

**Co-design of an mHealth application for family carers of people with dementia to address needs related to the functional disability of their care recipients**

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**Co-design of an mHealth application for family carers of  
people with dementia to address needs related to the  
functional disability of their care recipients**

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## **Synopsis**

Functional impairment is a major problem for people with dementia. In most cases, family carers often provide care for functional disabilities without adequate knowledge and training. Smart-technologies are one means that may help family carers to improve their knowledge and training for functional disability care.

This study aimed to develop an mHealth (smartphone) application for family carers of people with dementia to address their needs related to the management of functional disabilities of their care recipients. A mixed-method study was undertaken in Australia using an iterative co-design process consisting of two phases: (1) needs assessment, including an online survey and individual in-depth interviews with carers, and health and information technology [IT] experts; and (2) the development of content and prototype of an mHealth application. This study was informed by adult learning theory.

The needs assessment phase aimed to identify family carers' needs concerning the provision of functional disability care and use of mHealth applications when seeking health information. First, an exploratory, descriptive study was conducted through an online survey. Family carers of people with dementia living in the community with a diagnosis of any type and stage of dementia were recruited through dementia support websites and social media.

In the survey, 166 family carers participated. The majority of family carers reported a moderate (54.2%) to high (37.3%) need for education concerning the provision of functional disability care. In the sample, 74.1% of respondents presented with a high level of carer burden, while 86.7% and 77% of respondents reported adequate health literacy and eHealth literacy levels. Almost all the respondents (98.8%) owned one or more smart-mobile devices. Just over half had experience using mHealth applications (51.2%). Approximately half the respondents (48.2%) stated that they had

used mHealth applications to achieve health behaviour goals. The factors associated with the need for education about functional disability care were age, education and eHealth literacy level. The factors associated with having mHealth applications were employment status, eHealth literacy level and need for education about functional disability care.

Following the survey, a qualitative descriptive exploratory study via in-depth interviews (in-person or by telephone) was undertaken. A purposive sample of family carers living in the community in Australia was recruited. Five child carers and five spousal carers participated. Four key themes were identified: (1) challenges that contribute to psychological distress and burden; (2) essential role of support systems in dementia care; (3) perception of information and educational needs among family carers, and (4) experiences and attitudes of mHealth applications as an educational and supportive resource.

In the next stage, individual semi-structured interviews were conducted with experts following an interview guide. A convenience sample of experts who had experience with dementia care (two aged care nurses, two physicians, two occupational therapists) and an IT expert who had experience with mHealth application development participated in these interviews. Before conducting the interviews, a summary report based on the results of the online survey and individual interviews with carers, including areas proposed for the potential mHealth application, was distributed among the experts. All participants reported that managing needs related to functional disabilities were challenging for family carers. The experts claimed that barriers, challenges and difficulties that were highlighted by carers were common for family carers who provided care in the community. The experts agreed that the proposed content for the mHealth application was appropriate to address carers' needs related to functional disability care. There was a concern, however, about the integration of a 'chat

room' due to the need for continuous professional moderation, and this idea was, therefore, abandoned.

In the co-design process, the triangulation of data from the needs assessment phase informed the content framework for the mHealth application. The application consists of three modules: (1) an overview of dementia and care, (2) managing daily living activities and (3) carers' health and well-being. In addition to text information, currently available evidence-based online resources (websites, PDF articles and videos) were linked to the educational content. A nurse educator, an experienced geriatric nurse, a physician and two family carers reviewed the content. Readability of the content was checked based on the Flesch-Kincaid Readability Formula. Professional IT engineers developed an Android-based application using Java and Android Studio. Users can log into the application through a Google or Facebook login. The application was named the "Dementia Support for Carers app". The application can be accessed through an Android-based smartphone or tablet. The co-design process helped to design and develop a new application for family carers based on the end user's real-world experiences and the opinions and expertise of the stakeholders. However, before releasing this application into the App store, it is noted that testing of feasibility is essential.

This thesis consists of seven chapters. Notably, chapters four to six present three published or submitted research articles reflecting the results of the online survey, interviews and the co-design process of the mHealth application, respectively. This dissertation does not include a traditional discussion chapter as each research article consists of a discussion of the results and the major findings of the study.

## **Statement of Originality**

This work has not previously been submitted for a degree or diploma in any university.

To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Sarath Rathnayake

November 2019

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## List of Abbreviations

Following is a list of terms and abbreviations used throughout the thesis.

<b>Term</b>	<b>Definition</b>
ADI	Alzheimer's Disease International
ADLs	Activities of daily living
AIHW	Australia Institute of Health and Welfare
app	Application
APVAST	Adaptive Paced Visual Serial Attention Task
BADLs	Basic activities of daily living
CJ	Cindy Jones
COREQ	COnsolidated criteria for REporting Qualitative research
CVI	Content validity index
DVA	Department of Veteran Affairs
eHealth	Electronic health
eHEALS	eHealth literacy scale
eLearning	Electronic learning
GADL	General activities of daily living scale
GU	Griffith University
HREC	Human Research Ethic Committee
HTML	Hypertext Markup Language
IADLs	Instrumental activities of daily living
ICT	Information and communication technologies
IT	Information technology
K-WH	Kruskal-Wallis H test
mHealth	Mobile health

MHIQ	Menzies Health Institute Queensland
MIT	Mentalising imagery therapy
mLearning	Mobile learning
M-WU	Mann-Whitney U test
n	Number of participants
NCSEM	The National Centre for Social and Economic Modelling
NMDA	<i>N</i> -methyl-D-aspartate receptor antagonist
NSW	New South Wales
PC	Pauline Calleja
QLD	Queensland
QOL	Quality of life
SD	Standard Deviation
SDK	Software development kit
SPSS	Statistical Package for the Social Sciences
SR	Sarath Rathnayake
RCT	Randomised control trial
SA	South Australia
SD	Standard deviation
TAS	Tasmania
UK	United Kingdom
UN	United Nations
USA	United States of America
WHO	World Health Organisation
WM	Wendy Moyle
ZBS	Zarit Burden Scale

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## Dissemination of Study Results

### Peer-reviewed publications

1. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia*, 18(7-8), 3091-3112.  
doi:10.1177/1471301218768903
2. Rathnayake, S., Moyle, W., Jones, C. J., & Calleja, P. (2019). Development of an mHealth application for family carers of people with dementia: A study protocol. *Collegian*, 26(2), 295-301. doi:10.1016/j.colegn.2018.07.006
3. Rathnayake, S., Jones, C., Calleja, P., & Moyle, W. (2019). Family carers' perspectives of managing activities of daily living and use of mHealth applications in dementia care: A qualitative study. *Journal of Clinical Nursing*. Advanced online publication. doi:10.1111/jocn.15030
4. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (in press). Family carers' needs related to management of functional disability in dementia care and use of mHealth applications in health information seeking: An online survey. *Collegian*.
5. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Co-design of an mHealth application for family carers of people with dementia to address functional disability care needs. Manuscript submitted for publication.

## **Conference presentations**

### ***Oral presentations***

1. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2017, September). *mHealth applications as an educational resource for family carers of people with dementia: An integrative review*. Paper presented at the Brain and Behaviour Conference, Griffith University, Brisbane, Australia.
2. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2018, August). *mHealth applications for family carers of people with dementia: An integrative review*. Paper presented at the National Nursing Forum, Australian College of Nursing, Gold Coast, Australia.
3. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019, June). *Use of mHealth applications in health information seeking among carers of people with dementia*. Paper presented at the International Council of Nurses Congress 2019, Singapore.
4. Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019, November). *Needs, barriers and challenges concerning providing functional disability care and use of smartphone applications: Experiences of family carers of people with dementia*. Paper presented at the 18<sup>th</sup> National Conference of Emerging Researchers in Ageing, Sydney, Australia.

### ***Invited presentation***

1. Rathnayake, S. (2019, June). *The development of a smartphone application for family carers of people with dementia to address needs related to functional disability care*. Paper presented at the 3<sup>rd</sup> Qilu International Young Nursing Scholars Forum, Shandong University, Jinan, China.

## **List of Approved Publications in This Thesis**

Section 9.1 of the Griffith University Code for the Responsible Conduct of Research (“Criteria for Authorship”), in accordance with Section 5 of the Australian Code for the Responsible Conduct of Research, states:

To be named as an author, a researcher must have made a substantial scholarly contribution to the creative or scholarly work that constitutes the research output, and be able to take public responsibility for at least that part of the work they contributed. Attribution of authorship depends to some extent on the discipline and publisher policies, but in all cases, authorship must be based on substantial contributions in a combination of one or more of:

- Conception and design of the research project
- Analysis and interpretation of research data
- Drafting or making significant parts of the creative or scholarly work or critically revising it so as to contribute significantly to the final output.

Section 9.3 of the Griffith University Code (“Responsibilities of Researchers”), in accordance with Section 5 of the Australian Code, states:

Researchers are expected to:

- Offer authorship to all people, including research trainees, who meet the criteria for authorship listed above, but only those people.
- Accept or decline offers of authorship promptly in writing.
- Include in the list of authors only those who have accepted authorship
- Appoint one author to be the executive author to record authorship and manage correspondence about the work with the publisher and other interested parties.
- Acknowledge all those who have contributed to the research, facilities or materials but who do not qualify as authors, such as research assistants,

technical staff, and advisers on cultural or community knowledge. Obtain written consent to name individuals.

Included in this thesis are four papers, in Chapters 2, 4, 5, and 6, which are co-authored with my supervisors. My contribution to each co-authored paper is outlined at the front of the relevant chapter.

## **Chapter 2**

### ***Published***

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia, 18*(7-8), 3091-3112. doi:10.1177/1471301218768903

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## **Chapter 4**

### ***Accepted for publication***

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (in press). Family carers' needs related to management of functional disability in dementia care and use of mHealth applications in health information seeking: An online survey. *Collegian*.

## **Chapter 5**

### ***Published***

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## **Chapter 6**

### ***Submitted***

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Co-design of an mHealth application for family carers of people with dementia to address functional disability care needs. Manuscript submitted for publication.

Appropriate acknowledgements of those who contributed to the research but did not qualify as authors are included in each paper.

(Signed)

(Date) 12/11/2019

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# **Chapter 1 Introduction**

## **Introduction**

Functional impairment is one of the major problems for people with dementia. In most cases, it is the family carers who provide care for the functional disabilities of people with dementia, and without adequate knowledge and training. Smart-technologies are one means that may help family carers to improve their knowledge of and training in functional disability care. This PhD study examined the needs, barriers and challenges of family carers concerning the provision of functional disability care. Additionally, an mHealth application was designed and developed to address the needs that were found. This chapter provides an introduction and background to this study, including the significance of the study, research aims and questions, an outline of the thesis and a conclusion to the chapter.

## **Population ageing and epidemiology of dementia**

Population ageing is a global phenomenon driven by demographic changes as a result of falling fertility rates and an increase in life expectancy (United Nations [UN], 2017; World Health Organisation [WHO], 2015). In 2017, there were 962 million people aged 60 and over, comprising 13% of the world population, and projected to reach 2.1 billion by 2050 and 3.1 billion by 2100 (UN, 2017). Parallel to this demographic transition, a transition in epidemiology has occurred with a growing concern for chronic and degenerative diseases (WHO, 2011a). Dementia is one of the major chronic and degenerative problems in older age that causes disability and dependency. Over 50 million people are living with dementia worldwide (Alzheimer's Disease International [ADI], 2018), and this number is estimated to increase to 82 million by 2030 and 152 million by 2050 (WHO, 2017). According to ADI (2018), the worldwide cost of

dementia is estimated to be US\$1 trillion. Consequently, dementia can be considered a global health problem.

Australia is a country that has experienced an increased number of people with dementia. According to Dementia Australia (2018), currently 447,115 Australians are living with all forms of dementia, and without a major medical breakthrough, it is estimated that this number will increase to 1,076,129 by 2056. Dementia is the second leading cause of death (5.8% of all deaths in males and 11.3% of all deaths in females each year) (Australian Bureau of Statistics, 2018), the single greatest cause of disability in older people and the third leading cause of disability burden overall in Australia (Dementia Australia, 2019). The estimated cost of dementia in Australia in 2018 was more than \$15 billion, and it will be more than \$36.8 billion by 2056 (Dementia Australia, 2019). Consequently, Australia faces great challenges in meeting the health and social needs of people with dementia.

### **What is dementia?**

Dementia is defined as “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” (WHO, 2016b, pp. F00-F03). The essential feature of dementia is memory impairment (Shadlen & Larson, 2013), and a diagnosis of dementia requires that at least two core mental functions be impaired enough to interfere with daily living (Mayo Foundation for Medical Education and Research, 2017). According to the ‘Clinical Practice Guidelines for Dementia in Australia’ by Laver et al. (2016), the diagnosis for dementia is a systematic approach that includes patient and informant history taking, cognitive assessment, medication review, blood tests and computed tomography or magnetic resonance imaging to exclude other cerebral pathologies. Laver et al. (2016) further states that people with dementia need to

have one or more impairments of the areas of memory, communication, attention, thinking and judgement.

Dementia has three symptom categories: (1) neuropsychological changes (memory impairment, aphasia, apraxia, agnosia, attentional difficulties, and impairments in executive functioning, such as difficulties with abstraction, cognitive flexibility, inhibition, planning, organizing, and adaptation to novel stimuli); (2) neuropsychiatric problems with behavioural disturbances (depression, paranoid ideation, delusions, hallucinations, aggression, and wandering); and (3) deficits in activities of daily living (ADLs) (Grand, Caspar, & Macdonald, 2011). Based on the manifestation of symptoms, there are three stages of dementia: mild, moderate and severe. Forgetfulness, losing track of time and becoming lost in familiar places are the common symptoms of the mild stage (WHO, 2017). Becoming forgetful of recent events and people's names, becoming lost at home, difficulties in communication and behaviour changes, such as wandering and questioning, are common symptoms of moderate dementia (WHO, 2017). In mild dementia, deficits in ADLs are evident in a number of areas, but the person can function with minimal assistance; while in moderate dementia, functional deficits are more obvious and severe, and more assistance is required to maintain daily functioning at home or in the community (Draper, 2011). In the late stage, near-total dependency and inactivity can be seen (WHO, 2017), and affected people develop an almost total dependence on another person for ADLs (Draper, 2011). Other symptoms include becoming unaware of the time and place, difficulty in recognising relatives and friends, and difficulty walking, and people in this stage may display behavioural symptoms such as aggression (WHO, 2017). Thus, dementia can be identified as a complex progressive condition that has a wide variety of clinical challenges.

Dementia is categorised into two major groups: irreversible dementia and reversible dementia. Irreversible dementia incorporates the major syndromes with progressive symptoms and includes Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia (a combination of Alzheimer's disease, vascular dementia and Lewy body dementia) (WHO, 2017). Other conditions related to dementia are Pick's disease, Huntington's disease, traumatic brain injury, Creutzfeldt-Jakob disease, human immunodeficiency virus disease and Parkinson's disease (WHO, 2016b). Reversible dementia may be associated with cognitive or behavioural symptoms; however, these symptoms do not sufficiently meet the clinical criteria for the major syndrome of dementia (Tripathi & Vibha, 2009). The most common causes are depression, adverse effects of drugs, drug or alcohol abuse, space-occupying lesions, normal pressure hydrocephalus, metabolic conditions, endocrinal conditions (hypothyroidism) and nutritional conditions (vitamin B12 deficiency) (Tripathi & Vibha, 2009). Currently, there is no cure for dementia, and the focus of treatment is to slow the progression of the disease and enable the person with dementia to live well (Brooke, 2016). Currently, both pharmacological and non-pharmacologic approaches are used in the management of dementia.

### **Caring for people with dementia within the family: Role of the family carers**

Dementia is one of the significant problems which causes disability and dependency in old age (Singh, Hussain, Khan, Irwin, & Foskey, 2014). With the increasing number and severity of symptoms, daily functioning and participation in social activities become increasingly difficult for people with dementia (Zwaanswijk, Peeters, Beek, Meerveld, & Francke, 2013). As a result, they may seek help from others, and the primary supportive persons are usually informal carers because the majority of people with dementia live in the community (Wimo et al., 2013).

Informal carers, usually family members, are unpaid, and they provide ongoing help to a person living in the community who cannot care for themselves (Australia Institute of Health and Welfare [AIHW], 2012). According to the National Centre for Social and Economic Modelling [NCSEM] (2017), around 83% of all males with dementia (148,224) and 71% of females with dementia (157,699) live in the community in Australia, and approximately 46% of those living in the community receive informal assistance. According to the most recent data, in 2011, 42% of the carers of a person with dementia were spouses or partners and 44% were sons or daughters (AIHW, 2012). It is estimated that 81% of the primary co-resident carers and 42% of non-resident informal carers of people with dementia living in the community provide 40 or more hours of care per week (AIHW, 2012).

Families are recognised as the primary support for an individual with a chronic problem (Bamm & Rosenbaum, 2008), and the majority of people with dementia are reliant on family carers to maintain their independence and dignity (Xiao et al., 2014). Usually, family carers participate in the decision-making process concerning the provision of care for their care recipients (Digby & Bloomer, 2014), and they often provide physical and emotional support (Bastawrous, 2013), including assisting with the supervision of prescribed treatments, evaluation of physical changes, planning of the care recipients' daily routine, normalising this routine within the bounds of impairment and assisting with activities of daily living (ADLs) (Smale & Dupuis, 2004). This support relationship is the leading indicator behind the well-being of people with dementia (Singh et al., 2014). Without this help, people with dementia would need institutional care more quickly and may have a poorer quality of life (QOL) (Brodaty & Donkin, 2009). Therefore, quality carer support from the family is an essential factor to meet the care needs of people with dementia.

## **The burden of dementia on carers and needs for educational support**

Carer burden is a multi-facet concept, and there is a lack of consistency and rigour in defining the term 'carer burden' (Bastawrous, 2013). It encompasses the physical, psychological, emotional, social and financial stresses that individuals experience due to their caregiving role (George & Gwyther, 1986). Due to the complex nature of the problem, providing care for a person with dementia is a complex process, and family carers have to carry out complex tasks that they usually have not previously undertaken. Most of these tasks are similar to those carried out by professional carers and may be unpleasant, uncomfortable, psychologically stressful and physically exhausting (Foster, Herring, & Doron, 2014; Schulz & Martire, 2004). The role of the carer often results in loss of leisure time, reduced time for meeting friends and social isolation (Chaudhuri & Das, 2006). Empirical evidence shows that carer burden is a highly prevalent problem among family carers of people with dementia (Abdollahpour, Nedjat, Salimi, Noroozian, & Majdzadeh, 2015; Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014; Muangpaisan et al., 2010; Svendsboe et al., 2016). The major factors associated with the development of carer burden include a lower level of cognitive function, recurrent behavioural and emotional problems and disabilities in the ADL of care recipients as a result of providing long hours of care, social isolation, inadequate income, and age and gender of the carers (Leggett, Zarit, Taylor, & Galvin, 2010; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Yu, Wang, He, Liang, & Zhou, 2015). This problem is associated with the risk of development of comorbidities, productivity impairment, and greater resource use, poor health, wellbeing and QOL (Etters, Goodall, & Harrison, 2008; Farina et al., 2017; Goren, Montgomery, Kahle-Wroblewski, Nakamura, & Ueda, 2016; Svendsboe et al., 2016). Consequently, carer burden can be identified as a major problem for family carers of people with dementia.

Due to the complexity of dementia care, carers require greater knowledge and information to help their care recipients as well as to cope with their problems. However, the literature indicates that carers of people with dementia receive insufficient information from primary care providers as well as from available online sources (Peterson, Hahn, Lee, Madison, & Atri, 2016), and responding to the lack of education about dementia is a priority need of this population (Car et al., 2017). Recent evidence indicates that the support systems for carers of people with dementia living in the community remain limited (Bakker et al., 2013; Lloyd & Stirling, 2011), and they often demonstrate a lack of knowledge about services available in the community (Black et al., 2013; Lai & Chung, 2007). A recent Australian study revealed that the provision of information in the early stages of dementia, a lack of information for nonmedical support services and a lack of understanding of the needs of informal carers were essential aspects that need to be addressed (Singh et al., 2014). Therefore, it is essential to provide additional support for family carers to look after their family members with dementia living in the community.

### **Functional disability following dementia**

In addition to cognitive impairment and psycho-behavioural problems, functional disability is a significant indicator in the complexity of dementia care. This is a common reason for the loss of independence of people affected and a major part of the disease process. Functional disability can be defined as an inability to independently perform daily living activities (Carmo, Oliveira, & Morelato, 2016), and it leads to increase the assistance required to manage daily living activities over time due to the cognitive and physical impairment (Laver, Dyer, Whitehead, Clemson, & Crotty, 2016).

There are two groups of ADLs: basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs). BADLs are the fundamental skills needed to manage basic physical needs, for example, grooming, dressing,

toileting/continence, transferring/ambulating and eating (De Paula et al., 2014; Mlinac & Feng, 2016). IADLs are more complex activities related to independent living in the community, for example, abilities including using the telephone, shopping, food preparation, housekeeping, doing laundry, transportation, medication and handling finance (De Paula et al., 2014; Dolai et al., 2013). De Paula et al. (2014) have categorised ADLs into three groups (i.e., ADL self-care, ADL domestic and ADL complex). They referred to BADLs as ‘ADL self-care’ while dividing IADLs into two groups: ADL-domestic (doing minor household tasks, using the telephone, preparing meals and washing clothes and laundry) and ADL-complex activities (Managing finance, running simple errands, the responsibility of own medication and using transport). Usually, impairment in IADLs develops in the early stages of dementia and impairments in BADLs increase along with the progression of dementia (Mlinac & Feng, 2016; Nip, Lee, & Kwok, 2010). The assessment of functional disability is usually based on the measurement of difficulties in performing BADLs and/or IADLs (Andrieu et al., 2007) and these measures have been widely used (Chen et al., 2015; Millan-Calenti et al., 2010; Velázquez-Brizuela et al., 2014).

### **Impact of functional disability on the well-being of people with dementia and their family carers**

As dementia is a progressive disorder, there is a steady deterioration of the functional abilities that are necessary to live independently. The problems related to functional abilities of people with dementia are compounded by cognitive impairment, and those problems contribute to resistance to care (Rathnayake et al, 2019a; Van Rossum & Koek, 2016; Volicer, Bass, & Luther, 2007). People with dementia require assistance with ADLs leading to increased nursing care needs (Giebel, Sutcliffe, & Challis, 2015; Laver et al., 2016). Studies have found that functional difficulties are more prevalent among people with dementia (Andrieu et al., 2007; Charernboon &

Lerthattasilp, 2016; Gure, Kabeto, Plassman, Piette, & Langa, 2010; Kisoli et al., 2015), and this problem is one of the leading causes of the social and economic burden related to dementia (WHO, 2016b). It is positively associated with mortality in dementia (Barberger-Gateau et al., 2004; Verdan et al., 2014) and one of the main reasons for long-term institutionalisation (Afram et al., 2014; Eska et al., 2013). The evidence further shows that functional disabilities are associated with the development of depression and poor QOL of people with dementia (Giebel et al., 2015; Hargrave, Reed, & Mungas, 2000; Velázquez-Brizuela et al., 2014).

Carers also have significant challenges in meeting needs related to the management of functional difficulties of people with dementia. They often assist with daily living activities, such as transferring, toileting, bathing, and feeding of their care recipients without formal training, which can lead to increased risk of physical injuries (DiZazzo-Miller, Samuel, Barnas, & Welker, 2014). This situation leads to the development of negative consequences in the life of the carers; for example, previous research has established that functional disability is associated with stress (Leggett et al., 2010), depression (Andrieu et al., 2007), carer burden (Andrieu et al., 2007; Brodaty et al., 2014; Kang et al., 2014; Leggett et al., 2010) and poor QOL (Abdollahpour et al., 2015). Consequently, functional disability can be identified as a significant issue that negatively impacts on the health and well-being of people with dementia and their family carers.

### **Addressing family carers' needs related to functional disability care**

As family carers are the primary supportive source for people with dementia living in the community, an understanding of their needs concerning functional disability care is essential, and it will help to plan educational and supportive interventions. However, recent literature suggests that family carers of people with dementia often report unmet needs (De Cola et al., 2017; Zwingmann et al., 2019), and one of their main unmet

needs is how to manage daily living activities (McCabe, You, & Tatangelo, 2016). DiZazzo-Miller et al. (2014) state that most research which focused on family carers needs to pay attention to the psychological health and overall well-being of carers, and there is little attention placed on needs related to providing care for ADLs. Recent systematic reviews also support this argument, and the outcomes which include carer burden, anxiety, depression, social support and overall well-being were the most targeted areas in interventions that focused on family carers of people with dementia (Dam, De Vugt, Klinkenber, Verhey, & van Boxtel, 2016; Godwin, Mills, Anderson, & Kunik, 2013; Parra-Vidales, Soto-Perez, Perea-Bartolomé, Franco-Martín, & Munoz-Sanchez, 2017). Consequently, there is a paucity of information on the needs of family carers of people with dementia concerning functional disability care needs and related interventions.

Few researchers have identified functional disability care as one of the major problems faced by family carers when providing dementia care. For example, Chan et al. (2010) reported that providing ADL care is very demanding, and provision of daily care 24-hours a day all-year care is one of the main sources of carer burden. Moreover, Brown and Alligood (2004) found that grooming, bathing, dressing, toileting, feeding and ambulating were challenging activities that need help from others. Griffiths and Bunrayong (2016) identified that providing toileting care was the most challenging activity for family carers, and the second most challenging activity to perform was transferring, and this led to the development of back pain.

Few researchers further explored the needs of family carers concerning individual daily living activities. Ball et al. (2015) acknowledged that family carers experienced difficulties and challenges in providing feeding and nutrition-related care, and this led to carer burden. This study further reported that family carers were uninformed and unsupported in relation to feeding and nutrition-related care. In another

study, Anderson, Rose, and Taylor (2016) recognised that family carers need education related to nutrition, including information on preparing meals and food choices, care recipients' lack of appetite and eating behaviours, and finding nutrition-related information. Bliss et al. (2013) explored family carers' needs related to incontinence and skincare. The main educational needs they identified were information required about skills and strategies related to incontinence care, medications, surgery, diet, fluid intake, incontinence modification behaviours, how to prevent skin damage, and available supportive devices. According to this study, one of the main challenges was managing resistance to toileting, particularly before going outside of the house.

Few researchers seem to have focused on the development and implementation of interventions to address family carers' needs concerning functional disability care. However, the following studies showed good outcomes. DiZazzo-Miller et al. (2014) tested the feasibility of a family carer training program for assisting with BADLs of people with dementia, and this program consisted of three modules: communication and nutritional care, including techniques of eating and feeding; toileting and transferring; and bathing and dressing, including grooming. The training program showed a significant improvement in knowledge of the family carers in the above areas. Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) conducted a randomised control trial (RCT) of home environmental interventions to assess the effect on efficacy and distress in carers and on daily functions of people with dementia. Their intervention included support by occupational therapists for carers in the everyday challenges faced at home, and this study reported a lesser decline in IADLs as well as reduced distress of carers. Additionally, Bliss et al. (2013) have developed educational and supportive materials to address family carers' needs related to incontinence and skincare.

## **Mobile technology and healthcare**

### **Electronic health (eHealth)**

According to the WHO (2019), eHealth refers to the use of information and communication technologies (ICT) for health. These health interventions are delivered through text messages, emails, monitoring devices, mobile applications, computer programs, podcasts and personal digital assistants (Hutchesson et al., 2015). They are widely used in healthcare, for example, long-term illness management (Joiner, Nam, & Whittemore, 2017; Sin et al., 2018), mental health (Stratton et al., 2017), health promotion (Hutchesson et al., 2015), geriatric care (Watkins & Xie, 2014) and nursing practice (Gustafson et al., 2012; Hochstenbach et al., 2017). These interventions have the potential to decrease healthcare costs and improve the effectiveness and quality of care by helping the diagnosis process, facilitating better communication and providing support in patient-centred care (Granja, Janssen, & Johansen, 2018). However, using ICT to promote health and as an aid in healthcare, eHealth requires a skill set or literacy of its own (eHealth literacy) (Norman & Skinner, 2006a), and eHealth literacy is defined as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving health problems” (Norman & Skinner, 2006a, p.1).

### **Mobile health (mHealth) and mobile learning (mLearning)**

Today, mobile technologies, such as mobile phones, smartphones, hand-held computers, including tablets, iPads and mini-notebooks or netbooks and personal digital assistants, are popular (Broderick et al., 2014; Hochstenbach et al., 2017), and such technology combines mobile communication and computation (Mosa et al., 2012). A growing tendency to use this mobile technology with its innovative application in addressing health priorities has generated a new field of eHealth known as mHealth

(WHO, 2011). mHealth can be defined as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices” (WHO, 2011, p.6). In the literature, the term ‘eHealth’ has been used interchangeably with the term ‘mHealth’.

These technologies help to provide personalised healthcare, disease management and services to patients and their family members, and they offer a flexible mode of communication between health workers and their customers (Kalem & Turhan, 2015). The main advantages of using mobile devices, such as mobile phones, in healthcare are that these are highly personal, intelligent, cost-effective, highly accessible and always with people (Fiordelli, Diviani, & Schulz, 2013; Handel, 2011). In a survey conducted by the WHO (2011b), the majority of member countries reported offering at least one type of mHealth service. Consequently, mHealth and related interventions can be identified as a well-known global strategy in healthcare.

Increased usage and the ownership of mobile devices and other portable and wireless devices have caused the development of a new landscape of technology in supporting learning (Hashemi, Azizinezhad, Najafi, & Nesari, 2011). This has evolved as mLearning, and it is a branch of eLearning. According to Crompton (2013), mLearning can be defined as “learning across multiple contexts, through social and content interactions, using personal electronic devices” (p.4). In mLearning, the learner can study anywhere at any time without a physical connection to cable networks (Augustus, 2015; Hashemi et al., 2011). The main advantage of mLearning is that users can access educational content or resources, tools and materials at any time from a mobile device.

### **mHealth interventions and smartphone applications**

In healthcare today, a number of mHealth interventions are used. Health call centres, healthcare telephone helplines, emergency toll-free telephone services, mobile

telemedicine, health surveys, surveillance activities, awareness-raising and decision support systems are some of the mHealth interventions (WHO, 2011). The smartphone health application is also referred to as an mHealth application and is one of the best examples of using innovative technology and mHealth in healthcare. mHealth applications can be defined as “electronic tools or technologies intended for use by consumers, by patients or family members, that interact directly with users for the management of their health or healthcare, and in which data, information, or other recommendations are tailored and/or individualised; the system may or may not link to a health professional or health system services” (Dyer, Kansagara, McInnes, Freeman, & Woods, 2012, p. 1). A recent systematic review found that there were more than 3,673 mHealth applications related to the most prevalent health conditions (Martínez-Pérez, Torre-Díez, & López-Coronado, 2013). These applications are rapidly emerging as an effective source of health information and patient self-management (Handel, 2011). Empirical evidence demonstrates that mHealth applications are useful in a wide variety of health fields, for example, patient and carer teaching (Sureshkumar, Murthy, Munuswamy, Goenka, & Kuper, 2015), chronic disease management (Kirwan, Vandelanotte, Fenning, & Duncan, 2013; Quinn et al., 2011), health promotion (Glynn et al., 2014), mental health (Kinderman et al., 2016), nursing education (Kim, Shin, Lee, Kang, & Bartlett, 2017) and medical education (Man, Nguyen, & Lin, 2014). A recent systematic review found that mHealth applications play a vital role in health education (Mosa et al., 2012) and, therefore, are an effective intervention in healthcare with a variety of useful features.

### **Health literacy and mHealth applications**

Recently, health literacy has become more of a concern in health education, and health education is directed towards improving health literacy. Health literacy refers to a person’s ability to find, comprehend and use basic information and resources in order to

make appropriate decisions related to his or her health (Fleisher, Bhatia, Margus, Pruitt, & Dahodwala, 2014). Lower health literacy is associated with increased healthcare costs, more medication errors, ineffective and undesirable patient-provider communication, and inefficient use of healthcare services (Zamora & Clingerman, 2011). Consequently, improving health literacy is an essential strategy to improve health outcomes of individuals.

Health literacy can be identified as one of the major communication issues concerning the effective use of mHealth applications (Kreps, 2017). People with low health literacy face challenges to understand and act on health information when mHealth applications are poorly designed (Broderick et al., 2014). Hence, usability is critical. The International Organisation for Standardisation (1998) defined usability as to what extent users can use any product in an effective, efficient and satisfactory way to achieve specific goals in a particular context. Therefore, in relation to mHealth applications, it is essential to match the messages conveyed through mHealth applications with the health communication needs, orientations and competencies of users (Kreps, 2017). However, evidence indicates that most mHealth applications provide health information that is difficult to understand and utilise for users (Kreps, 2017). Therefore, in the development of effective mHealth applications, the health literacy skills and abilities of the users and usability of an application need to be considered (Broderick et al., 2014; Monkman & Kushniruk, 2013). However, application designers and content developers give little attention to users' general literacy, health literacy and digital literacy levels (Boulos, Brewer, Karimkhani, Buller, & Dellavalle, 2014). Broderick et al. (2014) emphasised six strategies in the development of mHealth applications that are integrated with health literacy concepts: learning about users, writing actionable content, displaying content clearly, organising

and simplifying, engaging users and evaluating and revising. These strategies can be used in the development of mHealth applications.

### **Research aims**

This study aims to develop an mHealth application for family carers of people with dementia to address needs related to the management of functional disabilities of their care recipients.

### **Research questions**

1. What are the needs of family carers when managing functional disabilities of people with dementia?
2. How can the needs of family carers concerning the management of functional disability in people with dementia be addressed through an mHealth application?
3. How can family carers of people with dementia use an mHealth application effectively to learn and receive support for their caregiving role?

### **Significance and rationale of the study**

Difficulties in the management of ADLs is one of the major problems faced by people with dementia, which leads to dependency, long-term institutionalisation and poor QOL. Their carers have an important role in managing ADLs of their care recipients. With the progressive and complex nature of dementia, caring for people with dementia demands specific knowledge and training in the skills needed, but often family carers do not have adequate knowledge and skills related to dementia care and in particular to functional disability care (DiZazzo-Miller et al., 2014). Therefore, it is essential to develop user-friendly resources that can effectively connect carers with contextually relevant educational sources (DiZazzo-Miller, Pociask, & Samuel, 2013). However, availability of such services in the community, affordability due to high cost (most

available programmes are not covered by insurance), and accessibility due to transportation, convenient time and location are some factors which may negatively affect carers in finding such services (Davis, Shehab, Shenk, & Nies, 2015). To address these problems, mHealth applications can be introduced as a helpful educational intervention for carers due to their availability, affordability and accessibility. Therefore, this study aims to develop an mHealth application for family carers of people with dementia to address needs related to the functional disability of their care recipients.

mHealth applications as a self-directed mLearning resource have distinct advantages compared with other methods, such as traditional learning or eLearning interventions. The organisation of traditional learning programs, such as face-to-face learning, requires several facilities and resources, for example, travel costs, availability of facilitators or trainers, scheduled times, venues and other related resources (Sissine et al., 2014). Also, both teachers and learners need to be physically present, and sometimes this may lead to content overload among trainees due to the limited time for learning. Information using mHealth applications can be made available and easily accessible online (Handel, 2011) and can provide real-time, demand-driven communication (Boulos et al., 2014); therefore, use of mHealth applications is a practical method to provide education for widely dispersed groups, such as family carers, because any person from urban, rural or remote areas can access mHealth applications.

Furthermore, online learning strategies are more sustainable than traditional didactic training (Sissine et al., 2014). Compared with written materials, mHealth applications provide an opportunity to combine audio, video and visual components and to link other data sources, such as YouTube and websites, adding additional advantages. mHealth applications further allow online materials to be printed. In addition, mobile

devices, where applications are used, are becoming smaller, lighter and less expensive (Wang & Liu, 2009); therefore, they are very convenient. Compared with eLearning, mLearning has several advantages, such as greater accessibility, lower prices compared with desktop computers, smaller size and weight and greater learner engagement (Giebel et al., 2015). However, there are some drawbacks related to mHealth applications, for example, usability issues, such as the user not having the knowledge to manage the application, possible cost relevant to development, maintenance and regular updating and issues related to health literacy (Boulos et al., 2014). Regardless of the existing draw-backs, mHealth applications could be an effective method to deliver education for family carers of people with dementia.

This study will generate new knowledge about needs related to the management of functional disabilities of carers of people with dementia, the use of smartphones in health information seeking and factors related to the development of an mHealth educational application for family carers. This knowledge will guide the development of an mHealth application for family carers of people with dementia concerning the management of functional disabilities of their care recipients. This application may be an important intervention for carers to improve their knowledge, skills and attitudes towards caring. Interacting with the potential mHealth application may help to decrease carer burden and improve well-being and QOL of family carers. The findings will also contribute to new knowledge; hence, this knowledge can be used by other researchers and health professionals to develop interventions for people with dementia and their carers.

## **Structure of the thesis**

This thesis consists of seven chapters:

**Chapter one** consists of the introduction and background to this study, including context, significance of the study, research aims and research questions of this study and structure of the thesis.

**Chapter two** provides a comprehensive integrative review of studies conducted to examine mHealth applications as an educational and supportive resource for family carers of people with dementia. It includes an introduction, a manuscript that has been published in the journal of *Dementia: The International Journal of Social Research and Practice*, and a conclusion to the chapter. Additionally, this chapter presents the theoretical framework used in this study.

**Chapter three** outlines the research methods and materials used in this study. This section includes an introduction to the chapter, study aims, objectives, instruments used, data analytical methods followed, application development process and ethical considerations related to this study.

**Chapter four** presents the findings of the online survey and related discussion. It includes the chapter introduction, a manuscript accepted in the *Journal of Collegian* and a conclusion to the chapter.

**Chapter five** consists of the results and related discussions of individual interviews with family carers of people with dementia and experts. It includes an introduction, a manuscript that has been published in the *Journal of Clinical Nursing*, a written report consisting of results and discussion based on the individual interviews conducted with experts and a conclusion to the chapter.

*Chapter six* presents the co-design process of the mHealth application development and related discussion, and it includes an introduction to the chapter, a drafted manuscript that has been submitted for publication and a conclusion to the chapter.

*Chapter seven* includes a brief overview of this study, including major results, the conclusions drawn from this study, the strengths and limitations of the study, recommendations for practice and further research, and future directions.

### **Chapter summary**

This chapter presented an introduction and background of the thesis. It consisted of a general overview of dementia, a general discussion on caring for people with dementia within the family, functional disability following dementia and carers' needs, and mHealth interventions particularly mHealth applications in healthcare. It further outlined the significance of this study. Finally, this chapter presented an outline of the thesis.

## Chapter 2 Literature review

### Introduction

This chapter presents an integrative review of the literature about mobile Health (mHealth) applications as an educational and supportive resource for family carers of people with dementia, including their uses, effectiveness, and relevant barriers and challenges in their development and implementation. The protocol for the integrative review has been registered in the International Prospective Register of Systematic Review (Rathnayake., Moyle., Jones., & Calleja., 2017). The chapter further includes the knowledge gap identified from this integrative review. An update of the literature from August 2017-July 2019 is also presented. Additionally, the theoretical framework followed in this study is presented.

### Purpose

The purpose of this chapter is to provide a critique of the literature concerning mHealth applications as an educational and supportive resource for family carers of people with dementia. The chapter consists of an integrative review published in the Journal of *Dementia: The International Journal of Social Research and Practice*.

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia, 18*(7-8), 3091-3112. doi:10.1177/1471301218768903

### **Statement of contribution to co-authored published paper**

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia*, 18(7-8), 3091-3112. doi:10.1177/1471301218768903

My contribution to the paper involved:

Conceptualising and designing the study, undertaking the systematic search, data extraction, analysis and interpretation, drafting and finalising the manuscript, and approval of the final version.

Minor modifications have been applied to the original publication to fit the thesis formatting.

(Signed)

(Date) 12/11/2019

Sarath Rathnayake

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External supervisor: Associate Professor Cindy Jones

## **mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review**

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review. *Dementia*, 18(7-8), 3091-3112. doi:10.1177/1471301218768903

### **Abstract**

Family carers encounter several challenges related to the care of people with dementia, and they need support in managing care recipients' health needs. This study aims to identify, appraise and synthesise the existing evidence on the use of mHealth/smartphone applications as an educational and supportive resource for family carers of people with dementia. An integrative literature review approach was used. Seven databases were searched. The search generated 117 articles, with seven meeting the inclusion criteria. Three categories and their attendant sub-categories emerged from the literature. The categories are 'carer support', 'evaluation strategies' and 'barriers and challenges.' mHealth applications appear to be a feasible intervention for family carers of people with dementia despite the limited available research and barriers for their development and implementation. Further research on mHealth applications with strong methodological rigour and more research on mHealth applications as an educational and supportive resource for carers of people with dementia are needed.

*Keywords:* carer, dementia, educational resource, integrative review, mHealth application

### **Background**

Dementia is one of the most challenging conditions in older age that impacts not only the people affected but also their families, carers, and society. It is a complex syndrome with progressive deterioration of cognitive functions and activities of daily living

(Grand et al., 2011). Globally, over 46 million people live with dementia, and this number is expected to increase to 131.5 million by 2050 (Alzheimer's Disease International [ADI], 2015). The global estimated cost of dementia in 2015 was US\$818 billion (ADI, 2015). The World Health Organisation [WHO] (2016a) recognises dementia as a public health priority and aims to focus on improving care and support for people with dementia and their carers.

