Evaluation of the implementation of an occupational therapy based dementia care program in the Australian health and aged context

by

Miia Rahja
BAppSc(OccTherapy)Hons BIntBus

Thesis
Submitted to Flinders University
for the degree of

Doctor of Philosophy
College of Medicine and Public Health
4 November 2019

DECLARATION

I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma at any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

The COPE Australia project was a large-scale implementation research project that was funded by the National Health and Medical Research Council (as part of the NHMRC Cognitive Decline Partnership Centre (grant no: GNT9100000)). The primary investigator team, research objectives, and funding were already confirmed when I commenced my candidature, however I was able to contribute to aspects of the project design and evaluation plan. Upon commencement of my candidature, the primary objective was to complete the case note audit, participant interviews and health economic evaluation described in this thesis. In addition, I assisted with ethics processes, supporting and engaging stakeholders, data collection and entry, analysis, and writing of results. I also was involved in regular meetings with the primary investigator team, and was closely involved in developing the final implementation and evaluation plans.

I was fully responsible for the two surveys presented in this thesis. This included the research study design, ethics application, data collection, extraction and cleaning, analysis, as well as writing of outcomes. The implications of these survey findings directly relate to the COPE Australia program implementation.

Signed:

Date: 4 November 2019

ACKNOWLEDGEMENTS

I would like to acknowledge all of those who have contributed their time and expertise to this thesis. Above all, I wish to acknowledge everyone who has been involved in the COPE Australia project, especially the project participants. Your participation has assisted in the development of recommendations that can be used to help Australians living with dementia. A special thank you also to the participants who let me in their lives and shared their stories with me. I feel privileged to have been able to visit your homes and learn from your experiences.

It was a delight and honour to work with my primary supervisor, Kate Laver. Kate, I could not have undertaken this process without your encouragement and guidance. I also thank my co-supervisors, Tracy Comans and Maria Crotty, for your support and advice. As my supervisors, you collectively encouraged and challenged me to develop my research knowledge and skills and ultimately helped me produce something meaningful. I am so lucky to have had the opportunity to learn from you.

Many thanks to Lindy Clemson for the opportunity to be involved in this inspiring project and the rest of the COPE Australia team, specifically Sally Day, Jennifer Culph and Justin Scanlan for sharing your passion with research and this project with me. Thank you also to the COPE project consumer and industry advisory group for the breadth of knowledge you shared.

Thanks also to the Centre for Health Services Research at the University of Queensland for making me feel welcome in your team. Above all, thank you to Kim-Huong Nguyen for mentoring me in health economics; your passion for this field is contagious.

I would like to thank the National Health and Medical Research Council Cognitive Decline Partnership Centre for the funding provided (grant no. GNT9100000). I am grateful for the PhD scholarship that enabled me to complete this work. A thank you also to the Cognitive Decline Partnership Centre (CDPC) and Flinders Centre for Clinical Change and Health Care Research (FCCCHCR) for their generous travel grants that enabled me to travel to and present my work at the World Federation of Occupational Therapists Congress in South Africa. I am also grateful for the domestic travel grant from the Emerging Researchers in Ageing (ERA) that enabled me to travel interstate to complete additional work in health economics during my candidature.

Lastly, a heartfelt thanks to my family and friends. Thank you for sharing your enthusiasm for my project, for listening and supporting me. I am grateful to have so many caring people around me.

CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF PUBLICATIONS AND CONFERENCE ABSTRACTS ARISING FROM THIS THESIS

PUBLICATIONS

Rahja, M., & Laver, K. (2019). What does the Australian public know about occupational therapy for older people? A population survey. *Australian Occupational Therapy Journal*. doi:10.1111/1440-1630.12578

Rahja, M., Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018). Are there missed opportunities for occupational therapy for people with dementia? An audit of practice in Australia. *Australian Occupational Therapy Journal*, 65, 565-574. doi:10.1111/1440-1630.12514

Rahja, M., Laver, K., Comans, T., & Crotty, M. (2018). What does the Australian general public know about treatments for dementia? A population survey. *Gerontology and Geriatric Medicine*, 4, doi:10.1177/2333721418793442

Rahja, M., Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018). Economic evaluations of occupational therapy approaches for people with cognitive and/or functional decline: A systematic review. *Health and Social Care in Community*, 26, 635-653. doi:10.1111/hsc.12553

MANUSCRIPTS UNDER REVIEW

Rahja, M., Culph, J., Clemson, L., Day, S., & Laver, K. (Under review). A second chance: Experiences of people with dementia and their families participating in a dementia reablement intervention. *Brain Impairment*.

Rahja, M., Nguyen, K.-H., Laver, K., Clemson, L., Crotty, M., & Comans, T. (Under review). Implementing an evidence based dementia care program in the Australian health context: A cost-benefit analysis. *Health and Social Care in the Community.*

CONFERENCE PRESENTATIONS AND POSTERS

**Denotes presenting author*

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2019, July). *A systematic review of economic evaluations of occupational therapy approaches for people experiencing cognitive and/or functional decline*: Oral presentation at the 28th Occupational therapy Australia National Conference and Exhibition Sydney, Australia

Rahja, M.* & Laver, K. (2019, July). *How does the Australian public understand the role of occupational therapy in supporting older people? A population survey:* Oral presentation at the 28th Occupational therapy Australia National Conference and Exhibition Sydney, Australia

Rahja, M.*, Comans, T., Day, S., Clemson, L., Crotty, M., & Laver, K. (2019, July). *Is there opportunity for more comprehensive interventions to support people with dementia? An audit of current occupational therapy practice in Australia:* Oral presentation at the 28th Occupational therapy Australia National Conference and Exhibition Sydney, Australia

Rahja, M.*, Culph, J., Day, S., Clemson, L., & Laver, K. (2019, July). *Participant experiences of receiving an evidence-based intervention to support people with dementia living in the community:* Oral presentation at the 28th Occupational therapy Australia National Conference and Exhibition Sydney, Australia

