared understanding of need and the lack of support for relationships are unlikely to be affected by this change.

7.2.4 Paper 4

Study Three (Chapter Five) explored the feasibility of communication training embedded with the CUES to support the development of pragmatic communication skills with community support workers. As an initial investigation into the use of the CUES with community-based support workers, Study Three satisfied the definition of a feasibility study: “a feasibility study asks whether something can be done, should we proceed with it, and if so, how” (Eldridge et al., 2016, p. 8). As a feasibility study, the pre-post design of Study Three was an appropriate method of piloting the CUES to train community-based support workers in effective dementia-specific communication strategies. The study demonstrated that the communication training led to a significant improvement in participants’ use of positive communication strategies in communicating with both the CUES and people with dementia within the study context. Future studies will benefit from accurate power and effect size calculations, and a clearly established study protocol. A future control group and randomisation would support an experimental design to improve the rigour of the study to strengthen the conclusions about the effectiveness of the CUES in improving communication skills.

The study sample included people from a broad background including staff, volunteers, and students, which supported the investigation and feasibility of the training with a wide audience. Participants included support workers, volunteers, management and students, all of

whom were regularly involved in the support of people with dementia. The sample of support workers in community-based social centres was drawn from a single community aged care provider. This sampling strategy was due to logistical difficulties in recruiting and training workers supporting people with dementia in their own homes because they worked across multiple locations and had highly variable work schedules. For the purposes of demonstrating the feasibility of the training, the decision was made to recruit centre-based staff working with people with dementia who resided in the community. The sample demographics aligned with those of Australian community-based support workers (Palesy et al., 2018) and were deemed to be representative of this population.

In addition to the limited sample size, half the participants were unavailable at two months post-training to complete the follow-up observations. The high rate of attrition was due to changes in employment and conclusion of fieldwork placements of participants who were tertiary students. The low number of participants available at follow-up limited conclusion that could be drawn about sustainability of improved communication skills over time.

7.2.5 Paper 5

Study Four (Chapter Six) investigated the feasibility and acceptability of the communication skills training with the CUES for community-based support workers. This study utilised a qualitative methodology to gather the perspectives of participants after they had completed the training and resumed working at the day centres. Utilising a qualitative approach to investigate the acceptability of training is important to understand its potential benefits and value, and determine any areas requiring further development in future training programs (Morris et al., 2018). The qualitative findings from Study Four elaborated on the previous, somewhat enigmatic finding of Study Three that participants' confidence in communicating with people with dementia decreased after the training. Study Four highlighted the benefits of the training, grounded in the experiences of the participants as reported by them following the training. Strategies including reflexivity and the use of field notes, as well as multiple coders improve the rigour and credibility of this study. However, further strategies such as member checking are recommended to be undertaken in future.

The participants in Study Four were drawn from the full sample of participants who completed the communication training, and were included on the basis they were available and willing to be interviewed. Half of the original cohort were not available at the time of the interviews; therefore, the qualitative data obtained may not represent the beliefs and perceptions of the entire cohort who completed the training. The interviews were kept short because they were conducted during work hours and other staff were not available to cover the participants' work duties during the interviews. The short time available for the interviews led to a sense of urgency at times, which may have restricted the level of detail and completeness of data collected from some participants.

7.3 Future directions

Supporting the quality of life of people with living with dementia and the carers who assist them to remain in the living in the community is a complex but essential responsibility. This research has identified that the needs and requirements of people with dementia and their carers are holistic and extend beyond the reach of current services. Australian and international governments have limited capacity to address and satisfy these complex and multi-faceted needs through service provision because of lack of appropriate resources, funding and governance (ADI, 2019). However, Study Two identified that there was potential to improve current services through policy changes including improved pathways to services and enacting quality indicators focussed on relationship-based care, and education of support workers and health professionals within the aged care and primary health care systems. Study Two also highlighted the importance of family, friends and the broader society in promoting care and providing ongoing support. People with dementia and carers identified they had experienced stigma and a lack of knowledge in the general community affecting their quality of life but the impact of stigma on quality of life was not commonly identified or highlighted by service providers. Such findings underscore the potential problems that arise when service providers do not respect the impact of stigma associated with dementia and the lack of knowledge and understanding of

dementia evident in the broader community on the availability of informal supports to people living with dementia and their carers.

Studies Three and Four identified how communication training with the CUES is feasible and produces improvements in communication behaviours that are subsequently demonstrable within the work context. While the qualitative data highlighted the value of the training by the CUES from the perspectives of the trainees, further research is required to compare outcomes from the communication training with the CUES and the traditional communication training currently offered to support workers in the sector. Specifically a large randomised controlled study utilising a mixed methods approach across multiple sites is required. Future studies should determine possible correlations between the efficacy of the communication training with the CUES and participants' prior knowledge of dementia. Independent variables including English as an additional language, gender, and years and type of practical experience working in dementia care should be investigated to determine the applicability and flexibility of communication training with the CUES with these population groups.

An important extension of this body of research would be trialling communication training with the CUES to informal carers of people with dementia. Communication training of informal carers (including spousal and family carers) was identified by participants in Studies Two and Four as an important and valuable future consideration. Systematic reviews have identified the critical need for training family carers in communication strategies (Eggenberger et al., 2013; Morris et al., 2018), and current training for Australian carers is limited to traditional didactic training or home-based video education. Therefore, development of a communication training package with the CUES specifically for family and other informal carers is recommended.

The evidence generated from this thesis indicates that the CUES, when embedded into communication training, enhanced the engagement of participants and increased the use of communication strategies that were positive and successful in promoting interpersonal communication with people living with dementia. The potential to embed VLE into future training may advance training outcomes for formal and informal carers, and broaden the understanding and appreciation of the impact of dementia on communication.

7.4 Conclusion

The body of work contained within this thesis has demonstrated the met and unmet needs of people with living with dementia and their spousal carers residing in Western Australia. The research highlighted the knowledge gap between providers and receivers of care. Effective communication is central to quality dementia care and this research demonstrated that communication training with the CUES was feasible and acceptable to community-based support workers. The qualitative components of the research used to ascertain the diverse needs for people with dementia and their spousal carers was novel in that it addressed the engagement priorities of the ICF and supported a deeper and more holistic understanding and appreciation of such need. Interviews with service provider identified gaps between those with normative understanding and those with lived experience; however, the commonly expressed need for improved communication represented a key opportunity to trial the feasibility of communication training with the CUES. The mixed methods approach to determining the feasibility and acceptability of the CUES within communication training efficiently demonstrated the improved training outcomes and provided detailed explanations of the experiences of participants.

This research is the first to investigate the use of the CUES within the context of communication skills training for Western Australian community support workers. The findings have highlighted the importance of feedback and active engagement in training and the preliminary data from this research provides support for future investigation of communication training with informal carers of people living with dementia. The innovations from this research

endorse the need to ensure adequate funding for more dementia research and effective knowledge translation of innovative research outcomes into practice and care provision.

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10-Jul-2020

Dear Mrs. Morrisby:

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