People with dementia have a wide variety of clinical manifestations that require increased levels of care, most of which is provided by family carers (Brodaty & Donkin, 2009), who are usually untrained for this demanding role (Peterson et al., 2016). Family members are frequently the main source of support for the provision of physical, emotional, social, psychological and financial support (Bamm & Rosenbaum, 2008; Janzen, 2001). However, they encounter several challenges related to the care of people with dementia. Empirical evidence indicates that carers of people with dementia present with moderate to high levels of burden (Abdollahpour et al., 2015; Medrano, Rosario, Payano, & Capellán, 2014; Muangpaisan et al., 2010) as well as burnout, anxiety, depression, hopelessness and poor quality of life (Bandeira et al., 2007; De Oliveira, Vass, & Aubeeluck, 2015; Medrano et al., 2014; Truzzi et al., 2012). Subsequently, they often need additional support, especially in seeking information about dementia, how to cope with symptoms of dementia, how to deal with behavioural problems and how to find support systems (Zwaanswijk et al., 2013). Studies have found that carers receive insufficient information related to managing problems of their care recipients (Livingston et al., 2010; Peterson et al., 2016). They may have limited education and care skills related to dementia as well as insufficient coping skills and limited information about available support services in the community (Black et al., 2013; DiZazzo-Miller et al., 2013; Karpathiou, 2015; Lai & Chung, 2007; Scott, Lewis,

Loughlin, & Chambers, 2005). Consequently, it may be beneficial to develop user-friendly educational resources for carers of people with dementia.

In recent history, there has been a rapid increase in the use of mobile technology in health. This unprecedented use of mobile technology with its innovative applications in addressing health needs has generated a new field called mHealth (WHO, 2011). mHealth or mobile health is defined as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices” (WHO, 2011, p. 6). The use of mobile technology in healthcare is advantageous because these devices are highly personal, intelligent, cost-effective, highly accessible and always with people (Fiordelli et al., 2013; Handel, 2011). The smartphone is the most attractive and well-known mobile device in mHealth (Lee, 2016) that combines mobile communication and computation (Mosa et al., 2012).

mHealth/smartphone applications are applications designed for smartphones and are rapidly emerging as effective health information sources (Handel, 2011). A recent systematic review found that there were more than 3,673 mHealth applications related to the most prevalent health conditions, for example, diabetes, asthma, depression, hearing loss, low vision, osteoarthritis, anaemia and migraine (Martínez-Pérez et al., 2013). A systematic review by Mosa et al. (2012) reported that the major areas addressed through mHealth applications were disease diagnosis, drug reference, medical calculations, literature search, clinical communication, hospital information system client applications, medical training, medical and nursing education and chronic disease management. Moreover, recent studies have found that mHealth applications are effective in a wide variety of health fields, for example, patient education (Sureshkumar et al., 2015), chronic disease management (Kirwan et al., 2013; Quinn et al., 2011), health promotion (Glynn et al., 2014), mental health (Kinderman et al., 2016), nursing

education (Kim et al., 2017) and medical practice (Man et al., 2014). As the use of mHealth applications rises, it is both timely and appropriate to review the literature on mHealth applications as an educational and supportive resource for carers of people with dementia. Exploring new knowledge related to the design, development and effectiveness of mHealth applications for carers of people with dementia will help to plan future mHealth interventions.

### **Review questions**

This integrative review aims to identify, appraise and synthesise the existing evidence on the use of mHealth applications as an educational resource and support for carers of people with dementia in order to answer the following questions:

- a. What is the contribution of mHealth applications as an educational resource and support for carers of people with dementia?
- b. What are the related barriers and challenges in the development and implementation of mHealth applications for carers of people with dementia?

### **Method**

#### **Design**

In this study, an integrative literature review approach using the framework of Whittemore and Knafl (2005) was used. Whittemore and Knafl (2005) claim that an integrative literature approach allows for the simultaneous inclusion of qualitative and quantitative studies in order to more fully understand the phenomenon of interest and combines data from the theoretical as well as empirical literature. The protocol for the integrative review has been registered in the International Prospective Register of Systematic Reviews (Rathnayake et al., 2017).

## **Literature search**

Seven electronic databases were searched: MEDLINE, CINAHL Plus with Full Text, Cochrane Library, PsycINFO (via Ovid), Embase, Scopus and PubMed. Search terms were organised into three conceptual areas: dementia OR Alzheimer\* AND carer\* OR caregiver\* OR famil\* OR spous\* AND “smartphone application\*” OR “mobile health application\*” OR “mHealth application\*” OR “smartphone app\*” OR “phone app\*”, “mobile app\*” OR “mobile health app\*” OR “mHealth app\*” OR “handheld computer\*” OR “personal digital assistant\*”. The mesh terms included were “dementia”, “Alzheimer’s disease”, “caregivers”, “spouses”, “family”, “smartphone”, “mobile application”, and “computer handheld”. Keyword searches were performed on title, abstract and keywords using Boolean (see Appendix A). The reference lists of selected articles were searched further to find any additional relevant articles and none were found.

## **Inclusion and exclusion criteria**

In this integrative review, peer-reviewed, full text, journal articles published in English from 2007 to 2017 and related to mHealth applications for carers of people with dementia were included. Articles were included if they were related to the evaluation of mHealth applications or identified possible barriers and challenges in developing and implementation of mHealth applications. This review excluded editorials, trial registration materials, technical notes and articles that only described the content development process for an application without a clear discussion of the study methodologies. Furthermore, articles discussing interventions that were based on other features of smartphones, such as text messaging or tracking systems were excluded.

## **Search outcomes**

The literature search combining the mesh terms, specific terms and keywords, found a total of 117 articles, including 10 from PubMed, 15 from Medline, 19 from CINAHL Plus with Full Text, two from Cochrane Library, six from PsycINFO (via Ovid), 25 from Embase and 40 from Scopus. After removing duplicates, 66 titles and abstracts of each information source retrieved were assessed for inclusion and exclusion criteria. Based on the preliminary review of the title and abstract content, 26 sources which did not meet the study inclusion criteria were excluded. Finally, a total of 40 articles were included in the full-text review using the same inclusion criteria. Three authors (SR, CJ & PC) reviewed content for appropriateness for inclusion. The initial average Kappa value showed 0.696, indicating substantial agreement among the three authors (McHugh, 2012). Any discrepancies were discussed, and seven articles which satisfied the inclusion criteria were included in the final analysis (Figure 2.1).

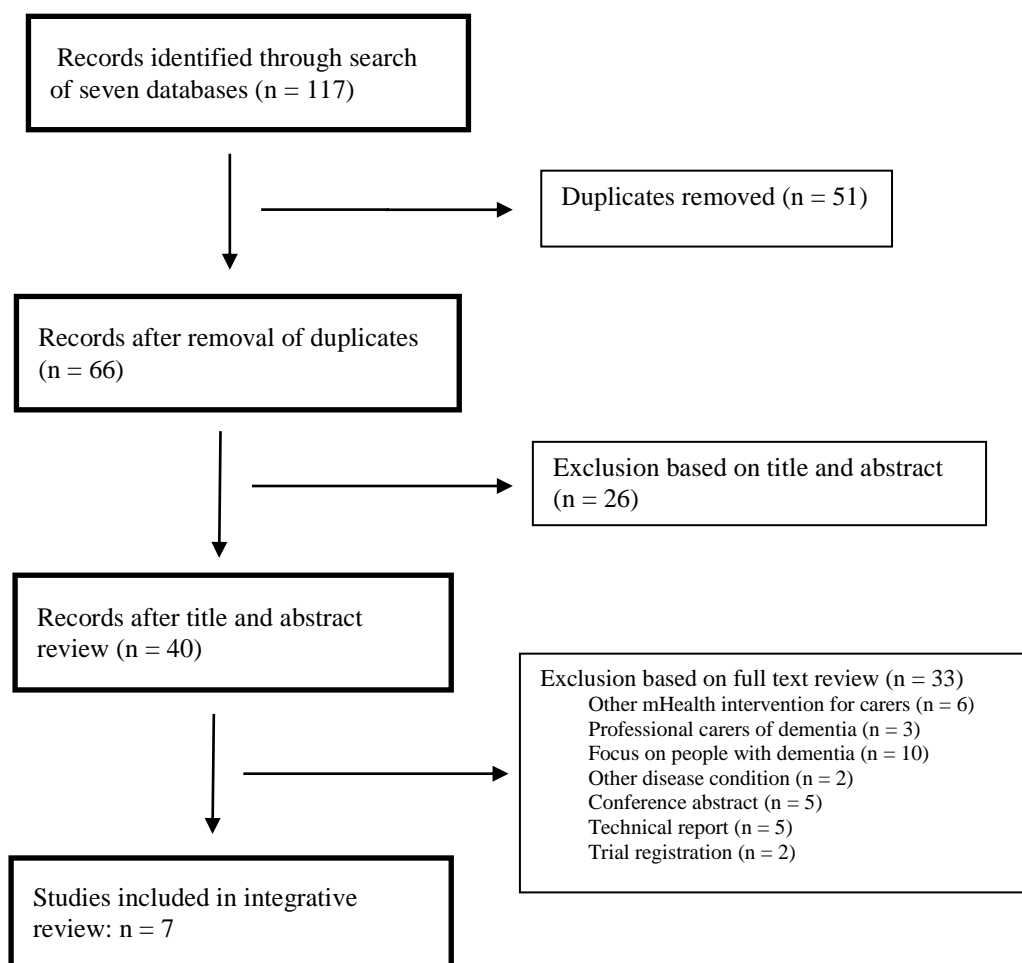


Figure 2.1: Integrative review flowchart: Selection of studies

### Data extraction and quality appraisal

Information from all included articles was entered into an Excel data spreadsheet, including authors, publication year, country, title, study aims, research methods and key findings. Based on the review questions and literature, two broad categories were identified: evaluation of the efficacy of mHealth applications and barriers and challenges experienced in relation to the development of applications. The quality of the primary sources was evaluated using a method suggested by Whittemore and Knafli (2005). The primary sources were coded according to two criteria relevant for the study: (1) methodological rigour and (2) data relevance (Whittemore & Knafli, 2005).

Methodological rigour was assessed based on the Mixed Methods Appraisal Tool-Version 2011 (Pluye et al., 2011) by three authors (SR, WM & CJ). Two studies

showed a moderate level of methodological rigour (Brown et al., 2016; Callan et al., 2016), and the others had poor rigour (Cho et al., 2016; Davis, Nies, Shehab, & Shenk, 2014; Davis et al., 2015; O’Connor, Bouamrane, O’Donnell, & Mair, 2016a; Reyes, Camargo, & Díaz, 2016). Data relevance was assessed based on a two-point scale (high or low) (Whittemore & Knafl, 2005). All included articles recorded high information values; therefore, they were included in the review.

### **Data synthesis**

As this integrative review includes both qualitative and quantitative studies, a narrative analysis was conducted as a way to integrate the identified evidence. The data was systematically organised using a data spreadsheet and was then compared and contrasted by two authors (SR, WM) to identify visible patterns and relationships between the studies. This process involved the identification of key evidence centred on three predetermined categories that are based on the review questions and literature: ‘carer support’, ‘evaluation strategies’ and ‘barriers and challenges.’ Sub-categories were generated based on the evidence identified under the major categories (see Table 2.1).

*Table 2.1: Categories and sub-categories*

<b>Categories</b>	<b>Sub-categories</b>
<b>Carer support</b>	Carer education Monitoring Cognitive training
<b>Evaluation strategies</b>	Feasibility testing Outcome assessment
<b>Barriers and challenges</b>	Technology barriers Literacy barrier Time barriers

## **Results**

### **Study characteristics**

Of the seven included articles, the oldest was from 2014. A summary of the selected articles is presented (see Table 2.2). Two papers were based on the same study, which focused on the design and piloting of a storytelling mHealth application for carers of people with dementia (Davis et al., 2014; Davis et al., 2015). Of the six studies, three were based in the USA and one each in South Korea, the United Kingdom (UK) and Colombia. The main objectives of the studies were design and testing feasibility of the applications and identifying related barriers and challenges. Of the selected articles, six of the articles discussed both design and evaluation of applications (Brown et al., 2016; Callan et al., 2016; Cho et al., 2016; Davis et al., 2014; Davis et al., 2015; Reyes et al., 2016), and one article identified the possible barriers and challenges with respect to the design of the applications (O'Connor et al., 2016a). The studies used either a mixed-method approach (Brown et al., 2016; Reyes et al., 2016), quantitative approach (Callan et al., 2016; Cho et al., 2016; Davis et al., 2014; Davis et al., 2015) or qualitative approach (O'Connor et al., 2016a). Only two studies used a theory in the development of the mHealth applications: family-centred theory (Brown et al., 2016) and resiliency model of family stress, adjustment and adaptation (Davis et al., 2014). A user-centred approach to design was followed by only two research groups (Brown et al., 2016; Reyes et al., 2016).

Table 2.2: Summary of the selected articles and methodological rigour

<b>Authors, Publication Year and country</b>	<b>Study aims</b>	<b>Theoretical framework</b>	<b>Research design</b>	<b>Setting and sample</b>	<b>Major findings/barriers and challenges</b>	<b>Methodological rigour (Pluye et al., 2011)</b>
Brown et al. (2016) USA	To evaluate the implementation of a newly developed mHealth application to provide information and support for carers of people with Alzheimer's disease or other forms of dementia.	Family-centred theory and user-centred design.	Mixed method-quasi-experimental feasibility study. Web-based carer survey, the primary care providers' survey and focus group discussion were conducted.	Community in collaboration with home healthcare agency. 11 carers of Alzheimer's disease, six case managers, and five primary care providers participated. The application was used for 11 weeks at home.	Ten out of 11 carers completed the survey. Six carers agreed or somewhat agreed that the application helped with their ability to organise and keep track of care recipients' health information. Five carers agreed or somewhat agreed that the application helped them to understand their choices and make better decisions about the health of care recipients. Five carers agreed that the application helped them feel more confident as they could figure out solutions when new situations or problems arise. Carers were satisfied or somewhat satisfied with the	Moderate

					<p>following sections of the application: carers' corner (n = 7), alert function (n = 7), assessment of behavioural and mood disturbances function (n = 7), and information about available services (n = 7). Carers reported the application was great (n = 6), easy to use (n = 7), and the tasks were straightforward (n = 7).</p> <p><b>Barriers and challenges</b> Having time to use the application with busy schedules, poor technical orientation among older adults, poor computer skills, fear of technology and lack of skills in using the application.</p>	
Callan et al. (2016) USA	To test the feasibility of administering a handheld computer-based self-administered	None reported.	Randomised control trial. Feasibility testing as a part of the trial. The application was used at least three	The primary carers of a spouse with dementia from the community were recruited through the Memory Disorders Clinic. 60	In the feasibility study, the minimum and maximum use of the application was 4 and 113 times. Twenty-two participants used it for at least 3 weeks (81.48%), and 15 participants used it for at least	Moderate

	cognitive training application (Adaptive Paced Visual Serial Attention Task) with minimal clinician intervention for spousal carers of people with dementia.		times per week for four weeks from weeks four to week eight.  Feasibility was measured by the frequency of and performance in using the application. Additionally, the level of worry, subjective stress, depression, anxiety, intrusive thoughts, and rumination, and sleep quality were assessed.	participants were recruited and randomised (i.e., 30 in the intervention group and 30 in the control group).  For feasibility testing, a subset of 27 people participated in the intervention group.	4 weeks (55.56%), demonstrating there was considerable regularity of use. Study results showed self-directed cognitive training was feasible through the application for spousal carers.  Based on the results of the RCT, the use of the handheld computer was not adversely associated with stress, worry and sleep quality. Use of the application (tasks performance) increased from the beginning to the end of the intervention.  <b>Barriers and challenges</b> Use of technology is a barrier to many older adults due to wide individual differences in age-related decline in cognitive abilities.	
Cho et al. (2016) South	To test the validity and usability of a	None reported.	Quantitative approach. A survey was	Setting not reported. Seventeen experienced users	The application focused on dementia testing, reviewing dementia test history and	Weak

Korea	healthcare application on wearable and mobile devices for carers of people with dementia and to evaluate its usefulness.		conducted to assess overall usefulness and satisfaction with the application.	participated in a survey following the use of the application.	<p>searching location of public health centres in the vicinity.</p> <p>None of the participants had tried a dementia screening test service previously. The majority of the participants indicated the application was easy to use. Dementia screening is more convenient through mobile applications than the traditional pen-and-paper type.</p> <p><b>Barriers and challenges</b> The small font size on the smartwatch and difficulties with understanding the questions.</p>	
Davis et al. (2014) USA	Developed a Story-Call smartphone application which allows participants to watch, record, and rate stories of success with	Resiliency Model of Family Stress, Adjustment and Adaptation.	Quantitative approach-pilot testing using pre-test post-test design.  Outcome measures were perceived as	Five female carers who are caring for community-dwelling people with dementia participated.	<p>Four participants completed the intervention.</p> <p>All participants stated that using the story call application would enable them to handle stress and family relationships more effectively and to find</p>	Weak

	<p>caring challenges, including personalised storytelling support, dementia care information, and community resources.</p>		<p>burden using the Zarit Short Burden Screen, and willingness to seek social support using Kaye's Gain through Group Involvement Scale.</p>		<p>community healthcare resources.</p> <p>High positive responses on Kaye's Scale.</p> <p>Learning to access and use the application seemed easy.</p> <p>Recommendations made under five areas: evaluation, recruitment, recruitment materials, augmentation of application and outreach enhancement.</p> <p><b>Barriers and challenges</b> None reported.</p>	
<p>Davis et al. (2015) USA</p>	<p>To pilot how well carers would be able to use minimal instructions to access the storytelling application prototype and successfully record stories</p>	<p>None reported.</p>	<p>Quantitative approach. Pilot testing with pre-test post-test design</p> <p>Outcome measures were perceived burden using Zarit Short Burden Screen,</p>	<p>Two-week pilot assessment in the community with five carers of community-dwelling older people to investigate the use of minimal instruction to access application prototype and successfully record</p>	<p>Four participants completed the intervention.</p> <p>Developed an interactive mobile application that records, archives, and presents a video by carers who share success stories about how they handle common dementia home care situations.</p>	<p>Weak</p>

	of their successes with dementia-care challenges.		and Willingness to seek social support using Kaye's Gain through Group involvement scale.	stories.	<p>The minimal directions enabled four of the five participants to easily access the mobile application, to record carers success stories, and to view others' stories. A desire for greater anonymity and security was voiced by all five. One participant withdrew, citing nervousness about being photographed as potentially leading to the availability of personal identification.</p> <p>Post-tests identified high satisfaction with the application and ease of use, and suggest that measuring outcomes for carer burden across a larger group will be feasible.</p> <p><b>Barriers and challenges</b> None outlined.</p>	
Reyes et al. (2015) Columbia	To develop a mobile application for	Theoretical framework- none	Quantitative approach.	This study focused on people with Alzheimer's disease	The application facilitates therapists and carers to track non-pharmacological	Weak

	<p>helping carers in non-pharmacological therapies to use with people with early and moderate Alzheimer's disease and to test its usability.</p>	<p>reported. User-centred design was used in designing the application.</p>	<p>To validate the proposed system, task completion with thinking aloud technique and questionnaire survey were used.</p>	<p>and their carers living in the community. Five carers evaluated the mobile application.</p>	<p>therapies and provide carers with a tool to control patient daily activities and, at the same time, to allow patients to perform cognitive exercises with the assistance of carers. It consists of a Reminiscence Therapy module, Reality Orientation Therapy Module, Psycho-Social Therapy Module and Cognitive Rehabilitation Therapy Module.</p> <p>Four participants completed the tasks correctly. One participant stated unclear instructions which were not descriptive enough in task completion.</p> <p>The following problems were reported by the participants: no direct access to the menu in 'my exercise' module; and the application does not have a return option in 'my calendar' module.</p> <p>Related to the terminology used in modules, the average</p>	
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					<p>rating was 4.825 with the best rating in ‘my memories’ module and worst rating in ‘my calendar’ module. All participants indicated the feasibility of the application for supporting therapeutic activities in people with Alzheimer’s disease.</p> <p><b>Barriers and challenges</b> Difficulty with some of the tasks, mostly on the location and absence of signage due to the inability to use the tablet computer.</p>	
O’Connor et al. (2016a) UK	To explore the barriers experienced by participants during the co-design of the ‘My House of Memories app’ which focus on sharing memories	None reported.	Qualitative exploratory case study design.	An in-depth focus group interview (n = 10) and individual interviews (n = 6) with people involved in the co-design of the ‘My House of Memories’ application, including four dementia patient-	<p><b>Barriers and challenges</b> Lack of digital literacy knowledge and skills among people with dementia and their carers were the main factors that affected the co-design of the application.</p> <p>Becoming familiar with the tablet computer and negative attitudes toward technology.</p>	Weak

	together for people with dementia and their carers.			carer dyads were conducted.	Difficulty understanding technical language by the software development team.	
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## Categories and sub-categories

### *Category 1: Carer support*

The first category “carer support” covers the main foci areas in the mHealth application studies. The following three sub-categories were identified: carer education, monitoring and cognitive training.

***Carer education:*** In the selected studies, the mHealth applications focused on providing education for the carers of people with dementia. In three studies, education was one of the main objectives for the development of the mHealth applications (Brown et al., 2016; Cho et al., 2016; Davis et al., 2014; Davis et al., 2015). Brown et al. (2016) focused on improving knowledge in relation to caring for people with dementia and carer wellness through an mHealth application, while Cho et al. (2016) focused on the status of the severity level of the problem and performing dementia screening tests to detect cognitive deterioration of the care recipients. In another study, learning from successful stories of the provision of care by carers through a storytelling application was used as an educational intervention to improve knowledge and skills of carers (Davis et al., 2014; Davis et al., 2015). This study reported that the application enabled the participants to handle stress and family relationships more effectively. Additionally, mHealth applications provided links to websites and contact information for local, state, and national caring resources and services as other important features (Brown et al., 2016; Cho et al., 2016).

***Monitoring:*** The main support interventions used in applications were the provision of psychological and emotional support for carers. The mHealth applications provided opportunities for monitoring carers’ burden and depression (Brown et al., 2016). The carer supportive mHealth application by Brown et al. (2016) featured a carer alert function to notify case managers to call or email the carer for non-urgent matters.

In addition, mHealth applications have featured monitoring of care recipients to assist carers. Maintaining care recipients' medication, observations related to memory and behavioural disturbances as well as sharing of records with care professionals were featured in the mHealth application developed by Brown et al. (2016) for carers of people with dementia. Reyes et al. (2016) developed an mHealth application which focused on the development of a system for supporting non-pharmacological interventions, including reminiscence therapy, reality orientation therapy, psycho-social therapy and cognitive rehabilitation therapy. In this application, carers can track non-pharmacological therapies and use these to manage a patient's daily activities while patients can perform cognitive exercises with the assistance of carers.

***Cognitive training:*** One mHealth application development study focused on testing the feasibility of hand-held computer-based self-administered cognitive training, called Adaptive Paced Visual Serial Attention Task, with minimal clinician intervention for spousal carers to manage their distress and improve coping. Self-directed cognitive training was found to be useful for spousal carers in problem-solving, coping and adaptation, planning, and persevering with goal-directed tasks (Callan et al., 2016).

### ***Category 2: Evaluation strategies***

The second category "evaluation strategies" incorporates the evaluation strategies involved in the design and implementation of the mHealth applications. In the process of mHealth application development, studies have focused on testing feasibility and assessing effectiveness based on outcomes.

***Feasibility testing:*** The mHealth application studies involving the development of applications consistently reported positive outcomes in feasibility testing. Three of the application development studies focused on the feasibility of the applications ( Brown et al., 2016; Callan et al., 2016; Reyes et al., 2016). In feasibility testing, the study period

varied from four weeks to 11 weeks. The main outcomes used in these studies were usability and user satisfaction, and the studies highlighted that users were satisfied and interventions were feasible. In a study by Brown et al. (2016), 11 carers of people with Alzheimer's disease participated, and usability tasks were performed with potential users before starting the feasibility study. The researchers assessed usability tasks, the utility of the application, the level of user satisfaction, the importance of the application, navigation and task completion. Participants perceived that the application was good, easy to use and tasks were straightforward. Callan et al. (2016) studied feasibility of a self-administered cognitive training application among 27 carers as a part of a RCT. User adherence was assessed through regularity of use of the application. They found that the hand-held computer-based application was feasible for cognitive training for spousal carers of people with dementia, and the use of the application was not adversely affected by stress, worry or poor sleep quality. Reyes et al. (2016) used the think-aloud technique with task completion and a questionnaire that focused on terminology, graphical content and usefulness of the mHealth application. In this feasibility study, five carers participated. The study group found that the application was feasible in supporting therapeutic activities in care recipients.

***Outcome assessment:*** There were no mHealth application studies evaluating education-related outcomes arising from the used of mHealth applications by carers of people with dementia. Three articles focused on evaluation of carer related outcomes and reported positive results in relation to use of mHealth applications in carers' activities (Callan et al., 2016; Davis et al., 2014; Davis et al., 2015). One RCT study found that the task performance by participants in the cognitive training application increased from the beginning to the end of the intervention period (Callan et al., 2016). One pilot study found that carers had a high willingness to seek social support (Davis et al., 2014; Davis et al., 2015). In addition, they found that the measurement of outcomes

for carer burden across a larger group would be feasible through an mHealth application intervention. Additionally, Cho et al. (2016) surveyed the overall usefulness of the educational and supportive application among experienced users and found that the application was easy to use.

### ***Category 3: Barriers and challenges***

The third category “barriers and challenges” outlines the barriers and challenges in relation to the development and implementation of the mHealth applications. The articles presented different barriers, and the following three sub-categories emerged: technology barriers, literacy barriers and time barriers.

***Technology barriers:*** Four studies highlighted carers’ lack of experience and skills in using an mHealth application was a major barrier to its use (Brown et al., 2016; Callan et al., 2016; O’Connor et al., 2016a; Reyes et al., 2016). Callan et al. (2016) postulated that use of technology was frequently presented as a barrier for many older adults due to their age-related cognitive decline. O’Connor et al. (2016a) found that carers faced problems with becoming familiar with tablet computers and from inaccurate perceptions of how carers use mobile technology. They further reported that negative attitudes towards technology were other important factors which limited carers’ participation in the design of the mHealth application. Brown et al. (2016) found that poor technical orientation and fear of technology among carers influenced the development and implementation of the applications. Furthermore, Reyes et al. (2016) identified that carers experienced difficulty with task completion, mainly in relation to the location, and absence of signage, which was attributed to poor skills in the use of tablet computers.

***Literacy barriers:*** The main literacy barriers include the lack of digital literacy knowledge and skills (O’Connor et al., 2016a). Small fonts used, for example, on a

smartwatch and questions that were difficult to understand added to the literacy barriers (Cho et al., 2016). In addition, Reyes et al. (2016) reported that one participant out of five stated that unclear instructions, which were not descriptive enough for task completion, affected correct completion of the tasks in the application. Additionally, one study found that software engineers faced difficulties in grasping the technical language in designing an mHealth application (O'Connor et al., 2016a).

***Time barriers:*** Two studies identified time as a barrier for engaging with mHealth applications. Brown et al. (2016) found that lack of time was one of the major barriers to accessing and using the application. This was mainly attributed to busy schedules and difficulties in using technology as a part of the carer's daily routine. Callan et al. (2016) also found negative views towards applications based on the time factor. They highlighted that carers initially viewed the mHealth application as a burden, i.e., as "just one more thing to do."

## **Discussion**

The aim of this integrative review was to identify, appraise and synthesise the existing evidence on the use of mHealth applications as an educational and supportive resource for carers of people with dementia. All seven articles included in this integrative review contained clear descriptions of the evaluation process of mHealth applications for carers of people with dementia or identified possible barriers and challenges to the development and implementation of the applications. Three out of the six studies were from the USA, and the oldest study was undertaken in 2014, indicating mHealth applications are relatively new and not a widely used intervention to educate and support carers of people with dementia. Although articles were appraised as having a high information value, their methodological rigour was poor or moderate and was a limitation of the studies. The use of theory in the process of intervention development is

crucial to increase the effectiveness of interventions (Craig et al., 2008), but only two studies reported the theoretical basis for the development of the applications. Furthermore, few studies have used a user-centred design in the development of applications. User input and feedback in a systematic manner can facilitate the development of effective user interfaces (Buller et al., 2013). This situation raises the need for rigorously designed studies with a clear theoretical framework that adopt a user-centred approach in the development of mHealth applications for carers of people with dementia.

This review resulted in three major categories and their attendant sub-categories, which may help in the planning of new mHealth applications and interventions for carers of people with dementia. The articles demonstrated that the mHealth applications were used for a wide variety of educational purposes, for example, improving knowledge in relation to caring for people with dementia, carer wellness, the severity level of the problem and performing dementia screening tests to detect cognitive deterioration. Although there is literature evidence that mHealth applications can be used for skill training (Gajecki et al., 2017; Srither & Lateef, 2016), in this review there was no focus on skill training through mHealth applications for carers. A recent systematic review found that mHealth applications play a very important role in health education (Mosa et al., 2012). However, in this review, the efficacy of educational applications was not evaluated or aligned with educational outcomes and was a limitation of those studies. In addition, the Mosa et al. (2012) review reported that mHealth applications were used for different purposes by carers of people with dementia. Some examples include monitoring of the psychological status of carers, monitoring of care recipients, and cognitive training for spousal carers.

The second category 'evaluation strategies' focused on different evaluative procedures involved in the designing and implementation of the mHealth applications.

The studies mainly focused on testing feasibility rather than an evaluation of the effectiveness of the mHealth applications. This is a major limitation of the studies. As mHealth applications interventions are relatively new interventions, assessing effectiveness is essential to validate the mHealth applications for carers. These studies consistently reported positive results for testing usability and user satisfaction, suggesting the mHealth applications were a feasible intervention for family carers of people with dementia. However, this review reveals a lack of high-quality research methodologies, such as randomised control trials, to evaluate the efficacy of mHealth applications. Making conclusions relevant to the outcomes of mHealth applications is difficult due to the limited assessment of outcomes. The inadequacy of the evaluative studies may be attributed to mHealth applications being a comparatively new intervention for modern healthcare and in particular for carers of people with dementia. This conclusion is supported by recent systematic reviews of modern technological interventions, such as computer and Internet-based interventions for carers of people with dementia (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014; Godwin et al., 2013; McKechnie, Barker, & Stott, 2014).

The third category 'barriers and challenges' examined the obstacles, barriers and challenges faced in the designing and implementation of the mHealth applications for family carers of people with dementia. These studies mainly focused on identifying the barriers related to the usability of applications. There was a lack of information that identified any challenges related to implementation, for example, system integration and network access (Gurupur & Wan, 2017). There is a need to address usability barriers in the design of mHealth applications. Problems with readability, small font size and the lack of digital literacy were some of the problems perceived by carers. People with low health literacy face challenges to understand and act on health information when mHealth applications are poorly designed (Broderick et al., 2014). It has been argued by

Boulos et al. (2014) that application designers and developers pay little attention to user's general, digital and health literacy level. Consequently, the health literacy skills and abilities of the users need to be considered in the development of effective applications (Broderick et al., 2014; Monkman & Kushniruk, 2013). The principles of universal design for learning provide a response to technology barriers via the adoption of multiple and flexible presentations, enabling the practice of tasks with different support as well as the provision of interesting and varied learning opportunities that stimulate learning (Dalton, 2017). In addition, keeping the user interface simple and selecting appropriate font type and size are important when designing a user-friendly interface for applications (Gurupur & Wan, 2017). Moreover, time limitation was another barrier reported in the use of mHealth applications even though there is literature evidence that mHealth applications can be easily accessible online (Handel, 2011) and can provide real-time, demand-driven communication (Boulos et al., 2014). Barriers to time limitations may be overcome as the learner sees the value and can use mHealth applications for information at any feasible time.

### **Limitations**

In this review, only publications published in English from seven databases were included, which may not take account of studies published in other languages. Grey literature was not considered.

### **Conclusions**

To date, mHealth applications are mainly used to improve the knowledge of carers of people with dementia, to monitor the health status of carers and any problems related to their care recipients as well as cognitive training for spousal carers. However, the use of mHealth applications in education and support for carers of people with dementia is in an early stage of development. The main impediments related to the development and

implementation of mHealth applications for carers of people with dementia are literacy and technology barriers, and time constraints. In spite of the difficulties reported of poor methodological studies to evaluate the effectiveness of mHealth applications for carers, the mHealth applications appeared to be a feasible intervention for carers of people with dementia. In particular, they will be useful if the barriers and challenges related to the development and implementation of mHealth applications for carers, such as literacy barriers and technology-related barriers in the use of applications, are addressed in any future developments. Further research is needed with not only stronger methodological rigour but the adoption of a user-centred approach in the development of mHealth applications as an educational and supportive resource for carers of people with dementia.

#### **Authors' contributions**

Conception and design: SR. Acquisition of data, analysis, and interpretation of data: SR, WM, CJ and PC. Manuscript preparation and the first draft of the manuscript: SR. Critical review and editing of the manuscript: WM, CJ and PC. All authors have read and approved the final manuscript.

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### **Declaration of Conflicting Interests**

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

### **Knowledge gap identified based on the literature review**

This integrative review found that there were a limited number of studies concerning mHealth application development and related interventions for carers of people with dementia. These studies poorly focused on carers' needs for functional disability care. The review further found that there was no Australian-based mHealth application interventions for the above population, particularly to address needs related to functional disability care. A lack of reporting of a theoretical basis of the studies and a lack of evidence related to the application of health literacy concepts and mHealth application development were identified. Finally, this review revealed that a poor methodological approach was used to examine the effectiveness of mHealth application interventions. Most studies were feasibility studies, and there was a poor focus on using RCTs.

### **Updates of the literature review**

The literature review for this study was updated based on the previous integrative review search strategy for the period from 1<sup>st</sup> September 2017 to 1<sup>st</sup> August 2019. This search found a total of 133 sources, including five from PubMed, 20 from Medline, 19 from CINAHL Plus with Full Text, two from Cochrane Library, four from PsycINFO (via Ovid), 42 from Embase and 44 from Scopus. A similar screening process was followed based on the similar inclusion and exclusion criteria. After removing duplicates, 93 titles and abstracts of each information source retrieved were assessed for the inclusion and exclusion criteria. Based on the preliminary review of the title and abstract content, 62 sources which did not meet the study inclusion criteria were

excluded. Finally, a total of 32 articles were included in the full-text review using the same inclusion criteria as the prior integrative review. Six articles which satisfied the inclusion criteria were included.

A summary of the selected articles is presented (see Table 2.3). Of the six included articles, four studies were based in the USA and one in Norway. The sixth article, a review article was from Yousaf et al. (2019). Four research studies used a mixed-method approach (Halbach, Solheim, Ytrehus, & Schulz, 2018; Hughes, Banerjee, Goodman, & Lawhorne, 2017; Sikder et al., 2019; Sourbeer et al., 2018), and one used a qualitative approach (Ruggiano et al., 2019). Halbach et al. (2018) used a user-centric approach in designing the mHealth application, and Ruggiano et al. (2019) used 'the technology acceptance model' in beta-testing of an mHealth application as their conceptual/theoretical framework.

Of the five research studies, only one study discussed the development process of an mHealth application (Halbach et al., 2018). All five studies focused on testing feasibility of the applications with informal carers, including testing usability and beta testing, indicating there was a lack of testing the effectiveness of mHealth applications, particularly using rigorous approaches, such as RCTs. The review article aimed to examine the available mHealth applications for people with dementia and formal and informal dementia carers (Yousaf et al., 2019). This review study found four primary studies that focused on educating and providing support for carers of people with dementia. One of these studies (Cho et al., 2016) has already been included in the published integrative review by the research team (Rathnayake et al., 2019b), and another study (Halbach et al., 2018) has been included in the current literature review update. Two other studies from the Yousaf et al. (2019) review included a study protocol of a feasibility study (Kernebeck et al., 2019) and a study that focused on professional carers of people with dementia (Thoma-Lürken, Bleijlevens, Lexis, &

Hamers, 2018). Based on the exclusion criteria, these two studies (Kernebeck et al., 2019; Thoma-Lürken et al., 2018) were excluded.

Similar to the published integrative review, providing education and support for carers was a major purpose of the mHealth applications. In two studies, providing education was the main purpose (Halbach et al., 2018; Ruggiano et al., 2019). Other supportive purposes included monitoring carers' stress and burden level (Hughes et al., 2017; Ruggiano et al., 2019), linking to available resources (Ruggiano et al., 2019), providing support for carers by delivering mentalising imagery therapy (MIT), including guidelines for practising guided imagery and mindfulness interventions (Sikder et al., 2019), and supporting carers to act upon symptoms, such as mood and agitation, collected by a tablet-based application (Sourbeer et al., 2018).

This literature update also identified several barriers and challenges related to the development and implementation of an mHealth application. Consistent with the published integrative review, technology-related barriers included the need for special skills in using mHealth applications, especially for older carers (Ruggiano et al., 2019), and attitudes related to the acceptance of technology in dementia care, for example, using the screen of smart-devices while providing direct care (Hughes et al., 2017). Similar to the published integrative review, other barriers included literacy-related barriers concerning the use of applications, such as small font size and navigation-related issues (Hughes et al., 2017), as well as time limitations for using mHealth applications in the caring role (Halbach et al., 2018; Hughes et al., 2017). Halbach et al. (2018) further state that time limitations lead to challenges in retaining participants when testing applications (i.e., feasibility studies), adding a challenge for completing research with this population. Additionally, this updated review identified possible frustration related to engagement with applications as a barrier when introducing mHealth applications. For example, Sikder et al. (2019) reported that

engagement with applications might cause an increase in carers' emotions. Finally, one study reported that the initial cost of development of the application is high (Halbach et al., 2018).