Rahja, M.*, Laver, K., Crotty, M., & Comans, T. (2019, July). *Exploring the preferences of older Australians choosing therapy and home support services: What matters and why?*: E-poster spotlight presentation at the 28th Occupational therapy Australia National Conference and Exhibition Sydney, Australia

Rahja, M*. & Laver, K. (2019, February). *Awareness about the role of occupational therapy in supporting older people in Australia: A population survey.* Oral presentation at the National Occupational Therapy Aged Care Symposium, Brisbane, Australia

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2019, February). *Economic evaluations of occupational therapy services for people with cognitive and/or functional decline: A systematic review*: Oral presentation at the National Occupational Therapy Aged Care Symposium, Brisbane, Australia

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2019, February). *Are we undertreating? An audit of current occupational therapy practice for people with dementia in*

Australia: Oral presentation at the National Occupational Therapy Aged Care Symposium, Brisbane, Australia

Rahja, M.*, Comans, T., Crotty, M., & Laver, K. (2018, July). *What does the Australian public know about treatments to improve functional ability of older people? Findings from two population surveys.* Oral presentation at the SA Gerontology Conference, Adelaide, Australia

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018, May). *Economic evaluations of occupational therapy services for people with cognitive and/or functional decline: A systematic review*: Oral presentation at the World Federation of Occupational Therapists Congress 2018, Cape Town, South Africa

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018, May). *Are we undertreating? An audit of current occupational therapy practice for people with dementia in Australia:* Poster presentation at the World Federation of Occupational Therapists Congress 2018, Cape Town, South Africa

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2017, November). *Economic evaluations of occupational therapy services for people with cognitive and/or functional decline: A systematic review*: Poster presentation at the 10th Health Services and Policy Research Conference, Gold Coast, Australia

Rahja, M.*, Laver, K., Comans, T., & Crotty, M. (2017, November). *The awareness of treatments for dementia in the general public in Australia: A population survey*. Oral presentation at the 10th Health Services and Policy Research Conference, Gold Coast, Australia

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2017, November). *Are we undertreating? An audit of current occupational therapy practice for people with dementia in Australia:* Poster presentation at the 10th Health Services and Policy Research Conference, Gold Coast, Australia

Rahja, M.*, Comans, T., Clemson, L., Crotty, M., & Laver, K. (2017, June). *Economic evaluations of occupational therapy services for people with cognitive and/or functional decline: A systematic review*: Oral presentation at the South Australia Gerontology Conference 2017, Adelaide, Australia

EVIDENCE OF IMPACT

Connections: The magazine of Occupational Therapy Australia, the peak body representing occupational therapy in Australia. (Upcoming, August 2019).*Occupational therapy for older people: A concept in need of myth busting*

Cognitive Decline Partnership Centre. (2018). *Dementia and activist occupational therapy.* Retrieved from: http://sydney.edu.au/medicine/cdpc/news-events-participation/dementia-and-activist-occupational-therapy.php

Aged Care Guide. (2018). *Australian universities take aim at understanding dementia.* Retrieved from: https://www.agedcareguide.com.au/talking-aged-care/australian-universities-take-aim-at-understanding-dementia

Australia's Science Channel. (2018). *Don't forget to plan for dementia care –and prevention.* Retrieved from: https://australiascience.tv/dont-forget-to-plan-for-dementia-care-and-prevention/

Citation at:

Royal Commission into Aged Care Quality and Safety. (2019). *Dementia in Australia: Nature, prevalence and care. Background Paper 3. May 2019.* Commonwealth of Australia. Retrieved 13 June, 2019 from: https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-3.pdf

Final results presentations:

Clemson, L., Laver, K*., Jeon, Y.-H., Comans, T., Scanlan, J. N., **Rahja, M***., . . . Gitlin, L. (2019, May). *Implementing an evidence-based program in Australia: Care of Persons with Dementia in their Environments (COPE).* Partner organisation presentation at the Queen Elizabeth hospital, Adelaide, Australia.

Clemson, L., Laver, K., Jeon, Y.-H., Comans, T., Scanlan, J. N., **Rahja, M***., . . . Gitlin, L. (2019, May). *Implementing an evidence-based program in Australia: Care of Persons with Dementia in their Environments (COPE).* Partner organisation presentation at the Griffiths rehabilitation, Adelaide, Australia.

Clemson, L., Laver, K., Jeon, Y.-H., Comans, T., Scanlan, J. N., **Rahja, M***., . . . Gitlin, L. (2019, May). *Implementing an evidence-based program in Australia: Care of Persons with*

Dementia in their Environments (COPE). Partner organisation presentation at the Alwyndor Age Care facility, Adelaide, Australia.

Clemson, L., Laver, K., Jeon, Y.-H., Comans, T., Scanlan, J. N., **Rahja, M***., . . . Gitlin, L. (2019, March). *The feasibility of implementing an occupational therapy based dementia care program in the Australian health context: The COPE Australia project*. Presentation at The University of Queensland Centre for Health Services Research Geriatric Medicine Seminar Series, Brisbane, Australia. https://chsr.centre.uq.edu.au/event/session/1545

ABBREVIATIONS

ACSQHC	Australian Commission on Safety and Quality in Health Care
ACT	Australian Capital Territory (Territory in Australia)
ADLs	Activities of Daily Living
AIHW	Australian Institute of Health and Welfare
AMPS	Assessment of Motor and Process Skills process scale
AT/EI	Assistive technology / Environmental interventions
B	Coefficient (for the constant)
BDOC	Bed Days of Care
CALD	Culturally and Linguistically Diverse
CBA	Cost-benefit analysis
CDC	Consumer Directed Care
CDI	Community Dependency Index
CDPC	Cognitive Decline Partnership Centre; also known as Centre on Dealing with Cognitive and Related Functional Decline in Older People
CG	Caregiver
CHSP	Commonwealth Home Support Program
CI	Confidence interval
COPE	Care Of Persons with dementia in their Environments; in Australia known as Care Of People with dementia in their Environments
COTiD	Community Occupational therapy in Dementia
CSRI	Client Service Receipt Inventory
CST	Cognitive Stimulation Therapy