Table 2.3: Summary of the selected articles (updated literature review)

<b>Authors, Publication Year and country</b>	<b>Study aims</b>	<b>Theoretical framework</b>	<b>Research design</b>	<b>Setting and sample</b>	<b>Major findings/barriers and challenges</b>
Halbach et al. (2018) Norway	To develop and test the feasibility of an Android and iOS based mobile application for relatives of people with dementia.	User-centric design	<p>A mixed-method study.</p> <p>The content for the application was based on a literature search and available research studies.</p> <p>A field test was conducted. An online questionnaire consisting of questions related to their opinions and thoughts was completed after using the application at home. Users' experiences were explored through focus group discussions.</p>	<p>In the focus group discussion, 13 informal carers of people with dementia, including spouses, siblings, sons and daughters, grandchildren, and friends, participated.</p> <p>For field testing, a sample of 17 relatives of people with dementia from three municipalities participated.</p> <p>In follow-up focus groups, nine participants participated.</p>	<p>The focus group discussion identified the main areas that need to be covered in the application: medical and psychological issues, how to communicate with persons with dementia, legal and financial issues, practical advice for everyday challenges, and available municipality and related health services.</p> <p>Additionally, a number of recommendations for application development were given, for example, provision of just-in-time help-when and where the need occurs, organisation of information according to specific categories, user groups, level of competence, and knowledge, and provision of multimodal information</p>

				<p>through short videos.</p> <p>The application consists of lectures, images, videos. The main content topic included were “what is dementia”, “communication”, “change in behaviour”, “everyday help”, “environments and society”, “legal and financial aspects, rights”, “relief”, and “hospital”.</p> <p>In the field testing, the response rate was 37% (n = 7). Participants were satisfied with the content of the application except for municipality-relevant information. Six participants rated all lectures as clear and comprehensive (partly agree and entirely agree), and one rated the whole range of lectures as partly disagree or entirely disagree. The content was rated as quite relevant or very relevant except for municipality content by all participants. Audio and speech</p>
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				<p>version of the text was viewed as neutral, and participants suggested the need for high-quality speech synthesis. Another comment highlighted was the poor pronunciation of medical terms. However, participants found these videos as 'quite or very useful'. Other points highlighted by participants were missing content or not covering the entire area and sometimes in-depth content, and issues related to navigation.</p> <p>Based on the follow-up focus group discussion, in general, participants were satisfied with the application and found it quite useful. Most preferred areas were videos and self-reflection section. The large font size was highly appreciated. The reading aloud option was generally viewed as less successful, and the quiz option as less attractive.</p>
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					<p><b>Barriers and challenges</b></p> <p>The retaining rate of participants in field testing was low with the time limitation of participants with their tight schedules of caregiving. Cost related to the development of content, particularly videos.</p>
<p>Hughes et al. (2017) USA</p>	<p>To explore the feedback related to the examination of the feasibility of a gaming technology application (Carer Assessment Using Serious Gaming Technology-CAST) that assesses stress among carers of people with dementia.</p>	<p>None reported.</p>	<p>A mixed-method study.</p> <p>Usability testing was done.</p> <p>Semi-structured interviews and filling a questionnaire were done following the engagement with the application by carers.</p>	<p>Ten informal carers of people with dementia from a program run by the Miami Valley Chapter of National Alzheimer's Association.</p>	<p>The application focused on the assessment of carers stress related to two games (a word scramble game and blackjack), and it helps carers to assess their own stress.</p> <p>In usability testing, the CAST application was demonstrated, and participants engaged with gaming activity. Users' performance related to gaming activity was measured by recording users' gameplay behaviour (e.g., the time taken to unscramble a word). After gameplaying, a carer stress questionnaire was also filled in, and semi-structured</p>

				<p>interviews were conducted.</p> <p>Based on the semi-structured interviews, participants stated that CAST application was easy to understand, and nine reported easy to use. Eighty percent of participants wanted to use the application daily. In general, carers said that this application is helpful, mainly assisting with self-awareness in their caregiving role.</p> <p>Moreover, they identified the application as a stress-relieving method too. However, half of the sample reported some frustration related to gaming technology, for example, too small text in screen and need of too many clicks for playing scramble. Main suggestions given by carers were establishing a reward system in the application and adding a section for the care recipient.</p> <p><b>Barriers and challenges</b> Attitudes concerning using</p>
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					<p>technology in care.</p> <p>Small font size and navigation-related problems affect the usability of the application.</p> <p>Potential frustration related to engaging with the application.</p> <p>Time limitation to using application.</p>
<p>Ruggiano et al. (2019). USA</p>	<p>To beta test an Android and web-based educational and support application (Care IT) among informal carers of people with Alzheimer's disease and other related dementias. To explore carers' experience with using soft-ware and perception of existing soft-ware and potential features relevant to caregiving experiences. To</p>	<p>The technology acceptance model</p>	<p>A beta-testing study. A qualitative approach was used.</p> <p>Individual interviews and focus group discussion following the beta-testing of Care IT.</p>	<p>Thirty-six carers of people with Alzheimer's disease and other related dementias from the community-based organisation in Alabama (18 participated in focus group discussions and 18 participated in individual interviews).</p>	<p>In beta testing, demonstration of Care IT with its features was done, and participants were asked to use the features. Care IT was used as an example of using technology to support caregiving. Then follow up interviews and focus group discussion were done. The questions focused more on the functions of the application in general.</p> <p>Based on the interviews and focus groups, all carers reported having access to the Internet through a laptop, tablet or smartphone. Carers stated that they do not use technology typically in caregiving</p>

	<p>determine the needs for regional and cultural revision concerning rural African American carers.</p>				<p>activities. However, two-third of carers have used a word or Excel sheet to keep a list of medication or symptoms, and three carers have used smartphone applications in caregiving.</p> <p>The main themes were based on the usefulness of technology and ease of use. Carers stated that technology should have actual or potential usefulness to generate their interest in using those technologies. The main themes were “linking members of the care network”, “facilitating meaningful interactions”, “personalised technologies”, and “ease of use”. Carers said that technology needs to facilitate linking network of carers and care providers which facilitate mainly communication, medication management, and sharing own problems. Moreover, meaningful interaction with technology</p>
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					<p>was identified as an essential feature, for example, tracking and monitoring of care recipients through Care IT. Another important finding was the need for personalised technologies because carers had unique experiences concerning providing care to their care recipients. Therefore, they identified that ‘one-size-fits-all’ approach may not help them. Most carers view that technology-focused need to be easy to use for AD/RD carers.</p> <p><b>Barriers and challenges</b> Technology is a barrier for using the application, especially for older spousal carers.</p>
Sikder et al. (2019). USA	To test the feasibility and efficacy testing of a mobile application intervention that deliver	None reported.	A mixed-method feasibility study (an open-label trial), consisting of follow up online survey and semi-structured interviews.	Twenty-one family carers of people with dementia from the community participated. Participants were recruited via	<p>The application consisted of an audio recording of MIT practices, including guided imagery and mindfulness interventions.</p> <p>An iOS-based application was</p>

	<p>mentalising imagery therapy (MIT) for family carers of Alzheimer’s disease and related dementias.</p>			<p>Facebook and Internet flyer, and known carers pool at the University of California, San Francisco. All participants completed an online survey, and eight participants were interviewed.</p>	<p>used by family carers for four weeks.</p> <p>The main outcome measures included depressive symptoms and mood of the caregiving experience.</p> <p>Seventeen participants completed the intervention and were included in the analysis. Average use of application was 14 days (<i>SD</i> 10). After the intervention, this study found improvement in depression and mood. Average helpfulness of the application was 2.87 based on the scale from -5 to +5.</p> <p>The interviews revealed that the application was supportive, particularly in improving emotional and cognitive well-being, for examples, improving the ability to remain “centred” despite caregiving challenges, and helping to learn “not to get overwhelmed” by their emotions. Carers identified this application as a user friendly</p>
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					<p>and the feature of notification as a good reminder in their work.</p> <p><b>Barriers and challenges</b> Engaging the application (i.e., focussing on specific caregiving experience) led to arousing emotions of carers.</p>
Sourbeer et al. (2018). USA	To investigate the usability of an Android-based application that focused on gathering real-time data from the carers of people with dementia.	None reported	<p>A two-stage usability testing study. A mixed-method approach was used.</p> <p>In the first stage, the participants completed five tasks using tablets. Based on the potential usability problems, the application was modified, and this revised application was tested in the second phase using a modified task list. Additionally, the</p>	<p>Participants were recruited from a local Alzheimer's Association Support Groups for carers of people with dementia. Thirty and 16 carers participated in phase one and two, respectively. In phase two data analysis, 15 were included as one participated in both phases.</p>	<p>Based on the system usability scale (the threshold of usability score 70/100), 43% and 73% of carers rated application as usable in-phase one and two, respectively. However, this rating was not statistically significant based on the Pearson Chi-square test (<math>p = .057</math>). Based on the qualitative data, in phase one, most issues were related to application design, for example, finding the icons for navigation. In phase two, process-related issues were noted, for example, unclear how to rate the application based on a 1-10 scale.</p>

			researchers observed the task performance by carers.		<b>Barriers and challenges</b> None outlined.
Yousaf et al. (2019).	To identify and review the existing mHealth applications for people with dementia and their carers, and synthesise the evidence in dementia care based on these mHealth applications.	None reported	This comprehensive study consists of two approaches: 1. A comprehensive review of published research articles based on six databases. 2. Searching Apple and Google Play stores for available applications for people with dementia and their carers.	Not relevant.	One of the main groups (theme) identified was carer guidelines and included four research articles. The main focuses of these applications were providing educating and support for carers of people with dementia. The four studies are:  1. Cho et al. (2016). This article has already been included and discussed in the published integrative review.  2. Halbach et al. (2018). This article has been included in this updated literature review.  3. Thoma-Lürken et al. (2019). This study focuses on mHealth application for professional carers. 4. Kernebeck et al. (2019). This article is a study protocol.

## **Theoretical framework**

The mHealth application is an innovative intervention used in modern healthcare. As indicated in the integrative literature review, researchers have used these mHealth applications to provide education and support for family carers of people with dementia. The literature indicates that most family carers of people with dementia are adults, usually spouses, middle-aged adult children or children-in-law (Davies, Maio, Rait, & Iliffe, 2014). The current study focused on developing an mHealth application for family carers of people with dementia to provide education and support, especially for needs concerning the management of functional disability of their care recipients. As this study focused on developing an educational platform (i.e., mHealth application) for adult learners (i.e., family carers of people with dementia), the research approach was underpinned by adult learning theory (andragogy) (Knowles, 1980, 1984).

Knowles (1984) stated that the fundamental goal of andragogy is to enable people to take responsibility for their own learning through enlightened enquiry and an analysis of personal experience. Based on andragogy, there are five assumptions relevant to adult learning:

1. Concept of learner: As people mature, orientation changes from dependent to self-directed learning.
2. Role of the learners' experience: As people mature, they accumulate a growing reservoir of experience that becomes a rich resource for learning.
3. Readiness to learn: When adult learners experience something, their readiness to learn focuses on coping with real-life tasks or problems.
4. Orientation to learning: Learners view education as a process of competency development that helps to achieve their full potential in life (Knowles, 1980).
5. Motivation to learning: As people mature, the motivation to learn is internal (Knowles, 1984).

Moreover, Knowles (1984) introduced four principles relevant to adult learning:

1. Adults need to be involved in the planning and evaluation of their instruction.
2. Experience (including mistakes) provides the basis for the learning activities.
3. Adults are most interested in learning subjects that have immediate relevance to their job or personal life.
4. Adult learning is problem-centred rather than content-oriented.

When individuals become mature, their needs and capacity for learning become self-directed, and they identify their own readiness to learn and organise their learning around life problems (Knowles, Holton, & Swanson, 1998). Usually, adult learners have many responsibilities concerning family matters, work-life, childcare and domestic care (Cercone, 2008). As most family carers of people with dementia are adults (Davies et al., 2014), they have roles in addition to the caregiving role within the family. A person with dementia presents many challenges to the family, and this real-life situation influences family members' motivation and orientation to learn. With this role transition (Brown & Bond, 2016), carers often feel unprepared for the caring role (DiZazzo-Miller et al., 2013). Therefore, the orientation to this role focuses on the development of the necessary knowledge and skills to address their needs related to providing care for family members. Usually, in the initial stages, carers seek support from health professionals, and later they use their own experience and additional resources, such as Internet resources, in continuous learning (McDonald, McKinlay, Keeling, & Levack, 2016). As family carers are adult learners, they take responsibility for their own learning, and this self-directed learning leads to the development of their expertise in providing continuous care (McDonald et al., 2016).

Self-directed learning is a central concept in andragogy, which suggests the locus of control in learning lies with the adult learner (Lowry, 1989). An mHealth application can be used as a self-directed learning tool because mobile Learning

(mLearning) platforms are learner-centred (Ongus, Wafula, & Ruvuta, 2016), and mHealth applications provide demand-driven education (Handel, 2011). Knowles (1980) stated that adults bring a wealth of experience. Based on the principles of Knowles (1980), the development process of health interventions needs to start with the assessment of experiences of learners, because learning is successful when it is relevant and assists in current and future work (Knowles, 1984). Therefore, the assessment of family carers' needs related to functional disability care needs to be concerned with developing an mHealth educational application. This assessment helps designers to plan needs-based interventions. Moreover, according to the principles of Knowles (1984), learners (i.e., carers in this case) must actively participate in the phases of development and feedback needs to be obtained from the carers. Based on these concepts, an mHealth application was developed to focus on the needs of carers of people with dementia.

### **Chapter summary**

This chapter presented the literature about mHealth applications as an educational and supportive resource for family carers of people with dementia, including their uses, effectiveness and relevant barriers and challenges in development and implementation. mHealth applications are used to support carers, including for education, monitoring and cognitive training. The main barriers related to the development and implementation of mHealth application-based interventions for informal carers were technology, and literacy barriers, as well as time limitations. This review raises the need for robust methodologies to develop and test the effectiveness of mHealth applications for the carers. Additionally, the chapter included a discussion about the theoretical background (i.e., adult learning theory) followed in this study.

## Chapter 3 Methodology

### Introduction

This chapter describes the methods used according to the aim and objectives of this study. Outlined are the research aim, objectives and research questions, the design and research framework, data collection and data analysis methods used in the needs assessment phase, and the co-design process of the mHealth application. The ethical aspects related to this study are also presented.

The research protocol related to this study has been published in *Collegian: The Australian Journal of Nursing Practice, Scholarship and Research*.

- Rathnayake, S., Moyle, W., Jones, C. J., & Calleja, P. (2019). Development of an mHealth application for family carers of people with dementia: A study protocol. *Collegian: The Australian Journal of Nursing Practice, Scholarship and Research*. doi:10.1016/j.colegn.2018.07.006

### Aims and objectives

This study aimed to develop an mHealth application that addresses the needs of family carers of people with dementia related to the management of functional disability of their care recipients. The specific objectives of this study were to:

1. Identify the needs, barriers and challenges faced by family carers of people with dementia related to their care recipient's functional disability.
2. Identify the needs, challenges and barriers of family carers of people with dementia related to the development of an mHealth application.
3. Develop an mHealth application to address the needs of family carers of people with dementia related to the management of their care recipient's functional disability.

## **Research questions**

This research was accomplished in two phases and aimed to address the following research questions.

### **Phase I**

1. What are the needs of family carers when managing functional disabilities of people with dementia?

### **Phase II**

2. How can the needs of family carers concerning the management of functional disability in people with dementia be addressed through an mHealth application?

## **Research design**

To achieve the aims of this study and to answer the research questions, a mixed-method approach consisting of two phases was used. The two phases consisted of (1) a needs assessment (i.e., online survey and individual interviews with family carers and individual interviews with health and information technology [IT] experts) and (2) the development of an mHealth application, including content development and designing a prototype.

## **Justification of the mixed-method approach**

Mixed method studies are more comprehensive in their nature because they utilise different methods to answer the different aspects of the overall research problem (O’Cathain, Murphy, & Nicholl, 2007). This approach enables researchers to integrate different views to provide a broader understanding of the phenomenon of interest (McKim, 2017; O’Cathain, Murphy, & Nicholl, 2010), and the integration of findings increases the confidence and validity of the results and conclusions drawn (O’Cathain et al., 2010). Additionally, the practice of mixed methods helps to reduce the shortfalls of

using quantitative methods alone (O’Cathain et al., 2007). The literature indicates that a mixed-method approach is a best-suited method to design and to evaluate multi-phase complex interventions (Farquhar et al., 2013) because it allows researchers to obtain a comprehensive understanding about the phenomenon of interest to be designed or developed (Ågerfalk, 2013). Therefore, a mixed-method approach was selected to design the mHealth education application. However, there are some barriers to mixed-method studies compared with pure qualitative or quantitative studies. Mixed method researchers need additional time because they have to collect and analyse two different types of data (Creswell & Clark, 2017). They further require additional funding for supplies and for assisting with data collection and analysis (McKim, 2017). Additionally, they require knowledge and training in both methodologies; however, many researchers are not experts in both methodologies (McKim, 2017).

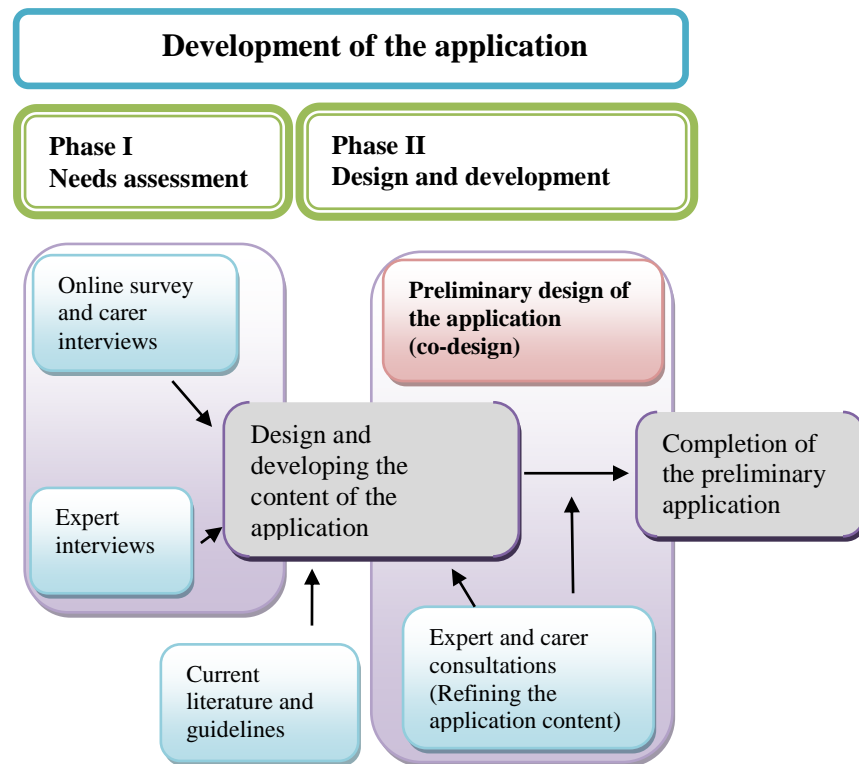
### **Setting**

This study was conducted in Australia. According to the The National Centre for Social and Economic Modelling [NCSEM) (2017), more than 413,106 Australians are living with dementia, and around 83% of males (148,224) and 71% of females with dementia (157,699) live in the community. Moreover, approximately 46% of those living in the community receive informal assistance. In 2011, 42% of the carers of a person with dementia were spouses or partners and 44% were sons or daughters (Australia Institute of Health and Welfare [AIHW], 2012).

### **Study framework**

Generally, the development of a well-planned health educational program includes three steps: needs assessment, program development and the evaluation of the effectiveness of the program (Kojuri et al., 2015). Based on this primary rule, the following framework was proposed (see Figure 3.1). The framework for this PhD illustrates two

phases in the PhD mHealth application development process: needs assessment and design and development of the application. Due to the PhD timeline and the amount of development required for the mHealth application development, the evaluation of effectiveness, the third step, will take place in a postdoctoral study.



*Figure 3.1:* mHealth application development framework (Modified from Rathnayake et al., 2019c).

### **Phase I: The assessment of needs related to the development of an mHealth application**

To address research question one, this phase aimed to assess relevant evidence related to the development of the mHealth application to address family carers’ needs related to functional care. This phase consisted of a survey and individual interviews with carers, and individual interviews with professional experts, including health and IT professionals.

## **Online survey**

### **Aim**

This study aimed to assess the needs of family carers of people with dementia concerning functional disability care and the use of mHealth applications in health information seeking.

### **Study design**

An exploratory, descriptive study was conducted through an online survey. The exploratory design helped to obtain insights and familiarity for the current status of the phenomenon of interest (Labaree, 2009). The exploratory approach is appropriate to explore information where no or inadequate information is available in the relevant research area of interest (Labaree, 2009).

An online survey has a number of advantages compared with a paper-and-pencil based survey or interview-based survey. Online surveys are more economical and time-efficient (Van Selm & Jankowski, 2006), and can be used to collect data from a population distributed across a large geographic region (Lefever, Dal, & Matthiasdottir, 2007; Van Selm & Jankowski, 2006), for example, family carers of people with dementia. Quick response is another important advantage of online surveys (Lefever et al., 2007). Data are stored electronically; therefore, they are readily available immediately to researchers (Eysenbach & Wyatt, 2002). Hence, it removes the need for data entry (Van Selm & Jankowski, 2006). Additionally, this method prevents interviewer bias (Van Selm & Jankowski, 2006). However, there are some limitations in online survey methods, for example, the need for Internet access and computer skills for completion, questions need to be simple and the need for a security system to ensure anonymity (Lefever et al., 2007). Representative sampling, response rates and the

generalisability of the findings are other issues related to the online survey method (Lefever et al., 2007; Van Selm & Jankowski, 2006).

### **Participants and sample size**

Participants for this survey were family carers of people with dementia living in the community in Australia. The family carers were informal, unpaid primary carers who were usually members of the immediate family but could be relatives, friends, and acquaintances who provided informal care at home for a person diagnosed with dementia, and were adults aged 18 years or older. In this study, a pragmatic approach (i.e., using websites and social media groups) was used to recruit the participants. There were 14 variables of interest in this survey; therefore, the minimum target sample was set as 140 (i.e., 10 participants per variable) (Hill, 1998).

### **Recruitment**

Participants were recruited using a non-probability convenience sampling technique (Van Selm & Jankowski, 2006) through dementia-related leading organisational websites in Australia (i.e., Menzies Health Institute Queensland, Dementia Australia Research Foundation and Carers QLD, NSW, SA, and TAS) and social media (i.e., Facebook and Twitter). In addition to the Facebook and Twitter accounts of the members of the research group, the carer groups available on Facebook were used for recruitment. This pragmatic approach gave more flexibility in the recruitment process.

### **Instrument**

Data for this survey were collected using a structured questionnaire designed with seven sections (see Appendix B). The student researcher (SR) developed the initial questionnaire based on the study aims, the background for this study and literature review. This draft was reviewed and revised by the supervisors (WM & CJ).

Disagreements were discussed, and a consensus was achieved to include the seven sections: demographic data, functional disability needs of care recipients, the educational needs of carers related functional disability care, carer burden, health literacy, eHealth literacy and the ownership of a smart-device and the use of the mHealth applications in health-seeking behaviour.

The questionnaire was developed using the LimeSurvey tool from the Griffith Survey Centre. Lime survey tool is a web-based, open-source survey application that has an easy-to-learn visual interface with advanced options, for example, question groups, user management, different question types and conditional questions, an ability to import and export questions, and automatic creation of printer version (Engard, 2009). This survey tool enables users to view and organise results into easily manageable data (Engard, 2009).

The online survey was pre-tested among four volunteers from the general population within a similar age group. Any feedback received from volunteers was incorporated into the final version of the questionnaire. No volunteers reported any difficulty in accessing the online questionnaire and answering the questions. No one reported difficulty reading or interpreting the survey questions. All questions were set in a mandatory mode to prevent incomplete responses. The survey took approximately 20 minutes to complete. Details of the seven sections are presented below.

### ***Section 1: Demographic data***

Section one consisted of socio-demographic questions about the carers in terms of demographic data, their current medical problems, relationship to the care recipient, the duration of caregiving, caregiving status and caring hours per week. The demographic data of carers included age, gender, marital status, highest educational qualification, current employment status and relationship to the care recipient. Additionally, this section included the information relevant to care recipients, such as care recipient's age,

the duration of dementia, the stage of dementia and the presence of other medical problems.

### ***Section 2: Functional disability needs of care recipients***

In this section, proxy-rated care needs related to the functional disability of people living with dementia were assessed by the General Activities of Daily Living Scale (GADL) (De Paula et al., 2014). This scale consists of 13 items under three groups of ADLs: ADL self-care (five items: bathing, dressing, toileting, transferring and feeding); ADL domestic (four items: doing minor household chores, using telephone, preparing meals and washing clothes and doing laundry); and ADL complex (four items: managing finance, running simple errands, responsibility of own medication and using transport). This scale shows good internal consistency of 0.849 (De Paula et al., 2014). Carers were asked to rate their ability to perform each of the tasks on a three-point Likert scale (0-dependent, 1-partially dependent and 2-independent). To describe the disability levels, the dependent and partially dependent categories were combined into one group called “dependent” where a zero score was allocated. A score of one was allocated if care recipients were independent. The total score ranged from zero to five for ADL self-care and zero to four for both ADL domestic and ADL complex. A score less than five for ADL self-care or four for ADL domestic and complex reflected the disability in GADL. Additionally, based on the activities listed in the GADL, carers were asked to indicate the most difficult ADL and IADL for them to assist their care recipients.

### ***Section 3: Educational needs of carers related functional disability care***

In section three, carers were asked about their perceived adequacy of knowledge to provide satisfactory care in relation to the 13 activities listed in the GADL (De Paula et al., 2014). To identify the educational needs of carers, a four-point scale was used

(1-inadequate, 2-needs improvement, 3-meets expectation, 4-exceeds expectation) with a score ranging from 13 to 52. A lower score indicates a higher need for education. To categorise the education needs of carers, 50% of total marks (i.e., 26 marks) was set for adequate knowledge, which was based on previous studies that used a similar cut-off point to categorise knowledge level (Liu, Li, Ratcliffe, & Chen, 2017; Qaddumi & Khawaldeh, 2014). A score of 26 and below (i.e.,  $\leq 50\%$  of the total marks) reflected a high need for education. In this study, a respective score of 27 to 39 (i.e., 51-75% of the total marks) and 40 to 52 (i.e., 76-100% of the total marks) reflected a moderate and low need for education.

#### ***Section 4: Carer burden***

In this section, carer burden was assessed by the four items-screening version of the Zarit Burden Scale (ZBS), which is a quick assessment of carers' current feelings of strain (Bédard et al., 2001). Correlations between the screening and the full version ranged from 0.83 to 0.93 (Bédard et al., 2001). Cronbach's alphas for the screening versions was 0.78. For scoring purposes, a five-point Likert scale was used (never-0, rarely-1, sometimes-2, quite frequently-3 and nearly always-4). A score above eight indicates a high level of carer burden (Bédard et al., 2001).

#### ***Section 5: Health literacy***

In this section, the health literacy level of carers was assessed by three health literacy screening questions: "*How often do you have someone help you read hospital materials?*"; "*How confident are you filling out medical forms by yourself?*"; and "*How often do you have problems learning about your medical condition because of difficulty understanding written information?*" (Chew, Bradley, & Boyko, 2004, p. 588). These three self-reported questions show high specificity for detecting inadequate health literacy in various populations (Chew et al., 2004; Chew et al., 2008; Wallace, Rogers,

Roskos, Holiday, & Weiss, 2006). For scoring purposes, a five-point Likert scale was used (never-1, occasionally-2, sometimes-3, often-4, and always-5) (Chew et al., 2004), and only for screening question two, reverse scoring was used (never-5, occasionally-4, sometimes-3, often-2, and always-1). Based on previous studies, the score was totalled and dichotomised: A score of 10 or greater was categorised as low health literacy and a score lower than ten as adequate health literacy (Levin, Peterson, Dolansky, & Boxer, 2014; Peterson et al., 2011).

### ***Section 6: eHealth literacy***

In section 6, eHealth literacy of carers was assessed by a validated self-reporting tool called the eHealth Literacy Scale (eHEALS) (Norman & Skinner, 2006b). The measure consists of eight items scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate higher eHealth literacy (total score range from 8 to 40). Based on the other studies, the cut-off for high eHealth literacy was set at 26 (Richtering et al., 2017; Tennant et al., 2015). The Cronbach alpha reliability in the original validation study was 0.88 (Norman & Skinner, 2006b).

There are two additional items in this tool that examine the perceived usefulness of the Internet to make health decisions and the perceived importance of accessing health resources on the Internet. These items were assessed based on a five-point Likert scale ranging from 1 (not useful at all) to 5 (very useful).

### ***Section 7: The ownership of a smart-device and use of mHealth applications in health-seeking behaviour***

Ownership of a smartphone/iPad/tablet was assessed by one question, “*Do you own a smartphone, iPad or tablet or smart-watch?*”. The use of mHealth applications for health information seeking consisted of four major areas: ‘having mHealth application’, ‘using applications for achieving health behaviour goals’, ‘helpfulness of applications

with medical care decision making’ and ‘using applications for asking a physician new questions or seeking a second opinion’ (Bhuyan et al., 2016). To assess the above four areas, the following questions were used: (1) *“On your smartphone or tablet, do you have any software applications or apps related to health?”*; (2) *“Does having the applications on your smartphone or tablet related to health help you achieve a health-related goal, such as quitting smoking, losing weight or increasing physical activity?”*; (3) *“Does having the applications on your smartphone or tablet related to health help you make a decision about how to treat an illness or condition?”*; and (4) *“Does having the applications on your smartphone or tablet related to health lead you to ask a doctor new questions, or to get a second opinion from another doctor?”* (Bhuyan et al., 2016. p.153). Answers were based on dichotomous categories of ‘yes’ or ‘no’.

Additionally, participants were asked about their willingness to participate in a personal interview and application development process. If they agreed, they were asked to leave their contact details (email address/contact number). A separate link for this survey was included in the main survey to assure the confidentiality and anonymity of the responses of the main survey.

### **Data collection**

Data collection was conducted between 1<sup>st</sup> of January 2018 and 1<sup>st</sup> of March 2018. The survey took approximately 20 minutes to complete. After obtaining ethics approval from the Griffith University Human Research Ethics Committee (Approval Number. 2017/947) (see Appendix C), an initial inquiry was sent to dementia support websites (i.e., Menzies Health Institute Queensland, Dementia Australia Research Foundation and Carers QLD, NSW, SA, and TAS). After receiving their approval, an invitation (see Appendix D) with a link to the written information sheet (see Appendix E) and the online questionnaire was distributed electronically. Moreover, the student researcher

(SR) obtained membership of Facebook groups specified for the carers of dementia and older people. The invitation with a link to the written information sheet and the online questionnaire was shared with those groups as well. Some Facebook groups allowed direct sharing. Some Facebook groups only allowed sharing the survey after obtaining permission from the administrators. Additionally, researchers distributed the invitation with a survey link through their social media accounts (i.e., Facebook and Twitter). Participants were able to complete the survey in multiple sittings where their responses could be saved and the survey completed at a later time.

### **Data analysis**

Data from the online survey were downloaded into and analysed using the Statistical Package for Social Sciences (SPSS) version 25 for Windows. With an online survey setting, a forced response option was set where participants were unable to submit if they had an incomplete item. Therefore, missing data was not expected. Descriptive statistics (e.g., frequency, percentage, means and standard deviation) were computed to characterise the sample based on demographic data, needs related to functional disability, carer burden, health and eHealth literacy levels, the ownership of smart-devices and the use of an mHealth application in health-seeking behaviours.

The Shapiro-Wilk test of normality was computed on the education needs score for functional disability care where the score was not normally distributed. The influence of socio-demographic variables and the level of health and eHealth literacy on needs of education for functional disability care and carer burden were computed by Mann-Whitney U test and Kruskal-Wallis H test, and mean rank was used to identify possible differences within categories in the above variables. The factors associated with having mHealth applications were assessed using Pearson's Chi-square test. The alpha level of significance was set at less than 0.05.

## **Individual interviews with carers of people with dementia**

### **Aim**

In-depth interviews (in-person or telephone interviews) were conducted to explore a supplementary understanding of the needs, problems, barriers and challenges faced by family carers relating to managing functional disabilities of their care recipients at home and using mHealth applications in health-seeking behaviours.

### **Study design**

A qualitative descriptive exploratory study was undertaken. The qualitative description basically helps to discover the 'who', 'what' and 'where' events or experiences and helps to gain an insight on poorly understood phenomena (Dempsey, 2008). This design helped to explore the needs of family carers of people with dementia concerning functional disability care and use of mHealth applications in health information seeking.

### **Participants and sample size**

Participants were the family carers of people with dementia living in the community in Australia. The family carers were unpaid primary carers who were usually members of the immediate family but included relatives, friends, and acquaintances who were aged 18 years and older and provided informal care at home for a person with dementia living in the community. Carers who self-reported as having psychological health problems, and/or difficulty in communication in English were excluded from participation in interviews.

In qualitative studies, the sample size varies from five to 50 (Dworkin, 2012) depending on whether the saturation of themes is sought. Guest, Bunce, and Johnson (2006) state that basic elements for meta-themes can be identified through six

interviews. A decision based on feasibility was made to interview a purposive sample of 10 carers who were caring for people with different stages of dementia.

### **Recruitment**

The online survey participants who consented to participate in an individual interview were invited via an email (See Appendix F) to take part in a personal interview.

### **Data collection**

Data collection was undertaken from February 2018 to April 2018. The 10 participants received written information sheets via email (see Appendix G). Nine carers participated in telephone interviews, while one carer participated in a face-to-face interview. In the face-to-face interview, written informed consent was obtained (see Appendix H). In telephone interviews, verbal consent was obtained before data collection. All participants completed a demographic data sheet either via telephone or in-person (see Appendix I). Participants were then interviewed by the student researcher. The participant who participated in a face-to-face interview was given a \$30 gift voucher to assist with transportation. All interviews were digitally-recorded with prior consent from the participants.

### **Interviews**

A semi-structured interview framework guided the interviews. The interview guide was developed based on the study aims and available literature (see Appendix J). The interview guide consisted of questions related to carers' experiences of the management of functional disabilities of people with dementia and the use of mHealth applications in health information seeking. Before starting the interview, the interviewer introduced functional disabilities (i.e., BADLs and IADLs). Carers were asked open-ended questions, for example, "*Could you please tell me what are the activities you find*

*difficult to perform for your family member?” and “Could you tell me the difficulties you face in providing support to your family member’s needs related to their daily activities?”*. At the end of each interview, they were asked to indicate whether they had anything else to add. All interviews were conducted at the premises of the School of Nursing and Midwifery, Nathan Campus, Griffith University, either in person or by telephone.

### **Individual interviews with health and information technology (IT) experts**

Semi-structured interviews were conducted to identify experts’ opinions on the provision of care, in particular, management of functional disabilities of people with dementia and the development of an mHealth application for family carers, including their understanding about existing smartphone-based interventions, attitudes towards mHealth educational interventions and possible barriers and challenges towards the development of an mHealth application.

### **Participants**

Participants were experts who had a minimum of 5 years of experience in providing dementia care or developing mHealth applications. A convenience sample of seven experts participated. Health experts included were healthcare professionals who were working in Australia and had experience in dementia care (e.g., aged care nurses, geriatricians, and occupational therapists). IT experts were engineers in IT who had experience with mHealth application development.

### **Recruitment**

Through the personal contact of the research team, the experts were invited via email (see Appendix K) or phone contact. Initially, 13 experts were invited (four aged care nurses, three physicians, three occupational therapists and three IT engineers). Seven

experts (two aged care nurses, two physicians, two occupational therapists and one IT engineer) expressed their willingness to contribute to expert consultation.

### **Data collection**

Written information (see Appendix L) about the study was sent via email to the experts who expressed their willingness to participate. One expert agreed to participate in a face-to-face interview while six experts participated in telephone interviews. Written informed consent (see Appendix M) was given by the expert who participated in a face-to-face interview. Verbal consent was obtained from other experts who participated in telephone interviews. Based on the results of the online survey and individual interviews with carers, a summary report was prepared by the members of the research team (SR, CJ and WM) (see Appendix N). It consisted of the overall findings of the online survey and individual interviews with carers and the proposed content for the mHealth application. An external expert in aged care nursing further reviewed this summary report. This summary report was circulated among all the experts, and they were asked to read it before the interview. They also filled a demographic data sheet before the interview (see Appendix O). The student researcher (SR) interviewed the experts. All interview sessions were digitally recorded with prior consent. All interviews were conducted at the premises of the School of Nursing and Midwifery, Nathan campus, Griffith University either in person or by telephone.

### **Interviews**

A semi-structured interview framework guided the interviews. The interview guide was developed based on the study aims (see Appendix P). It consisted of questions related to experts' experiences of the management of functional disabilities of people with dementia and the use of mHealth applications in providing education and support. They were asked open-ended questions, for example, "*What are the main difficulties you face*

*when managing/planning activities of daily living for people with dementia?” and “How do you view the family carers’ role in providing care in managing daily living activities of people with dementia?”. Additionally, they were asked about their opinion on needs, problems and barriers reported by family carers in online survey and interviews (i.e., executive summary report), for example, “What are your thoughts about the needs, barriers and challenges reported by family carers in the online survey and personal interviews relating to their management of daily living activities of people with dementia?” and “What are your thoughts about the educational and supportive needs reported by family carers in the online survey and personal interviews relating to the management of daily living activities of people with dementia?”. In the interview with IT experts, the questions focused on exploring their experience with mHealth application development, for example, “What are your thoughts about the content of the proposed mHealth application to help family carers manage daily living activities of people with dementia?”. At the end of each interview, they were asked to indicate whether they had any suggestions for further improvement of the proposed mHealth application.*

### **Data analysis (interviews with carers and experts)**

Using SPSS version 25, descriptive statistics (i.e., number and percentage) were used to report the participants’ characteristics of the two studies. Audio digital files were transcribed verbatim. Transcripts were compared with the original digital files for accuracy, and all personal identifiers were removed from the transcripts.

Inductive thematic analysis, according to the six steps stated by Braun and Clarke (2006), was used to analyse the data obtained from the interviews with family carers. This method facilitates an accessible and theoretically flexible approach to the analysis of qualitative data (Braun & Clarke, 2006). The six steps followed were:

1. Familiarisation of the data by reading and re-reading and noting down initial ideas.
2. Initial coding in a systematic way across the entire data set.
3. Recognising themes by grouping all data relevant to the potential theme.
4. Reviewing themes leading to the generation of a thematic map.
5. Giving clear definitions and names for the themes.
6. Producing a scholarly report based on the analysis (Braun & Clarke, 2006).

Following the reading and familiarisation of the transcripts, the student researcher (SR) and one of his supervisors (PC) conducted the initial coding of the first three transcripts. Consensus for elements disagreed on was reached with an additional supervisor (CJ). Based on the above codes, the student researcher completed the initial coding for the whole data set. When new codes were identified, these codes were discussed with the other supervisors (CJ & PC). The student researcher (SR) and the additional supervisor (CJ) familiarised themselves with the data by reading all codes and initial themes identified, which were then discussed with all supervisors (WM & PC). The discussion was continued among the team until consensus was reached and the final themes emerged.

In data analysis of qualitative interviews with experts, the student researcher (SR) and one of the supervisors (PC) conducted the coding. The consensus was achieved among the student researcher and the supervisor. The student researcher and supervisor (PC) familiarised themselves with the data by reading all codes, and initial categories were identified. Findings related to experts' views on functional disability care needs and use of mHealth applications in dementia care of family carers were reported descriptively. Results related to validation of the findings of online survey and carer interviews and suggestions for application development were integrated into the application development process.

## **Phase II: Design and development of the mHealth application**

In order to address research question two, this phase aimed to develop an mHealth application to address family carers' needs related to functional care consisting of two phases: the development of content for the proposed application and the technical development of application prototypes. This user-centric preliminary application was designed and developed following the iterative co-design process (Bate & Robert, 2006; Broderick et al., 2014; Ward et al., 2018) incorporated with the concepts related to developing a health literate mHealth application proposed by Broderick et al. (2014).

### **Co-design**

Co-design is the recent shift in product development (Ward et al., 2018). In co-design, service providers, consumers and designers work together to identify the problem and design a solution (Ward et al., 2018). To achieve the optimum effectiveness, all sectors work together by using their knowledge, resources and contributions (Loffer & Bovaird, 2013). In recent health interventions development, co-design has been widely used (Davies et al., 2016; Goeman, Dickins, Iliffe, Pond, & O'Keefe, 2017; Ward et al., 2018). In developing health interventions, the service suppliers (i.e., health staff), end-users (i.e., patients, families or carers), and intervention developers (e.g., IT experts) equally engage in designing a new intervention (Ward et al., 2018). In this study, this design technique was used to design the mHealth application for the family carers of people with dementia.

### **Framework for designing mobile health literate applications according to**

#### **Broderick et al. (2014)**

The design of the application content and a user-friendly interface for a mobile health application was guided by the framework proposed by Broderick et al. (2014). The framework consists of six strategies: 'learn about your users', 'write actionable content',

‘display content clearly’, ‘organise and simplify’, ‘engage users’ and ‘evaluate and revise your site’ (Broderick et al., 2014).

### **The development of the content for the application**

Aligned with the co-design process, the triangulation of data was carried out using data from the online survey and qualitative interviews with carers and the opinions from the experts, and the initial content framework was proposed. Consensus on the modules that need to be included in the application was achieved by the members of the research group (SR, CJ, WM and PC) who have extensive experience in dementia care practice/research, or/and education. Based on the carers’ needs, extensive literature review and evidence-based care guidelines, the sub-topics/areas that need to be addressed in the application were identified by the student researcher (SR). After an extensive review by the supervisors (WM and CJ), the final content framework was developed. Furthermore, based on the current relevant literature and evidence-based guidelines, detailed content was drafted by the student researcher (SR). The content was reviewed by the supervisors (WM and CJ) until consensus was achieved.

Readability of the text information was checked for the application content based on the Flesch-Kincaid Readability Formula (Kincaid, Fishburn, Rogers, & Chissom, 1975) using online-utility.org website ([https://www.online-utility.org/english/readability\\_test\\_and\\_improve.jsp](https://www.online-utility.org/english/readability_test_and_improve.jsp)). The content was drafted to have readability around grade eight because the average Australian reading level is considered as being grade eight (Cheng & Dunn, 2015). In content drafting, British English was used. The concepts related to developing a mobile health literate application proposed by Broderick et al. (2014) (e.g., ‘write actionable content’ and ‘plain language with everyday words’) were integrated. Arial font was used (Broderick et al., 2014). Arial is one of the popular mobile web-safe sans-serif fonts that is highly readable even on mobile surfaces (Broderick et al., 2014).

After finalisation of the content, it was further reviewed by a panel of experts, including a nurse educator who has extensive experience in educational methodology and research to meet the educational requirements, a geriatric nurse and a physician who have extensive experience in dementia care and two carers who participated in the online survey and qualitative interviews. Due to the PhD timeline and the lengthy time required for the mHealth application development, only five experts were able to be identified and included in the review process. The experts and carers were asked to rate the content for its appropriateness and clarity based on a four-point Likert scale from strongly agree (1) to strongly disagree (4) and to make any suggestions for further improvement. An overall rating of ‘disagree’ or ‘strongly disagree’ indicated a need for a major revision of the content, while an overall rating of ‘agree’ or ‘strongly agree’ reflected appropriateness and clarity of the content, with no changes required for the developed application content. Additionally, based on the rating of the five experts, a content validity index (CVI) was computed. A CVI > 0.80 was considered as adequate for content validity (Polit & Beck, 2006). Additionally, the reminder feature that focused on sending reminders through notification was included. Carers can set a notification/reminder for a particular task (e.g., time for giving medication), an appointment date or any events using the year calendar and 24-hour clock.

### **Designing and developing the application prototype**

An Android-based application was developed by professional application developers. After the initial face-to-face meeting, ongoing discussions were continued through telephone, emails and SMS messages until the completion of the application development process. In the initial meeting, the content, features and structure for the application were discussed. The application was developed in Android using Java and Android Studio. Google and Facebook login were used to access the application, and it linked to the user’s profile, including the details of the users. The modules and their

sub-topics were organised within the menu and sub-menus. The main menus were placed as a drop-down list under the home icon. Based on the framework for mobile health literate applications (Broderick et al., 2014), a simple and engaging home page was integrated. The user-friendly navigation features, such as ‘touch’ and ‘slide’ options, were included. Based on the consensus of the research team, the name for this application was proposed, and the student researcher (SR) designed the application logo under the direction of the research team and design experts.

### **Ethical considerations**

Ethical approval for the online survey was obtained from the Human Research Ethics Committee, Griffith University (GU-HREC Approval Number-2017/906) (see Appendix C) before data collection. Submission of the completed online questionnaire by participants reflected their implied consent. This requirement was included at the beginning of the online survey. A downloadable detailed written information sheet in PDF format was linked to the online survey. It consisted of a detailed description of the study, including the aims, the role of the participants, consent, potential risk and benefits and confidentiality. Participation in this study did not pose any foreseeable risks as participants were asked to answer questions related to needs concerning managing functional disabilities of care recipients and the use of mHealth applications in health information seeking, including the level of health literacy and eHealth literacy. Participants were informed that the information collected in this online survey was confidential and anonymous, and their participation was voluntary. They were further informed that there was no penalty for refusing participation in the study, and they could discontinue the survey at any stage of their participation. To ensure the confidentiality and privacy of participants, they were asked not to post any personal information or comments on the invitation post. The comments feature was disabled in

social media. If this was not possible (i.e., Facebook), the researcher monitored and removed all comment posts.