CWS	Carer well-being and support Questionnaire
DESeRvE	Dementia Stigma Reduction Program
DF	Degrees of freedom
DVA	Department of Veterans' Affairs
EQ5D	Euroqol 5 Dimensions
ERA	Emerging Researchers in Ageing
FCCCHCR	Flinders Centre for Clinical Change and Health Care Research
FH	People with falls history
HC	Healthcare consumer
HCP	Home Care Packages
HRQOL	Health Related Quality of Life
IADLs	Instrumental Activities of Daily Living
ICER	Incremental Cost-Effectiveness Ratio
IDDD	Interview of Deterioration in Daily
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
LAMP	Low Activities of daily living Monitoring
MCG	Matched control group
MOOC	Massive Open Online Course
NDIS	National Disability Insurance Scheme
NF	People with no falls history
NHCU	Nursing Home Care Unit
NHMRC	National Health and Medical Research Council

NNIDR	National Institute for Dementia Research
NSW	New South Wales (State in Australia)
NT	Northern Territory (Territory in Australia)
OECD	Organisation for Economic Co-operation and Development
OT	Occupational therapy
PD	Person with Parkinson's Disease
PSSRU	Personal Social Services Research Unit
PWD	Person with dementia
QALY	Quality Adjusted Life Year
QLD	Queensland (State in Australia)
QoL	Quality of Life
QOL-AD	Quality of Life in Alzheimer's Disease
RCT	Randomised Controlled Trial
ROI	Return on Investment
RUD	Resource Use in Dementia
RUI	Resource Use Inventory
SA	South Australia (State in Australia)
SCQ	Sense of Competence Questionnaire
SCRGSP	Steering Committee for the Review of Government Service Provision
SD	Standard deviation
SE	Standard error
SEIFA	Socio-Economic Indexes for Areas

SF-36	Short Form 36
SPSS	Statistical Package for the Social Sciences
SW	Social work
TAP	Tailored Activities Program
TAS	Tasmania (State in Australia)
TCP	Transitional Care Program
TOT	Total
USD	United States dollar
VIC	Victoria (State in Australia)
WA	Western Australia (State in Australia)
WTP	Willingness to Pay
YOD	Young onset dementia

SUMMARY

Dementia is a public health priority worldwide. Evidence-based programs to improve the wellbeing of people with dementia and their caregivers exist, but are rarely implemented in routine care. The World Health Organization has called for member states to employ evidence-based research into daily practice with the aim of improving the lives of people living with dementia. To address this call, the Australian Government has provided funding to several initiatives. Included was 'The COPE Australia project' that was funded by the NHMRC Cognitive Decline Partnership Centre. The project is registered with the Australian New Zealand Clinical Trials Registry (ID: ACTRN12617000238370). The project sees the implementation of an occupational therapy based dementia care program, Care of People with dementia in their Environments (COPE), in the Australian health and aged context (www.copeprogram.com.au). This thesis evaluates the implementation of the COPE program in Australia, and highlights the key implications for ongoing program implementation at policy, service provider, and consumer levels. The thesis begins with a preamble and background. Schemes available to access community-based services in Australia are identified and the role of non-pharmacological interventions, specifically occupational therapy, in supporting people with dementia is described. The aims for the thesis are also detailed and original contribution to research is outlined. Six interconnecting studies have been completed to evaluate the COPE program implementation. The first study, described in chapter two, is a systematic review of economic evaluations of occupational therapy services for people experiencing age related cognitive and/or functional decline. The purpose is to identify approaches to occupational therapy interventions that can deliver better functional and economic outcomes for people with age related decline. Next, chapters three and four detail the findings from two online population surveys (n=1,000) about the Australian public's current level of knowledge about treatments for dementia and occupational therapy services for older people. These findings are used to evaluate the possible uptake of the COPE program, and explore the implications for program promotion. Chapter five describes a case note audit of current occupational therapy approaches for people with dementia living in the community. The audit reveals a gap between current evidence and practice in regard to services delivered by occupational therapists in Australia; recommendations are made for improvements to service delivery. Chapter six presents findings from interviews about how participating in the COPE program impacted on the lives of people living with dementia and their family caregivers. Chapter seven presents a detailed cost-benefit analysis of the COPE program implementation from multiple perspectives and confirms the beneficiaries of the program. The thesis concludes with chapter eight; a reiteration of the thesis aims and synthesis of the work completed. A discussion regarding the strengths and limitations, as well as key outcomes is presented. Practical implications for the COPE program implementation in Australia are also discussed, and areas for future research are identified.

CHAPTER 1: PREAMBLE AND BACKGROUND FOR THESIS

This thesis evaluates the implementation of an occupational therapy program for people with dementia living in the community. The program is implemented in the existing Australian health and aged context. Six interconnecting projects were completed as part of this work. Findings from each project are first discussed and later synthesised in the final chapter.

Dementia is a term used to describe a set of symptoms associated with multiple diseases affecting the brain (World Health Organization, 2012). It is a progressive condition that leads to a loss of cognitive and physical function, eventually leading to death. Dementia is characterised by impairment in language, memory, perception, personality and cognitive skills affecting a person's ability to participate in everyday activities (Burns & Iliffe, 2009). People with dementia often exhibit changes in their behaviour due to difficulties they may experience with mood, anxiety and agitation, reduced motivation, restlessness and sleep disturbances (Cummings, 2001). Dementia cannot be cured and there are no medications that can effectively slow or stop disease progression (Kenigsberg et al., 2016). Following a diagnosis of dementia, the average life-span is typically about 7 to 10 years; some can live with dementia over 20 years (Brodaty, Seeher, & Gibson, 2012; Fitzpatrick, Kuller, Lopez, Kawas, & Jagust, 2005). While dementia is not a normal part of ageing, it primarily occurs in people aged 65 and over (Livingston et al., 2017).

As dementia progresses a person becomes increasingly dependent on others, such as family or friends, to assist with care and to remain at home (AIHW, 2012). These people are called 'informal caregivers'. Informal care is provided to assist the person with activities of daily living (ADLs; such as personal care), instrumental activities of daily living (IADLs; such as transport and cleaning), social participation, and to address changes in behaviours (AIHW, 2012). This care aims to improve quality of life (QoL) for the person with dementia and delay or avoid entry into residential aged care services (also known as nursing homes) (Drame et al., 2012).

The program discussed in this thesis is primarily delivered by occupational therapists, in the person's home. Occupational therapy is concerned with participation in daily activities taking into consideration a person's cognitive and functional capacities in a given environment (Occupational Therapy Australia, 2019). Occupational therapists work with people of all ages and abilities using specialised knowledge and skills which work to increase or maintain a person's functional independence, quality of life and social participation (Steultjens et al., 2004). Therapists do so by analysing the interaction between a person, the environment the person is in, the type of activity the person is engaged in, and the person's performance in the activity (American Occupational Therapy Association, 2008). For older people and people with age related cognitive and/or functional decline, occupational therapy can lead to positive effects in functional ability (Steultjens et al., 2004; Steultjens, Dekker, Bouter, Leemrijse, & van den Ende, 2005; Wilkins, Jung, Wishart, Edwards, & Norton, 2003), independence (Beswick et al., 2008), social participation (Papageorgiou, Marquis, Dare, & Batten, 2016), as well as reduced caregiver burden (Laver, Milte, Dyer, & Crotty, 2017).

The current Australian Clinical Practice Guidelines and Principles for Care for People with Dementia (Guideline Adaptation Committee, 2016) recommend that to promote independence:

> *People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modifications to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification, and education and skills training for their carer(s) and family (p. 36).*

The World Health Organization in their global action plan (2017) called for implementation of evidence-based programs that enhance function and capability in people with dementia. In 2016, the Australian National Health and Medical Research Council Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People provided funding for an implementation research project that addressed this call. The project was titled: 'Evidence-based programs to improve the wellbeing of people with dementia and their carers: Implementing COPE in the Australian health context' (ID: ACTRN12617000238370). The project was funded for a duration of three years under the leadership of Chief Investigator, Professor Lindy Clemson. COPE stands for 'Care Of Persons with dementia in their Environments'. In Australia, COPE is known as 'Care Of People with dementia in their Environments'.

COPE is a non-pharmacological dyadic intervention that uses a systematic approach to care where an occupational therapist works collaboratively with people with dementia and their caregivers. The purpose is to support physical and cognitive function and quality of life for people with dementia, and the wellbeing of their caregiver. COPE was designed in the United States by Professor Laura Gitlin and Cathy Piersol, and was found to be effective in improving functional independence and participation in activities of daily living of people with dementia and improved caregiver wellbeing in a randomised controlled trial (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Further detail about COPE is described in section 1.1.5.1. The COPE Australia project aims to change current dementia care practice in Australia and inform policy through translation and implementation of the COPE program in standard dementia care provision (Clemson et al., 2018). A study protocol for the project has been published (Clemson et al., 2018) and is included as Appendix A of this thesis. Figure 1-1 depicts an overview of the implementation model used within the COPE Australia project. The suite of studies included in this thesis were completed as part of the project and are used to evaluate some of the 'outcomes' illustrated in the Figure. The outcomes addressed in the studies included in this thesis are related to feasibility, acceptability, uptake, costs, as well as service delivery and client level outcomes, including satisfaction.

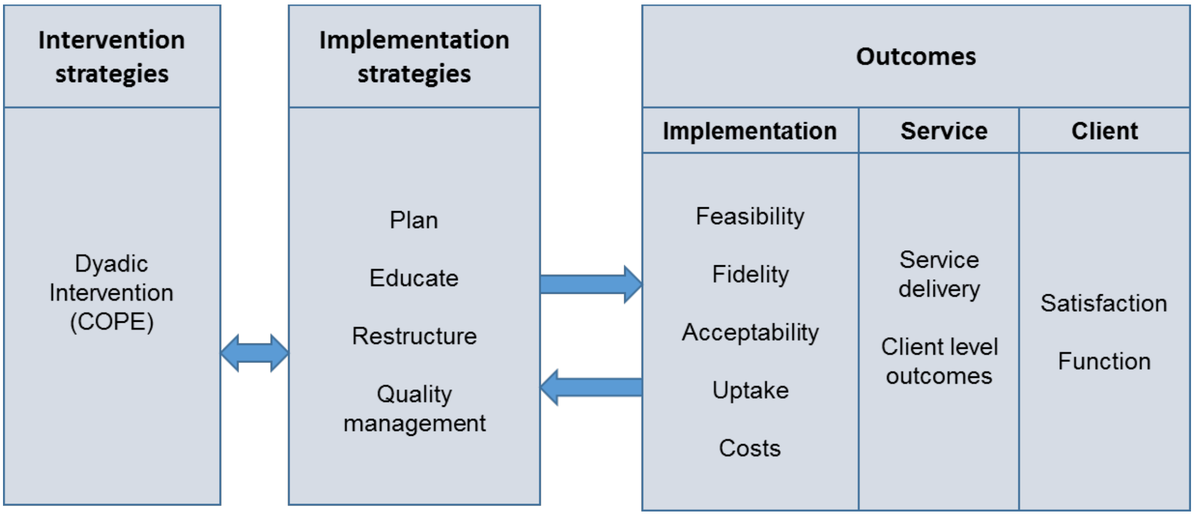


Figure 1-1 Implementation model used within the COPE project (Clemson et al., 2018).