Prior to the commencement of the individual interviews with carers and experts, ethical approval for the main study, including interviews with carers and experts and the application development process, was obtained from the Human Research Ethics Committee, Griffith University (GU-HREC Approval Number. 2017/947) (see Appendix Q). In each stage, participants were assured that the information collected in these two studies was confidential and anonymous, and their participation was voluntary. They were informed that there was no penalty for refusing participation in the studies and they could refuse at any stage of the data collection period.

In interviews with family carers and experts, for each participant, a written information sheet in PDF format about the studies, including the nature of the studies, the aims, the role of the participants, informed consent, risk, benefits and confidentiality was sent via email before arranging the interviews. In the face-to-face interview, written informed consent was obtained, while in telephone interviews, verbal consent was obtained before data collection. There were no risks associated with participation in these studies as carers and experts were asked to answer questions related to their experiences in managing daily living activities of people with dementia and the use of mHealth application in health information seeking.

All data collection forms were given a code number. Coded information was used in data management. Data were stored in the student researcher's password-protected computer. The consent forms, data collection forms and verbatim transcripts will be stored in a locked filing cabinet at Griffith University, Menzies Health Institute, Queensland for 5 years before being destroyed. Digital-records were destroyed after completion of transcription.

The data collection forms in these studies were treated in a strictly confidential way. There was no personal identification information in the data. The data was managed by the student researcher (SR) with confidentiality measures adhered to throughout the study. Only authorised personnel (i.e., members of the research team) were permitted to access the data.

### **Chapter summary**

This chapter has discussed the methods and materials that were used in this study. A two-phase study was undertaken: needs assessment and the development of the application prototype. The needs assessment phase consisted of three studies: an online survey with family carers, individual interviews with family carers and individual interviews with experts. The findings of these studies were used in the second stage of this study, which consists of the design and development of the mHealth application for family carers of people with dementia. An Android-based application was developed by professional application designers. The health literacy concepts related to developing mHealth application proposed by Broderick et al. (2014) was used in formatting the content and designing the application.

## Chapter 4 Results and discussion-Online survey

### Introduction

This chapter presents the findings of the online survey conducted as a part of phase I of this study (needs assessment phase).

The objectives of this study were to:

1. Identify the needs, barriers and challenges faced by family carers of people with dementia-related to their care recipient's functional disability.
2. Identify the needs, challenges and barriers of family carers of people with dementia related to the development of an mHealth application.

Following these objectives, this chapter consists of a co-authored manuscript based on the results of the online survey conducted with family carers of people with dementia.

Within this manuscript, the findings of the online survey with family carers of people with dementia are reported. This paper has been published in *Collegian: The Australian Journal of Nursing Practice, Scholarship and Research*.

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (in press). Family carers' needs related to management of functional disability and use of mHealth applications in dementia care: An online survey. *Collegian*.

### **Statement of contribution to co-authored published paper**

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors are:

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (in press). Family carers' needs related to management of functional disability and use of mHealth applications in dementia care: An online survey. *Collegian*.

My contribution to the paper involved:

Critical review of the literature to inform the design of the study, conceptualising and designing the study, enrolment of participants, data collection, analysis and data interpretation, writing of the draft manuscript, revision of the manuscript for important intellectual content and approval of the final version.

Minor modifications have been applied to the original publication to fit the thesis formatting.

(Signed) (Date) 12/11/2019  
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**Family carers' needs related to management of functional disability in dementia care and use of mHealth applications in health information seeking: An online survey**

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**Abstract**

**Background**

Family carers of people with dementia face different challenges in providing care for daily living activities of their care recipients. Today, mHealth applications are widely used in healthcare.

**Aim**

To examine the needs of family carers of people with dementia concerning the management of functional disability of people with dementia, carer burden and use of mHealth applications when seeking health information.

**Methods**

A total of 166 family carers, who were recruited through leading dementia support organisations in Australia, research institutes, and social media, completed an online survey. In data analysis, descriptive statistics, Pearson's Chi-square test, Mann-Whitney U test and Kruskal-Wallis H test were used.

**Findings**

People with dementia were dependent on family carers for complex activities (e.g., taking medication) (99.4%), domestic activities (e.g., washing clothes) (97%), and

self-care (e.g., bathing) (79.5%). Family carers reported a moderate-to-high need for education in functional disability care (62.6%). Bathing was reported as the most difficult activity to perform (30.1%). Three-quarters of carers reported carer burden (74.1%). Most carers (98.8%) owned a smart-device, and 51.2% of family carers reported having an mHealth application. Educational needs for functional disability care were associated with age (highest among those between 36-65 years) and eHealth literacy of carers (greater among carers with adequate eHealth literacy). Carer burden was associated with stage of dementia (highest in advanced dementia) and experiencing chronic medical problems of care recipients. Possession of an mHealth application was associated with employment status (currently employed), adequate eHealth literacy and higher educational needs.

## **Conclusion**

Providing functional disability care is one of the priorities for education. These educational needs can potentially be provided via mHealth applications. Health professionals can use these findings to plan educational interventions to address carers' needs.

*Keywords:* Carer burden, dementia, family carers, functional disability, health literacy, mHealth application.

## **Summary of relevance**

### ***Problem***

Little is known about educational needs related to functional disability care and use of mHealth applications in health information seeking among family carers of people with dementia.

### ***What is already known***

Family carers provide functional disability care without adequate knowledge and skills. mHealth applications are widely used in healthcare.

### ***What this paper adds***

Family carers reported a moderate-to-high need for education in functional disability care. Bathing is the most difficult activity. Almost all carers owned a smart-device. Half of the carers use mHealth applications in health decision making. Carers' educational needs can potentially be provided via mHealth applications.

## **Introduction**

Dementia is a chronic and degenerative syndrome that occurs predominately in older age (World Health Organisation [WHO], 2019). It is characterised by deterioration in cognitive function, behaviour and the ability to perform daily living activities (WHO, 2019). Around 50 million people are living with dementia worldwide, and this figure increases by nearly 10 million every year (WHO, 2019). The cost of dementia care is high, with the worldwide cost of dementia estimated to be US\$818 billion (Alzheimer's Disease International [ADI], 2015). Due to the ageing population, the growth in the numbers of people living with dementia has become a global health challenge.

In Australia, where this study was conducted, the number of people with dementia is more than 413,106 (The National Centre for Social and Economic Modelling [NCSEM], 2017). Furthermore, around 83% of all males with dementia (148,224) and 71% of females with dementia (157,699) live in the community, and approximately 46% of those receive informal assistance (NCSEM, 2017). Approximately 200,000 Australians provide unpaid care to a person with dementia (Dementia Australia, 2015). The majority are family carers, and these consist of 42% of spouses or partners and 44% of sons or daughters (Australia Institute of Health and

Welfare [AIHW], 2012). They provide a wide range of support, including assisting with activities of daily living (ADLs), hygienic care and managing psycho-behavioural symptoms that lead to carer burden (Dementia Australia, 2015).

### **Background/Literature**

Functional disability, defined as an inability to independently perform daily living activities (Carmo et al, 2016), can have a significant negative impact on people living with dementia, such as increased nursing care needs, long-term institutionalisation, high mortality, depression and poor quality of life (Afram et al., 2014; Giebel et al, 2015; Fagundes, Danielle, Kátia, & Assis, 2017; Velázquez-Brizuela et al., 2014; Verdan et al., 2014). ADLs refer to the management of basic physical needs (e.g., bathing, dressing, toileting and feeding) (Mlinac & Feng, 2016). Instrumental activities of daily living (IADLs) refer to complex activities related to independent living, for example, undertaking household chores, preparing meals, managing finances and being responsible for the administration of medication (De Paula et al., 2014; Mlinac & Feng, 2016). The need to support IADLs often develops in the early stages of dementia and support for ADLs increases alongside the progression of dementia (Mlinac & Feng, 2016). When people with dementia are living in the community, family carers have an essential role in assisting with ADLs and IADLs as well as ensuring the safety and well-being of their care recipient (ADI, 2009).

Caregiving for a person with dementia can be challenging, and in most cases, family members who live in the same household provide informal care. However, they require specific knowledge and training to provide appropriate care, especially for maintaining daily living tasks. However, family carers often do not have adequate knowledge and skills, and they, therefore, assist with daily living activities of their care recipients without formal training (DiZazzo-Miller et al., 2014). Carer burden often refers to the stressors resulting from the psychological impact of providing care, for

example, distress, depression, anxiety or feeling of exhaustion (Dementia Australia, 2015). This is a significant concern that has been directly associated with problems related to the management of daily living activities (Abdollahpour, Noroozian, Nedjat, & Majdzadeh, 2012). Impairment of daily living activities is often related to behavioural changes (O'Connor et al., 2016b) and communication difficulties of people with dementia (Badarunisa, Sebastian, Rangasayee, & Kala, 2015), and these problems are also highly associated with the development of carer burden (Cheng, 2017; Savundranayagam, Hummert, & Montgomery, 2005).

Despite an apparent need, there are limited studies that have focused on family carers' needs related to functional care for people living with dementia. For example, needs related to feeding and nutrition (Ball et al., 2015), incontinence and skincare (Bliss et al., 2013) as well as planning related interventions, such as family carer training program for assisting the BADLs of people with dementia (DiZazzo-Miller et al., 2014), home environmental interventions by occupational therapists on efficacy and distress in carers, and to support daily functions of people with dementia (Gitlin et al., 2001). Consequently, it is imperative to identify family carers' needs related to providing care for ADLs that guide education and other interventions.

### **Smartphone technologies**

Recently, smartphone technologies have made a significant impact on healthcare, and smartphone applications (apps) are popular to support innovative technological interventions. These applications, also called mobile health (mHealth) applications when related to health, are rapidly emerging as an effective source of information on health and patient self-management (Handel, 2011). Using mHealth applications, information can be made readily available and easily accessible online (Handel, 2011), and can provide real-time, demand-driven communication (Boulos et al, 2014). Recent systematic reviews report that these applications are effective in health education,

including self-management of diseases (Mosa et al., 2012), health promotion (Lee et al., 2018) and changing health behaviours (Han & Lee, 2018). Recent studies have reported that mHealth applications significantly improve the knowledge of family carers, for example, carers of older people (Stratton, 2017) and carers of children with cerebral palsy (Ghazisaeedi, Safari, Sheikhtaheri, & Dalvand, 2016). Therefore, mHealth applications are a practical method to provide education for widely dispersed groups, such as family carers.

According to the recent integrative review by Rathnayake et al. (2019b), there were a limited number of studies concerning mHealth application development and related interventions for carers of people with dementia. Mainly these applications have been used for educational and monitoring purposes, and cognitive training for spousal carers. For example, with educational applications, Brown et al. (2016) developed an mHealth application to improve knowledge concerning care of people with dementia and carer wellness. Davis, Nies, Shehab, and Shenk (2014) designed an mHealth application that focused on learning from successful stories of the provision of care by carers through a storytelling application. mHealth applications have been used in information seeking (Bhuyan et al., 2016); however, there are no reported studies that examine the prevalence of use of mHealth applications in information seeking amongst family carers of people with dementia. With the advancement of digital technologies, new interventions have been developed to assist carers, but health literacy and eHealth literacy levels of family carers are poorly addressed (Efthymiou, Middleton, Charalambous, & Papastavrou, 2017). In the development of mHealth applications, the literacy level of users is a very important factor that needs to be considered. Boulos et al. (2014) state that application designers and content developers often pay little attention to general literacy, health literacy and eHealth literacy levels of users. When the mHealth applications are poorly designed, most application users face challenges

related to understanding and acting on health information, and these difficulties are worse for users with low health literacy (Broderick et al., 2014). Currently, there are no reported studies reporting health literacy and eHealth literacy of family carers of people with dementia.

## **Aims**

This study examined the needs of family carers of people with dementia in relation to the management of functional disability of their care recipients and identified the use of mHealth applications in health information seeking. Additionally, it assessed the level of carer burden, health literacy and eHealth literacy among family carers.

## **Research questions**

1. What are the educational needs of family carers in relation to the management of functional disability of people with dementia?
2. What is the carer burden of family carers of people with dementia?
3. What are the levels of health literacy and eHealth literacy of family carers of people with dementia?
4. What is the level of use of mHealth applications in health information seeking among family carers of people with dementia?
5. What are the factors affecting educational needs in relation to the management of functional disability, carer burden, and use of mHealth applications in health information seeking among family carers of people with dementia?

## **Methods**

### **Study design, participants and recruitment**

This survey was conducted as part of a larger study that aimed to design and develop an mHealth application for family carers of people with dementia. This main study

consisted of two stages: needs assessment and prototype development. This survey was a part of the needs assessment phase and helped researchers to gain a general understanding of the needs of family carers concerning functional disability care and use of mHealth applications in health information seeking. The study protocol related to this study has been published elsewhere (Rathnayake et al., 2019c). In this exploratory, descriptive study, an online survey was conducted with family carers of people with dementia living in the community throughout Australia with a diagnosis of any type and stage of dementia. Carers were informal, unpaid primary carers who were usually members of the immediate family but could be relatives, friends, and acquaintances who provided informal care in the home, and were an adult aged 18 years or older. There were 14 variables of interest in this survey. The minimum sample required for this study was set as 140 (i.e., 10 participants per variable) (Hill, 1998). Participants were recruited through websites of leading dementia support organisations in Australia (i.e., Dementia Australia Research Foundation and Carers Queensland (QLD), New South Wales (NSW), South Australia (SA), and Tasmania (TAS), and research institutes (i.e., Menzies Health Institute Queensland [MHIQ]), and through social media platforms (i.e., Facebook and Twitter).

### **Instruments**

A structured questionnaire designed with seven sections and developed using the LimeSurvey tool at Griffith University was used to collect data. Section one consisted of socio-demographic questions about the family carers and their care recipients.

In section two, care needs related to the functional disability of people with dementia were assessed by the General Activities of Daily Living Scale (GADL), which has a good internal consistency of 0.849 (De Paula et al., 2014). Construct validity (factor analysis), and criterion-related validity (receiver operating characteristic analysis and logistic regression) have been established (De Paula et al., 2014). This scale

consists of 13 items under three groups: ADL self-care (five items), ADL domestic (four items) and ADL complex (four items). Family carers were asked to rate the ability of their family member with dementia to perform each of the tasks on a three-point Likert scale (0 = dependent, 1 = partially dependent and 2 = independent). In this study, dependent and partially dependent categories were combined into one group called “dependent” where a zero score was allocated. A score of one was allocated if the care recipient of dementia was independent. The total score ranged from zero to five for ADL self-care and zero to four for both ADL domestic and ADL complex. A score of less than five for ADL self-care or four for ADL domestic and complex reflected disability in GADL. Based on the listed activities, carers were also asked to indicate the most difficult ADL for them to assist their care recipients in each of the three groups of the GADL.

Section three assessed the educational needs of family carers related to the management of functional disability of care recipients. Carers were asked about their perceived adequacy of knowledge to provide satisfactory care in relation to the 13 activities listed in the GADL (De Paula et al., 2014). To identify the educational needs of family carers, a four-point scale was used (1 = inadequate, 2 = needs improvement, 3 = meets expectation, 4 = exceeds expectation) with a score ranging from 13 to 52. A lower score indicates a higher need for education. To categorise family carers’ education needs, 50% of total marks (i.e., 26 marks) was set for adequate knowledge, which was based on previous studies that used a similar cut-off point to categorise knowledge level (Liu et al., 2017; Qaddumi & Khawaldeh, 2014). Hence, a score of 26 and below (i.e.,  $\leq 50\%$  of the total marks) reflected a high need for education. In this study, a respective score of 27 to 39 (i.e., 51-75% of the total marks) and 40 to 52 (i.e., 76-100% of the total marks) reflected a moderate and low need for education.

In section four, carer burden was assessed by the four-item screening version of the Zarit Burden Scale (ZBS), which provides a quick assessment of carers' current feelings of strain (Bédard et al., 2001). Cronbach's alpha of this screening version was good at 0.78 (Bédard et al., 2001). Validity has been established by testing correlation with a full version of the Zarit Burden scale, and it ranged from 0.83 to 0.93 (Bédard et al., 2001). Using a five-point Likert scale (never = 0, rarely = 1, sometimes = 2, quite frequently = 3 and nearly always = 4), a total score ranges from four to 16, and scores above eight indicated a high level of carer burden (Bédard et al., 2001).

Section five assessed the health literacy level of family carers using three health literacy screening questions: "*How often do you have someone help you read hospital materials?; How confident are you filling out medical forms by yourself?; and How often do you have problems learning about your medical condition because of difficulty understanding written information?*" (Chew et al, 2004 p. 588). These three self-reported questions can be used to detect health literacy (Chew et al., 2004). A five-point Likert scale was used (never = 1, occasionally = 2, sometimes = 3, often = 4, and always = 5). In scoring, for screening question two, reverse scoring was used (never = 5, occasionally = 4, sometimes = 3, often = 2 and always = 1). Based on previous literature, scores were totalled, and a score of 10 or greater was categorised as demonstrating low health literacy and a score lower than ten as adequate health literacy (Levin et al., 2014; Peterson et al., 2011).

Section six assessed eHealth literacy of family carers using the eHealth Literacy Scale (eHEALS) with a reliability of 0.88 (Norman & Skinner, 2006b). Construct validity has been established by factor analysis (Norman & Skinner, 2006b). This measure consists of eight items scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) with a total score range from 8 to 40, and higher scores indicate a higher level of eHealth literacy. Based on previous literature,

the cut-off point used to demonstrate high eHealth literacy level was set at 26 (Richtering et al., 2017). This scale further consists of two items that assess the perceived usefulness of the Internet to make health decisions and the perceived importance of accessing health resources on the Internet based on a five-point Likert scale ranging from 1 (not useful at all) to 5 (very useful).

In section seven, the ownership of a smartphone/iPad or tablet/smart-watch was assessed by one question: *“Do you own a smartphone or tablet/iPad or smart-watch?”* Moreover, the use of mHealth applications for health information seeking generally (not specific to seeking dementia-related information) were assessed by the following questions: (1) *“On your smartphone or tablet, do you have any software applications or apps related to health?”*; (2) *“Does having the health apps on your smartphone or tablet help you achieve a health-related goal, such as quitting smoking, losing weight or increasing physical activity?”*; (3) *“Does having the health apps on your smartphone or tablet help you make a decision about how to treat an illness or condition?”*; and (4) *“Does having the health apps on your smartphone or tablet lead you to ask a doctor new questions, or to get a second opinion from another doctor?”* (Bhuyan et al., 2016, p. 153). These questions were answered by either a ‘yes’ or ‘no’ response.

### **Data Collection**

Data collection was conducted between January to March 2018. An invitation (advertisement) with a link to the written information sheet and the online questionnaire was distributed electronically via dementia support websites and social media. Users of the websites and social media groups were able to access the survey during the study period. The survey took approximately 20 minutes to complete.

## **Ethical Considerations**

This study was approved by the Griffith University Human Research Ethics Committee (Ref No. 2017/906). Submission of the completed online questionnaire by participants reflected their implied consent. To ensure the confidentiality and privacy of the participants, they were asked not to post any personal information or comments on the invitation post. The comments feature was disabled in social media. If this was not possible (i.e., Facebook), the researcher monitored and removed all comment posts.

## **Data analysis**

The IBM SPSS Statistics version 25 for Windows was used to analyse the data from the online survey. In the online survey setting, a forced response option was set where participants were not able to submit the online questionnaire if they had not responded to all the questions. Therefore, there were no missing data. Descriptive statistics (e.g., frequency, percentage, means and standard deviation) were computed to examine the respondents' characteristics based on socio-demographic data, needs related to functional disability, carer burden, health and eHealth literacy, smartphone ownership and the use of an mHealth application in health-seeking behaviours. The Shapiro-Wilk test of normality was computed on the education needs score for functional disability care where the score was not normally distributed. Therefore, non-parametric tests were used where the influence of socio-demographic variables, the level of health literacy and eHealth literacy on needs of education for functional disability care and carer burden were computed by Mann-Whitney U test and Kruskal-Wallis H test. Mean rank was used to identify possible differences within categories in the above variables. The factors associated with having mHealth applications were assessed using Pearson's Chi-square test. The alpha level of significance was set at less than 0.05.

## **Results**

### **Socio-demographic profile of the respondents and their care recipients**

In this study, while 276 people accessed the survey online, only 166 family carers (60%) completed. Therefore, the incomplete response rate was 40%. As we used a pragmatic approach (dementia-related websites and social media) in the participant recruitment process, anyone could access the survey, but only those who were willing to participate and felt the survey was relevant to their role may have completed it. This situation may attribute to the above 40% incomplete responses. The socio-demographic characteristics of the family carers and their care recipients are shown in Table 4.1.

*Table 4.1:* Descriptive statistics for socio-demographic characteristics of the respondents and their care recipients (n = 166)

<b>Demographic characteristic</b>		<b>n ( %)</b>
<b>Age in years</b>	18-25	4 (2.4)
	26-35	8 (4.8)
	36-45	20 (12.0)
	46-55	59 (35.5)
	56-65	54 (32.5)
	66 -75	15 (9.0)
	76-85	5 (3.0)
	86 and over	1 (0.6)
<b>Gender</b>	Male	17 (10.2)
	Female	149 (89.8)
<b>Marital status</b>	Married	109 (65.7)
	Single	25 (15.1)
	Divorced	23 (13.9)
	Widowed	3 (1.8)
	Other	6 (3.6)
<b>Education</b>	No formal education	1 (0.6)
	Primary school education	3 (1.8)
	High school education	38 (22.9)
	Trade/technical/vocational training	51 (30.7)
	University undergraduate degree	47 (28.3)
	Post-graduate degree	26 (15.7)
<b>Employment status</b>	Presently unemployed	49 (29.5)
	Retired	52 (31.3)
	Employed/part-time	39 (23.5)
	Employed/full time	26 (15.7)
<b>Presence of chronic medical problems</b>	Yes	94 (56.6)
	No	72 (43.4)
<b>Relationship to care recipients</b>	Spouse	49 (29.5)
	Child	78 (47.0)
	Son/daughter-in-law	11 (6.6)
	Other	28 (16.9)

<b>Caregiving status</b>	Only carer	95 (57.20)	
	Caring with a family member	42 (25.3)	
	Caring with paid carer	29 (17.5)	
<b>Caregiving duration in years</b>	Less than 1	19 (11.4)	
	1-3	63 (38.0)	
	3-5	35 (21.1)	
	More than 5	49 (29.50)	
<b>Caregiving hours</b>	Weekdays	0-6	46 (27.7)
		7-12	24 (14.5)
		13-18	16 (9.6)
		19-24	80 (48.2)
	Weekend	0-6	30 (18.1)
		7-12	26 (15.7)
		13-18	11 (6.6)
		19-24	99 (59.6)
<b>Care recipients' age in years</b>	Less than 65	26 (15.7)	
	65-75	44 (26.5)	
	76-85	62 (37.3)	
	86 and over	34 (20.5)	
<b>Duration of disease of care recipients in years</b>	Less than 1	12 (7.2)	
	1-3	54 (32.5)	
	3-5	50 (30.1)	
	More than 5	50 (30.1)	
<b>Stage of dementia</b>	Early stage	30 (18.1)	
	Middle stage	78 (47.0)	
	Late stage	37 (22.3)	
	Do not know	21 (12.7)	
<b>Presence of other co-morbidities of care recipients</b>	Yes	99 (59.6)	
	No	67 (40.4)	

### **Needs related to daily living activities of people with dementia**

The internal consistency of the GADL in this study was tested by Cronbach's alpha and showed a coefficient of 0.927, indicating that the GADL was a reliable measure. A respective 79.5%, 97% and 99.4% of care recipients presented ADL disability in self-care (i.e., score of less than 5), domestic and complex activities (i.e., score of less than 4). As reflected in Table 4.2, the most dependent ADL self-care activity reported by respondents for care recipients was dressing and undressing (69.9%), preparing meals (91.6%) for ADL domestic activities and managing finance (97.6%) for ADL complex activities. Respondents also reported bathing (30.1%) as the most difficult ADL self-care activity to assist their care recipients. doing minor household chores (10.8%) for ADL domestic activity and managing finance (23.5%) for ADL complex activity.

Table 4.2: Care needs of people with dementia and their carers related to functional disability (n = 166)

Activity	Care needs of people with dementia related to functional disabilities				Most difficult activity for carers n (%)	Educational needs of carers related to functional disability care			
	Totally depend-ent n (%)	Partially depend-ent n (%)	Depend-ent n (%)	Indepen-ent n (%)		Inadeq-uate n (%)	Needs improve-ment n (%)	Meets expectat-ion n (%)	Exceeds expectat-ion n (%)
<b>ADL self-care</b>									
The patient is able to choose and change clothes by himself/herself (dressing and undressing)	57 (34.3)	59 (35.5)	116 (69.9)	50 (30.1)	15 (9.0)	9 (5.4)	25 (15.1)	93 (56.0)	39 (23.5)
The patient is able to make his/her way to the toilet, undress, clean him/herself properly and dress again (toileting)	46 (27.7)	57 (34.3)	103 (62.0)	63 (38.0)	49 (29.5)	13 (7.8)	44 (26.5)	88 (53.0)	21 (12.7)
The patient is able to use the shower, soap, and bath sponge properly (bathing)	64 (38.6)	42 (25.3)	106 (63.9)	60 (36.1)	50 (30.1)	20 (12.0)	44 (26.5)	80 (48.2)	22 (13.3)
The patient is able to transfer from his/her bed or chair unaided (transferring)	24 (14.5)	43 (25.9)	67 (40.4)	99 (59.6)	6 (3.6)	18 (10.8)	27 (16.3)	90 (54.2)	31 (18.7)
The patient is able to feed himself/herself with tableware (feeding)	14 (8.4)	51(30.7)	65 (39.2)	101 (60.8)	10 (6.0)	10 (6.0)	24 (14.5)	93 (56.0)	39 (23.5)

**ADL domestic**

The patient is able to do minor household chores (doing minor house hold chores)	77 (46.4)	55 (33.1)	132 (79.5)	34 (20.5)	18 (10.8)	7 (4.2)	17 (10.2)	91 (54.9)	51 (30.7)
The patient is able to use the telephone (make and receive calls) (using telephone)	81(48.8)	50 (30.1)	131 (78.9)	35 (21.1)	4 (2.4)	12 (7.2)	12 (7.2)	87 (52.4)	55 (33.1)
The patient is able to prepare his/her own meals (preparing meals)	116 (69.9)	39 (23.5)	152 (91.6)	11(6.6)	13 (7.8)	14 (8.4)	15 (9.0)	86 (51.8)	51 (30.7)
The patient is able to do his/her own washing and ironing (washing clothes and laundry)	116 (69.9)	28 (16.9)	144 (86.7)	22 (13.3)	7 (4.2)	10 (6)	11 (6.6)	96 (57.8)	49 (29.5)

**ADL complex**

The patient is able to manage his/her own money or financial matters (managing finance)	136 (81.9)	26 (15.7)	162 (97.6)	4 (2.4)	39 (23.5)	18 (10.8)	31(18.7)	73 (44.0)	44 (26.5)
The patient is able to run simple errands by himself/herself (running simple errands)	132 (79.5)	24 (14.5)	156 (94)	10 (6)	25 (15.1)	18 (10.8)	18 (10.8)	82 (49.4)	48 (28.9)
The patient is able to take his/her medication at the correct dose and time by himself/herself (responsibility of own medication)	119 (71.7)	32 (19.3)	151 (91)	15 (9)	33 (19.9)	16 (9.6)	33 (19.9)	76 (45.8)	41 (24.7)

The patient is able to go to distant places by himself/herself using some form of transportation (using transport)	144 (86.7)	16 (9.6)	160 (96.4)	6 (3.6)	8 (4.8)	7 (4.2)	22 (13.3)	87 (52.4)	50 (30.1)
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### **The educational needs of family carers: General ability in providing care for daily living activities**

Educational needs of family carers related to managing functional disability of people with dementia are reported in Table 4.2, where respondents reported a greater educational need for ADL self-care activities when compared to domestic activities and complex activities. Furthermore, based on the cut-off point for educational needs, the majority of respondents reported a moderate need for education (54.2%), while 37.3% and 8.4% respondents reported high and low needs for education, respectively.

### **Carer burden among respondents**

Internal consistency of the screening version of ZBS in this study was assessed by Cronbach's alpha and showed a coefficient of 0.784, indicating the scale was reliable. The mean carer burden score was 10.32 ( $SD \pm 3.161$ ). Based on the cut-off point for carer burden, 74.1% of respondents presented with a high level of carer burden.

### **Health literacy and eHealth literacy among respondents**

The mean health literacy score was 5.46 ( $SD \pm 2.71$ ). Of the respondents, 86.7% reported an adequate health literacy level. A Cronbach's alpha of 0.935 was found for the eHEALS in this study, indicating that the scale was reliable. Three-quarters of the respondents (77%) reported an adequate eHealth literacy level, with a mean score of 29.08 ( $SD \pm 6.36$ ).

### **The use of the Internet in health decision making among respondents**

Most respondents (84.3%) reported that the Internet was very important or important in accessing health resources, while 10.8% of respondents were unsure, and the remaining 4.8% felt that the Internet was not important or not important at all. Nearly half of the respondents agreed that the Internet was useful in health decision making (48.8%),

followed by 28.9% who felt it was very useful (28.9%), 15.1% were unsure and 7.2% did not find it useful.

### **Ownership of mobile devices and the use of an mHealth application for health-seeking behaviour among respondents**

Almost all the respondents (98.8%) indicated that they owned one or more smart-mobile devices. Most of them had a smartphone (94%), iPad/tablet (66.6%) and/or smart-watch (6.6%). Among the respondents, just over half had experience using mHealth applications (51.2%) and stated that they had used applications to achieve health behaviour goals (48.2%). Moreover, nearly one-third of respondents reported that mHealth applications were helpful in making medical care decisions (31.3%), while 36.1% of respondents stated that having an mHealth application on their smartphone or tablet led to them presenting to their doctors with new questions or to get a second opinion from another doctor.

### **Influencing factors of carer burden and need for education in the functional disability care**

The Mann-Whitney U test showed that carer burden was significantly higher ( $U = 2759$ ,  $p = .041$ ) among respondents who had chronic medical problems (mean rank = 90.15) than those without chronic medical problems (mean rank = 74.82). Furthermore, Kruskal-Wallis H test showed that there was a significant difference in carer burden relating to the stage of dementia of care recipients ( $H = 8.507$ ,  $p = .037$ ). The highest carer burden was observed in respondents whose care recipients were in the late stage of dementia (mean rank = 98.88) than those in mild (mean rank = 65.22) and moderate (mean rank = 81.94) stage of dementia (see Table 4.3).

A significant difference in the need for education in functional disability care was found across different age groups ( $H = 7.802$ ,  $p = .020$ ). The highest educational

needs were reported by respondents aged between 36-65 years (mean rank = 88.63), then aged groups of 18-35 years (mean rank = 67.04) and then over 65 years (mean rank = 60.40). Interestingly, respondents who had adequate eHealth literacy (mean rank = 84.02) reported a significantly greater need for education ( $U = 1602.5$ ,  $p = .001$ ) than those without adequate eHealth literacy (mean rank = 61.67) (see Table 4.3).

Table 4.3: Influencing factors of carer burden and need for education in functional disability care (n = 166)

Variable	Carer burden				Need for education in functional disability care		
	n	Mean rank	M-WU/ K-WH value	Sig.	Mean rank	M-WU/ K-WH value	Sig.
<sup>2</sup> Age in years			0.749	0.688		7.802	0.020*
18-35	12	89.46			67.04		
36-65	133	84.17			88.63		
Over 65	21	75.86			60.40		
<sup>1</sup> Gender			1237.5	0.877		1034	0.215
Male	17	81.79			69.82		
Female	149	83.69			85.06		
<sup>2</sup> Marital status			1.335	0.513		5.200	0.074
Single	25	90.98			99.76		
Married	109	83.89			77.67		
Other	32	76.34			90.67		
<sup>2</sup> Education			1.673	0.643		3.800	0.284
Up to school education	42	75.29			85.89		
Vocational training	51	86.86			92.32		
Undergraduate education	47	86.02			74.26		
Postgraduate education	26	85.62			79.04		
<sup>1</sup> Employment status			3110	0.566		2931.5	0.245
Presently employed	65	86.15			80.02		
Presently unemployed	101	81.79			88.90		
<sup>1</sup> Presence of chronic medical problems			2759	0.041*		2972	0.179
Yes	94	90.15			79.12		
No	72	74.82			89.22		

<b><sup>2</sup> Relationship to the care recipient</b>			1.312	0.726		3.473	0.324
Spouse	49	87.77			73.69		
Child	78	83.37			88.81		
Daughter/son-in-law	11	69.95			93.14		
Other	28	81.71			82.07		
<b><sup>2</sup> Caregiving status</b>			3.425	0.180		1.661	0.436
Only carer	95	88.51			82.18		
Caring with a family member	42	72.11			79.49		
Caring with paid carer	29	83.60			93.64		
<b><sup>2</sup> Caregiving duration in years</b>			3.359	0.340		3.500	0.321
Less than 1	19	65.39			82.68		
1-3	63	88.02			79.96		
3-5	35	85.63			75.87		
More than 5	49	83.18			93.82		
<b><sup>2</sup> Care recipient age in years</b>			3.477	0.324		4.017	0.260
Less than 65	26	92.67			83.71		
65-75	44	82.72			78.39		
76-85	62	75.87			79.20		
86 and over	34	91.41			97.79		
<b><sup>2</sup> Duration of disease of the care recipient in years</b>			4.294	0.231		1.218	0.749
Less than 1	12	66.67			79.33		
1-3	54	81.21			88.99		
3-5	50	79.63			79.14		
More than five	50	93.88			82.93		

<b><sup>2</sup>Stage of dementia</b>		8.507	0.037*	6.986	0.072
Early stage	30	65.22		66.78	
Middle stage	78	81.94		82.52	
Severe stage	37	98.88		97.73	
Do not know	21	88.31		85.95	
<b><sup>1</sup>Presence of medical problems of the care recipient</b>		2970.5	0.252	3145.5	0.573
Yes					
No	99	80.01		81.77	
	67	88.66		86.05	
<b><sup>1</sup>Health literacy</b>		1262.5	0.717	1096.5	0.220
Adequate health literacy	148	83.97		85.09	
Inadequate health literacy	18	79.64		70.42	
<b><sup>1</sup>eHealth literacy</b>		2365.5	0.797	1602.5	0.001*
Adequate eHealth literacy	128	84.02		89.98	
Inadequate eHealth literacy	38	81.75		61.67	
<b><sup>2</sup>Need for education in functional disability care</b>		1.175	0.556		
High demand	14	87.21			
Moderate demand	90	86.63			
Low demand	62	79.56			

<sup>1</sup> Mann-Whitney Test; <sup>2</sup> Kruskal-Wallis Test; \* statistical significance at  $p$ -value < 0.05

### **Factors associated with having mHealth applications**

Pearson's Chi-square test showed that factors associated with having mHealth applications were respondents' employment status ( $\chi^2 = 4.566, p = .033$ ), eHealth literacy ( $\chi^2 = 4.069, p = .040$ ) and need for education in functional disability care ( $\chi^2 = 6.079, p = .048$ ). The majority of unemployed respondents (55.4%) reported not having an mHealth application. Moreover, respondents who presented with adequate health literacy (55%) and those with moderate demand for education in functional disability care (56.7%) reported having an mHealth application.

### **Discussion**

This study examined the needs of family carers of people with dementia in relation to the management of functional disability of their care recipients and the use of mHealth applications in health information seeking. Our study found that eight-in-ten people with dementia were reported by their carers to experience problems in either self-care, domestic or complex activities that needed support from others. Similar to this finding, recent studies have found that functional disability is a highly prevalent problem among people with dementia living in the community (Charernboon & Lerthattasilp, 2016; Gure et al., 2010; Kisoli et al., 2015). Overall, functional disability in domestic and complex activities (i.e., IADL disabilities) experienced by people living with dementia was more frequently reported by carers compared to disability in self-care activities. This finding is supported in recent studies, which have confirmed that IADL disabilities are more prevalent compared to disabilities in self-care activities (Fagundes et al., 2017). Importantly, the literature suggests that functional disability is the main predicting factor of mortality for people living with dementia compared to dementia itself. This is because disability is the leading risk for death related to dementia (Barberger-Gateau et al., 2004). Verdán et al. (2014) reported that better functional

performance of people living with dementia is related to lower mortality rate. Therefore, nurses and other community care workers need to give priority to early detection and prevention of functional disability to prevent negative consequences for people living with dementia (Fagundes et al., 2017). A recent systematic review suggests that dyadic interventions, exercise and treatment with acetylcholinesterase inhibitors, and memantine, *N*-methyl-D-aspartate receptor antagonist (NMDA) are useful in minimising the functional decline in people with dementia (Laver et al, 2016). Furthermore, attention on modifiable risk factors of functional decline, for example, depression, pain, exercise and other health behaviours is essential (Mlinac & Feng, 2016).

This study further explored the educational needs of family carers in relation to the management of functional disability of people with dementia. Recently reported studies have focused on identifying needs related to one daily living activity, for example, needs related to feeding (Ball et al., 2015) and toileting (Bliss et al., 2013). Our study provides a broad understanding of family carers' needs related to managing daily living activities of care recipients, focusing on self-care, domestic and complex activities.

Although disabilities in IADLs were more prevalent among care recipients, family carers reported increased challenges and difficulties in the provision of ADL care compared with IADL care. Chan et al. (2010) reported that helping people living with dementia to manage their functional disability is demanding for carers because functional deficits are directly associated with the complexity of dementia care. Literature suggests that family carers do not receive adequate training in the skills needed to assist their care recipients, in particular in functional disability care (DiZazzo-Miller et al., 2014). Our study also found that most family carers reported the need for education, particularly on ADLs related to self-care. The most difficult

activities to perform for carers were bathing and toileting, while the highly reported educational needs were related to bathing, toileting and transferring. These suggest that family carers need more support and education in performing skilled care activities. Bliss et al. (2013) and Mullins, Bliss, Rolnick, Henre, and Jackson (2016) also found that improving knowledge and skills of carers related to toileting needs, particularly incontinence, were essential for family carers. Additionally, Ball et al. (2015) reported that family carers of people with dementia were often uninformed on feeding and nutrition-related care. Consequently, nurses and other health professionals need to identify and address the educational needs of family carers related to functional disability care.

Caring for the functional disability of people living with dementia has been associated with negative outcomes in carers, for example, stress, carer burden and poor quality of life (QOL) (Abdollahpour et al., 2012; Brodaty et al, 2014; Farina et al., 2017; Leggett et al, 2010). Recent systematic reviews report that most of the interventions for family carers of people living with dementia focused on the outcomes of carer burden, anxiety, depression, social support and overall well-being (Dam et al, 2016; Godwin et al, 2013; Parra-Vidales et al, 2017), with little attention placed on improving their knowledge and skills to provide functional disability care for their care recipients (DiZazzo-Miller et al., 2014). Therefore, the results of our study highlight the need for interventions that address family carers' educational needs related to functional disability care.

Moreover, our study found that carer burden was very high among family carers, and this finding is supported in previous studies (Abdollahpour et al., 2012; Brodaty et al., 2014; Svendsboe et al., 2016). In Australia, carers can receive services and support, such as education, training and information services, case management approaches, psychosocial help, support from social groups and respite care services (Dementia

Australia, 2015). However, carer burden remains high. This high level of carer burden might be attributed to the complex nature of dementia that demands high care for managing symptoms and maintaining daily living activities (Küçükgüçlü, Söylemez, Yener, Barutcu, & Akyol, 2017). In Australia, a lack of time for self, social isolation, exhaustion and a sense that dementia is taking over are common problems of family carers; therefore, they need support (Dementia Australia, 2015). Furthermore, evidence in the literature suggests that family carers in Australia face difficulties in finding suitable services (Robinson et al., 2009). Therefore, addressing the care burden of family carers of people with dementia is a priority.

Moreover, our study reported that carer burden was higher among family carers with chronic medical problems. They have to care for themselves while providing care to their care recipients, adding additional burden (Sullivan & Miller, 2015). Evidence suggests that the presence of medical problems further leads to poor QOL (Tüzün, Aycan, & İlhan, 2015). Consequently, nursing interventions focusing on carer burden may need to address the unique needs and challenges experienced by carers who have chronic medical problems.

To summarise, the burden of caregiving negatively affects family carers' health, wellbeing and QOL as well as resulting in early nursing home placement of care recipients (Etters et al, 2008; Farina et al., 2017; Svendsboe et al., 2016). Consequently, this problem needs to be addressed further. Resilience-building is an essential strategy to cope with the burden that focuses on extending social assets, increasing key psychological resources, maintaining physical health status, upholding the quality of life and improving the availability of key external resources (Parkinson, Carr, Rushmer, & Abley, 2017).

Another factor associated with carer burden was the stage of dementia of care recipients. Family carers who provide care for care recipients with late-stage dementia

reported a higher burden compared to those caring for care recipients with mild and moderate dementia. The findings of this online survey are in line with previous studies (Mioshi et al., 2013; Montgomery, Goren, Kahle-Wroblewski, Nakamura, & Ueda, 2018). The onset of any stage of dementia can be a challenge for family carers; however, late-stage dementia is very significant because of carers increased caregiving responsibilities related to the increased dependency of care recipients (Elif, Taskapilioglu, & Bakar, 2017). In planning interventions for people with dementia and their family carers, nurses and care providers need to pay special attention to specific problems related to the different stages of dementia. According to our study, 13% of family carers do not know the stage of dementia of their care recipient; therefore, it is essential to support carers to learn or identify the stage of dementia of their care recipients. Knowing such information will help them select suitable activities for their care recipients based on their stage of dementia.