This chapter now proceeds to provide further background for the research undertaken in this thesis. The section begins with an overview of the population ageing and prevalence of dementia worldwide and in Australia; including the societal and economic implications. As the COPE program is delivered at a person's home, the section also discusses supports and care schemes available for people with dementia living in the community (in Australia). Knowledge about community-based care schemes is important when this thesis evaluates the feasibility, acceptability, uptake and costs of the COPE program implementation. The chapter then describes non-pharmacological interventions, specifically occupational therapy, for people with dementia and their caregivers living in the community. This description outlines current evidence for interventions that specifically address functional ability and changes in a person's behaviour that are attributable to dementia. The steps the Australian Government has taken in order to improve the delivery of these interventions in the community is also outlined. The chapter then moves on to describe theories applicable to this thesis and; concludes with rationale, aims, and the candidate's original contribution made towards research.

1.1 Background

1.1.1 Ageing population and prevalence of dementia

People are living longer, and the population distribution is shifting towards older ages, known as 'population ageing' (World Health Organization, 2015a, 2015b, 2018). By 2030 there will be 1.4 billion people aged 60 years or over worldwide, a projected increase of 56% from 2015 (World Health Organization, 2015a). In Australia, there will be 8.7 million people aged 65 and over by

2056, constituting 22% of Australia's total population (Australian Institute of Health and Welfare, 2017).

As a person ages, a number of physiological changes occur. These changes include deterioration in a person's hearing and seeing, as well as decline in cognition and/or function related to non-communicable diseases (such as diseases of the lungs and heart) or other degenerative neurological conditions such as dementia and Parkinson's Disease (World Health Organization, 2015b). Ageing is the single largest risk factor for the development of dementia, and dementia has been recognised as a public health priority that requires urgent attention (World Health Organization, 2012). Dementia is the leading cause of burden of disease and the leading cause of disability burden in older people in Australia (Brown, Hansnata, & La, 2017).

In 2015, around 47 million people worldwide lived with dementia, a number larger than the population of Spain (Alzheimer's Disease International, 2015). In Australia, over 400,000 people were diagnosed with dementia (Brown et al., 2017). It is believed that 1 in 10 people aged 65 or over have dementia in Australia (AIHW, 2012). Further estimates suggest that once every three seconds a new case of dementia is developed, thus the number of people with dementia is predicted to almost triple by 2050 (Alzheimer's Disease International, 2013; Brown et al., 2017). Common implications of dementia, and other age related decline, are lower quality of life and increased health and social care costs (World Health Organization, 2015b).

1.1.1.1 Economic and societal implications of dementia

Countries worldwide have completed cost of illness studies, with each reporting that dementia poses a burden for the economy (e.g. Abdin et al., 2016; Access Economics, 2003; Alzheimer Society of Canada, 2010; Brown et al., 2017; Ku, Pai, & Shih, 2016; Prince et al., 2014; Quentin, Riedel-Heller, Luppa, Rudolph, & Konig, 2010; Wimo et al., 2011). In 2016, dementia cost Australia A$14.25 billion, equating to an approximate cost of A$35,550 per person with dementia (Brown et al., 2017). Direct costs attributable to the disease include those related to medications, hospital admissions and consultations with health practitioners. These direct costs make up the majority of the cost, while 38% of the costs relate to indirect costs such as loss of workforce productivity of both people with dementia and their caregivers (Brown et al., 2017; Chong et al., 2013; Gustavsson et al., 2010). Furthermore, 85.1% of people with dementia who live in the community access some form of informal care from family or friends (Michalowsky et al., 2016).

1.1.2 Informal caregivers of people with dementia

In Australia, there are approximately 200,000 informal caregivers of people with dementia and these are almost twice as likely as any other co-resident primary caregiver to provide 40 or more hours of care per week (81% versus 42%) (AIHW, 2012; Brown et al., 2017). Nearly half of caregivers are employed in the workforce and are required to reduce work hours due to caregiving commitments; leading to higher economic impact on society due to indirect costs such as forgone earnings (Brown et al., 2017).

Caring for a person with dementia comes with many responsibilities, including the need to consider how to keep the person with dementia engaged in activities, adjust to changes in behaviour and in communication, ensure safety at home, and find additional supports and services to enable the person with dementia to remain at home (Edwards, 2015; Jennings et al., 2015). As a result, many caregivers face early retirement, reduced working hours and other financial burden (Chen, 2016; Moore, Zhu, & Clipp, 2001), as well as psychological distress (Schulz, O'Brien, Bookwala, & Fleissner, 1995) that may lead to increased caregiver burden. Caregiver stress and burden add to the economic and societal burden of dementia, and pose a further impact on the Australian health and social care sector (World Health Organization, 2015b). Caregiver impact is further discussed in chapter 6.

1.1.3 Care of people with dementia living in the community

In Australia, over 70% of people with dementia live in the community (AIHW, 2012). While informal caregivers are in a key position to support them to remain at home, many also receive formal services that are (mostly) funded by the state or Commonwealth Government (Commonwealth of Australia, 2013a). The services are delivered via a state Local Health service, a non-government organisation, or a private practitioner (Brown et al., 2017; Commonwealth of Australia, 2013a). Yet, the extent to which services are accessed varies. A range of supports and services at home has long been available for older Australians (Productivity Commission, 2011a). For example, short-term services include intervention programs that aim to improve function and independence and Transitional Care Programs (TCP) that are time limited (typically to 12 weeks), goal and therapy specific, and are accessed following an acute illness or admission to hospital. Another program is the Commonwealth Home Support Program (CHSP). The CHSP provides ongoing or short-term entry-level support and includes home and personal care, assistance with meals and food preparation, transport, shopping, allied health, social support and planned respite (Department of Health Australia, 2017b).