Our study reported relatively high health literacy (86.7%) and eHealth literacy (77%) levels among family carers of people with dementia. Although health literacy and eHealth literacy have been identified in other populations, Efthymiou et al. (2017) reported that health literacy and eHealth literacy levels are poorly explored among carers, particularly for carers of people living with dementia. To the authors' knowledge, this study is the first reported study to examine health literacy and eHealth literacy of family carers of people with dementia in Australia. According to the Australian Commission on Safety and Quality in Health Care (2014), almost 60% of adults in Australia present with low health literacy. Compared to this figure, family carers' health literacy level was relatively high in our study at 86.7%, which could be attributed to a potential bias in recruitment. The majority of carers in our study possessed a minimum of a high school qualification. As our study utilised an online survey for data collection, carers were assumed to be proficient Internet users with the

requisite knowledge and skills to seek and access information online. The majority of carers also viewed the Internet as an important resource to access health information, which was useful in health decision-making. In carer populations where they have access and motivation to use the Internet and possess relatively high health and eHealth literacy, the planning and implementation of eHealth interventions are likely to be feasible. Nurses and other health professionals can plan eHealth interventions to address health problems of family carers who use the Internet.

This study further reported that almost all respondents owned one or more mobile device, and most of them had a smartphone. This figure is higher than the national figure in Australia, where 88% of Australians have a smartphone (Drumm, White, Swieger, & Davey, 2017). These figures indicate that the use of smartphones among the general public is increasing, and the initiation of smartphone-based interventions is timely and appropriate. Interestingly, this study also showed that half of the respondents had experience with mHealth applications, and they used those applications in achieving health behaviour goals. There were no comparable figures found for mHealth applications usage for similar carer populations. However, recent surveys found a relatively high use of mHealth applications in various countries. For example, mHealth applications were used by (a) 38.9% of people with chronic health problems in the US (Robbins, Krebs, Jagannathan, Jean-Louis, & Duncan, 2017), (b) 16.5% of older adults in Germany (Rasche et al., 2018), (c) 73% of pregnant women in Australia (Lupton & Pedersen, 2016) and (d) 24.1% of smartphone and tablet owners in Hong Kong (Shen et al., 2017) .

We further found that eHealth literacy and education needs for functional disability care were significantly associated with the use of mHealth applications. As eHealth literacy is a strong predictor in technology use (Neter & Brainin, 2012), particularly in the use of mHealth applications (Bol, Helberger, & Weert, 2018),

mHealth application-based interventions are, therefore, appropriate for people who have a high level of eHealth literacy. Usually, older people are slower in using modern technologies compared to younger groups (Vaportzis, Giatsi Clausen, & Gow, 2017). Our study found that younger carers had more interest in education in functional disability care compared to carers over 65 years. Consequently, this finding suggests that planning and implementation of mHealth application interventions are feasible for carers of people with dementia, especially for younger carer groups who are more adept with technology. Recent systematic reviews found that mHealth applications were effective interventions in health education and support (Kitsiou, Paré, Jaana, & Gerber, 2017; Xiong et al., 2018). These applications further help family carers to reduce their burden and improve health outcomes (Grossman, Zak, & Zelinski, 2018). Therefore, nurses and other health professionals can use these applications to provide education and support, particularly in addressing needs related to functional disability care.

### **Limitations of the study**

As this study is a cross-sectional study, it does not support the test of a causal relationship among variables. Although an electronic survey has many advantages, for example, reduced cost, wider distribution, speed and ease of data management, and convenience for respondents (Van Selm & Jankowski, 2006), there are a number of limitations. For example, carers who do not have the resources or the skills to access and fill out an online survey are unable to participate. Importantly, we distributed the online survey through dementia-related websites and social media; therefore, only carers who accessed the relevant websites and social media participated in this study. These factors reduce the representativeness of the sample and the generalisability of the results.

## **Conclusions**

To the authors' knowledge, this study is the first reported study related to health literacy, eHealth literacy and the use of mHealth applications in health information seeking among family carers of people with dementia. Functional disability is a common problem among people with dementia that results in the need for increased care. Family carers in this study expressed a significant need for education in managing daily living activities of their care recipients. Internet-based interventions are recommended as one way to support carers of people with dementia in the provision of functional disability care. Given that the vast majority of family carers in this study owned or used a smart-device and have used smartphone applications in health decision making, there is the potential for education and support for carers of people living with dementia to be provided via mHealth applications.

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## **Chapter summary**

This is the first result chapter in relation to this study. This chapter consisted of the findings of the online survey that examined family carers' needs of functional disability care and use of mHealth applications in dementia care. This study found that family carers expressed a significant need for education in managing functional abilities of their care recipients and that mHealth applications may contribute to the provision of education for them.

## **Chapter 5 Results and discussion-Individual interviews with family carers and experts**

### **Introduction**

This is the second result chapter and presents the findings of individual interviews conducted with family carers and experts as a part of phase I of this study (needs assessment phase).

The objectives of individual interviews with carers were to:

1. Explore family carers' needs related to managing activities of daily living (ADLs), particularly the barriers and challenges, and information needs.
2. Explore family carers' perception towards mobile Health (mHealth) applications, particularly needs related to obtaining information through these applications in dementia care.

The objectives of individual interviews with experts were to:

1. Explore the opinions of experts on needs, barriers and challenges faced by family carers of people with dementia.
2. Explore opinions on developing an mHealth application to address functional care needs of carers of people with dementia.

Following these objectives, this chapter consists of a co-authored manuscript based on the results of individual interviews with family carers of people with dementia and a report based on the results of interviews with experts.

Within this manuscript, the findings of the individual interviews with family carers of people with dementia are reported. This manuscript has been published by the *Journal of Clinical Nursing*.

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Family carers' perspectives of managing activities of daily living and use of mHealth applications in dementia care:

A qualitative study. *Journal of Clinical Nursing*. Advanced online publication.

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### **Statement of contribution to co-authored published paper**

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Family carers' perspectives of managing activities of daily living and use of mHealth applications in dementia care: A qualitative study. *Journal of Clinical Nursing*. Advanced online publication.

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My contribution to the paper involved:

Critical review of the literature to inform the design of the study, conceptualising and designing the study, enrolment of participants, data collection, analysis and data interpretation, writing of the draft manuscript, revision of the manuscript for important intellectual content and approval of the final version.

Minor modifications have been applied to the original publication to fit the thesis formatting.

(Signed) (Date) 12/11/2019

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## **Family carers' perspectives of managing activities of daily living and mHealth applications in dementia care: A qualitative study**

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### **Abstract**

#### **Aim**

This qualitative study examined the needs, barriers and challenges experienced by family carers of people with dementia concerning the management of their care recipients' functional disabilities, and their experiences and opinions of using mHealth applications in health information seeking.

#### **Background**

Functional disability is a significant problem among people with dementia, and management can be challenging for family carers. Evidence suggests that mHealth applications can support knowledge needs of patients and families.

#### **Design**

A qualitative descriptive exploratory study.

#### **Methodology**

In-depth interviews were conducted with a purposive sample of family carers using a semi-structured interview guide. An inductive thematic analysis method was used. The COREQ reporting guideline was followed.

## **Results**

Five spousal and five child carers participated in this study. Four key themes were identified: (1) challenges faced that contribute to psychological distress and burden; (2) essential role of support systems in dementia care; (3) information and educational needs of family carers, and (4) experiences and attitudes of mHealth applications as an educational and supportive resource.

## **Conclusion**

Providing functional care is demanding, challenging and stressful, and leads to carer burden. The complexity of dementia is a barrier in the organisation of functional care, and access to a support network is vital to care provision. The information needs of family carers can potentially be addressed through an mHealth application.

## **Relevance to clinical practice**

This study provides important information on family carers' needs and the barriers and challenges related to functional care for people with dementia. Findings from this study can assist nurses and other health professionals in the planning of educational and supportive programs for family carers. Furthermore, the use of mHealth applications could positively contribute to the delivery of these programs.

***Keywords: functional disability, dementia, family carers, mHealth applications***

## **Summary**

### **What does this paper contribute to the wider global clinical community?**

- Functional disability of people with dementia is one of the leading reasons for distress and burden among family carers.

- Family carers require education and support from healthcare professionals, government and community care service providers to manage functional care of their care recipients with dementia.
- mHealth applications can be used as an educational and supportive resource to address the functional care needs of the carers of people with dementia.

## **Introduction**

Dementia is a chronic health problem in older age that leads to disability and dependency. Due to the complex nature and high demand for care, dementia can negatively affect the person with dementia, their carers and society. In dementia care, family caregiving is a critical component as the majority of people with dementia live in the community and rely on family members for support. Families are recognised as experts in supporting a person with a chronic condition (Bamm & Rosenbaum, 2008). However, the role of family carers is very complex and diverse, as they have to manage the impact of the situation on the family while fulfilling the needs of their care recipients (Cabote, Bramble, & McCann, 2015). Informal carers of people with dementia work long hours and may provide 40 or more hours of care per week in the community (Australia Institute of Health and Welfare [AIHW], 2012).

## **Background**

Functional decline is a considerable problem for people with dementia. Usually, deterioration in the basic activities of daily living (BADLs) (e.g., bathing and toileting) is significant in the late stages of dementia while decline in complex activities, referring to instrumental activities of daily living (IADLs) (e.g., using telephone and managing finance), starts in the early stages (Mlinac & Feng, 2016). Providing care for a person's functional disabilities is complex, requires long hours, and carers often face several challenges (Brodaty & Donkin, 2009). Additionally, the caregiving process may be

more challenging when the person with dementia has reduced insight, agitation and resistance to care (Farina et al., 2017). Negative consequences for carers related to the provision of functional care are widely reported and include carer burden, psychological distress, anxiety, depression and poor quality of life (QOL) (Abdollahpour et al., 2012; Abreu, Tolson, Jackson, & Costa, 2018; Farina et al., 2017; Kang et al., 2014; Svendsboe et al., 2016). Moreover, the lack of knowledge, skills and training is a significant challenge faced by family carers when related to functional care (Cova et al., 2018; DiZazzo-Miller et al., 2014). As a result, carers can have low confidence in the provision of care (Jennings et al., 2015). To date, there are limited studies that assess carers' needs related to the provision of functional care, in particular, BADLs, for example, carers being uninformed on feeding and nutrition-related care, toileting needs, incontinence and skincare (Ball et al., 2015; Bliss et al., 2013; Mullins et al., 2016). Therefore, an exploration of carers' needs related to managing ADLs, particularly the barriers and challenges, and information needs, may be useful in the development of education programs and resources via mobile health solutions.

The role of modern mobile technology in healthcare is significant. Mobile health (mHealth) is defined as “medical and public health practice supported by mobile devices, such as mobile telephones, patient monitoring devices, personal digital assistants, and other wireless devices” (World Health Organisation [WHO], 2011b, p. 6). Kotz, Gunter, Kumar, and Weiner (2016) claim that these technologies have the potential to enhance the quality of healthcare, expand access to services, decrease costs, and enhance personal wellness and public health. Smartphone applications (apps), also called mHealth apps are a recent innovation in mobile technology and are widely used in health. These mHealth applications are emerging as a cost-effective means to provide healthcare information that is readily accessible through mobile communication technologies (Handel, 2011). These applications can provide further individualised

healthcare and education at users' convenience (Boulos et al, 2014; Santoro, Castelnovo, Zoppis, Mauri, & Sicurello, 2015). Moreover, the use of mHealth applications is a practical method to provide education for widely dispersed groups, such as family carers, because any person from urban, rural or remote areas can access mHealth applications. In a systematic review, Martínez-Pérez et al. (2013) state that there are more than 3,673 mHealth applications related to the most prevalent health conditions. These applications are increasingly used in different health fields, including medical practice, health promotion, medical and nursing education as well as mental health and chronic disease management (Rathnayake et al., 2019c), and these are readily accepted by the general public (Kayyali et al., 2017). However, a recent literature review reported that mHealth applications are not widely used among carers of people with dementia, but they are used in carer education, monitoring and cognitive training (Rathnayake et al., 2019b). For example, Brown et al. (2016) developed an mHealth application to deliver education concerning providing care for people with dementia and to improve the wellness of carers. Reyes et al. (2016) developed an mHealth application for carers that includes a system for supporting non-pharmacological interventions, such as reminiscence therapy, reality orientation therapy, psychosocial therapy and cognitive rehabilitation therapy. Although mHealth applications are yet to be widely used amongst carers of people with dementia, these applications may present a feasible solution to provide them with functional care information to improve care outcomes (Rathnayake et al., 2019b). Consequently, an exploration of family carers' perception towards mHealth applications, particularly related to obtaining information through these applications, is timely.

## **Methodology**

### **Study design**

A qualitative descriptive exploratory study was undertaken as a part of a project that guided the development of an mHealth application to improve functional care for carers of people with dementia. In-depth interviews (in-person or by telephone) were conducted with the family carers of people with dementia living in the community in Australia.

### **Participants**

A purposive sample of ten family carers living in the community in Australia was recruited to ensure the inclusion of child and spousal carers as well as those providing care for family members at varying stages of dementia. The sample size is deemed appropriate for the nature of this study in identifying basic themes, following Guest et al. (2006). The family carers were unpaid primary carers who were aged 18 years and older and provided informal care at home for a person diagnosed with dementia. Carers who self-reported as experiencing major psychiatric disorders (e.g., major depression and schizophrenia) were excluded to avoid additional burden. Carers who had difficulty communicating in English were also excluded.

Potential carers who expressed their willingness to participate in interviews were recruited from a previously conducted online survey about functional care. An invitation email with an information sheet, including study aims and objectives, was sent to carers who expressed an interest in being interviewed, and a mutually suitable interview time was arranged.

## **Data collection**

Data collection was undertaken from February 2018 to April 2018 using a semi-structured interview guide (see Table 5.1). Nine carers participated in telephone interviews, and one carer participated in a face-to-face interview. All participants completed a demographic data sheet prior to the interviews that were conducted by the first author (SR) in a private office at Griffith University. Interview questions were developed around the study aims and available literature. They consisted of open-ended questions related to carers' experiences of the management of functional disabilities of people with dementia and the use of mHealth applications in health information seeking. The interview guide was pre-tested among three individuals from the general population to test its readability and understandability. The average duration of the interviews was 43 minutes and ranged from 32 minutes to 73 minutes. This varying length of interview times resulted because some participants had more to explore about their needs and experiences related to interview items, while others were limited in their responses. Furthermore, some participants spoke quickly, while others were much slower with their responses. All interviews were digitally-recorded after consent was obtained from the participants.

Table 5.1: Interview guide

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**Personal information and background**

- Can you please tell me a little about yourself?

**Questions**

- As a family carer, what type of help do you provide in meeting your family member's needs related to their daily activities?
  - Could you please tell me what are the activities you find difficult to perform for your family member?
  - Could you tell me the difficulties you face in providing support to your family member's needs related to their daily activities? (For example, difficulties with knowledge and skills, and availability of resources etc.)
  - What information do you believe you need to know to help you to manage the daily activities of your family member?
  - What are the major barriers and challenges you face in getting information to help you care for your family member?
  - Do you have any experience with health-related smartphone applications or any other smartphone applications?
  - Do you think a smartphone application for carers of people with dementia would be helpful for you to learn about managing the daily activities of your family member?
    - What do you see are the advantages of a smartphone application?
    - What do you see are the disadvantages of a smartphone application?
  - What are the major barriers and challenges you face to access smartphone applications to receive appropriate information to help you in your caregiving role?
  - Is there anything else you would like to add to our understanding of managing disabilities of your family member in daily activities and smartphone applications as an educational tool?
  - Do you have any questions or further responses?
- 

**Ethical considerations**

The study was approved by the Griffith University Human Research Ethics Committee (Reference Number: 2017/947). Verbal and written consent was obtained for telephone and face-to-face interviews, respectively. Digital recordings of the interviews were deleted after transcription of the data.

## **Data analysis**

Digital files were transcribed verbatim. Transcripts were compared with the original digital files for accuracy, and all personal identifiers were removed from the transcripts. The participants did not receive transcripts for member checking but received a lay summary of the findings. Inductive thematic analysis, according to the six steps stated by Braun and Clarke (2006), was used. The six steps followed were as follows: (1) familiarisation of the data by reading and re-reading and noting down initial ideas; (2) initial coding in a systematic way across the entire data set; (3) recognising themes by grouping all data relevant to the potential theme; (4) reviewing themes leading to the generation of a thematic map; (5) defining and naming of themes by giving clear definitions and names for the themes; and (6) producing a scholarly report based on the analysis.

Following the reading and familiarisation of the transcripts, two authors (SR & PC) conducted the initial coding for the first three transcripts. Consensus for elements disagreed on was reached with a third author (CJ). Based on these codes, SR completed the initial coding for the whole data set. When new codes were identified, these codes were discussed with other authors (PC & CJ) for review. Data were then grouped into themes by two authors (SR & CJ), which were then discussed and confirmed by the other authors (PC & WM). The discussion continued among the authors until consensus was reached, and the final themes emerged. The COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007) was followed in the reporting of this study (See Appendix R).

## **Results**

### **Participants' characteristics**

The demographics of interviewed carers are shown in Table 5.2. The majority of the carers were females ( $n = 9$ ), and the mean age was 59.4 years ( $SD = 11.4$ ). The sample consisted of five child carers and five spousal carers who were caring for three care recipients in the early stage of dementia, five in the middle stage and two in the later stage.

Table 5.2: Participant demographics (n = 10)

<b>Characteristics: Carer and care recipients</b>	<b>Percentage (%)</b>
<b>Age</b>	
Below 65 years	80
65 years and older	20
<b>Gender</b>	
Male	10
Female	90
<b>Marital status</b>	
Married	60
Single	20
Widowed/divorced	20
<b>Education</b>	
High school and below	50
Above high school	50
<b>Employment status</b>	
Presently unemployed	40
Presently employed	30
Retired	30
<b>Carer relationship to the care recipient</b>	
Child	60
Spouse	40
<b>Duration of caregiving</b>	
Less than one year	20
1-3 years	20
3-5 years	30
Above 5 years	30
<b>Care recipients' age</b>	
Less than 65 years	10
65-74 years	10
75-84 years	40
85 years and older	40
<b>Care recipients' type of dementia</b>	
Alzheimer's disease	50
Frontotemporal dementia	20
Lewy body dementia	20
Early onset dementia	10
<b>Stage of dementia</b>	
Early stage	30
Middle stage	50
Late stage	20

## Findings

Four key themes emerged from the interviews (see Table 5.3). These themes are discussed and supported by exemplary quotations extracted from the transcripts. Carers were de-identified using a participant number (e.g., P1) in the reporting.

*Table 5.3: Themes and sub-themes*

No	Themes	Sub-themes
1	Challenges faced that contribute to psychological distress and burden	Complexity of the disease (i.e., recurrent changes in the symptoms) Memory impairment Resistance to care Communication difficulties Presence of co-morbidities of care recipients Role reversal Functional disabilities lead to carer burden
2	Essential role of support systems in dementia care	Family support Government support Direct care facilities available in the community Carer support groups and social media
3	Information and educational needs of family carers	Lack of knowledge and skills among carers Information sources and educational opportunities Difficulty in finding reliable information Inadequate availability of information and data fragmentation Insufficient information received from support personnel Barriers to accessing information
4	Experiences and attitudes of mHealth applications as an educational and supportive resource	Attitudes towards mHealth applications Barriers and challenges related to the use of smartphone applications (i.e., cost, technology, time, and personal characteristics) Features suggested for an application Content related to functional disability care need to be included in a potential application

### **Theme one: Challenges faced that contribute to psychological distress and burden**

This theme highlights the barriers and challenges concerning the management of functional care. The most difficult activities reported by carers were bathing, toileting, dressing, transferring and feeding (i.e., BADLs) as well as medication management and shopping or going on a small trip (i.e., IADLs). The majority of challenges and barriers are related to factors associated with the signs and symptoms of the care recipients' condition. One of the main barriers for providing care for ADLs was the complexity of the condition, particularly continuing changes in the symptoms and the need to consider different management strategies. One carer stated that the second episode is rarely the same as the first episode:

*It's funny what works and what doesn't. What works this time may not work next time. It's a continuation of trying something different pretty much every time because very rarely is there a second episode that's the same as the first. (P2)*

Carers also reported that aggressive and agitative behaviours impeded organisation of functional care, while wandering and distractive behaviour made it difficult to go shopping, run simple errands or go on a trip:

*You couldn't take him out anywhere because he'd get very upset if you tried to guide him in a crowd, and he would become very volatile, very loud about what was going on, how people would be in his way. It was difficult. (P7)*

Other significant challenges faced by carers were memory impairment, resistance to care and communication difficulties. Carers reported that memory impairment leads to reduced recognition of carers and hinders a productive relationship with care recipients. Poor orientation to date and time also leads to difficulties with the organisation of care: *"He doesn't know; he's always asking what day it is. Everything is written on the calendar. He understands the work. He just gets confused with days"* (P5). Care recipients are reported to have forgotten how to complete daily living tasks;

therefore, carers have to remind them how to undertake routine tasks and spend more time supervising those activities that now take more time to complete: *“I think it’s the repetitive nature of cleaning teeth. Mum forgets what she’s doing at the time, so she just keeps cleaning. So, it just takes hours” (P1)*. Carers further highlighted that memory impairment leads to difficulties in medication management and the lack of understanding and recognition of money leads to difficulty in handling finance and shopping.

Care recipients may be resistant to or completely reject care, including showing a lack of interest and reduced engagement in self-care activities. Although they have difficulties in meeting their functional needs, they seek independence in completing those activities, which can lead to other challenges. One carer stated that her father was at high risk of falling, but he wanted to maintain independence. He would not allow her to provide care for him and as a result, he suffered a fall: *“... he’s like. ‘I can manage it; I can manage it and then it was too late when he was falling over ...’ (P4)*.

Communication difficulties were identified as a significant barrier to supporting ADLs and carers reported this hinders the effective coordination of care: *“I think it was very difficult in so many areas because he found it difficult to understand what you were trying to tell him. Sometimes I could speak to him, and he would not hear or reply to me” (P7)*. When current communication methods failed, introducing a new communication method was challenging as it is difficult for people with dementia to learn new communication skills. One carer reported that when the idea of using a bell was introduced to her mother, she took a long time to learn how to ring a bell for attention. Carers also said that an inability to use the telephone increased care needs, especially in care coordination: *“He did not use the telephone, so I would actually have to have the care workers ring me, and then I would have to go and tell him what time they were coming” (P4)*.

The presence of co-morbidities and related health problems of care recipients creates a complex care situation, particularly in the provision of BADLs. Family carers reported that fatigue and physical weaknesses of care recipients affect their independence in daily living: *“He doesn’t need any physical help with toileting or bathing. With his physical condition, weakness, he’s very, very slow. It takes more time to complete the works”* (P5). The risk of aspiration due to dysphagia, inadequate fluid intake, the risk of falls and fractures, infections, arthritis, incontinence and constipation were the other main problems reported by carers that increased difficulties in supporting functional care.

Most family carers stated that giving functional disability care leads to distress, in particular where there is a role reversal of carers. The loss of dignity and privacy of care recipients during self-care, especially in toileting and bathing, increased the emotional distress of carers: *“It’s like having another child basically, but you need to act in a respectful manner because it’s your mum, but it’s difficult to do that caring role when it is your mum”* (P10). Most family carers reported fatigue concerning support for ADLs, especially in self-care activities. The dependency of care recipients and their high demand for care and support lead to an elevated physical toll on carers: *“At the end of the day, I am tired, very tired. I have no physical energy to work for him”* (P3), and this adversely impacted on their quality of life.

### **Theme two: Essential role of support systems in dementia care**

This theme discusses positive and negative support systems available for carers for the provision of functional care. Family carers indicated that support from other family members, government, direct care organisations within the community and peers play a significant role in their provision of functional care. They emphasised that family support creates a positive caring environment, primarily where this support system

provides a break or respite for the primary carer. However, a lack of family support was reported:

*Well, I don't have any support from the family. One lives here, one lives in Brisbane, and one lives in Canberra. The other thing, the daughter here, she feels I should put him in a home, that's all. Other than that, they don't interfere or participate. (P9)*

Nevertheless, where there were many family members involved in the care, this often helped the situation: *"I am lucky that I can be home for a lot of days. I have two brothers who live close here, and they can pop in once a week or something" (P10).*

Carers further addressed supportive mechanisms available from the government, for example, carer payments, pensions and support from the department of veteran affairs (DVA). One carer stated that DVA supported them to access services without financial burden: *"My mum is with DVA, and so in terms of availability of resources, we had no worries, no problems because DVA is really good with funding things" (P1).* However, most carers reported that direct support received from the government was inadequate:

*I don't believe the government gives a great deal of care. I live in a rural area, and up until the middle of last year, my husband was the only patient in this area with Alzheimer's. There's no support here. Our support comes from 50 kilometres away. (P3)*

Generally, family carers held positive attitudes towards direct care organisations available in the community that provide respite care, daycare, home care and paid carer support services. They reported that such services helped them to take a break and reduced their distress and burden: *"I had staff who would come and relieve me for 3 hours so I could go and have a sleep" (P4).* However, they highlighted that arranging

those services is somewhat challenging due to untimely communication with the paid care workers and care organisations:

*What difficulties going through My Aged Care. I was going away for 10 days, and I wanted to organise social visits. The people didn't get back to me in time. The morning we were leaving for our holiday, at lunchtime, that's when they came and did the paperwork to organise the social visit. (P8)*

Family carers highlighted carer support groups as an essential support mechanism in the community: *"I do believe there are fantastic groups out there that do give the carer support. Carers Online is one"* (P3). They stated that these support groups are beneficial in sharing experiences, particularly care tips. Most carers said that they are in Facebook groups for dementia carers and highlighted that these platforms help to share experiences, obtain information or to learn caregiving tips and provide emotional support: *"I found a Facebook page about carers, and I joined that. People are very supportive ... so I feel like that could be the support system ... the Facebook page, it's more emotional support ..."* (P8).

### **Theme three: Information and educational needs of family carers**

This theme encapsulates the information and educational needs of carers. Family carers highly valued the available information sources and opportunities for education. The primary information sources highlighted were support staff, training programs, online resources, websites and printed materials. However, carers viewed the lack of personal knowledge and skills as a challenge when giving functional care. They said that available information was not adequate, may not be applicable or relevant to their care needs, and improvements are required. They further reported difficulties in finding relevant and credible information: *"It is hard to get relevant information, and I'll get three out of those that help. You can go round and round"* (P9).

Information and support fragmentation were other issues reported by carers. One carer said that sources of information or support may at times only provide content or assistance relevant to one problem or a part of care. Consequently, they had to go to several places to receive information or support, and this process was frustrating:

*You go to this person, and you'll say, 'okay', this like, 'oh yeah, we can help you with this part of it', but then you have to go to the next person, and then they say to you, 'oh yeah, but we don't do that anymore. (P7)*

They also highlighted that most online sources and print materials did not cover all areas. Additionally, carers reported inadequate skills in using technology to access online sources as well as limited available time to search for information and participate in educational programs.

The primary support workers who provided educational support, particularly in managing ADLs included nurses, occupational therapists, incontinence nurses, general practitioners and paid carers. Although they provide information and education, family carers stated that sometimes these were inadequate in meeting their care needs. One carer stated that health workers did not explain health records and investigations adequately. Carers highlighted difficulties in obtaining information from care staff, for example, in relation to respite care, due to healthcare staff's busy workload.

#### **Theme four: Experiences and attitudes of mHealth applications as an educational and supportive resource**

This theme relates to individual experiences and attitudes towards mHealth applications of carers of people with dementia. Most family carers had a positive attitude toward mHealth applications and perceived it could be a viable option for them to access health information related to functional care: *"Apps would be beneficial for carers to know what's new, what's out there, what happens and to maintain the currency of information, tools and services"* (p10). They further highlighted that mHealth

applications can be time effective in providing support and information, all in one place:

*“I don’t get a lot of time, but when you are looking, you’d like just to be able to go straight to it ... to find what you’re looking for, all right and, timesaving” (P3).*

Nevertheless, carers highlighted several barriers and challenges related to using mHealth applications. The need for a smartphone or tablet as well as Internet facilities or mobile data are cost-related barriers highlighted by carers. There were reported concerns about the memory capacity of their smartphone in running applications and their potential in reducing phone processing speed and battery life. Carers further stressed that technology would be a challenge, especially for older carers, as mHealth applications demand specific technical skills. For example, one carer highlighted that she had to ask for help from her husband to organise the applications on her phone. In addition, older carers highlighted that they have limited time for using mHealth applications with their caring role:

*I don’t spend a lot of time on my phone or device. The only time I get is when the husband is at respite, and generally, I have to spend that time catching up on work that needs to be done. (P3)*

Additionally, they stated that health conditions of carers (e.g., poor vision), the awareness of available mHealth applications and information-seeking patterns might hinder the use of applications. Nevertheless, given the growing popularity and use of smartphones and tablets, including mHealth applications, carers acknowledged the need to have mHealth applications designed for carers of people with dementia: *“The generation that’s coming up now, on the phone all the time. They really know how to use a phone” (P9).*

Family carers highlighted that mHealth applications need to be simple: navigation needs to be user-friendly and able to provide quick access to information. A participant stated, *“If you’ve got something, sort of a concern, it’s better off to be able*

*to just quickly open an app, and find the information you need as opposed to searching through something like Google” (P6).* Features of mHealth applications suggested by carers that might be useful were comprised of sending reminders to take medications, sending alert/caring tips to encourage carers, calendar and appointment arrangements and leisure activities, such as the delivery of music. Finally, carers proposed that the mHealth applications should include content in the following areas: information on dementia, including types, progression and management; information related to managing ADLs and aggressive behaviours; information on available services, facilities, information sources, training opportunities and equipment; and information and strategies for looking after carers’ health and well-being.

## **Discussion**

This study provides insights into the needs, barriers and challenges faced by family carers of people with dementia concerning the management of functional disability of their care recipients and their perceptions of using mHealth applications in health information seeking. To our knowledge, this is the first reported qualitative inquiry that provides insight into these areas related to functional care that guides the development of an mHealth application.

### **Carer burden related to functional care**

Carer burden is a significant issue amongst carers of people with dementia. In line with previous studies, this study confirmed that providing functional care is demanding, challenging and stressful (Abdollahpour et al., 2012; Kang et al., 2014; Svendsboe et al., 2016). Increased functional limitations of people with dementia were associated with the development of fatigue among carers (Osaki et al., 2016). The issue of fatigue is further exacerbated by the lack of time for leisure activities (Osaki et al., 2016), and carers in our study reported that they had no time for rest or leisure activities. Hirano et

al. (2010) reported that leisure activities were inversely associated with the care burden of dementia. Carer burden leads to poor health status and reduced quality of life for carers (Farina et al., 2017; Svendsboe et al., 2016). Consequently, educational and support programs can provide strategies to assist family carers in managing distress and burden experienced during ADL care provision.

### **Challenges and barriers faced by carers related to providing functional care**

In this study, the different challenges and barriers leading to family carers' distress and burden were found to be related to functional care where it was impeded by the complex nature of dementia, including memory impairment, resistance to care and communication difficulties. Management of ADLs in people with dementia is also reported in the literature as a contributing factor to carer burden (Chan et al., 2010; Yu et al., 2015). The changing nature of dementia symptoms is a significant barrier in care planning and organisation due to a decline in memory and executive function leading to social and occupational impairments in people with dementia (Abreu et al., 2018; Tarawneh & Holtzman, 2012).

Resistance to care is another significant barrier to the provision of functional care. This is a common problem of people with dementia who are dependent and have a severe cognitive impairment, and resistance to care increases when their ability to understand conversation deteriorates (Volicer, Bass, & Luther, 2007). In this study, difficulties in communication as a result of dementia challenged carers in providing functional care. In general, memory and language decline cause the development of communication difficulties among people with dementia (Wilson, Rochon, Leonard, & Mihailidis, 2012a), and these problems negatively affect the carer-care recipient relationship, leading to increased time spent on functional care and increased carer stress and burden (Wilson, Rochon, Mihailidis, & Leonard, 2012b). Therefore, the use

of appropriate communication mechanisms is an essential strategy in providing successful functional care (Wilson et al., 2012a).

Carers' stress related to role reversal found in this study coincides with the findings of a previous study (Samuelsson, Annerstedt, Elmståhl, Samuelsson, & Grafström, 2001). They found that husbands, taking on the caregiving role for their wives living with dementia, reported worry, weariness, guilt, distress and isolation. Often carers have to move from the role of a spouse, child, sibling or friend to the role of 'carer'. Taking new responsibilities leads to an imbalance in previous relationships and the assistance received from each other (Llanque, Savage, Rosenburg, & Caserta, 2016). They have to provide unpaid care for their care recipients at the same time managing their own health, finance and work (Brodaty & Donkin, 2009). Consequently, it appears that cognitive changes, including memory impairment, communication difficulties and resistance to care as well as problems related to role reversal, are the critical barriers to providing functional care.

From the views of the carers in our study, various health problems of people with dementia increase the needs and complexity of functional care. Physical weakness and fatigue were significant barriers in assisting with tasks, such as bathing, dressing and toileting. Other health issues that complicated functional care provision included dysphagia, falls and fractures, infections, arthritis, incontinence and constipation. These health problems and co-morbidities are highly prevalent among people with dementia, and aggravate the progression of dementia and increase the particular challenges of care (Bunn et al., 2014). Consequently, care support services and providers, as well as health professionals, need to take into consideration the challenges and barriers faced by carers related to providing functional care when planning strategies to support family carers.

## **Role of the support system in providing functional care**

Our study found that support systems available within the community, for example, family support, government support, direct support services available within the community and peer support groups, including social media groups, have an essential role in family-centred dementia care. Healthcare professionals are the key personnel in addressing the emotional, practical and informational needs of family carers (Ekstedt, Stenberg, Olsson, & Ruland, 2014). While carers in our study do value the support received from the healthcare professionals, they felt that it was neither adequate nor timely. Formal community care services (e.g., respite care, daycare, home care and paid carer support services) are essential mechanisms in community dementia care.

However, inadequate support services remain a significant problem in the community dementia care (Parkinson et al., 2017), and the availability of such facilities is limited or finding suitable services is difficult (Robinson et al., 2009). Carers in our study also expressed these issues. The lack of awareness about available support services within the community is another barrier to access those services (DiZazzo-Miller et al., 2013). Therefore, it is essential to increase carers' awareness about available supportive services. Alternative support systems are required. Peer support, including social media groups, reduces social isolation, stress and risk of depression as well as improves informational and emotional support, self-efficacy, a sense of support and psychological well-being of carers (Bateman et al., 2017; Parkinson et al., 2017). Consequently, the establishment of care-networks within the community for carers is imperative. Further in-depth understanding of the contribution of social media groups in dementia care support for family carers is needed. Although carers in Australia receive several services and support, including education, training, case management approaches, psychosocial help, support from social groups and respite care services (Dementia Australia, 2015), this study demonstrates the inadequacy of support systems for carers

as a problem. Carers viewed that the government needs to improve direct support, particularly welfare facilities.

### **Educational and information needs of carers**

Family carers reported inadequate knowledge and skills towards providing functional care, and this is in line with previous literature (Cova et al., 2018; DiZazzo-Miller et al., 2014; Jennings et al., 2015). A recent literature review identified the needs associated with functional care as one of the main types of information and knowledge needs of carers of people with dementia (McCabe et al., 2016). Similar to our study, carers have previously indicated that they received inadequate information and faced difficulties in finding credible and reliable information (Peterson et al., 2016). Health literacy and eHealth literacy are essential skills for finding credible and reliable information (Keleher & Hagger, 2007; Norman & Skinner, 2006a). Therefore, health professionals have a significant role in educating carers by providing accurate information and direction in finding credible and reliable sources.

Carers in our study highly regarded the role of health professionals in providing information. However, they reported some challenges in communicating with healthcare professionals. Recent studies have also reported ineffective communication between health professionals and informal carers of people with dementia (Caswell, Pollock, Harwood, & Porock, 2015; Peterson et al., 2016). This is, in part, due to health professionals having a poor understanding of the problems experienced by carers and, therefore, simply disregarding their problems (Manthorpe et al., 2013). Consequently, not only do health professionals need to understand and address problems faced by carers, but they also need to apply effective communication strategies when providing education to carers.

## **mHealth application as an educational and supportive resource**

Today, mHealth applications are widely used in healthcare. In our study, family carers had positive attitudes towards mHealth applications. They identified mHealth applications as a supportive intervention to address information and education needs related to functional care, mainly to obtain timely health information. This is likely to be the result of information on mHealth applications being easily accessible online (Handel, 2011), and providing real-time, demand-driven communication (Boulos et al., 2014). In our study, carers further identified mHealth applications as a platform to obtain time effective support and information, all in one place. Today, mobile devices, where applications are used, are becoming smaller, lighter and less expensive (Wang & Liu, 2009). Literature indicates that mHealth applications can provide personalised support and education at a convenient time (Boulos et al, 2014; Santoro et al, 2015). Therefore, mHealth application interventions may help address the knowledge needed by carers to support functional care given to people with dementia.

Family carers identified time limitations, cost and technology as significant barriers to their use of mHealth applications, and this is congruent with other study findings about mHealth applications for family carers (Rathnayake et al., 2019b; Williamson, Gorman, & Jimison, 2014). However, the use of mHealth applications can minimise some challenges in traditional educational methods, for example, affordability due to high cost and accessibility due to transportation, time and location (Davis et al., 2015). Recent reviews reported that these applications were effective in health education and support (Kitsiou et al., 2017; Xiong et al., 2018). Despite the reported limitations, mHealth applications offer the opportunity to be a feasible education and support resource for family carers of people with dementia to address knowledge needs related to functional care.

## **Limitations**

Findings of this study are limited by the small sample of carers, and it is likely that people who were health literate are more likely to have responded. Therefore, the findings of the study may not be fully reflective of the wider carer population.

Additionally, we did not examine the influence of socio-demographic factors; therefore, future studies are needed to explore the influence of factors such as gender, socio-economic status, culture or ethnicity in functional care needs and the use of mHealth applications.

## **Conclusion**

Results of this study provide insights into the needs, barriers and challenges concerning functional care and the use of mHealth applications of carers of people with dementia living in Australia. Family carers of people with dementia present with care burden as a result of the provision of functional care. The complexity of the dementia syndrome, including memory impairment, the changing nature of symptoms and communication difficulties is one of the most significant barriers in providing functional care. Access to a support network is vital to the provision of functional care. Inadequate knowledge and skills in providing functional care is a significant challenge. Finding credible and reliable information, information and support fragmentation together with insufficient information received from healthcare professionals were some of the issues highlighted by carers in information seeking. mHealth applications appear to offer an opportunity for family carers to use to improve their knowledge and, therefore, to provide support with attention placed on end-users' health literacy levels when designing these educational mHealth application interventions. Further research is needed that compares mHealth applications with the other usual forms of support identified by the carers in this study.

### **Relevance to clinical practice**

This study provides an insight into the needs, barriers and challenges of family carers concerning functional care for recipients with dementia. Findings from this study will help nurses and community care workers to plan and organise functional care education and support for carers of people with dementia living in the community. Our study findings highlight the need for nurses, healthcare professionals and agencies as well as the government to review the adequacy of their existing support systems and, where necessary, to address the needs of family carers of people with dementia to reduce the need for long-term institutionalisation and unnecessary hospital admission. Community healthcare nurses can also monitor and support carers of people with dementia as carer distress, and the burden is a common issue related to the challenges of functional care. The findings of this study support the use of mHealth applications in education and support for family carers of dementia. As indicated in our study, finding credible and reliable information is a difficult task for carers; therefore, community health nurses and other care professionals can help their clients to locate credible data sources. Finally, findings from our study can assist application developers, clinicians and researchers to develop mHealth application-based interventions for family carers of people with dementia.

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## Conflict of interest

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## Results of expert interviews

This section consists of the results and relevant discussion concerning the individual interviews conducted with health and (information technology) IT experts.

## Participants' characteristics

A convenience sample of six health experts participated in the expert interviews, including two aged care nurses, two physicians and two occupational therapists who were working in Australia and experienced with dementia care, and an IT expert who had experience with mHealth application development. Table 5.4 presents their socio-demographic characteristics. The sample consisted of two males and five females.

Table 5.4: Socio-demographic data of experts (n = 7)

Expert	Age in years	Gender	Highest Educational qualification	Expert category	Years of experience
1	60	Female	Postgraduate degree	Aged care nurse and research fellow	30
2	64	Male	Postgraduate degree	Physician (old age mental health) and university professor	35
3	47	Female	Postgraduate degree	Registered nurse in aged care nursing	9
4	47	Male	Bachelor degree	Physician (dementia care)	24
5	45	Female	Bachelor degree	Occupational therapist	8
6	40	Female	Postgraduate degree	Occupational therapist and research fellow	20
7	51	Male	Postgraduate degree	University professor in IT	23

## Findings

### **Challenges faced by family carers of people with dementia in providing functional disability care: Experts' perspectives**

Health experts viewed that family carers have an important role in providing functional disability care for people with dementia living in the community, and they face several barriers and challenges when providing care. One of the main barriers stated was the complexity of dementia. They highlighted that cognitive and perceptual difficulties increased the complexity of functional disability care. According to experts, behavioural changes, including aggression and communication difficulties with a person with dementia, were the most difficult challenges faced by family carers:

*I think it is the practical aspects of providing care and understanding some of the changes that come with dementia in relation to the person's ability to follow instruction, and also things like the fact that with dementia so often they have perceptual difficulties as well. Those sorts of things are often difficult for carers to understand. (Expert 1)*

*Sometimes, some dementia patients don't speak, and you have to approach in a manner that when they're ready to have their care, not when we want to give them care. So sometimes you have to...If the patient, the resident is not ready to have a shower, for example, then you have to come back and then go back and try again. (Expert 3)*

One expert stated that people with dementia need control over their daily living activities, and they do not give this control to others, and this situation leads to care resistance. This resistance to care was identified as another significant challenge.