Ongoing services for more complicated care needs can be further accessed through different schemes. Traditionally in Australia, a service provider has completed a needs assessment for an older person, then prioritised and allocated supports for their clients based on funding available to the provider (Productivity Commission, 2011a). However, in 2012, following the recommendations of the Australian Government's independent research and advisory body (known as the Productivity Commission), the Australian Government released proposed reforms detailed in the document titled: ‘Living Longer. Living Better.’ (Department of Health Australia, 2012). The proposed reforms, which superseded the earlier home care programs, were introduced in response to the Commission's recommendation for the need to modernise the Australian aged care sector and make it more sustainable for the ageing of Australia's population. The reforms involved the initiation of Consumer Directed Care (CDC) in Australia (Department of Health Australia, 2012). Consumer Directed Care programs exist worldwide, but they may vary country to country. However, the concept behind each is similar; to give consumers and/or their representatives more choice and control over the delivery of their care services (e.g. Da Roit & Le Bihan, 2010). This is in contrast to the traditional programs which consist of service delivery decisions that are typically made by professionals. Now, consumers (care recipients and/or their representatives) in Australia receive individualised budgets that are allocated based on independently assessed care needs and they are expected to inform their care provider of their service preferences based on their self-identified needs (Department of Health Australia, 2012). Table 1-1 summarises the main characteristics of this model.

It should also be noted that following another report by the Productivity Commission (2011b) about Australia's disability services, the Government has initiated the National Disability Insurance Scheme (NDIS) (Commonwealth of Australia, 2013b). The scheme works in a manner similar to the Consumer Directed Care program, providing eligible consumers (people aged under 65 with disabilities, their families or caregivers) with individualised budgets that they can use to help with independence and day to day life such as social participation, education and employment (Commonwealth of Australia, 2013b). While people with dementia, particularly those with young onset dementia (YOD; any form of dementia that has been diagnosed in people aged under 65), may access healthcare services under the NDIS model, the scheme is not discussed in further detail as the focus of this thesis is on older people (aged 65 years and over).

Considered together, community based care schemes for people living with dementia are provided in order to enable the person to remain at home for as long as possible, thus delaying entry into residential care home. Clinical practice guidelines state that caregivers of people with dementia should be offered access to programs that enable them continue provide care for the person with dementia at home (Guideline Adaptation Committee, 2016; Guideline Committee, 2018). The evidence underpinning this guideline recommendation comes from research studies that have found individualised caregiver support programs, psychoeducation and skills building programs, and multicomponent intervention programs (that is, programs that consist of multiple sessions and at least two of the aforementioned approaches) to be effective in reducing caregiver impact (Jensen, Agbata, Canavan, & McCarthy, 2015; Laver et al., 2017; Olazaran et al., 2010; Vandepitte et al., 2016). These programs are termed 'non-pharmacological' as they are not described in a pharmacopoeia.

Table 1-1 Main characteristics of the Consumer Directed Care model in Australia. Adapted from Northern Sydney Primary Health Network (n.d.).

Domain	Description of characteristics
Funding	Individualised budgets (Levels 1-4) afforded by the Government and allocated based on independently assessed care needs. Budget is owned by the consumer and/or their representative who make the spending choices.
Service approach	Begins with identifying what matters to consumer. Works to improve the consumer's health and wellbeing through supporting them to be as independent as possible.
Service purpose	Assists the consumer to remain healthy and independent for as long as possible.
Assessment of care needs	Care needs (including goals and supports) are self-identified together with the (independent) assessor; typically through a once-off conversation. May involve self-assessment and/ or professional assessment for specific issues when indicated and agreed by the person and/or their representative.
Planning of care needs	Goals are identified by the consumer and they receive assistance for planning care needs around these goals as requested or required.
Services available	Consumer chooses care/ services accessed, including who delivers care, when and where. The choice of services is made within the earlier allocated budget and may include help at home; personal care support; social participation support including group activities; allied health services and; care coordination.
Payment for services	All services have fees that are discussed with and paid by the consumer.
Cost of services	All services are costed individually. Consumer is aware of the funds available to them and receive statements about their spending and care package funds.
Approach to care coordination	Care coordinator facilitates and / or advises on consumer's requests and / or care needs as requested.
Selection of care staff	Consumer has more say in finding staff to meet their care needs and preferences. Care staff can be outsourced from organisation outside of where package funding is held.
Level of direction about services accessed/ provided	Consumer chooses and directs decision about their package spending, but is guided by service providers to ensure compliance to legal requirements.

1.1.4 Non-pharmacological interventions for people with dementia

Non-pharmacological interventions have been recommended as first line therapy of choice to address behavioural changes related to dementia as they do not produce side effects similar to medications (Guideline Adaptation Committee, 2016; Guideline Committee, 2018). A number of non-pharmacological interventions and care options for people living with dementia exist. Over 40 interventions that address functional capacity and caregiver impact have demonstrated improved outcomes (Laver, Clemson, Bennett, Lannin, & Brodaty, 2014; Maslow, 2012; McClaren, LaMantia, & Callahan, 2013). These interventions have been reported to delay functional decline, reduce caregiver impact, improve caregiver knowledge, and delay admission to aged care facility (Laver, 2016).

The intervention approaches to produce improved outcomes may vary. However, evidence suggests that interventions that involve tailored multiple components (for example caregiver education and skills building, and engaging the person with dementia in activities), and consist of at least five consultation sessions are the most effective (Laver, 2016). A meta-analysis found that functional decline associated with dementia can be delayed through occupational therapy or multi-component interventions (McLaren, LaMantia, & Callahan, 2013). Prominent were interventions designed to improve the home environment, the ability of the person with dementia and the skills of their caregiver.

1.1.5 Occupational therapy for people with dementia

Occupational therapists have a unique set of knowledge and skills that they use to analyse how a person engages in activities in a given environment. Therapists consider the person’s cognitive and functional capabilities and make recommendations to help maintain or improve the person’s independence, functional capacity, and ability to participate in meaningful day-to-day activities (Occupational Therapy Australia, 2019). Therapists apply a holistic approach to care and involve people of all ages and abilities, including caregivers (American Occupational Therapy Association, 2008).

People with dementia (and their caregivers) have identified that they prefer care that can maximise independence, and assist caregivers to better support the person with dementia to remain at home (Low, White, Jeon, Gresham, & Brodaty, 2013). The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia contain a number of recommendations relevant to occupational therapists that may address these preferences (Laver, 2016). A number of different occupational therapy intervention approaches can support people with dementia to retain independence (Guideline Adaptation Committee, 2016). These include environmental adaptations, prescription of assistive technologies, education about dementia to the person and their caregiver, teaching compensatory strategies for activities of daily living (ADL) or instrumental activities of daily living (IADL), functional mobility training, cognitive retraining and stress management/relaxation training (Occupational Therapy Australia, 2019). The current Clinical Practice Guidelines (2016) suggest that occupational therapy interventions that are individualised for the needs and abilities of the person with dementia and involve multiple components (for example, caregiver education, skills training and engaging the person with dementia in activities) are the most effective. Examples of occupational therapy programs that have been found to be effective with people with dementia living in the community are further discussed in chapter 5. One such program is Care Of People with dementia in their Environments (COPE; Gitlin, Winter, et al., 2010).

1.1.5.1 Care Of People with dementia in their Environments (COPE)

Care Of People with dementia in their Environments (COPE) is a non-pharmacological intervention to support physical and cognitive function, and quality of life, in people with dementia and the wellbeing of their caregiver (Gitlin, Winter, et al., 2010). COPE was designed in the United States using earlier research and recommendations on best practices. The program uses a multidisciplinary approach to care and combines the unique skills of occupational therapists, together with nursing skills for medical management. It consists of up to ten occupational therapy and two nurse contacts over a period of up to four months (Gitlin, Winter, et al., 2010). Figure 1-2 depicts the flow of the program. The occupational therapist works collaboratively with the caregiver and person with dementia to identify areas of concern. Caregivers are educated to problem solve different approaches around modifying their communication, the home environment and steps to encourage participation in activities of daily living for the person with dementia. The therapist also educates the caregiver about how to engage the person with dementia in enjoyable activities based on their level of cognitive and functional ability. A nurse provides support for medical management and education around medication, hydration, pain and continence. Earlier research investigating the COPE program suggests that COPE can improve functional independence and participation in activities of daily living of people with dementia. Caregivers have reported improved wellbeing, confidence in environmental modifications, problem solving skills and coping with changes in behaviours (Gitlin, Winter, et al., 2010). Further outcomes related to the COPE program are also described in chapters 6 and 7.

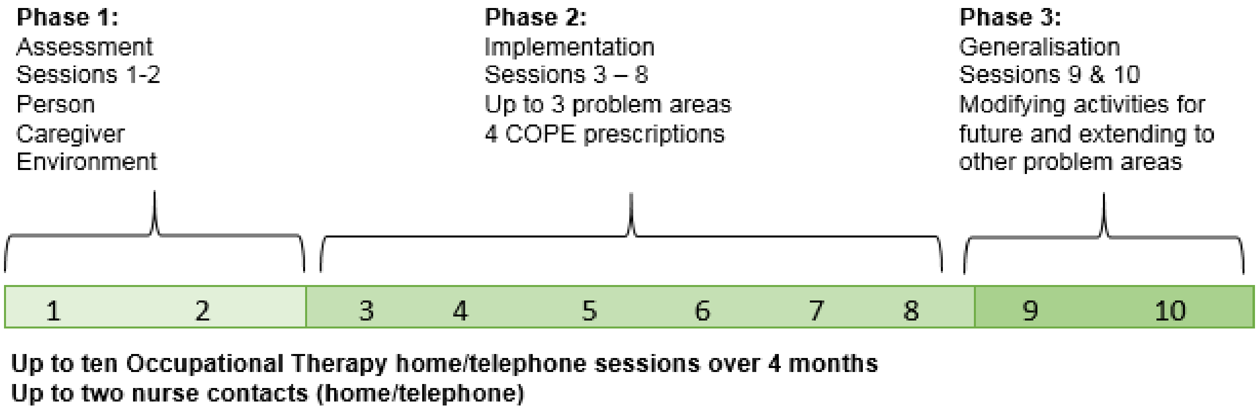


Figure 1-2 Structure and flow of the COPE program

1.1.6 From research to practice

Many research trials have shown that interventions to support people with dementia are effective, yet only a few of these have been translated to a real-world settings (Jennings et al., 2015; Maslow, 2012). Implementation research is the exploration of processes carried out in the implementation of initiatives, or programs, in a given context. It evaluates the contextual factors that impact these processes and is often used to support the integration of programs into existing heath systems at a national level (Peters, Tran, & Adam, 2013). The purpose of implementation research is to maximise the uptake of evidence-based programs by prospective users, and explore and understand what works in the real-world (Jackson, Janamian, van Weel, & Dunbar, 2014;

Peters et al., 2013). Implementation research also aims to evaluate if evidence-based programs can produce similar outcomes when provided outside of a clinical trial (Maslow, 2012). Implementation research is more common in the United States with studies now engaging in strategies to increase the uptake and use of non-pharmacological interventions that address behavioural changes for people with dementia living in the community (e.g. Burgio et al., 2009; Czaja et al., 2018; Gitlin, Jacobs, & Earland, 2010; Martindale-Adams et al., 2017). Countries in Europe (Dopp et al., 2015) and China (Hong Kong) (Cheung et al., 2015) are also beginning to engage in implementation research. Australia is yet to follow.

Dementia care in Australia is fractured. Care and education around the condition is often provided by multiple services or health professionals. Interventions that have proven to be effective in trials are not readily accessible (Clemson et al., 2018). There is currently a lack of evidence-based occupational therapy interventions to support people with dementia in Australia (Brodaty & Cumming, 2010). Yet, policy makers, people with dementia and their caregivers expect supports that are based on best available research evidence (Brodaty & Cumming, 2010). In 2014, the Australian Government announced a $200 million budget to boost dementia research in the country, and support research projects aimed at improving the lives of Australians impacted by dementia; 45 different projects with focus on prevention, diagnosis and treatment received funding (Commonwealth of Australia, 2014). Included were three projects that incorporate implementation strategies of programs that address behavioural changes related to dementia. These programs were the earlier described Care of People with Dementia in their Environments (COPE; Clemson et al., 2018): Interdisciplinary Home-bAsed Reablement Program (I-HARP; Jeon et al., 2017) and; Tailored Activities Program (TAP; http://researchers.uq.edu.au/research-project/32114). This thesis evaluates the implementation of the Care Of People with dementia in their Environments (COPE) program.