Experts further viewed that family carers do not like to place their family members in nursing homes because they expect to provide care themselves. One expert claimed that carers worried about providing satisfactory care for their family member;

therefore, they become personally embarrassed about issues related to ADLs. Experts said that family carers can organise and provide care successfully compared with professional carers because they know the history of their carer recipients: *“I think ADL is kind of sensitive. Some people worry. They feel embarrassed talking about things like toileting or worry that they’re going to be judged if they’re not feeding their family members”* (Expert 5).

Experts further stated that providing functional care is a stressful experience for family carers. One expert said that, usually, difficulties faced at the beginning of the day lead to feelings of stress during the carers’ day. Another expert stated that most carers cannot rest during the day:

*The carers just couldn’t get any rest at all. Their patients used to go around switching the lights on and sometimes trying to cook something and then forgetting all about it, burning the food and then going out and just going for a walk.* (Expert 4)

Experts reported that most carers were also older adults and may have medical problems; therefore, these personal characteristics increased the stress and burden of carers. One expert stated that some carers cannot rely on their own memories, and as a result, they forget tasks. This increases their stress levels, which may be reduced if they are provided with written information. Experts also viewed that role reversal was one of the barriers in organising and providing care because role change in managing tasks (e.g., medication management and financial management) increases stress: *“When it’s been the person with dementia that’s managed the finances all the time, and suddenly that shifted across to the carer, I’ve certainly noticed that it can cause really quite significant stress”* (Expert 1). One expert emphasised that usually the symptoms and problems of people with dementia gradually increased, and these increasing care needs reduce the coping abilities of family carers, and, therefore, they become overwhelmed.

Experts stated that providing functional disability care for people with dementia is not only difficult for family carers but also difficult for professional carers. Because these challenges vary from one person to another person with dementia, they need individualised care: *“I think that it’s important that we understand the difficulties facing each carer and each person living with dementia are unique in their own way because you’re dealing with a kind of individual supplied history and all of that”* (Expert 5). Therefore, the availability of family members in the community can help with the provision of individualised care for a person with dementia within the community:

*I suppose the main challenge in supporting people with dementia in the community is the availability of informal carers. Some people don’t have access to a family network, which makes it very difficult to support people in their own home if they don’t have a support network. (Expert 1)*

However, experts argued that although the family has an important role in providing functional disability care in the community, they had a poor understanding of dementia and its consequences: *“Certainly, a lot of carers don’t have a very good understanding of the condition itself and the progression of the condition and some of the behaviours that may occur as a result of dementia”* (Expert 1). Furthermore, they faced difficulties in accessing support within the community, and this was one of the major challenges faced: *“I think a lot of people are not aware of the support systems that they can get or perhaps are not able to access them in a timely manner. They might also be reluctant to ask for help”* (Expert 5).

Experts highlighted that maintaining the well-being of carers was a very important aspect in their caregiving role. They emphasised that health workers, particularly social workers, have an essential role in providing support for family carers. Finally, experts highlighted that carers need opportunities to access support, including

learning new knowledge and sharing their experiences. Carer groups were identified as one way to share the experience and to reduce stress:

*I think carer support groups or carer support forums can be very useful for them. When I've spoken to carers, sometimes going to those forums-most of the ones that I've done, they've been face to face forums rather than online forums. They've just found them really helpful as a way of sharing experiences. I think it is just the relief to know that they're experiencing what other people are experiencing. (Expert 1)*

### **Experts' opinions on developing an mHealth application to address functional care needs of carers of people with dementia**

Experts identified mHealth applications as an important education and support resource for carers of people with dementia. One expert identified applications as very helpful to access information, and these applications have the ability to organise and manage the tasks:

*It will be handy to have that; then you can say if you have the app then if you know where to contact people you can just look it up in the app and then find out the telephone numbers and or you can have a diary or something? It's just a task, you can create a task, if you want to or if you wanted to remember something like you have to do this, and then you just create a task. (Expert 3)*

Experts further identified some important underlying reasons for the need for an application for family carers. They emphasised that there were a number of information sources available for carers; however, they faced difficulties in using or processing this information and receiving accurate information and to make decisions related to care, for example, selecting equipment. Therefore, experts viewed that mHealth applications can be used to provide correct and essential information for carers:

*There is plenty of information out there that addresses the concerns. In my view, the big issue is not so much that there are accessible information gaps but rather the aptitude and willingness of carers to look for the information.*

*(Expert 2)*

Experts said that carers need individualised information, and one expert stated that there is a need for privacy for carers when accessing information, and mHealth applications can be used to provide individualised information:

*I think they really need individualised information. I think they need to know the basics of what dementia is or what the type of dementia their family member has, but it needs to draw them quite quickly too, what kinds of thing can I try?*

*Why might this be happening? (Expert 5)*

Experts further stated that carers do not have adequate time to access information due to the caregiving role and the fact that they have to navigate too much information. Therefore, the mHealth application is very helpful for them to find information in one place: *“It’s also having the time to access information. I think apps can really be very worthwhile in that perspective and actually collecting it in one location that is easily accessible” (Expert 1).*

Moreover, experts identified potential barriers and challenges that might be faced by family carers when using mHealth applications. They stated that the affordability of smartphones is one of the major challenges when introducing mHealth applications. One expert said that using mHealth applications is difficult when the size of the phone is small. The main significant issue identified by experts was technology-related barriers, and they stated that carers need special knowledge and skills to use applications, especially carers in older age. One expert stated that carers in younger generations are more likely to use applications compared with older carers:

*I can certainly see the younger carers. These tend to be the adult children of the person with dementia they're supporting. They would find that a lot easier as people with younger onset dementia and carers in that age group would be more likely to access apps. (Expert 1)*

Experts viewed that readiness to use the application by carers is a very important factor affecting use of mHealth applications. One expert stated that some carers may not find mHealth applications as useful resources: *“Of course, some carers will not find it is very useful for reasons ranging from not finding this style of device useful”*(Expert 2).

## **Discussion**

These interviews were conducted to examine the views and opinions of industry experts regarding the needs, barriers and challenges faced by family carers of people with dementia in providing functional disability care and use of mHealth applications. The findings of this study provide a complementary understanding of carers' needs in relation to mHealth applications. Similar to the findings of the individual interviews with family carers, the experts also claimed that poor understanding was one of the major barriers behind organising functional disability care, while this problem was worsened by the complexity of dementia, including cognitive problems, behavioural problems and communication difficulties. Similar to family carers, experts also identified care resistance as one of the main barriers for providing functional disability care, and resistance to care leads to the development of stress among carers. Therefore, looking after the well-being of family carers is essential, and experts saw the need for good support networks. Similar to carers, the experts also highlighted that carer support groups have a significant role in supporting carers, in particular, sharing experiences and relieving stress.

Similar to carers, experts also identified that mHealth applications can be used as an educational and supportive resource for family carers of people with dementia. They highlighted that these applications can provide real-time education for carers by providing essential information. Similar to carers, experts identified several barriers for accessing applications, for example, affordability of the applications, size of the applications and related technological barriers. Experts further highlighted carers' readiness to use applications as an important factor in introducing mHealth applications.

Additionally, these expert interviews helped to validate the proposed mHealth application content based on the online survey and individual interviews with carers. These results were integrated into the mHealth application development process as discussed in the next chapter.

### **Chapter summary**

This chapter consisted of the findings of interviews conducted with the family carers of people with dementia and industry experts to examine needs, barriers and challenges faced by family carers when providing functional disability care and the use of mHealth applications. These two studies show that providing functional disability care is a significant challenge for family carers of people with dementia, and support networks within the community have an important role in supporting them. Despite the possible challenges and barriers in using mHealth applications, the findings of these two studies suggest that mHealth applications can potentially be used to provide education and support for family carers of people with dementia.

## **Chapter 6 Development and discussion of mHealth application**

### **Introduction**

This chapter describes the second stage of the study (i.e., the development of the mHealth application). In order to address research question two, this phase aimed to develop an mHealth application to address family carers' needs related to functional disability care. Following this objective, this chapter consists of a co-authored manuscript submitted for publication. Within this manuscript, the co-design process used and the prototype development of the mHealth application are presented.

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Co-design of an mHealth application for family carers of people with dementia to address functional disability care needs. Manuscript submitted for publication.

### **Statement of contribution to co-authored published paper**

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:

Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Family carers' perspectives of managing activities of daily living and use of mHealth applications in dementia care: A qualitative study. Manuscript submitted for publication.

My contribution to the paper involved:

Critical review of the literature to inform the design of the study, conceptualising and designing the study, enrolment of participants, data collection, analysis and data interpretation, development of the content and application, writing of the draft manuscript, revision of the manuscript for important intellectual content and approval of the final version.

Minor modifications have been applied to the original publication to fit the thesis formatting.

(Signed) (Date) 12/11/2019  
(Sarath Rathnayake)

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External supervisor: Associate Professor Cindy Jones

## **Co-design of an mHealth application for family carers of people with dementia to address functional disability care needs**

Reference: Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2019). Family carers' perspectives of managing activities of daily living and use of mHealth applications in dementia care: A qualitative study. Manuscript submitted for publication.

### **Abstract**

#### **Objective**

The co-design of a mobile health (mHealth) application for family carers of people with dementia to address functional disability care needs is presented.

#### **Participants**

Participants included family carers of people with dementia, aged care nurses, physicians, occupational therapists and information technology (IT) experts.

#### **Methods**

The co-design process involved two phases: (1) a needs assessment phase (an online survey and in-depth interviews with family carers, and expert consultation); and (2) the development of an mHealth application (content and prototype development). Data triangulation from phase one informed the content of the mHealth application.

#### **Results**

Data triangulation resulted in three content modules: “an overview of dementia and care”, “management of daily living activities”, and “carers’ health and well-being”. The content was based on contemporary literature and care guidelines with input from family carers and dementia care experts. IT engineers developed the mHealth application.

## **Conclusion**

An Android-based mHealth application was designed to address the functional care needs of family carers. The co-design process ensured the incorporation of end-users' real-world experiences and the opinions and expertise of key stakeholders in the application prototype development. It is to be noted that before releasing the application into the app store, testing its feasibility and effectiveness is also essential.

*Keywords:* dementia, family carers, functional disability, mHealth application.

## **Introduction**

Dementia is a global health challenge that is common in an older population. It is a complex syndrome characterised by the progressive deterioration of cognitive function, changes in behaviour and impairment in activities of daily living (ADLs) (Grand et al., 2011; World Health Organisation [WHO], 2017). An inability to independently carry out ADLs is referred to as functional disability (Carmo et al., 2016). There are two groups of ADLs: basic ADLs (BADLs) (i.e., bathing, dressing, toileting, transferring and feeding) and instrumental ADLs (IADLs) (e.g., using the telephone, handling finance and managing medications). Impairment in ADLs is one of the most common reasons for increased dependency among people with dementia, which leads to increased nursing care needs (Giebel et al., 2015; Laver et al., 2016), poor quality of life (Giebel et al., 2015) and institutionalisation (Eska et al., 2013).

As the majority of people with dementia tend to live in the community (Brooks, Ross, & Beattie, 2015), family carers are needed to support their ADL needs. Due to the deterioration of ADLs in people with dementia, providing functional care is very complex, and, usually, family carers need specialised knowledge and skills to assist or provide this care. The requisite skills are similar to those carried out by professional carers, for example, when assisting with bathing and toileting. However, family carers are often unprepared for the caregiving role (Connolly & Milligan, 2014) as most carers

provide this care without formal training (Connolly & Milligan, 2014; DiZazzo-Miller et al., 2014; Rathnayake et al., 2019c), and they provide long hours of care (Brodaty & Donkin, 2009). Studies report that providing functional care is a stressful experience for carers and leads to distress and burden (Kang et al., 2014; Svendsboe et al., 2016), and most carers are at high risk of experiencing social isolation, physical and psychological health problems and reduced quality of life (Alfakhri et al., 2018; Brodaty & Donkin, 2009; Laks, Goren, Duenas, Novick, & Kahle-Wroblewski, 2016; Oba, Matsuoka, Kato, & Narumoto, 2018). Therefore, they need support in providing functional disability care.

The lack of support for carers is a significant problem (Brown et al., 2017), and family carers' demand for education related to functional care is high (Vaingankar et al., 2016). Recent systematic reviews show that most carer-based interventions focus on managing cognitive impairment and behavioural changes and providing carers with psychological support (Piersol et al., 2017; Wu et al., 2018). However, there are limited interventions focusing on functional care support, and few studies were found to assess carers' needs and plan interventions in relation to functional care (Ball et al., 2015; Bliss et al., 2013; DiZazzo-Miller et al., 2014; Furlong & Wuest, 2008; Gitlin et al., 2001). Most available interventions are not suitable for carers as they are time-intensive, costly and burdensome (Brown et al., 2017). Consequently, it is essential to introduce user-friendly and time-effective educational and supportive interventions.

### **mHealth applications**

Due to the popularity of smart-devices (i.e., phones and iPad/tablets) with their user-friendly features, there is a trend for interventions that use mHealth applications to provide healthcare education and support. In a recent review, Zhao, Freeman, and Li (2016) reported that less time consumption, user-friendly design, real-time feedback, individualised elements, detailed information and health professional involvement have

increased the effectiveness of mHealth applications. Additionally, smart-devices are cost-effective and have distinct features, such as ease of availability and accessibility (Brown et al., 2016; Fiordelli et al., 2013; Handel, 2011). Hence, mHealth application interventions can potentially be used to provide timely education and support for carers that may help to reduce their stress and burden (Brown et al., 2017; Grossman et al., 2018; Handel, 2011). A recent integrative review reported that there is a limited number of mHealth application interventions for carers of people with dementia and although the introduction of these interventions is feasible, literacy-related issues can be a barrier for carers (Rathnayake et al., 2019b). Poorly designed mHealth applications create challenges in accessing health information for users with low health literacy (Broderick et al., 2014). Therefore, it is essential to take into consideration the health literacy levels of users when designing mHealth application-based interventions (Boulos et al., 2014).

### **Co-design process**

In recent times, there has been a shift in the development of new products, firstly from a supplier-centred design (i.e., service providers design a product) to a user-centred design (i.e., based on the needs of users), and now to co-design (Ward et al., 2018). In co-design, designers, service providers/suppliers and consumers work together to identify the problem and design a solution (Ward et al., 2018). To achieve better outcomes, all parties have an active role (Bate & Robert, 2006), contribute and work together by using their knowledge and resources (Loffer & Bovaird, 2013). Co-design in health interventions involves the equal partnership of the people who engage in a health intervention, such as service suppliers (i.e., health staff), end-users (i.e., patients, families and carers), and intervention developers (e.g., IT experts) (Ward et al., 2018). In recent history, this method has been widely used to develop health interventions (Davies et al., 2016; Goeman et al., 2017; Ward et al., 2018). This paper reports on the

co-design, specifically the development process, of an mHealth application for family carers of people with dementia to address functional disability care needs.

## **Methodology**

### **Research design**

In this mixed-method study, an mHealth application for family carers of people with dementia to address functional disability care needs was developed based on the co-design process (Ward et al., 2018) and followed two phases: needs assessment and the development of an mHealth application. This paper provides a brief report on the key outcomes of phase one, i.e., needs assessment and focuses on reporting the process of phase two (i.e.,) the development of the mHealth application. This study was approved by the Griffith University Human Research Ethics Committee (Ref 2017/947).

The co-design process incorporated the principles of adult learning theory, i.e., the active participation of adult learners (Knowles, 1984). Based on adult learning theory (Knowles, 1980, 1984), mature learners take responsibility for their learning through their inquiry and personal experiences where they are self-directed and motivated to learn. They organise learning around their life problems. Based on these principles, we developed a self-directed learning platform through an mHealth application for family carers of people with dementia to address their functional care needs.

### **Phase I: Needs assessment**

Phase I focused on identifying the needs of family carers in relation to functional disability care via an online survey and individual interviews with carers as well as healthcare and IT experts. The findings from the survey and interviews informed the content of the mHealth application.

The online survey was conducted to examine the general understanding of the current needs of carers in relation to functional care and their use of mHealth applications in health information seeking (as reported in Rathnayake et al. [in press]). In the online survey, carers reported a need for education in relation to functional care, with bathing deemed as the most challenging care activity, and also supported the view that education related to functional care could potentially be delivered through an mHealth application.

Individual in-depth interviews with family carers aimed to: (a) gain an in-depth understanding of family carers' perceptions towards the needs, barriers and challenges faced when managing functional disabilities of their care recipients; and (b) identify the experiences of and opinions for using mHealth applications in health information seeking (as reported in Rathnayake, et al., 2019a). Provision of functional care was found to lead to the development of carer distress and burden, and performing ADLs was regarded by carers to be difficult. Carers held a positive attitude toward mHealth applications for education and support (Rathnayake et al., 2019a).

Expert interviews aimed to identify health and IT experts' opinions on the provision of care, especially the management of functional disabilities of people with dementia and the development of an mHealth application for family carers. A summary report, based on the results of the online survey and individual interviews with family carers, was provided to the experts prior to the interviews. The report also included content and features proposed for the potential mHealth application as follows:

- Overview of dementia and management of behaviour and symptoms of dementia.
- Information on ADL with a focus on self-care activities (i.e., bathing, dressing, toileting, transferring, feeding); medication management; using public transport; running simple errands).

- Information on available care equipment and support services.
- Discussion board/chat room to connect with other family carers of people with dementia.
- Carers' Corner:
  - Importance of caregiving for the carer.
  - Strategies to support the health and well-being of the carer.
  - Task reminder and calendar features.

The findings and opinions of carers from the online survey and qualitative interviews were validated in the expert interviews. Healthcare experts agreed that managing needs related to functional disabilities was very challenging for carers, while barriers, challenges and difficulties that were highlighted by carers were common for family carers who provided care in the community. Experts highly regarded mHealth applications as a solution for providing demand-driven education as well as an important educational and supportive resource for family carers of people with dementia with the ability to organise and manage information and tasks. They identified the calendar and reminder functions as a very useful application feature for carers.

Experts further commented on issues that may be impacted by creating an mHealth application. Those included the need for individualised information, difficulties in receiving accurate information and using or comprehending of available information, the lack of time to access information, navigation issues related to the availability of a number of sources and difficulties in making decisions about equipment.

They further agreed that the proposed application content was appropriate to address carers' needs related to functional care except for the concept of a 'chat room' due to the need for a moderator for this feature. The IT expert agreed that the proposed content and features were not difficult to include in the design and development of an

application prototype. Experts further raised that maintaining up-to-date information is essential, and the application should be very simple and easy to use. The use of positive and supportive language was highlighted to increase the readability of application content. Other suggestions included the use of videos and cartoons to help carers to understand the provision of providing functional disability care. In addition to the carers' opinion (Rathnayake et al., 2019a), experts suggested including the importance of physical exercise and information on where to access general practitioners. They further emphasised that the prototype needed to be checked with carers before releasing the application.

Experts further identified possible challenges and barriers in relation to the application use. They stated that some carers may not find an mHealth application a useful resource and that they should have the appropriate emotional capacity to make the best use of the applications. As most carers are older people, they may have a lack of knowledge about how to use the mHealth application, and experts stated that younger carers are more likely to access mHealth application compared with older carers. Other barriers stated by experts were need for technical skills in application usage, affordability of smartphone and size of the phone.

## **Phase II: Development of the application**

A user-centric preliminary mHealth application was designed and developed following an iterative co-design process (Bate & Robert, 2006; Broderick et al., 2014; Ward et al., 2018). This process incorporated the concepts related to developing a health literate application proposed by Broderick et al. (2014), which consisted of two stages: content development and prototype development. This process followed a series of steps (See Figure 6.1).

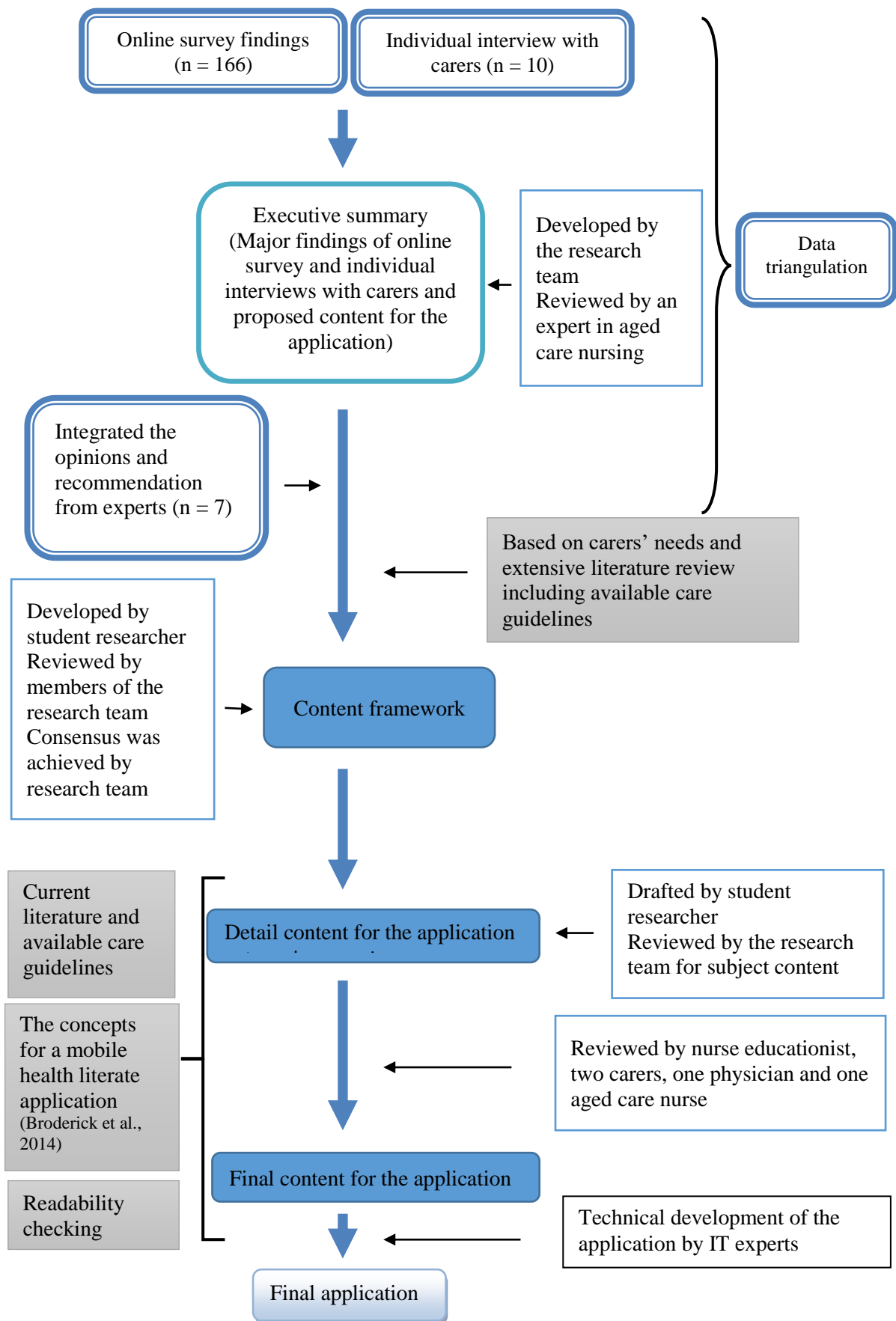


Figure 6.1: The overview of the content and application development process

## **Development and validation of the application content**

Aligned with the co-design process, triangulation of data from the online survey and qualitative interviews with carers and opinions from the experts informed the content framework consisting of three modules: (1) an overview of dementia and care, (2) managing daily living activities, and (3) carers' health and well-being (see Figure 6.2). Consensus on the framework was made by the members of the research group, all of whom have extensive experience in dementia care practice, research and/or education. "Carers' corner" in the preliminarily proposed content was re-named as "Carers' health and well-being". The chat room feature was removed following the experts' view of the need for continuous moderation by health professionals. This was replaced by the inclusion of links to carer support groups (e.g., social media support group) in the application, as the importance of available peer groups in carers' well-being was identified during interviews with carers and experts.

Based on the current relevant literature and evidence-based guidelines (eg., Alzheimer's Queensland, 2018; Dementia Australia, 2018; Davis, Byers, Nay, & Koch, 2009; Laver et al, 2016; Mlinac & Feng, 2016; Ray & Fitzsimmons, 2014; Stone, 2014; Tible, Riese, Savaskan, & von Gunten, 2017; Torrington & Tregenza, 2013; Wijerathna, 2015), detailed content was drafted by the first author (SR). The research team, who have extensive expertise in dementia care practice and research (WM & CJ), reviewed the content over several sessions until consensus was achieved. In addition to text information, links to currently available evidence-based online resources, such as websites, articles and videos, were included in the educational content. Images were also included wherever necessary.

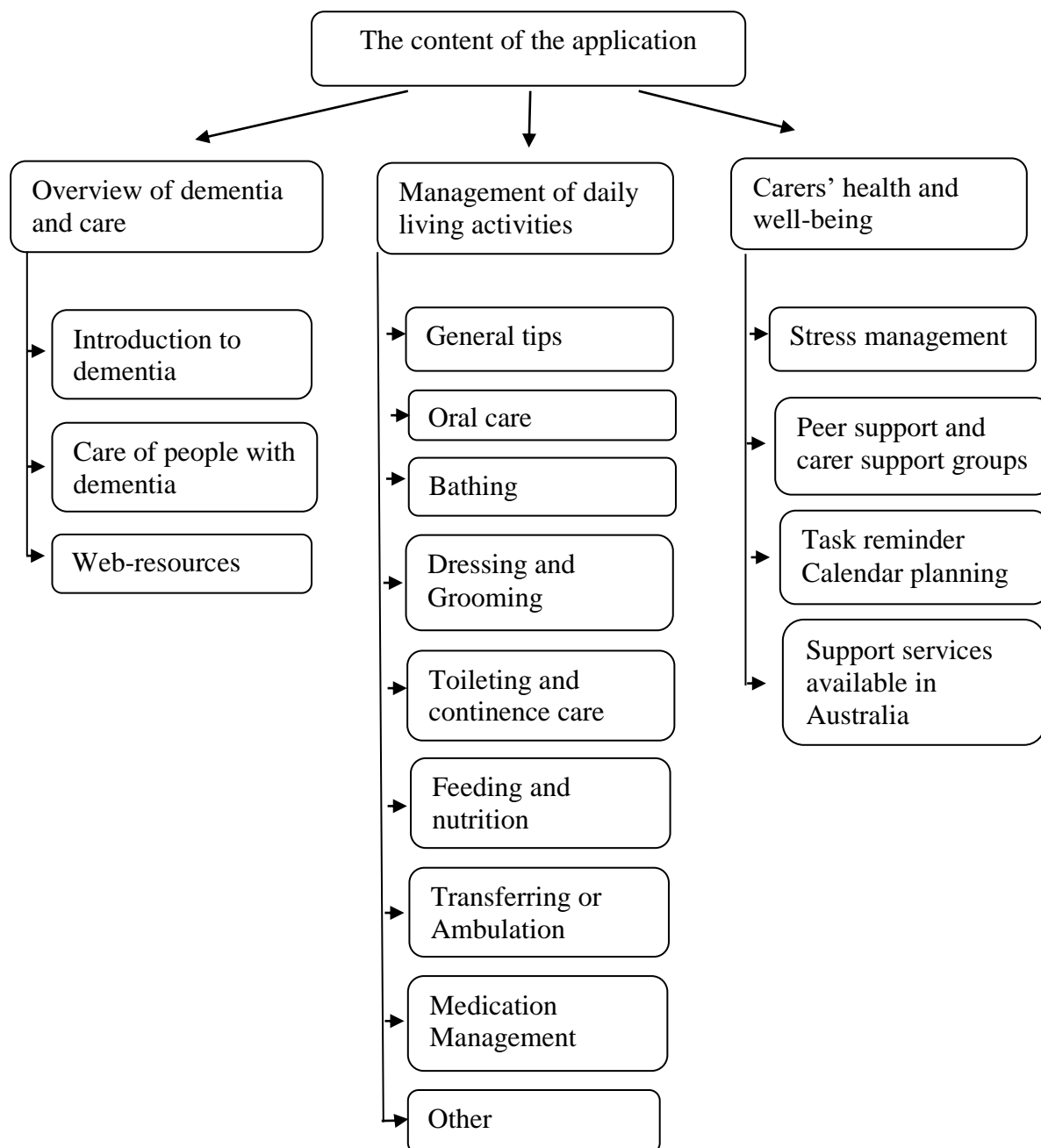


Figure 6.2: The content framework

After the research team finalised the application content, this was further reviewed by a panel of experts. Due to the timeline of this study and the lengthy time required for the mHealth application development, only five experts were able to be identified and included in the review process. This expert panel included (a) a nurse educator who has extensive experience in educational methodology and research, to meet the educational requirements; (b) an experienced geriatric nurse and a physician who both have extensive experience in dementia care; and (c) two carers who

participated in the online survey and qualitative interviews. A content validity index (CVI) was computed from the above experts, and they were asked to rate the content for its appropriateness and clarity based on a four-point Likert scale from strongly agree (1) to strongly disagree (4), and to make any suggestions for further improvement. An overall rating of ‘disagree’ or ‘strongly disagree’ indicated a need for a major revision of the content while an overall rating of ‘agree’ or ‘strongly agree’ reflected appropriateness and clarity of the content, with no changes required for the developed application content. Based on the rating of five assessors, a content validity index (CVI) was computed (see Table 6.1).  $CVI > 0.80$  was considered as adequate for content validity (Polit & Beck, 2006). In the present study, the CVI for the given criteria (appropriateness and clarity) reported an accepted level for the three modules.

*Table 6.1: Content validity index*

<b>Module</b>	<b>Appropriateness</b>	<b>Clarity</b>
Module 1- Part 1		
Introduction to dementia	0.95	0.90
Module 1 - Part 2		
Care of people with dementia	0.95	0.95
Module 2		
Managing activities of daily living	0.95	0.95
Module 3		
Carer health and well-being	0.95	0.95

## **Content overview of the application**

***Module 1: Overview of dementia and care.*** This module consists of three sections that introduce dementia and its management. The section “Introduction to dementia” briefly provided basic information about dementia with its signs and symptoms, types, stages and progression. The section “Care of people with dementia” included basic information about care strategies for dementia, including person-centred care, effective communication, pharmacological and non-pharmacological management, pain

management as well as the management of behavioural and psychological symptoms of dementia. Users can access detailed information through online resources linked to the above topic areas. Under the “Websites” section, we included links to credible national and international dementia organisations, for example, Dementia Australia and Alzheimer’s Disease International.

***Module 2: Management of daily living activities.*** This module is the primary focus of this application. It includes caregiving strategies for six activities related to ADLs (i.e., oral care, bathing, dressing and grooming, toileting and continence, transferring and mobilizing) and four IADLs (i.e., medication management, driving, using telephone and shopping). In addition to general care tips for managing ADL and IADLs, we included caregiving tips or interventions for common problems or questions that can arise during the provision of functional disability care. Aligned with the concepts of andragogy (i.e., problems of carers rather than content) (Knowles, 1984), an example of common problem areas related to the activity of ‘oral care’ included: (1) my care recipient forgets to brush his or her teeth, (2) my care recipient needs assistance to brush his or her teeth, (3) my care recipient is unable to brush his or her teeth, (4) my care recipient has dentures, (5) my care recipient is complaining of pain in his/her teeth and (6) I notice bleeding when providing oral care.

Additionally, this module focused on a brief introduction to the three important concepts related to functional disability care: ‘assessment of ADLs’, ‘positive care approach’ and ‘dementia-friendly environment’. The concept of ‘assessment of ADLs’ briefly describes the importance of the assessment of care needs related to ADLs. The concept of a ‘positive care approach’ focuses on using existing skills and abilities in care rather than what the person with dementia is no longer able to do. The concept of a ‘dementia-friendly environment’ briefly describes making a safe and secure environment at home to promote ADLs of the care recipient.

**Module 3: Carers' health and well-being.** To address the reported distress and burden to functional care, this module focused on the health and well-being of carers and consists of three sections. The section "Stress management" includes basic information related to the management of carers' stress, including the importance of exercise, meditation and music. In the section "Peer support & carer support groups", we included information for and links to currently available peer support groups and social media support groups. Features such as 'calendar' and 'reminders to appointments' and 'events' were included under the section of "Task reminder and calendar planning". Under the section "Support services available in Australia", weblinks and contact information of local, state and national carer resources and services were included.

### **Formatting the content**

In line with the framework proposed for a health literate application by Broderick et al. (2014), the concepts of 'write actionable content' and 'plain language with everyday words' were used in the application. For all medical terms and concepts that may be difficult to understand, a glossary of these terms was included. Broderick et al. (2014) recommend short sentences of 15-20 words. In the app content, the average words per sentence were 5.56, 7.14, and 7.15 for modules 1, 2 and 3, respectively. Furthermore, bullet points were used rather than a paragraph structure. The recommended minimum font size was 12. In our application, we used the dynamic font size that facilitates re-sizing the font size based on the device. Images were used where necessary, and links were labelled clearly (Broderick et al., 2014). Additionally, black text and white background (Boyco, 2017; Broderick et al., 2014) with Arial font were used. Arial font style is one of the popular mobile web-safe sans-serif fonts that is highly readable even on mobile surfaces (Broderick et al., 2014). The content of the application was organised under three modules, and British English was used.

## **Readability**

Readability for the application content was checked using the Flesch-Kincaid Readability Formula (Kincaid et al., 1975) via the online-utility.org website ([https://www.online-utility.org/english/readability\\_test\\_and\\_improve.jsp](https://www.online-utility.org/english/readability_test_and_improve.jsp)). The desired readability was maintained around the level of eight as the average Australian reading level is at grade eight (Cheng & Dunn, 2015). Readability index was 9.33, 6.36 and 8.23 for modules 1, 2, and 3, respectively.

## **Development of the application prototype**

Professional IT engineers (i.e., application developers) were employed to develop the application using an Android system. After an initial discussion via telephone between the first author and the application developers, three face-to-face meetings took place with ongoing discussions occurring over the phone or via texts or email correspondences until the completion of the application development. The application was named “Dementia Support for Carers” as the primary function of the application was to provide education and support for carers of people living with dementia.

## **Logo of the application**

The first author (SR) designed the application logo under the direction of the research team (see Figure 6.3), and then the application developers digitally developed it. The logo depicts the carers receiving information and support from health professionals to look after their care recipients through a smartphone device in the community (i.e., home). The symbol of a heart represents love and compassion as required in dementia care. The colour red was used as it denotes energy and love as well as it being an eye-catching colour that helps to draw attention (Cerrato, 2012).



Figure 6.3: mHealth Application logo

### Sign-in or log-in page

Users can log into the application via Google or Facebook (see Figure 6.4). The user profile includes the following details: name, email address, gender, country, age group and the role of the user (i.e., family carer, health worker/professional, a person with dementia, student, researcher and others). The first time use of the application requires the user to register by entering their profile details.

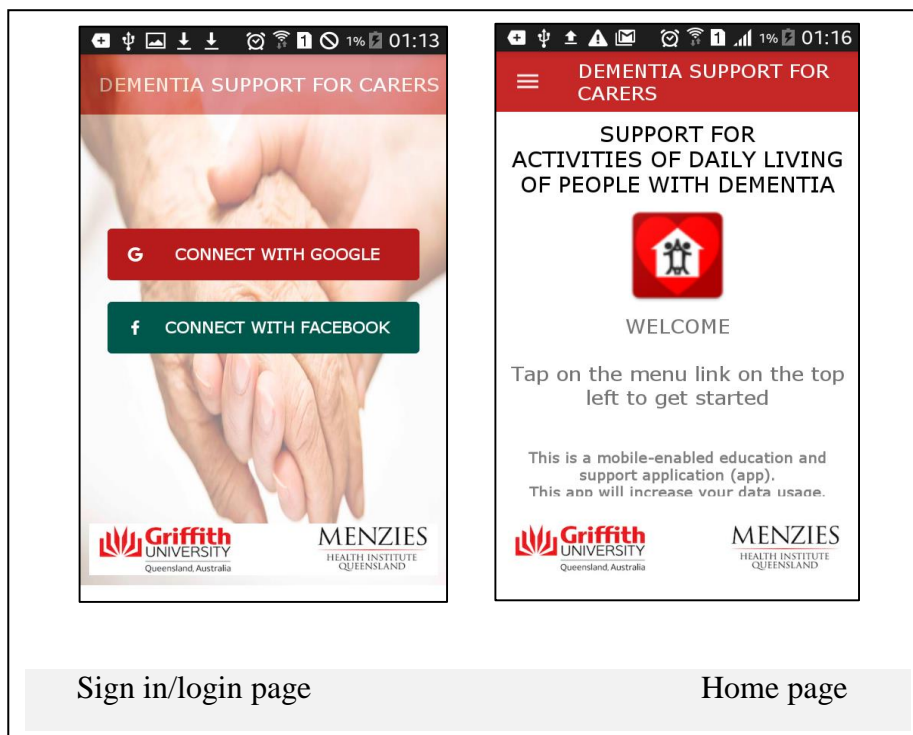


Figure 6.4: Login and home pages

## User interface and content organisation

Based on the Broderick et al. (2014) framework for health literacy applications, a simple and engaging home page was created. User-friendly navigation features, such as touch and slide options, were included. Users can access relevant text information and links through either touching or sliding the menu, sub-menu, icons or links. The home page consists of a “Home” (line menu) icon ( ≡ ) on the top left corner, and the user can easily access the home page or menu pages using this icon. Users can shuffle from the current page to the previous page using the back icon ( ← ). Additionally, permission was sought and granted to use the logos of Griffith University and Menzies Health Institute, Queensland in the application interface (see Figure 6.4).

The organisation of the application main content menus (i.e., ‘Home Page’, ‘Dementia and care’, ‘Management of daily living’, ‘Carer health and well-being’, ‘About this app’, ‘Instructions’ and ‘Glossary’) and the organisation of sub-menu ‘Dementia and Care’ are reflected in Figure 6.5.

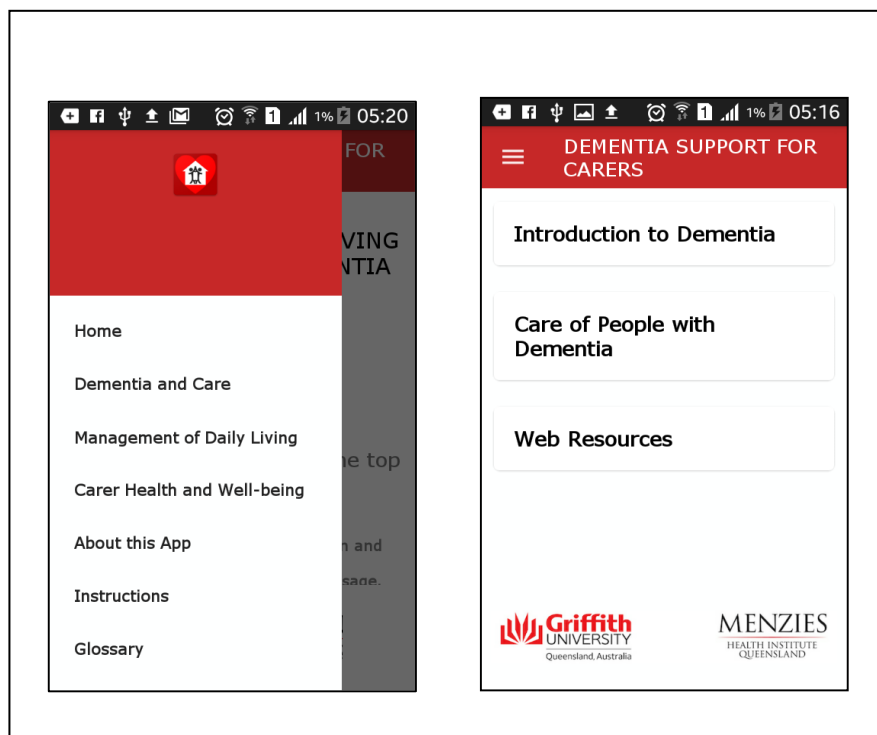
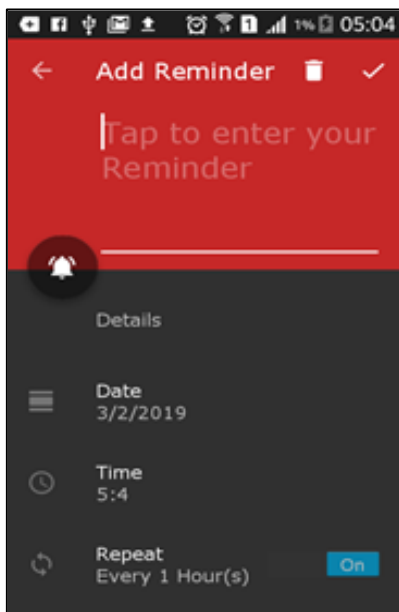


Figure 6.5: Menu and sub-menus organisation

Additionally, the application included a feature that focuses on sending reminders through notification. Carers can set a notification/reminder for a particular task (e.g., time for giving medication), an appointment date or any events using the year calendar and 24-hour clock. There is also a snooze function to reset the alarm based on the given time gap (i.e., minute, hour, day, week or month) (See Figure 6.6).



*Figure 6.6:* Reminder feature

### **Technical description of the application**

The application was developed in Android using Java and Android Studio. The Android software development kit (SDK) provides a variety of user interface elements and modules to plug into the application that helps users to use it easily and in a flexible way. Firebase was used to store data in the backend real-time database as it seamlessly integrates into the SDK. Using Google sheet, the script was run to add all the formatted data into the database. Login was achieved using Google and Facebook. Background services provided by Android SDK platform were used to add and run reminders through notification at particular times along with snooze. Hypertext markup language (HTML) was used to display the content of the application. As indicated earlier, we have developed an Android-based application. The authors are working with the

developers towards developing the application on an iOS-based platform to increase its accessibility and wider distribution.

## **Discussion**

This paper describes the process of developing a mobile-enabled mHealth application for family carers of people with dementia to address needs related to functional disability care. Consistent with the previous health intervention studies (Davies et al., 2016; Goeman et al., 2017; O'Connor et al., 2016a; Ward et al., 2018), a co-design process guided the development of the application. To our knowledge, this is the first reported mHealth application development study based on the co-design process that addresses the functional disability care needs of family carers of people with dementia. This co-design process has been used in a previous study by O'Connor et al. (2016a) to develop an mHealth application for people with dementia and their carers to share memories. Co-design is a recent method used in designing health interventions (Ward et al., 2018). Assessment of the needs of primary users is an essential strategy to increase the effectiveness of the intervention (Broderick et al., 2014; Kojuri et al., 2015). The needs assessment enabled us to obtain in-depth views of carers' needs concerning functional care and mHealth application use. Additionally, it helped us to integrate other stakeholders' (i.e., service providers and designers) views and expertise into the application development process. This is the main advantage of the co-design process compared with the user-centric design because in user-centric approaches, the product is mainly based on the needs of primary users (Ward et al., 2018).

Technology-based interventions facilitate carers to access support at all times of the day, at their convenience (Brodaty & Donkin, 2009). To date, most of the available interventions for carers are time-intensive and costly (Brown et al., 2017). For example, traditional learning programs, such as face-to-face learning, requires a number of facilities and resources, for instance, travel costs, availability of facilitators or trainers,

scheduled times, venues and other related resources (Sissine et al., 2014). In addition, both teachers and learners need to be physically present, and sometimes this may lead to content overload among trainees due to the limited time periods for learning. Our mHealth application intervention uses a technology-based approach that is less time-consuming (Zhao et al., 2016). Furthermore, it can serve a larger population in a mobile form compared with traditional forms (Grossman et al., 2018) because any person from urban, rural or remote areas can access mHealth applications if they have smartphone access.

Moreover, modern technology supports more informal and self-directive learning with help from new technologies (Song & Bonk, 2016). Self-directed learning is a central concept of adult learning (Knowles, 1980, 1984; Lowry, 1989), and mHealth applications are widely recognised as self-directive learning platforms (Camargo, Bary, Boly, Rees, & Smith, 2011) that allow the users to take in as much or as little as is needed at the time, reducing learning overload. Therefore, this mHealth application-based platform might be helpful as a self-directed learning resource for family carers of people with dementia.

This application aims to be a user-friendly application for carers. We used a user-friendly interface (Zhao et al., 2016) with many features, for example, line menu icon (home icon), touch, and slide options to increase the usability of the application. Additionally, we integrated health literacy concepts related to developing an mHealth application (Broderick et al., 2014) and checked the readability of the content. Boulos et al. (2014) argue that there is a poor focus on including those concepts into mHealth application development. Therefore, we expect the application of these concepts will increase the usability further. This carer focused mHealth application was designed by health professionals who were experts in dementia care. Zhao et al. (2016) state that the

engagement of health professionals in developing mHealth applications increases the credibility and efficacy of applications.

The researchers faced several challenges during this mHealth application development study. Initial cost relevant to the development of the application is one of the main drawbacks of mHealth application-based interventions (Boulos et al., 2014). The co-design process is time-intensive (McBride et al., 2017). In this study, carers and key stakeholders participated and engaged with a number of research activities in several stages; therefore, this process took 16 months to complete. Additionally, during the interviews, carers often wanted to discuss and explore issues around caregiving other than functional disability care needs. It was also challenging to arrange interviews with experts due to their workload. The researchers' inexperience with the technical development of the application, for example, organising content to suit the application interface, technical vocabulary and technical methods used in designing, and application developers' inexperience with integrating health literacy concepts in the application were other challenges.

During the interviews, carers stated that including a feature or facility to include favourite music into the application would be very helpful (Rathnayake et al., 2019a); however, as our major focus was functional disability care, we did not include the above feature in the application. Future investigations might focus on introducing music-related interventions through smart-technologies for carers of people with dementia. Initially, we intended to include a discussion board/chat room for carers as they highlighted the need for timely information, notably receiving a timely response from health professionals for their problems related to caring in the need's assessment phase. However, the inclusion of such a platform requires moderation by health professionals and can be laborious and time-consuming. It is acknowledged that skills training via video demonstration would be ideal for educating carers; the application

development was limited by the time and cost required to develop and produce these training videos. Therefore, there is room for improvement to the current application to include skill training videos concerning functional disability care, and a chat room with professional moderation and entertainment features for carers.

Additionally, one-time-only feedback on the application content was solicited from a small sample of carers and experts. While the CVI was computed and strong agreement obtained for both appropriateness and clarity of the application content, further validation of the application in its entirety (i.e., user testing) is required before the application is introduced and distributed widely to carers.

## **Conclusion**

We have developed an Android-based mHealth application for family carers of people with dementia to address needs related to managing functional disabilities of their care recipients. The application can be accessed through an Android-based smartphone or tablet. The co-design process helped to design and develop a new application for carers based on their real-world experiences and the opinions as well as the expertise of the key stakeholders, including healthcare and IT professionals. Before the release of the application to the public, testing of this application with carers of people with dementia for its feasibility and effectiveness is essential.

## **Acknowledgements**

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**Disclosure of interest**

The authors report no conflict of interest.

**Chapter summary**

This chapter consisted of the development process of an Android-based mHealth application for family carers of people with dementia to address needs related to managing functional disabilities of their care recipients. The triangulation of data from the needs assessment phase (an online survey, individual interviews with family carers and industry experts) informed the content framework for the mHealth application. The application consists of three modules: (1) an overview of dementia and care, (2) managing daily living activities, and (3) carers' health and well-being. The content validity of the modules was established. Following the concepts for developing a health literate application, an Android-based mHealth application was designed and developed.

## **Chapter 7 Conclusion**

### **Introduction**

First, this chapter consists of an overview and the conclusions drawn from the study. Further, it presents the strengths and limitations of the study, and recommendations for practice and future research, including future directions of this project. Finally, the chapter summary is presented.

### **Overview of the study**

This study aimed to develop an mHealth application for family carers of people with dementia to address their needs related to the management of functional disabilities of their care recipients. The principles of adult learning theory were followed (Knowles, 1980, 1984), and a mixed-method study was undertaken using an iterative co-design process (Bate & Robert, 2006; Broderick et al., 2014; Ward et al., 2018) consisting of two phases. In the first phase, an online survey and in-depth interviews with family carers and experts were conducted to identify needs of and barriers and challenges faced by family carers concerning the management of functional disabilities of their care recipients and the use of mHealth applications. In the second phase, based on the findings of phase one, the content for the application was drafted, and an Android based-application was developed consisting of three modules: (1) an overview of dementia and care; (2) managing daily living activities, and (3) carers' health and well-being.

### **Conclusions drawn from the study**

The conclusions drawn from this study are presented as follows:

1. Functional disability is a common and serious problem among people with dementia that results in the need for increased care.

2. Family carers present with inadequate knowledge and skills in functional disability care and they need education in related areas.
3. Family carers present with carer burden that may be as a result of the provision of functional care, and this is a highly prevalent problem.
4. Health and eHealth literacy levels of family carers of people with dementia in Australia are relatively high.
5. Memory impairment, the changing nature of symptoms, communication difficulties and care resistance are some of the most significant barriers in the provision of functional care.
6. Access to a support network, including peer support, may help family carers with the provision of functional disability care.
7. Finding credible and reliable information, information and support fragmentation and insufficient information received from healthcare professionals were some of the challenges faced by carers in information seeking.
8. The main educational needs of family carers of people with dementia identified in this study were as follows: information on dementia, including types, progression and management; information related to managing ADLs; information on available services, facilities, information sources, training opportunities and equipment; and information and strategies for looking after carers' health and well-being.
9. Family carers have a positive attitude towards mHealth applications as an educational and supportive resource.
10. The barriers related to the use of mHealth applications include cost, the memory capacity of the mobile device, technology and literacy-related barriers, time limitations and carers' readiness to use the application.

11. There is the potential for education and support for family carers of people living with dementia to be provided via mHealth applications.
12. This study is the first known mHealth application development study based on the co-design process that addresses the functional disability care needs of family carers of people with dementia.

### **Strengths of the study**

As this study was based on a mixed-method approach, it enabled researchers to integrate different views in the application development process. This integration helped to increase the confidence and validity of the findings and conclusions drawn related to the application development process (O’Cathain et al., 2010). The assessment of the needs of primary users is an essential strategy to increase the effectiveness of the intervention (Broderick et al., 2014; Kojuri et al., 2015; Knowles., 1980). We followed the co-design process, including a needs assessment phase. This process helped the researchers to design and develop the mHealth application based on the family carers’ real-world experiences and opinions, with the expertise of the key stakeholders, including healthcare and information technology (IT) professionals. It helped to answer the actual needs of family carers as well as to improve the usability of the application (Christel et al., 2018).

In the development, health literacy concepts concerning developing a health literate mHealth application were applied (Broderick et al., 2014). We used a user-friendly interface with many features (home icon, touch and slide options) to increase the usability of the application. Additionally, the readability of the educational content was assessed, and content validity was established. These strategies help to increase the usability of the application; therefore, this application is assumed to be a user-friendly self-directive educational and supportive platform for family carers of people with dementia. This application was developed by professional application developers,

adding strength to this study. In addition to the information and caregiving tips for managing daily living activities, this application consists of links for additional information, for example, web-resources, online articles and YouTube videos. It further includes links for the websites of national and international dementia-related organisations, and local and national support services related to dementia. These features have increased the comprehensiveness of this application, and carers can access information from a wide range of sources in one place.

### **Limitations of the study**

In the needs assessment phase, an online survey approach was used. Carers who did not have the resources or the skills to access and fill out an online survey were, therefore, unable to participate. Additionally, dementia-related websites and social media were used to recruit participants; therefore, only carers who accessed relevant websites and social media participated in this study. These factors reduce the representativeness of the sample and the generalisability of the results. With the explorative nature of individual interviews with carers and experts, and the timeframe of the study, a small sample of family carers (ten) and experts (seven) participated in the study, and data saturation was not possible. Therefore, the findings of these studies may not be fully reflective of the wider carer and expert population.

In the content development, a Delphi approach may be the best method for content validation. In this study, one-time-only feedback was solicited from a small sample of carers and experts, adding a limitation to this study. The initial cost relevant to the development of the application is one of the main drawbacks faced by the researchers. Additionally, the co-design process was time-intensive. Skill training via video demonstration would be ideal for educating users through online/electronic platform. However, the development of these skill training videos demand more time

and cost; therefore, researchers were unable to integrate researchers-developed skill training videos into this application.

## **Recommendations**

### **Recommendations for practice**

This PhD study found that functional disability was a highly prevalent problem among people with dementia; therefore, nurses and other community care workers need to give priority to the early detection and prevention of functional disability to prevent negative consequences for people living with dementia. It is also essential that they plan interventions to support the needs related to functional disabilities of people with dementia living in the community.

This study identified that family carers had inadequate knowledge and skills concerning functional disability care, especially in performing skilled care activities, for example, bathing, toileting and transferring. Carers need more support and education in these areas; therefore, nurses and other community health professionals need to identify and address the educational needs of carers related to the above areas. Furthermore, family carers reported that they received inadequate information and faced difficulties in finding credible and reliable information; therefore, nurses and other health professionals have a significant role in educating carers by providing accurate information and direction in finding credible and reliable sources. Additionally, this study reported that carers faced challenges in communicating with healthcare professionals. Hence, nurses and other health professionals need to address problems related to communication with health staff faced by carers and also apply effective communication strategies when providing education to family carers.

This study further reported that carer burden was a significant problem among family carers of people with dementia who provide functional disability care. Therefore,

nurses and other health professionals need to identify distress and burden of carers and plan educational and supportive programs to address their distress and burden. The complexity of the dementia syndrome, including memory impairment, resistance to care and communication difficulties as well as problems related to role reversal, were significant barriers related to organising functional disability care; therefore, nurses and other health professionals need to pay special attention to the above factors when planning and implementing educational and supportive programs for family carers. Moreover, this study found family carers presenting with chronic medical problems were at a higher risk of developing distress and burden. Therefore, nursing interventions that focus on carer burden need to address the needs and challenges experienced by carers who have chronic medical problems. This study also recognised that the stage of dementia was an associated factor in developing carer burden. Hence, nurses and care providers need to pay special attention to specific problems related to the different stages of dementia.

This study found that support systems available within the community have an essential role in family-centred dementia care. The support systems included family support, government support, direct support services available within the community, and peer support groups, including social media groups. However, it further found that the availability of such facilities was limited, and finding suitable services was sometimes difficult. A lack of awareness about available support services was also reported. The establishment of care-networks within the community for family carers is essential. Furthermore, it is essential to increase carers' awareness of available supportive services. Establishment or expansion of alternative support systems is required, for example, peer support groups, including social media groups.

According to this study, family carers reported relatively high health literacy and eHealth literacy level, increased use of smartphones and tablets/iPads as well as use of

mHealth applications. Additionally, they had positive attitudes towards the Internet and mHealth applications in health decision making. Therefore, nurses and other care providers can use these media to provide education and support and can plan eHealth and mHealth educational interventions to address health problems, particularly educational needs related to functional disability care of carers who use the Internet and mobile devices. However, this study identified several barriers and challenges related to design and implementation of mHealth based interventions, for example, literacy, technology and cost-related barriers, time limitations and readiness to use of the above applications. Therefore, these factors need to be considered when planning those interventions to family carers in the community.

### **Recommendations for future research**

There are a number of implications arising from this study for future research. This study found that family carers of people with dementia present with inadequate knowledge and skills related to functional disability care; therefore, it is essential to explore their educational needs further and to plan research studies to address carers' educational needs related to functional disability care. This study reported that carer burden was a significant problem as a consequence of functional disability care. An in-depth understanding of carer burden, especially factors affecting carer burden, is essential to plan supportive interventions; therefore, further research is recommended. This study further reported that support networks, particularly peer support, including social media groups, have a significant role in carers' lives; consequently, an in-depth understanding of the contribution of social media groups in dementia care support for family carers may be useful.

The study findings support that planning and implementation of mHealth applications are feasible for family carers of people with dementia. However, there are limited mHealth application-based interventions for family carers; accordingly, there is

a need to expand related research, particularly intervention studies on carers' needs concerning functional disability care. In future studies, rigorously designed studies with a clear theoretical framework used in the development of mHealth applications for carers are essential. Moreover, researchers need to pay special attention to using health literacy concepts when designing and developing mHealth application-based studies for the above population.

Based on the integrative review's findings, this PhD study identified that most current studies are feasibility studies, and there is a lack of randomised control trials (RCTs). As mHealth applications are relatively new interventions, the assessment of their effectiveness is essential to validate these applications for carers; therefore, planning future research on mHealth applications with strong methodological rigour, for example, RCTs are recommended. It is crucial to expand research on mHealth applications as an educational and supportive resource for family carers of people with dementia.

This study explored possible barriers and challenges related to the development and implementation of mHealth applications and related interventions, for example, literacy and technology-related barriers, cost factors, time limitations and readiness to use by carers. Researchers need to pay special attention to these factors when designing and developing mHealth application-based studies for the carers of people with dementia.

### **Future directions**

Further validation of the application is required. It is recommended that a feasibility study with a group of family carers is conducted before introducing this application to a wider carer population. Furthermore, it is important to test the effectiveness of this application using a gold standard methodology, such as RCTs. The expansion from Android to the iOS platform is also essential to enable a larger population of carers to

use the application. Carers were interested in the mHealth application having a chat room feature, the addition of skill training videos, and an entertainment feature for the application, such as a platform to include their favourite music, videos, and movies. Therefore, improvement to the current application could include such features. Following a feasibility study, a large scale RCT is needed to establish the effects of the mHealth application on carers' knowledge and burden.

### **Chapter summary**

This chapter presented the conclusions for this study. It included an overview of the study, methods, major findings and conclusions. Further included are the study strengths and limitations, recommendations for practice and future research, and further directions for the study. This study is the first known educational mHealth application development study based on the co-design process that addresses the functional disability care needs of family carers of people with dementia. It developed an Android-based mHealth application for family carers of people with dementia to address their functional disability care needs.

## Appendices

### Appendix A: Additional search strategy

#### Data base-Medline (EBSCOhost)

- S1 (MH "Dementia") (139,404)
- S2 (MH "Alzheimer Disease") (78,695)
- S3 TI dementia OR AB dementia (85,402)
- S4 TI Alzheimer\* OR AB Alzheimer\* (116,691)
- S5 S1 OR S2 OR S3 (207,335)
- S6 (MH "Caregivers") (27,898)
- S7 (MH "Spouses") (8,443)
- S8 (MH "Family") (68,532)
- S9 TI caregiver\* OR AB caregiver\* (46,582)
- S10 TI carer\* OR AB carer\* (11,462)
- S11 TI spous\* OR AB spous\* (15,935)
- S12 TI famil\* OR AB famil\* (904,558)
- S13 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 (985,038)
- S14 (MH "Smartphone") (1,183)
- S15 (MH "MobileApplications") (2,122)
- S16 (MH "Computers, Handheld") (2,963)
- S17 TI "smartphone application\*" OR AB "smartphone application\*" (64)
- S18 TI "mobile health application\*" OR AB "mobile health application\*" (155)
- S19 TI "mHealth application\*" OR AB "mHealth application\*" (143)
- S20 TI "smartphone app\*" OR AB "smartphone app\*" (89)
- S21 TI "phone app\*" OR AB "phone app\*" (479)
- S22 TI "mobile app\*" OR AB "mobile app\*" (1623)

- S23 TI “mobile health app\*” OR AB “mobile health app\*” (233)
- S24 TI “mHealth app\*” OR AB “mHealth app\*” (284)
- S25 TI “handheld computer\*” OR AB “handheld computer\*” (236)
- S26 TI “personal digital assistant\*” OR AB “personal digital assistant\*” (963)
- S27 S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR  
S23 OR S24 OR S25 OR S26 (7909)
- S28 S5 AND S13 AND S27 (17)
- S29 S5 AND S26 AND S27 2007.01.01-2017.09.31; English Language (15)

**Data base: CINAHL Plus with Full Text**

- S1 (MH “Dementia”) (29,679)
- S2 (MH “Alzheimer’s Disease”) (23,664)
- S3 TI dementia OR AB dementia (34, 640)
- S4 TI Alzheimer\* OR AB Alzheimer\* (23,760)
- S5 S1 OR S2 OR S3 OR S4 (63,854)
- S6 (MH “Caregivers”) (25,047)
- S7 (MH “Spouses”) (7,579)
- S8 (MH “Family”) (31,668)
- S9 TI caregiver\* OR AB caregiver\* (31,559)
- S10 TI carer\* OR AB carer\* (10,402)
- S11 TI famil\* OR AB famil\* (180,152)
- S12 TI spous\* OR AB spous\* (7,196)
- S13 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 (231,980)
- S14 (MH “Smartphone”) (812)
- S15 (MH “Mobile Applications”) (2149)
- S16 (MH “Computers, Hand-Held”) (3533)
- S17 TI “smartphone application\*” OR AB “smartphone application\*” (25)

- S18 TI “mobile health application\*” OR AB “mobile health application\*” (95)
- S19 TI “mHealth application\*” OR AB “mHealth application\*” (72)
- S20 TI “smartphone app\*” OR AB “smartphone app\*”
- S21 TI “phone app\*” OR AB “phone app\*” (220)
- S22 TI “mobile app\*” OR AB “mobile app\*” (981)
- S23 TI “mobile health app\*” OR AB “mobile health app\*” (143)
- S24 TI “mHealth app\*” OR AB “mHealth app\*” (125)
- S25 TI “handheld computer\*” OR AB “handheld computer\*” (99)
- S26 TI “personal digital assistant\*” OR AB “personal digital assistant\*” (557)
- S27 S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR  
S23 OR S24 OR S25 OR S26 (7181)
- S28 S5 AND S13 AND S27 (20)
- S29 S5 AND S13 AND S27 2007.01.01-2017.09.31; English Language (19)

#### **Data base: Cochrane Library**

- #1 MeSH descriptor: [Dementia] (4,594)
- #2 MeSH descriptor: [Alzheimer Disease] (2,549)
- #3 “dementia”:ti,ab,kw (7,706)
- #4 “Alzheimer\*”:ti,ab,kw (7,133)
- #5 #1 or #2 or #3 or #4 (12,324)
- #6 MeSH descriptor: [Caregivers] (1,739)
- #7 MeSH descriptor: [Spouses] (297)
- #8 MeSH descriptor: [Family] (7,671)
- #9 caregiver\*:ti,ab,kw (6,040)
- #10 carer\*:ti,ab,kw (1,479)
- #11 spous\*:ti,ab,kw (1,191)
- #12 famil\*:ti,ab,kw (25,121)

- #13 #6 or #7 or #8 or #9 or #10 or #11 or #12 (34289)
- #14 MeSH descriptor: [Smartphone] (80)
- #15 MeSH descriptor: [Mobile Applications] (156)
- #16 MeSH descriptor: [Computers, Handheld] (285)
- #17 “smartphone application\*”:ti,ab,kw (16)
- #18 “mobile health application\*”:ti,ab,kw (16)
- #19 “mHealth application\*”:ti,ab,kw (17)
- #20 “smartphone app\*”:ti,ab,kw (18)
- #21 “phone app\*”:ti,ab,kw (82)
- #22 “mobile app\*”:ti,ab,kw (457)
- #23 “mobile health app\*”:ti,ab,kw (20)
- #24 “mHealth app\*”:ti,ab,kw (21)
- #25 “handheld computer\*”:ti,ab,kw (28)
- #26 “personal digital assistant\*”:ti,ab,kw (129)
- #27 #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or  
#25 or #26 849
- #28 #5 and #13 and #27 Publication Year from 2007 to 2017 2

**Data base: PsycINFO (via Ovid)**

1. dementia/ or alzheimer’s disease/ (62778 )
2. dementia.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
3. original title, tests & measures] (61727)
4. Alzheimer\*.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
5. original title, tests & measures] (54686)
6. 1 or 2 or 3 (90378)
7. caregivers/ (24341)
8. family/ (42721)

9. caregiver\*.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
10. original title, tests & measures] (47896)
11. carer\*.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
original  
12. title, tests & measures] (8721)
13. famil\*.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
original  
14. title, tests & measures] (409687)
15. spous\*.mp. [mp=title, abstract, heading word, table of contents, key concepts,  
original  
16. title, tests & measures] (25808)
17. 5 or 6 or 7 or 8 or 9 or 10 (454494)
18. mobile devices/ (1648 )
19. "smartphone application\*".mp. (24)
20. "mobile health application\*".mp. (33)
21. "mHealth application\*".mp. (31)
22. "smartphone app\*".mp. (40)
23. "phone app\*".mp. (184)
24. "mobile app\*".mp. (731)
25. "mobile health app\*".mp. (53)
26. "mHealth app\*".mp. (71)
27. "handheld computer\*".mp. (120)
28. "personal digital assistant\*".mp. (439)
29. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (2890)
30. 4 and 11 and 23 (6)
31. limit 24 to (english language and yr="2007 -Current") (6)

### **Data base: Embase**

- #1 'dementia'/exp (295,800)
- #2 'alzheimer disease'/exp (160,522)
- #3 'dementia':ab,ti OR 'alzheimer\*':ab,ti (233,635)
- #4 #1 OR #2 OR #3 (333,898)
- #5 'caregiver'/exp (58,684)
- #6 'family'/exp (435,768)
- #7 'spouse'/exp (13,845)
- #8 'caregiver\*':ab,ti OR 'carer\*':ab,ti OR 'spous\*':ab,ti OR 'famil\*':ab,ti  
(1,190,613)
- #9 #5 OR #6 OR #7 OR #8 (1,461,261)
- #10 'smartphone'/exp (3,365)
- #11 'personal digital assistant'/exp (1,085)
- #12 'smartphone application\*':ab,ti OR 'mobile health application\*':ab,ti OR  
'mHealth application\*':ab,ti (470)
- #13 'smartphone app\*':ab,ti OR 'phone app\*':ab,ti OR 'mobile app\*':ab,ti OR  
'mobile health app\*':ab,ti (2,748)
- #14 'mHealth app\*':ab,ti OR 'handheld computer\*':ab,ti OR 'personal digital  
assistant\*':ab,ti (1,582)
- #15 #10 OR #11 OR #12 OR #13 OR #14 (7,779)
- #16 #4 AND #9 AND #15 (25)

### **Data base: Scopus**

1. TITLE-ABS-KEY ( dementia ) (156,840 )
2. TITLE-ABS-KEY ( alzheimer\* ) (180,085)
3. ( TITLE-ABS-KEY ( dementia ) ) OR ( TITLE-ABS-KEY ( alzheimer\* ) )  
(278,150)

4. TITLE-ABS-KEY ( caregiver\* ) (85,278)
5. ( TITLE-ABS-KEY ( caregiver\* ) ) OR ( TITLE-ABS-KEY ( carer\* ) ) OR ( TITLE-ABS-KEY ( spous\* ) ) OR ( TITLE-ABS-KEY ( famil\* ) ) (1,989,988)
6. TITLE-ABS-KEY ( carer\* ) (18,084)
7. TITLE-ABS-KEY ( spous\* ) (40,011)
8. TITLE-ABS-KEY ( famil\* ) (1,907,217)
9. TITLE-ABS-KEY ( “smartphone application\*” ) (1,420)
10. TITLE-ABS-KEY ( “mobile health application\*” ) (328)
11. TITLE-ABS-KEY ( “mHealth application\*” ) (255)
12. TITLE-ABS-KEY ( “smartphone app\*” ) (1,579)
13. TITLE-ABS-KEY ( “phone app\*” ) (3,192 )
14. TITLE-ABS-KEY ( “mobile app\*” ) (23,631)
15. TITLE-ABS-KEY ( “mobile health app\*” ) (412)
16. TITLE-ABS-KEY ( “mHealth app\*” ) (432 )
17. TITLE-ABS-KEY ( “handheld computer\*” ) (3,807)
18. TITLE-ABS-KEY ( “personal digital assistant\*” ) (7,685)
19. ( TITLE-ABS-KEY ( “smartphone application\*” ) ) OR ( TITLE-ABS-KEY ( “mobile health application\*” ) ) OR ( TITLE-ABS-KEY ( “mHealth application\*” ) ) 1,975  
( TITLE-ABS-KEY ( “smartphone app\*” ) ) OR ( TITLE-ABS-KEY ( “phone app\*” ) ) OR ( TITLE-ABSKEY ( “mobile app\*” ) ) OR ( TITLE-ABS-KEY ( “mobile health app\*” ) ) OR ( TITLE-ABSKEY ( “mHealth app\*” ) ) OR ( TITLE-ABS-KEY ( “handheld computer\*” ) ) OR ( TITLE-ABSKEY ( “personal digital assistant\*” ) ) (37,519)
20. ( ( TITLE-ABS-KEY ( dementia ) ) OR ( TITLE-ABS-KEY ( alzheimer\* ) ) ) AND  
( ( TITLE-ABSKEY ( caregiver\* ) ) OR ( TITLE-ABS-KEY ( carer\* ) ) OR (

TITLE-ABS-KEY ( spous\* ) ) OR ( TITLEABS-KEY ( famil\* ) ) ) AND ( ( ( TITLE-ABS-KEY ( “smartphone application\*” ) ) OR ( TITLE-ABSKEY ( “mobile health application\*” ) ) OR ( TITLE-ABS-KEY ( “mHealth application\*” ) ) ) ) OR ( ( TITLE-ABS-KEY ( “smartphone app\*” ) ) OR ( TITLE-ABS-KEY ( “phone app\*” ) ) OR ( TITLEABS- KEY ( “mobile app\*” ) ) OR ( TITLE-ABS-KEY ( “mobile health app\*” ) ) OR ( TITLE-ABSKEY ( “mHealth app\*” ) ) OR ( TITLE-ABS-KEY ( “handheld computer\*” ) ) OR ( TITLE-ABSKEY ( “personal digital assistant\*” ) ) (42)

21. ( ( TITLE-ABS-KEY ( dementia ) ) OR ( TITLE-ABS-KEY ( alzheimer\* ) ) ) AND ( ( TITLE-ABSKEY ( caregiver\* ) ) OR ( TITLE-ABS-KEY ( carer\* ) ) OR ( TITLE-ABS-KEY ( spous\* ) ) OR ( TITLEABS-KEY ( famil\* ) ) ) AND ( ( ( TITLE-ABS-KEY ( “smartphone application\*” ) ) OR ( TITLE-ABSKEY ( “mobile health application\*” ) ) OR ( TITLE-ABS-KEY ( “mHealth application\*” ) ) ) ) OR ( ( TITLE-ABS-KEY ( “smartphone app\*” ) ) OR ( TITLE-ABS-KEY ( “phone app\*” ) ) OR ( TITLEABS-KEY ( “mobile app\*” ) ) OR ( TITLE-ABS-KEY ( “mobile health app\*” ) ) OR ( TITLE-ABSKEY ( “mHealth app\*” ) ) OR ( TITLE-ABS-KEY ( “handheld computer\*” ) ) OR ( TITLE-ABSKEY ( “personal digital assistant\*” ) ) English 2007-2017... (40)

#### **Data base: PubMed NCBI**

- #1 (Dementia[MeSH Terms]) OR Alzheimer Disease[MeSH Terms] (1,397,15 2)
- #2 (dementia[Title/Abstract]) OR alzheimer\*[Title/Abstract] (173,953)
- #3 (((Dementia[MeSH Terms]) OR Alzheimer Disease[MeSH Terms])) OR ((dementia[Title/Abstract]) OR alzheimer\*[Title/Abstract]) (210,043)
- #4 ((Caregivers[MeSH Terms]) OR Family[MeSH Terms]) OR Spouses[MeSH Terms] (295360)

- #5 (((caregiver\*[Title/Abstract]) OR carer\*[Title/Abstract]) OR famil\*[Title/Abstract]) OR spous\*[Title/Abstract] (987,260)
- #6 (((Caregivers[MeSH Terms]) OR Family[MeSH Terms]) OR Spouses[MeSH Terms])) OR (((caregiver\*[Title/Abstract]) OR carer\* [Title/Abstract]) OR famil\*[Title/Abstract]) OR spous\*[Title/Abstract]) (1,163,306)
- #7 (Mobile Applications[MeSH Terms]) OR Computers, Handheld[MeSH Terms] (5,689)
- #8 “smartphone application\*”[Title/Abstract] (37)
- #9 “mobile health application\*”[Title/Abstract] (54)
- #10 “mHealth application\*”[Title/Abstract] (58 )
- #11 “smartphone app\*”[Title/Abstract] (18)
- #12 “phone app\*”[Title/Abstract] (135 )
- #13 “mobile app\*”[Title/Abstract] (463)
- #14 “mHealth app\*”[Title/Abstract] (71)
- #15 “handheld computer\*”[Title/Abstract] (130)
- #16 “personal digital assistant\*”[Title/Abstract] (554)
- #17 (((((((((((Mobile Applications[MeSH Terms]) OR Computers, Handheld[MeSH Terms])) OR ((Mobile Applications[MeSH Terms]) OR Computers, Handheld[MeSH Terms])) OR “smartphone application\*” [Title/Abstract]) OR “mobile health application\*”[Title/Abstract]) OR “mHealth application\*” [Title/Abstract]) OR “smart phone app\*” [Title/Abstract]) OR “phone app\*”[Title/Abstract]) OR “mobile app\*” [Title/Abstract]) OR “mHealth app\*”[Title/Abstract]) OR “handheld computer\*”[Title/Abstract]) OR “personal digital assistant\*”[Title/Abstract] (6563)
- #18 ((((((Dementia[MeSH Terms]) OR Alzheimer Disease[MeSH Terms])) OR (dementia[Title/Abstract]) OR alzheimer\*[Title/Abstract]))) AND

(((((Caregivers[MeSH Terms]) OR Family[MeSH Terms]) OR Spouses[MeSH Terms])) OR (((caregiver\*[Title/Abstract]) OR carer\*[Title/Abstract]) OR famil\*[Title/Abstract]) OR spous\*[Title/Abstract])) AND (((((((((((Mobile Applications[MeSH Terms]) OR Computers, Handheld[MeSH Terms])) OR ((Mobile Applications[MeSH Terms]) OR Computers, Handheld[MeSH Terms])) OR “smartphone application\*”[Title/Abstract]) OR “mobile health application\*”[Title/Abstract]) OR “mHealth application\*”[Title/Abstract]) OR “smartphone app\*”[Title/Abstract]) OR “phone app\*”[Title/Abstract]) OR “mobile app\*”[Title/Abstract]) OR “mHealth app\*”[Title/Abstract]) OR “handheld computer\*”[Title/Abstract]) OR “personal digital assistant\*”[Title/Abstract]) Filters: published in the last 10 years; English (10)

## **Appendix B: Online survey questionnaire**

### **Welcome**

#### **Survey Introduction**

Thank you for participating in this online survey. We value your views and experiences. Your answers will be treated as strictly confidential and will be used only to design a smartphone app (also called mHealth app) for carers of people with dementia to address needs related to the management of daily living activities of care recipients.

This survey aims to understand your needs related to the management of daily living activities (for example, feeding, bathing, toileting, transferring, housekeeping etc.) of your family member with dementia and the use of a smartphone app in health-seeking behaviours.

This questionnaire consists of seven sections: (1) demographic information, (2) level of daily living activities of your care recipient, (3) your educational needs related to management of daily living activities, (4) the level of feelings related to providing care, (5) health literacy, (6) eHealth literacy level and (7) the ownership of smartphone/iPad/tablet and the use of smartphone apps in seeking health information. Please answer every question. If you are unsure how to answer a question, please mark the response for the closest answer to how you feel. We value your honest responses, and your responses will remain anonymous and be kept strictly confidential.

This survey will take approximately 20 minutes to complete. You can start completing the survey at any time, and your answers can be saved. You can complete and submit at a later time.

If you have any concerns or complaints about the ethical conduct of this research project, please contact the Manager, Research Ethics on (07)3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au).

Please note that the completion and submission of this survey mean that you consent to participate in this study. Please click on the link below to obtain a detailed information sheet for the research project: Information Sheet (PDF File)  
(<https://drive.google.com/open?id=1AxfLRJ12hSBJISxkxWLCgVGTKNLD-rDx>)

#### **A note on privacy**

This survey is anonymous. The record of your survey responses does not contain any identifying information about you unless a specific survey question explicitly asked for it. If you used an identifying token to access this survey, please rest assured that this token will not be stored together with your responses. It is managed in a separate database and will only be updated to indicate whether you did (or did not) complete this survey. There is no way of matching identification tokens with survey responses.

## Part I: Socio-demographic data

**Instruction:** This part requests your personal data. Answer ALL the questions below.

Read the following questions and please select the correct answer.

1. Which age category below includes your age?

- |                                      |                                             |
|--------------------------------------|---------------------------------------------|
| <input type="checkbox"/> 18-25 years | <input type="checkbox"/> 26-35 years        |
| <input type="checkbox"/> 36-45 years | <input type="checkbox"/> 46-55 years        |
| <input type="checkbox"/> 56-65 years | <input type="checkbox"/> 66 -75 years       |
| <input type="checkbox"/> 76-85 years | <input type="checkbox"/> 86 years and older |

2. What is your gender?

- Male                       Female                       Other

3. What is your marital status?

- Married                       Single                       Divorced  
 Widowed                       Other

4. What is the highest educational qualification you have achieved? If currently enrolled, highest degree received to date?

- No formal education  
 Primary school education  
 High school degree  
 Trade/technical/vocational training  
 University undergraduate degree  
 Post-graduate degree

5. What is your current employment status?

- Presently unemployed                       Employed/part time  
 Employed/full time                       Retired

6. Are you suffering from any health problems or impairment?

- Yes                       No

If yes, please state the medical problem/problems

.....

7. What is your relationship to the care recipient?

- |                                              |                                      |
|----------------------------------------------|--------------------------------------|
| <input type="checkbox"/> Spouse              | <input type="checkbox"/> Child       |
| <input type="checkbox"/> Son/daughter-in-law | <input type="checkbox"/> Grand child |
| <input type="checkbox"/> Brother/sister      | <input type="checkbox"/> Relatives   |
| <input type="checkbox"/> Friend              | <input type="checkbox"/> Other       |

8. How old is your care recipient?

- Less than 65 years                       65-75 years  
 76-85 years                                 86 years and over

9. How many years has your family member had dementia?

- Less than one year                       1-3 years  
 3-5 years                                     More than 5 years

10. What stage of dementia does your care recipient have?

- Early stage                                     middle stage  
 Severe stage                                 Do not know

11. Does your care recipient have medical problems other than dementia?

- Yes                                               No  
If yes, please state the medical problem/problems

.....

12. How long have you been caring for your recipient?

- Less than one year                       1-3 years  
 3-5 years                                     More than 5 years

13. Are you the only carer for your family member?

- Yes  
 No, I am caring alternatively with another family member  
 No, I have a paid carer to assist

14. How many hours per day do you usually spend with your family member with dementia?

Weekdays ..... hours  
Weekend ..... hours

## Part 2: Functional disability needs of care recipients

**Instruction:** This part is to assess the level of help needed in the daily living activities of your care recipient. Please state his/her level of ability in performing the following basic activities. Please use the following criteria to answer your questions.

**Independent:** performs the activities spontaneously, independently, without help or supervision from other persons or special equipment

**Partially dependent:** needs supervision, help or special equipment to perform the activity safely and correctly

**Dependent:** needs constant help or supervision to perform the activity safely and correctly

	Activity	Independent	Partially dependent	Dependent
1	The patient is able to choose and change clothes (dress and undress) by himself/herself			
2	The patient is able to make his/her way to the toilet, undress, clean him/herself properly and dress again			
3	The patient is able to use the shower, soap, and bath sponge properly			
4	The patient is able to transfer from his/her bed or chair unaided			
5	The patient is able to feed himself/herself with tableware			
6	The patient is able to do minor household chores			
7	The patient is able to use the telephone (make and receive calls)			
8	The patient is able to prepare his/her own meals			
9	The patient is able to do his/her own washing and ironing			
10	The patient is able to manage his/her own money or financial matters			
11	The patient is able to run simple errands by himself/herself			
12	The patient is able to take his/her medication at the correct dose and time by himself/herself			
13	The patient is able to go to distant places by himself/herself using some form of transportation			

What is the most difficult basic living activity you have with your family member from the following list? Tick one only.

Dressing and undressing	
Toileting	
Bathing	
Transferring	
Feeding	

What is the most difficult activity you have with your family member, which you need help to manage their daily life from the following list? Tick one only.

Doing minor household chores	
Using telephone	
Preparing meal	
Washing clothes and laundry	
Managing finance	
Running simple errands	
Responsibility of own medication	
Using transport	

### Part 3: Educational needs of carers related functional disability care

Instruction: This part refers to your general ability in providing care for the following daily activities.

Do you think that your knowledge and skills are adequate to provide satisfactory care for your family member in the following activities?

	<b>Inadequate</b>	<b>Needs improvement</b>	<b>Meets expectation</b>	<b>Exceeds expectation</b>
Dressing and undressing				
Toileting				
Bathing				
Transferring				
Feeding				
Doing minor household chores				
Using telephone				
Preparing meals				
Washing clothes and laundry				
Managing finance				
Running simple errands				
Responsibility of own medication				
Using transport				

#### Part 4: Carer burden

Instruction: Please tick the appropriate box of how you feel in relation to each of the questions. Please mark one response for each question.

Questions	Never	Rarely	Some time	Quite frequently	Nearly always
1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
3. Do you feel strained when you are around your relative?					
4. Do you feel uncertain about what to do about your relative?					

#### Part 5: Health literacy

Instruction: I would like to ask you for your opinion and about your experience using the hospital materials, medical forms and written information. Please state your answer for the following three questions.

Please mark one response for each question.

Questions	Never	Occasionally	Some time	Often	Always
How often do you have someone help you read hospital materials?					
How confident are you filling out medical forms by yourself?					
How often do you have problems learning about your medical condition because of difficulty understanding written information?					

## Part 6: eHealth literacy

Instruction: I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience right now.

1. How useful do you feel the Internet is in helping you in making decisions about your health?

- Not useful at all
- Not useful
- Unsure
- Useful
- Very useful

2. How important is it for you to be able to access health resources on the Internet?

- Not useful at all
- Not useful
- Unsure
- Useful
- Very useful

Please mark one response for each question.

	<b>Question</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Undecided</b>	<b>Agree</b>	<b>Strongly agree</b>
1	I know what health resources are available on the Internet					
2	I know where to find helpful health resources on the Internet					
3	I know how to find helpful health resources on the Internet					
4	I know how to use the Internet to answer my questions about health					
5	I know how to use the health information I find on the Internet to help me					
6	I have the skills I need to evaluate the health resources I find on the Internet					

7	I can tell high-quality health resources from low-quality health resources on the Internet					
8	I feel confident in using information from the Internet to make health decisions					

**Part 7: The ownership of a smart-device and use of mHealth applications in health-seeking behaviour**

Instruction: This part is to assess smartphone ownership and use of smartphone applications in health information seeking.

1. Do you own any of the following mobile devices?

- Smartphone                       iPad  
 Tablet                                 Smart-watch

2. Use of mHealth/smartphone app for health-seeking behaviour.  
Please answer the following questions.

	<b>Question</b>	<b>Yes</b>	<b>No</b>
1	On your smartphone or tablet, do you have any software apps or apps related to health?		
2	Does having the apps on your smartphone or tablet related to health help you achieve a health-related goal, such as quitting smoking, losing weight or increasing physical activity?		
3	Does having the apps on your smartphone or tablet related to health help you make a decision about how to treat an illness or condition?		
4	Does having the apps on your smartphone or tablet related to health lead you to ask a doctor new questions, or to get a second opinion from another doctor?		

- After this survey, the researchers will conduct individual interviews (in-person or telephone) with carers of people with dementia that guide the development of smartphone apps. You are further invited to participate in an individual interview and to assist in the development process of a smartphone app. If you are willing to participate in an individual interview or in the app development process, I kindly request you to leave your contact details. Researchers will contact you in future.

Phone No: .....

Email: .....

**Thank you very much for your participation in this survey**

## Appendix C: Ethical approval-online survey

9/2/2019

Mail - Sarath Rathnayake - Outlook

Full Research Ethics Clearance 2017/906

RIMS Griffith

Tue 21/11/2017 13:30

To: Pauline Calleja <p.calleja@griffith.edu.au>; Cindy Jones <C.Jones@griffith.edu.au>; Wendy Moyle <w.moyle@griffith.edu.au>; Sarath Rathnayake <sarath.rathnayake@griffithuni.edu.au>  
Cc: research-ethics <research-ethics@griffith.edu.au>; Kim Madison <k.madison@griffith.edu.au>

GRIFFITH UNIVERSITY HUMAN RESEARCH ETHICS REVIEW

Dear Prof Wendy Moyle

I write further to the additional information provided in relation to the provisional approval granted to your application for ethical clearance for your project "An online survey on needs of family carers of people with dementia in relation to functional disability and use of smartphone applications in health seeking behaviours" (GU Ref No: 2017/906).

This is to confirm that this response has addressed the comments and concerns of the HREC.

The ethics reviewers resolved to grant your application a clearance status of "Fully Approved".

Consequently, you are authorised to immediately commence this research on this basis.

Regards

Kim Madison | Human Research Ethics

Office for Research

Griffith University | Nathan | QLD 4111 | Level 0, Bray Centre (N54)  
T +61 7 373 58043 | email k.madison@griffith.edu.au

## **Appendix D: Online survey invitation**

### **Invitation to participate in an online survey for carers of people with dementia (Griffith University Ethics Ref No: 2017/906)**

Family carers of older people with dementia living in Australia are invited to help the research team from Griffith University, Australia (Professor Wendy Moyle, Doctor Cindy Jones, Doctor Pauline Calleja and Mr. Sarath Rathnayake) with their research project “Development of an mHealth application (smartphone app) for family carers of people with dementia to address health literacy needs related to functional disability of care recipients”. We invite you to participate in an online survey which forms part of a PhD study by Mr. Sarath Rathnayake.

#### **What is the research about?**

This research project aims to develop a smartphone app for carers of people with dementia to help manage functional disabilities (for example, feeding, bathing, dressing, grooming, transportation and housekeeping, etc.) of their family members with dementia.

#### **What is the aim of the online survey?**

To help us to develop a smartphone app. We aim to (1) identify any difficulties you have in attending to the daily living activities of your family member with dementia and (2) your current use of smartphone apps in health information seeking.

#### **Who can participate?**

Nonpaid carers who are usually members of the immediate family or other relatives, friends, or acquaintances who provide care at home for a person with any type of dementia/Alzheimer’s disease and are an adult aged 18 years or older can participate.

#### **What participation involves?**

Completion of an online survey which will take approximately 20 minutes.

#### **What are the benefits of participating?**

Your contribution will help to identify needs related to support of family members who care for a person with dementia. This knowledge will be used to help develop a smartphone app for carers of people with dementia.

#### **How can you participate?**

To complete the survey, please click on the link below:

<https://prodsurvey.rcs.griffith.edu.au/prodls200/index.php/646684?lang=en>

If you wish to complete the survey by telephone or via a printed survey, please contact Mr. Sarath Rathnayake, sarath.rathnayake@griffithuni.edu.au; phone: +61405 374 522.

NOTE: To maintain your own privacy and the privacy of others, please do not post any personal information, questions or comments relating to the research. All posts will be deleted by the research team. For more information regarding this research project, please contact Professor Wendy Moyle, w.moyle@griffith.edu.au, phone: +61 (07) 373 55526.

## **Appendix E: Online survey information sheet**

### **Development of a smartphone app (mHealth app) for family carers of people with dementia to address health literacy needs related to the functional disability of care recipients**

#### **Survey information sheet**

(Griffith University ethics reference number for the project: 2017/906)

#### **Who is conducting the research?**

Prof. Wendy Moyle (Chief investigator)

Email: w.moyle@griffith.edu.au Phone: (07) 37355526

Dr. Cindy Jones

Email: c.jones@griffith.edu.au Phone: (07) 3735 8440

Dr. Pauline Calleja

Email: p.calleja@griffith.edu.au Phone: (0 7) 3735 7389

Mr. Sarath Rathnayake (PhD candidate in Nursing, student researcher)

Email: sarath.rathnayake@griffithuni.edu.au Phone: 0405 374 522

Griffith University School of Nursing and Midwifery

170 Kessels Road

Nathan QLD 4111 Australia

#### **Introduction**

Difficulties in daily living activities is a major problem for people with dementia, and their carers have an important role in managing daily living activities of their care recipients. But, family carers of people with dementia face different difficulties in managing daily living activities of their care recipients at home.

#### **What is the research about?**

This research project aims to develop a smartphone app (also called mHealth app) for carers of people with dementia to help manage functional disabilities (for example, feeding, bathing, dressing, grooming, transportation and housekeeping, etc.) of their family members with dementia.

#### **What is the aim of online survey?**

To help us to develop a smartphone app we aim to (1) identify any difficulties you have in attending to the daily living activities of your family member with dementia and (2) your current use of smartphone apps in health information seeking.

#### **Why you have been invited to participate?**

You have been invited to participate in this study as you are a carer of a person with dementia.

#### **Who can participate?**

Nonpaid carers who are usually members of the immediate family or other relatives, friends, or acquaintances who provide care at home for a person with any type of dementia/Alzheimer's disease and are an adult aged 18 years or older can participate.

### **Participation in this study will involve**

Completion of a survey to provide us with information on your needs related to functional disabilities of care recipients and the use of smartphone apps in health seeking behaviours. In addition, demographic information of participants and care recipients, information on carer burden, health literacy and eHealth literacy.

The survey can be completed either online, over the phone or via a printed survey based on your preference. The survey will take approximately 20 minutes and can be completed in multiple occasions. If you need any assistance in reading the survey, Mr. Sarath Rathnayake will be delighted to read it for you.

### **Consent to participate**

Although we would appreciate your participation, your participation in this study is voluntary. You are not under any obligation to consent to participate in this study. If you choose to participate and later change your mind, you are free to withdraw from the study at any time. If you consent to participate in this survey, please complete the "Survey". Completion of this survey will be taken as your consent to participate in the research.

### **Potential risks of participation**

Participation in this study poses no foreseeable risks as the study will ask to fill the questionnaire on needs related to managing functional disabilities of your carer recipients and the use of smartphone apps in health-seeking behaviours including the level of health literacy and eHealth literacy.

### **Benefits of participating**

Your contribution will help to identify needs related to support of family members who care for a person with dementia. This knowledge will be used to help develop a smartphone app for carers of people with dementia.

### **Confidentiality**

Confidentiality of participants and any collected data will be maintained throughout and after the completion of the survey. Please do not place your name or any identification data on the questionnaire. Electronic files and/or documents arising from this study will not contain any identifying terms. The data collected forms in this survey will be treated in the strictest confidence and reported in general terms that do not involve any identifying features. All data will be kept confidential. Upon completion of the survey, all data will be stored in a locked filing cabinet at Griffith University, Menzies Health Institute, Queensland for a period of 5-years before being destroyed. Please note that information collected for, used in or generated by this project will be stored in a database for future use in similar research by the researchers or a third party for which ethical approval will be sought.

If you access this online survey through social media, for example, Facebook, to maintain your own privacy and the privacy of others, please do not post any personal information, questions or comments relating to the research. All posts will be deleted by the research team.

Research results will be reported in an academic thesis, and may also be disseminated via journal articles and/or conference presentations. However, Participants' data will not be identifiable in any publication or reporting.

At the end of the survey, you will be invited to participate in the second part of this study (personal interviews or the development of the app). If you are willing to participate, you can provide your personal details using the relevant link ensuring your answers in the survey will be not related with your personal details.

### **Feedback**

A summary report of the overall findings obtained from the study will be made available to you at the completion of the study. If participants are interested in the results of the research, they will be asked to email to the student researcher to ask to receive a summary of the results. The student researcher will send them a lay summary via an email after completion of the research.

### **Complaints mechanism**

This survey received ethical approval from Griffith University Human Research Ethics Committee. Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Humans. If you have any concerns or complaints about the ethical conduct of the research project, you should contact the Manager, Research Ethics on +61 (0)7 3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au)

### **Disclosure statement**

The conduct of this survey involves the collection, access and /or use of your unidentified personal information. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information, consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.

If you have any concerns regarding this project, you can contact Professor Wendy Moyle, or Griffith University Manager, Research Ethics.

## **Appendix F: Invitation letter for individual interview with carers of people with dementia**

**(Griffith University ethics reference number: 2017/947)**

Dear.....

I am Sarath Rathnayake, from Griffith University, and a PhD student. I am also a member of a research team that is working on the research project related to the development of a smartphone app (also called mHealth app) for family carers of people with dementia to address needs related to management of functional disabilities of their care recipient. You recently took part in an online survey related to the above project. We really appreciate your time and valuable responses that you have provided. We would like to invite you to participate in an individual interview that forms the next part of the same project.

The individual interview provides an opportunity to share your experiences and views with the research team in relation to problems, barriers and challenges faced by you relating to managing difficulties of daily living activities of your care recipient at home and the use of smartphone apps (mHealth apps) in health information seeking. The individual interview session will last for approximately 45 minutes, can be undertaken in person or via telephone and will be digitally recorded.

Your views will help us to develop a smartphone app for carers of people with dementia in relation to management of daily living activities of care recipients. Further details are provided in the attached study information sheet.

We hope you are willing to take part in an individual interview. Please reply to this email or contact Mr. Sarath Rathnayake by phoning 0405374522. We thank you for your consideration of this request.

If you have any questions or require further information regarding this research project, please contact Professor Wendy Moyle by email: [w.moyle@griffith.edu.au](mailto:w.moyle@griffith.edu.au); or phone: (07) 373 55526.

Yours sincerely

Sarath Rathnayake

## **Appendix G: Information sheet for participants in individual interviews**

### **Development of a smartphone application (mHealth app) for carers of people with dementia**

**(Griffith University ethics reference number for the project: 2017/947)**

Prof. Wendy Moyle (Chief investigators)

Email: w.moyle@griffith.edu.au

Phone: (07) 37355526

Dr. Cindy Jones

Email: c.jones@griffith.edu.au

Phone: (07) 3735 8440

Dr. Pauline Calleja

Email: p.calleja@griffith.edu.au

Phone: (07) 3735 7389

Mr. Sarath Rathnayake (PhD candidate in Nursing, student researcher)

Email: sarath.rathnayake@griffithuni.edu.au

Phone: +61405374522

Griffith University School of Nursing and Midwifery  
170 Kessels Road  
Nathan QLD 4111 Australia

This study will be conducted as a part of the PhD study of Mr. Sarath Rathnayake.

#### **Introduction**

Difficulties in daily living activities is a major problem for people with dementia, and their carers have an important role in managing daily living activities of their care recipients. But, family carers of people with dementia face different difficulties in managing daily living activities of their care recipients at home.

#### **Why you have been invited to participate in this study?**

You have been invited to participate in this study as you are a carer of a person living with dementia.

#### **What is the purpose of the study?**

The purpose of this study is to develop a smartphone app (also called mHealth app) for carers of people with dementia to address needs related to management of functional disability of their care recipients.

#### **Participation in this study will involve**

Participation in this individual interview aims to explore problems, barriers and challenges faced by family carers relating to managing functional disability of their care recipients at home and using smartphone apps in health seeking behaviours.

Interview sessions will last for approximately 45 minutes. Interviews will be conducted at Griffith University Nathan, Mount Gravatt, Logan, South Bank or Gold Cost Campus or a place convenient to you such as your nearest public place (public library) or by telephone. Interviews will be digitally recorded to ensure accurate transcription, and the digital audiotape will be erased once transcribed.

### **Consent to participate**

Although we would appreciate your participation, your participation in this study is voluntary. You are not under any obligation to consent to participate in this study. If you choose to participate and later change your mind, you are free to withdraw from the study at any time. If you consent to participate in this study, please complete the 'consent form'. We hope that you will consider participating in this study as it has the potential to understand carers' needs related to the management of daily living activities of care recipients and needs related to use of smartphone apps in health-seeking behaviours. Hence, this can help to develop a smartphone app to help manage daily living activities of care recipients.

### **Benefits**

This study will yield knowledge on the problems, barriers and challenges faced by you relating to managing functional disability of your care recipients at home and using smartphone apps in health-seeking behaviours. This knowledge will guide the development of a smartphone app for carers of people with dementia in Australia in relation to the management of functional disabilities of care recipients. This app may be an important intervention for carers of people with dementia to improve their knowledge and skills towards caring for people with dementia. Interacting with the developed smartphone app may help to decrease carer burden and improve well-being and quality of life of their care recipients. Besides, a \$30 gift voucher will be given to help with your transportation to the interview.

### **Risk**

Participation in this study poses no foreseeable risks as the study will only seek information on problems, barriers and challenges faced by you relating to managing functional disability of your care recipients at home and using smartphone apps in health-seeking behaviours. You will only be asked to reveal to the researcher what you feel comfortable to discuss and allow a digital recording of the interview. It is recommended that you stop the interview immediately and discuss with the researcher any concerns that may arise during the interview.

### **Confidentiality**

Confidentiality of participants and any collected data will be maintained throughout and after the completion of the study. Electronic files and/or documents arising from this study will not contain any identifying terms. The data collected from this study will be treated in the strictest confidence and reported in general terms that do not involve any identifying features. All data will be kept confidential. Upon completion of the study, all data will be stored in a locked filing cabinet at Griffith University, Menzies Health Institute, Queensland, for a period of 5 years before being destroyed. Please note that information collected for, used in or generated by this project will be stored in a database for further use in similar research by the researchers or a third party for which ethical approval will be sought.

### **Feedback**

A summary report of the overall findings obtained from the study will be made available to you at the completion of the study.

### **Complaints mechanism**

The study has received ethical approval from the Griffith University Human Research Ethics Committee. Griffith University conducts research in accordance with the National Statement of Ethical Conduct in Research involving Humans. If you have any

concern or complaints about the ethical conduct of the research project, you should contact the Manager, Research Ethics on +61 (07) 3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au)

**Disclosure statement**

The conduct of this study involves the collection, access and/or use of your unidentified personal information. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will, at all times be safeguarded. For further information, please consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publication/griffithuniversity-privacy-plan> or telephone +6(07) 3735 4375.

Thank you for your consideration of participation in this study. We hope that you will agree to participate in the study. If you agree to participate in this study, please complete the attached consent form.

**Appendix H: Informed consent form for participants (carers of people with dementia) in individual interviews**

**(Griffith University ethics reference number for the project: 2017/947)**

Prof. Wendy Moyle (Chief investigator)  
Email: w.moyle@griffith.edu.au Phone: (07) 37355526

Dr. Cindy Jones  
Email: c.jones@griffith.edu.au Phone: (07) 3735 8440

Dr. Pauline Calleja  
Email: p.calleja@griffith.edu.au Phone: (07) 3735 7389

Mr. Sarath Rathnayake (PhD candidate in Nursing, student researcher)  
Email: sarath.rathnayake@griffithuni.edu.au Phone: 0405374522

Griffith University School of Nursing and Midwifery  
170 Kessels Road  
Nathan QLD 4111 Australia

I have read the information sheet and consent to be contacted by the researchers for an individual interview that will seek information on problems, barriers and challenges faced by family carers relating to managing functional disability of their care recipients at home and using smartphone apps (also called mHealth apps) in health-seeking behaviours. In addition I understand that the individual interview will be digitally recorded so that it can be accurately transcribed. The digital audiotape will be erased following transcription of the interview.

I understand that the study will be conducted as described in the information sheet, a copy of which I have retained. I realise that participation is voluntary, and I can withdraw from the interview at any time and that I do not have to give any reasons for withdrawing. I agree with the use of my data in future research projects that are an extension of, or closely related to this study. All the data collected is for the purpose of this project and will remain confidential and be stored in a locked filing cabinet within Griffith University for a period of 5 years prior to it being destroyed. All published material from this project will only be released in general terms, and no personal identification will be recognised.

If I have any concerns regarding this project, I can contact Professor Wendy Moyle, or Griffith University Manager, Research Ethics.

Name of the participants: .....

Signature of the participants..... Date:.....

Contact details:

Phone Office/home or mobile No:.....  
Email: .....

**Appendix I: Demographic data sheet for family carers of people with dementia in individual interviews**

**(Griffith University ethics reference number for the project: 2017/947)**

**Instruction:** This section requests your personal data.  
Read the following questions and please select the correct answer.

1. What is your age? .....

<input type="checkbox"/> 18-25 years	<input type="checkbox"/> 26-35 years
<input type="checkbox"/> 36-45 years	<input type="checkbox"/> 46-55 years
<input type="checkbox"/> 56-65 years	<input type="checkbox"/> 66 -75 years
<input type="checkbox"/> 76-85 years	<input type="checkbox"/> 86 years and older

2. What is your gender?  
 Male             Female             Other
3. What is your marital status?  
 Married             Single             Divorced  
 Widowed             Other
4. What is the highest educational qualification you have achieved? If currently enrolled, highest degree received to date?  
 No formal education  
 Primary school  
 High school  
 Trade/technical/vocational training  
 University undergraduate degree  
 Post-graduate degree
5. What is your current employment status?  
 Presently unemployed             Employed/part-time job  
 Employed/full-time job             Retired
6. What is your relationship to the care recipient? You are a.....  
 Spouse             Child  
 Son/daughter-in-law             Grandchild  
 Brother/sister             Relative  
 Friend             Other
7. How old is your care recipient?  
 Less than 65 years             65-75 years  
 76-85 years             86 years and over

8. What type of dementia is your care recipient having?

.....

9. What stage of dementia is your care recipient?

Early stage

Middle stage

Severe stage

Do not know

**Thank you for your participation**

## **Appendix J: Interview guide for the family carers of people with dementia**

The purpose of this interview is to understand the experience of family carers of people with dementia in supporting their care recipients' activities of daily living. This interview guide is to gather more detailed and specific responses around the experiences of supporting functional disabilities of people with dementia and to the use of smartphone apps (also called mHealth apps) as an educational and supportive tool for family carers.

Functional disabilities include:

### **Difficulties in basic living activities:**

Dressing and undressing  
Toileting  
Bathing  
Transferring  
Feeding

### **Difficulties in instrumental activities of daily living:**

Doing minor household chores  
Using telephone  
Preparing meals  
Washing clothes and laundry  
Managing finances  
Running simple errands  
Responsibility of own medications  
Using transport

## **In-depth Interview Guide**

### **Personal information and background**

1. Can you please tell me a little about yourself?

Probe: Personal information about the interviewee  
Education  
Employment  
Family  
Interest/hobbies

### **Questions**

2. As a family carer, what type of help do you provide in meeting your family member's needs related to their daily activities?

Probe: Support given to the family member with dementia  
Duration and time spent in caring

3. Could you please tell me what are the activities you find difficult to perform for your family member?

Probe: Activities of daily living  
Instrumental activities of daily living  
Most difficult activities

4. Could you tell me the difficulties you face in providing support to your family member's needs related to their daily activities? (For example, difficulties with knowledge and skills, and availability of resources etc.)

Probe: Knowledge and skills related  
Current difficulties: work life, family matters, time  
Availability of resources  
Availability of the information  
Support received from health sector

5. What information do you believe you need to know to help you to manage the daily activities of your family member?

Probe: General understanding of dementia  
Information relevant to activities of daily living and instrumental activities of daily living  
Knowledge about sources of information and receiving information  
Current information needs

6. What are the major barriers and challenges you face in getting information to help you care for your family member?

Probe:

Personal factors: education level, knowledge on technology  
Other factors: environmental and social factors

7. Do you have any experience with health-related smartphone apps or any other smartphone apps?

Probe: positive or negative experiences

8. Do you think a smartphone app for carers of people with dementia would be helpful for you to learn about managing the daily activities of your family member?

What do you see are the advantages of a smartphone app?  
What do you see are the disadvantages of a smartphone app?

9. What are the major barriers and challenges you face to access smartphone apps to receive appropriate information to help you in your caregiving role?

Probe:  
Personal factors: cost, technology, time.  
Other factors: Environmental and social factors.

**End**

10. Is there anything else you would like to add to our understanding of managing disabilities of your family member in daily activities and smartphone apps as an educational tool?
11. Do you have any questions or further responses?

**Thank you for your participation**

## **Appendix K: Expert interview invitation**

### **Development of an mHealth App for Family Carers of People with Dementia**

Dear .....

I am Sarath Rathnayake, from Griffith University, a PhD student and a member of the research team that is working on the research project entitled “Development of an mHealth educational and supportive application for family carers of people with dementia to address needs related to functional disability of care recipients”.

As an expert in dementia or a health professional experienced in the care of someone with dementia or an expert in the field of information technology, you are invited to participate in an individual interview (in-person or telephone interview) that is a part of the above research project conducted at Griffith University by Professor Wendy Moyle, Doctor Cindy Jones, Doctor Pauline Calleja and Mr. Sarath Rathnayake.

The aim of this interview is to identify your opinions on the provision of care, especially the management of functional disabilities of people with dementia; and the development of an mHealth app for family carers including possible barriers and challenges.

Before the interview, you will have an opportunity to review an executive summary of the key findings of our recent online survey and interviews conducted with family carers of people with dementia as well as the proposed content for the mHealth app by the research team.

Interviews will be conducted at Griffith University Nathan, Mount Gravatt, Logan, South Bank or Gold Coast campus or at your nearest public place (e.g., library) or over the phone. The individual interview will last approximately 20-40 minutes. The individual interview will be digitally recorded.

We believe that your expertise will be extremely beneficial in the development of an mHealth app for family carers of people with dementia related to the management of functional disabilities of their care recipients.

Moreover, after the development of educational and supportive content for the prototype, we would like to invite you to evaluate the mHealth app for content appropriateness and clarity.

If you are willing to participate, please inform us by email (Sarath.rathnayake@griffithuni.edu.au) or contact Mr. Sarath Rathnayake, phone 0405374522. We thank for your consideration in this request.

If you have any questions or require further information regarding this research project, please contact Professor Wendy Moyle by email: w.moyle@griffith.edu.au; or phone: (07) 373 55526.

Yours sincerely  
Sarath Rathnayake

## **Appendix L: Information sheet for experts in individual interviews**

### **Development of an mHealth application (smartphone application) for carers of people with dementia**

**(Griffith University ethics reference number for the project: 2017/947)**

Prof. Wendy Moyle (chief investigator)

Email: w.moyle@griffith.edu.au

Phone: (07) 37355526

Dr. Cindy Jones

Email: c.jones@griffith.edu.au

Phone: (07) 3735 8440

Dr. Pauline Calleja

Email: p.calleja@griffith.edu.au

Phone: (0 7) 3735 7389

Mr. Sarath Rathnayake (PhD candidate in Nursing, student researcher)

Email: sarath.rathnayake@griffithuni.edu.au Phone: 0405374522

Griffith University School of Nursing and Midwifery

170 Kessels Road

Nathan QLD 4111 Australia

#### **Introduction**

Functional disability is a major problem for people with dementia, and their carers have an important role in managing daily living activities of their care recipients. But, family carers of people with dementia face different difficulties in managing activities of daily living of their care recipients.

#### **Why you have been invited to participate in this study?**

You have been invited to participate in this study as you are considered to be an expert (e.g., aged care nurse, physician, social worker and IT expert) that can assist in the development of an mHealth app for carers of a people with dementia to help manage care recipients' activities of daily living.

#### **What is the purpose of the study?**

The purpose of this study is to develop an mHealth app for carers of people with dementia to address needs related to management of functional disability of their care recipient.

#### **Participation in this study will involve**

You will be interviewed by the researcher (in-person or telephone) to identify your opinion on the provision of care, especially management of functional disability of people with dementia or/and the development of an mHealth app for carers including their understanding about existing mHealth app based interventions, attitudes towards mHealth educational interventions and possible barriers and challenges towards the development of a mHealth app.

Interview sessions will last for approximately 30 minutes. Interviews will be conducted at Griffith University Nathan, Mount Gravatt, Logan, South Bank or Gold Coast Campus or at the nearest public place (e.g. Library) or over the phone. Interviews will

be digitally recorded to ensure accurate transcription, and the digital audiotape will be erased once transcribed.

### **Consent to participate**

Although we would appreciate your participation, your participation in this study is voluntary. You are not under any obligation to consent to participate in this study. If you choose to participate and later change your mind, you are free to withdraw from the study at any time. If you consent to participate in this study, please complete the 'consent form' (for in-person interview). For telephone interview, verbal consent will be sorted. We hope that you will consider participation in this study as it has the potential to understand carers' needs related to the management of daily living activities of people with dementia and the use of mHealth apps in carer education. Hence, this can help to develop a mHealth app for carers of people with dementia to help manage daily living activities of their care recipients.

### **Benefits**

This study will yield expert opinions towards the development of a mHealth app for carers of people with dementia to help manage functional disability of their care recipients. This app may be an important intervention for carers of people with dementia to improve their knowledge and skills towards care of people with dementia. Interacting with the developed mHealth app may help to decrease carer burden and improve well-being and quality of life of care recipients.

### **Risk**

Participation in this study poses no foreseeable risks as the study will only ask for your opinion on the development of a mHealth app for carers of people with dementia to help manage their care recipients' functional disability. You will only be asked to reveal to the researcher what you feel comfortable to discuss and allow a digital recording of the interview. It is recommended that you stop the interview immediately if you feel uncomfortable and discuss with the researcher any concerns that may arise during the interview.

### **Confidentiality**

Confidentiality of participants and any collected data will be maintained throughout and after the completion of the study. Electronic files and/or documents arising from this study will not contain any identifying terms. The data collected from this study will be treated in the strictest confidence and reported in general terms that do not involve any identifying features. All data will be kept confidential. Upon completion of the study, all data will be stored in a locked filing cabinet at Griffith University, Menzies Health Institute, Queensland for a period of 5 years before being destroyed. Please note that information collected for, used in or generated by this project will be stored in a database for further use in similar research by the researchers or a third party for which ethical approval will be sought.

### **Feedback**

A summary report of the overall findings obtained from the study will be made available to you at the completion of the study.

### **Complaints mechanism**

The study has received ethical approval from Griffith University Human Research Ethics Committee. Griffith University conducts research in accordance with the National Statement of Ethical Conduct in Research involving Humans. If you have any

concern or complaints about the ethical conduct of the research project, you should contact the Manager, Research Ethics on +61 (07) 3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au)

**Disclosure statement**

The conduct of this study involves the collection, access and/or use of your unidentified personal information. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information, please consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publication/griffithuniversity-privacy-plan> or telephone +6(07) 3735 4375.

Thank you for your consideration of participation in this study. We hope that you will agree to participate in the study. If you agree to participate please complete the attached consent form.

## Appendix M: Informed consent form for experts

### Development of a mHealth educational and supportive application for family carers of people with dementia to address needs related to functional disability of care recipients

(Griffith University Ethics Reference - 2017/947)

#### Consent Form - Expert Interviews

Prof. Wendy Moyle (Chief Investigator)

Email: w.moyle@griffith.edu.au

Phone: (07) 37355526

Dr. Cindy Jones

Email: c.jones@griffith.edu.au

Phone: (07) 3735 8440

Dr. Pauline Calleja

Email: p.calleja@griffith.edu.au

Phone: (0 7) 3735 7389

Mr. Sarath Rathnayake (PhD Candidate in Nursing, Student Researcher)

Email: sarath.rathnayake@griffithuni.edu.au

Phone: 0405374522

Griffith University School of Nursing and Midwifery

170 Kessels Road

Nathan QLD 4111 Australia

I have read the information sheet and consent to be contacted by the researchers for an expert interview that will seek my opinion on the provision of care, especially management of functional disabilities of people with dementia and the development of an mHealth app for family carers including possible barriers and challenges. I understand that the interview will be digitally recorded so that it can be accurately transcribed. The digital audiotape will also be erased following the transcription of the interview.

I understand that the study will be conducted as described in the information sheet, a copy of which I have retained. I realise that my participation is voluntary and I can withdraw from the study at any time and that I do not have to give any reasons for withdrawing. All the data collected is for this study and will remain confidential and will be stored in a locked filing cabinet within Griffith University for a period of 5 years prior to it being destroyed. I agree to the use of my data in future research projects that are an extension of, or closely related to this study. All published material from this study will only be released in general terms and no personal identification will be recognised.

If I have any concerns regarding this study, I can contact Professor Wendy Moyle, or Dr Cindy Jones, or Griffith University Manger, Research Ethics.

Name of the participant: .....

Signature of the participant.....

Date:.....

Contact Details

Phone Office/Home or Mobile No: .....

Email:.....

## Appendix N: Executive summary based on online survey and individual interviews

### EXECUTIVE SUMMARY

#### Key Findings from the Online Survey and Personal Interviews with Family Carers of People with Dementia

##### Research Team:

Mr. Sarath Rathnayake, Prof. Wendy Moyle, Dr. Cindy Jones & Dr. Pauline Calleja

School of Nursing & Midwifery, Griffith University  
Griffith University Menzies Health Institute – Healthcare Practice & Survivorship Program

##### Online Survey

Aim: To identify the needs of family carers of people with dementia in relation to providing care for daily living activities of their care recipients.

Key Findings: Overall, findings suggest that carer burden is high, with the need for further educational support in eight daily living activities that focus on self-care and complex activities. Given that the vast majority of family carers owned or used a smart device, there is potential for education and support to be provided via mHealth apps.

One hundred and sixty-six family carers completed the online survey, with the majority being females (89.8%), aged between 45-65 years, and with an undergraduate degree or above (44%).

Care burden was reported by three-quarters of family carers (74.1%), with recipients dependent on them for complex (99.4%), domestic (97%), and self-care (79.5%) activities.

The top-five most difficult daily living activities to perform reported by family carers were:

##### Self-care

Bathing (30.1%)  
Toileting (30.1%)

##### Complex

Managing finance (23.5%) Medication management (19.9%)  
Running simple errands (15.1%)

Three-in-five family carers (62.6%) reported a moderate-to-high need for education. Family carers requested education in the following daily living activities

##### Self-care

Bathing (38.5%)  
Toileting (34.3%)  
Transferring (27.1%)  
Feeding (20.5%)  
Dressing and Undressing (20.5%)

##### Complex

Managing Finance (29.5%)  
Medication Management (29.5%)  
Running Simple Errands (21.6%)

One-in-ten (13.3%) family carers reported inadequate health literacy, and two-in-ten (22.9%) reported inadequate eHealth literacy specifically. The vast majority (98.8%) of family carers owned a smart-device (i.e., smartphone, iPad/tablet, smart-watch), and half (51.2%) reported using mHealth apps.

## **Personal Interviews**

Aim: To explore problems, barriers and challenges faced by family carers relating to managing daily living activities of their care recipients at home and using smartphone apps in health seeking behaviours.

Participants: 10 family carers of people with dementia (9 female and 1 male, with an average age of 59 years).

Four themes were identified:

### **Difficulties experienced in care giving leading to psychological distress and carer burden**

Family carers reported difficulties in caregiving that results from the complex nature of dementia. These include the following: cognitive impairment in areas of memory, orientation, judgement, and decision making ability; behavioural problems, such as aggression; and low motivational and high dependency level of the care recipients. Communication difficulties and other health problems of care recipients, such as immobility, dysphagia, falls risk, fracture, constipation, incontinence and arthritis provide further challenges to caregiving. These challenges were further impeded by the lack of knowledge relating to the provision of care in daily living activities. Importantly, the new role as a carer can give rise to psychological distress over the care recipient's loss of dignity and privacy during care provision. Family carers reported fatigue from their caregiving role, which negatively impacted on their family and work life, with limited available time for rest and recreational activities.

### **Availability of support for family carers**

Support received from immediate (e.g., spouse/partners) and extended family (e.g., siblings) were perceived as important by family carers. Family carers also acknowledged the importance of funding support from government sources (e.g., Centrelink and Department of Veteran Affairs), but felt it was insufficient. Others indicated the importance of available community services, such as home care and short-and long-term respite care. Interestingly, several family carers highlighted the benefits of carer support group via social media (e.g., Facebook), as useful platforms to share care experiences.

### **Sources of information for family carers**

Family carers stated that they received care-related information in-person (e.g., training workshops), online (e.g., websites and webinars) and via printed materials from various sources including community service providers and peak body organisations (e.g., Alzheimer's Australia), as well as from Google web-searches. Such information was perceived, at times, to be either inadequate or non-applicable to family carers' needs for specific knowledge or information in a particular area of care. Some indicated that available information was fragmented and needs improvement. Knowledge gaps reported by family carers included information on the following: the types, progression, and management of dementia-related behaviours and symptoms; the management of daily living activities (e.g., toileting, transferring, feeding, dietary management, incontinence and medication management); and care equipment and available support resources.

### **Smartphone application as an educational and supportive resource for family carers**

Smartphone apps are acknowledged by family carers to be widely accepted, and more so by the younger than older generation, yet some questioned the availability of smartphone apps as an educational and supportive resource for those caring for people with dementia. While family carers perceived smartphone apps as a potential resource to provide timely information as well as to support improved knowledge and care provision for people with dementia, only a couple of family carers were experienced with smartphone apps.

Family carers stated that changing attitudes and behaviours might be needed for the uptake of smartphones apps among older family carers who are less tech-savvy or skilled. In addition, the lack of time to look for, and access, reliable online sources and smartphone apps, coupled with the cost related to smartphone and Internet/mobile data, were reported by family carers to hinder the access and use of smartphone apps. This was perceived to be further influenced by personal characteristics of family carers, including poor vision, low literacy level and no or limited experiences with smartphone apps.

Family carers suggested that smartphone app content should be regularly reviewed and updated as well as the inclusion of the following features:

- Easy navigation of apps' content
- Recording of carers problems
- Tasks reminder
- Calendar with appointment scheduling
- Sharing of care experiences with other family carers

Importantly, family carers suggested the following content should be included in the smartphone app:

- Overview of dementia
- Management of behaviour and symptoms of dementia
- Supporting daily living activities
- Care equipment, support services and facilities, available training opportunities and other sources of information
- Strategies to support health and well-being of carers

### **Proposed Content of a Smartphone App as an Educational and Supportive Resource for Family Carers**

Based on the findings from both the online survey and personal interviews of family carers of people with dementia, the following proposed content will be included in the smartphone app:

- Overview of dementia and management of behaviour and symptoms of dementia.
- Information on activities of daily living with a focus on self-care activities (i.e., bathing, dressing, toileting, transferring, feeding), medication management, using public transport and running simple errands).
- Information on available care equipment and support services.
- Discussion board/chat room to connect with other family carers of people with dementia.

- Carers' Corner
  - Importance on caring for the carer.
  - Strategies to support the health and well-being of carers.
  - Task reminder and calendar features.

**Appendix O: Individual interview with experts-Demographic data questionnaire**

**(Griffith University ethics reference number for the project: 2017/947)**

Thank you for your participation in this interview.

Please select one response that is the most descriptive of you or fill in the blank space as appropriate.

1. Age

18-25 years

36-45 years

56-65 years

26-35 years

46-55 years

66 years and over

2. Gender?

Male

Female

Other

3. Highest educational qualification

High School

Trade/technical/vocational training

Bachelor degree

Post-graduate degree

4. Occupation .....

5. Years of experience/expertise.....

**Thank you for completing this data sheet**

## **Appendix P: Interview guide for experts**

**(Griffith University Ethics Reference Number: 2017/947)**

The purpose of this individual interview is to understand experts' experiences of providing care for people with dementia, particularly activities of daily living and the use of mHealth apps.

### **Provision of care for people with dementia in the community**

Where, and what types of care, do you provide for people with dementia?

### **Management of daily living activities for people with dementia**

1. What are the main difficulties you face when managing/planning activities of daily living for people with dementia?
2. How do you view the family carers' role in providing care in managing the daily living activities of people with dementia?
3. What are your thoughts about the barriers and challenges reported by family carers in the online survey and personal interviews relating to their management of daily living activities of people with dementia? Do you have anything to add?
4. What are your thoughts about the educational and supportive needs reported by family carers in the online survey and personal interviews relating to the management of daily living activities of people with dementia? Do you have anything to add?
5. What are your perceptions about mHealth apps as an educational and supportive resource for family carers of people with dementia?
6. What do you think are the most important smartphone features (for examples text, video, alert functions, calendar scheduling etc.) that should be included in an mHealth app for daily living activities?
7. What are the possible barriers and challenges associated with the development of an mHealth app for family carers of people with dementia?
8. What are your thoughts about the content of the proposed mHealth app to help family carers manage daily living activities of people with dementia? Do you have anything to add?

### **Suggestions for the development of mHealth app (smartphone app) for family carers of people with dementia, in relation to the management of daily living activities of care recipients**

9. Do you have any suggestions for the development of an mHealth app for family carers of people with dementia in relation to the management of daily living activities of their care recipients?

(Questions five to nine will be used in an interview with information technology engineers)

**Thank you for your participation**

## Appendix Q: Ethical approval for the main project

6/3/2019

Mail - sarath.rathnayake@griffithuni.edu.au

Your Human Ethics Protocol 2017/947 has been Fully approved

RIMS Griffith

Mon 04/12/2017 14:34

To: Pauline Calleja <p.calleja@griffith.edu.au>; Cindy Jones <C.Jones@griffith.edu.au>; Wendy Moyle <w.moyle@griffith.edu.au>; Sarath Rathnayake <sarath.rathnayake@griffithuni.edu.au>;  
C:-research-ethics <research-ethics@griffith.edu.au>; Gary Allen <G.Allen@griffith.edu.au>;

Importance: High

GRIFFITH UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE

Dear Prof Wendy Moyle

I write in relation to your application for ethical clearance for your project "Development of an mHealth application for family carers of people with dementia to address health literacy needs related to functional disability of care recipients" (GU Ref No: 2017/947). The research ethics reviewers resolved to grant your application a clearance status of "Fully Approved".

This is to confirm receipt of the remaining required information, assurances or amendments to this protocol.

Consequently, I reconfirm my earlier advice that you are authorised to immediately commence this research on this basis.

The standard conditions of approval attached to our previous correspondence about this protocol continue to apply.

Regards

Dr Gary Allen  
Senior Policy Officer

<https://outlook.office.com/owa/?realm=griffithuni.edu.au&path=/mail/search/tp>

1/2

## Appendix R: CONsolidated criteria for REporting Qualitative research

### (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. COnsolidated criteria for REporting

Qualitative research (COREQ): a 32-item checklist for interviews and focus groups.

*International Journal for Quality in Health Care*. 2007. 19(6): pp. 349-357

No. Item	Guide questions/description	Reported on Page
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 5 Main document
2. Credentials	What were the researcher's credentials? For example, PhD, MD.	Page 1 Title page
3. Occupation	What was their occupation at the time of the study?	Page 1 Title page
4. Gender	Was the researcher male or female?	Page 1 Title page
5. Experience and training	What experience or training did the researcher have?	Page 1
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Page 5 Main document.
7. Participant knowledge of the interviewer	What did the participants know about the researcher? For example, personal goals, reasons for doing the research.	Page 5 Main document
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? For example, Bias, assumptions, reasons and interests in the research topic .	Page 5 Main document
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? For example, grounded theory, discourse analysis, ethnography, phenomenology, content analysis.	Page 1 & 4 Main document
<i>Participant selection</i>		
10. Sampling	How were participants selected? For example, purposive, convenience, consecutive, snowball	Page 1 & 5 Main document

11. Method of approach	How were participants approached? For example, face-to-face, telephone, mail, email	Page 4 Main document
12. Sample size	How many participants were in the study?	Page 1 & 5 Main document
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 5 Main document. (Potential carers who expressed their willingness to participate in interviews were recruited from a previously conducted online survey about functional care. Therefore, no one refused).
<b><i>Setting</i></b>		
14. Setting of data collection	Where was the data collected? For example, home, clinic, workplace	Page 5 Main document
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Page 4 & 5. Main document  Inferred as “In-depth interviews (in-person or by telephone)” and “Nine carers participated in telephone interviews, and one carer participated in a face-to-face interview”.
16. Description of sample	What are the important characteristics of the sample? For example, demographic data, date	Page 7 Main document Table 2
<b><i>Data collection</i></b>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 5 Main document Table 1
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 6 Main document

20. Field notes	Were field notes made during and/or after the interview or focus group?	Reflective notes were taken.
21. Duration	What was the duration of the interviews or focus group?	Page 6 Main document
22. Data saturation	Was data saturation discussed?	No Inferred in page 5 Main document  “The sample size is deemed appropriate for the nature of this study according to Guest, Bunce and Johnson (2006) in identifying basic themes”.
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 6 Main document
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Page 6 & 7 Main document
25. Description of the coding tree	Did authors provide a description of the coding tree?	No. Themes and sub-themes were provided in a table. Table 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 6 & 7 Main document
27. Software	What software, if applicable, was used to manage the data?	Data were manually manipulated.
28. Participant checking	Did participants provide feedback on the findings?	Page 7 Main documents
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? For example, participant number	Page 8 to 14 Main document

30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, there was. Page 8 to 14 Main document
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, they were. From page 8 to 14 Main document
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion of major and minor themes From page 14 to 19 in main document

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