1.1.7 Implementing the COPE program in the Australian health context

In 2016, the National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Centre (CDPC) funded ‘the COPE Australia project’. The funding was provided in order to begin bridge the gap between what is considered evidence-based care for people living with dementia in the community and current clinical practice (grant no: GNT9100000). As of 2016, the project has been implementing the aforementioned COPE program in the existing Australian health and aged context, beginning in the states of New South Wales and South Australia. The primary objective of the project is to identify strategies and processes that impact on the implementation and uptake of the COPE program within existing health care systems in Australia. The project seeks to identify and explain the factors that contribute to intervention adoption by asking “what, why and how” the COPE program will work in the country (Clemson et al., 2018). At the conclusion of the project, an action plan is prepared for the dissemination of the COPE program to the wider Australian health context. Such an action plan needs to provide a clear description of how programs such as COPE can fit the current funding models (such as those discussed in section 1.1.3), and impact health service providers, people living with dementia and the wider Australian community. Thus, there is a need to evaluate a number of outcomes related to the COPE program implementation.

The implementation model used in the COPE Australia project follows a format recommended by Proctor et al. (2009). The model was illustrated in Figure 1-1, and described in detail in the study protocol (Appendix A; Clemson et al., 2018). In short, the COPE program is the intervention strategy. The implementation strategy consists of a number of components including developing relationships with government, non-government and private organisations that provide services for people with dementia under the different schemes described in section 1.1.3. The project's primary outcome of interest is related to implementation including feasibility, fidelity, acceptability, uptake and costs. At the completion of the project, the COPE Australia research team completes a detailed evaluation about the processes and outcomes related to the translation of the COPE program in the Australian health and aged context. A critical component of program evaluation is to provide deciding bodies with information that assists with understanding the social, economic and environmental impacts of the proposed program. A preferred approach is a cost-benefit analysis (CBA; Department of Treasury and Finance, 2013). The main characteristic of a cost-benefit analysis is that monetary value is assigned for all costs and outcomes related to the program implementation using recognised methodologies (Campbell & Brown, 2015). In health economics, a cost-benefit analysis enables the identification of who gains from the program implementation and who endures the costs from multiple perspectives (including society as a whole, service provider and/or individual) (Campbell & Brown, 2005). This is done by identifying, evaluating and comparing costs and benefits of the proposed program implementation. Thus, to inform future implementation and allow a decision to be made on whether programs such as COPE should be made available to Australians, a cost-benefit analysis is warranted, and is described in further detail in chapter 7.

Successful implementation of health programs depends on a number of factors including detailed understanding of the environmental context, partnerships with relevant decision makers and target audiences, and economic feasibility of the proposed programs (Glasgow & Emmons, 2007). Yet, barriers to successful implementation exist at systems, economic, social, and value levels (Glasgow & Emmons, 2007). For example, societal attitudes or beliefs about the benefits that can be achieved from participating in health programs may impede the uptake of these programs. Thus, as this thesis evaluates the implementation of the COPE program in Australia, there is a need to recognise that people (the end users) may not take action to engage in such programs to improve their health (Volpp, Loewenstein, & Asch, 2015). While the COPE program has the potential to advance dementia care in Australia, earlier experiences suggest that adherence to new health care initiatives, including preventative programs, can be poor (Berkman et al., 2011; Kripalani, Yao, & Haynes, 2007). There may be many reasons for this non-adherence. Health literacy in its broader context has been recognised as the key driver that encourages change in health behaviour and related outcomes. Health literacy is conceptualised as a person's ability to make informed decisions about their health in their daily life and is structured around their basic health knowledge, health-care systems knowledge and use, and health related behaviour (Kickbusch & Maag, 2008). Health behaviour is described as the actions taken by a person or group of people and the causes, correlates and consequences of those actions. These causes, correlates and consequences include changes in quality of life and coping skills, implementation uptake and policy development, and social change (Parkerson et al., 1993).

Theories, sometimes known as models, can be used to explore health related decision making and their use is recommended for campaigns that aim to devise health related behavioural change (Glanz, Rimer, & Viswanath, 2015a). They are made up of constructs, more commonly known as concepts, used to describe a particular philosophy (Glanz & Rimer, 1995). Both terms, theory and model, can be used to describe human behaviour and some theories have the word model in them (Glanz & Rimer, 1995). In short, theory is often used to explain why people act or fail to act in certain way; models are used to translate theories into practice (Glanz & Rimer, 1995). From now on these terms are used interchangeably, depending on the work cited. In healthcare, an understanding of a theory can assist researchers and health professionals to assess health related behaviour or intervention impact in more depth (Glanz, Rimer, & Viswanath, 2015b). Theories that describe health-related human behaviour enable researchers to explore the associations between a person's (or people's) knowledge and their health-related behaviour, for example by analysing perceived health threats, barriers to healthcare use, benefits of healthcare interventions and convenience to accessing health services (Flood et al., 2010; Khdour, Hawwa, Kidney, Smyth, & McElnay, 2012). A number of theories exist which may be used to explore the adoption of programs such as COPE in Australia. The choice of theory can shape the way health behaviour is interpreted (Rimer & Brewer, 2015). Some of the more common theories used to explore health service adoption at an individual level are:

- Andersen's Model of Health Service Use (Andersen, 1968, 1995)
- Health Belief Model (Hochbaum, 1958; Hochbaum, Rosenstock, & Kegels, 1952)
- Transtheoretical Model of Behaviour Change (Prochaska, 1979)
- Theory of Planned Behaviour (Ajzen, 1985; Fishbein & Ajzen, 1975)

The below describes these theories in more detail. Table 1-2 synthesises their main concepts and how they may apply to this thesis.

1.1.7.1 Andersen's Model of Health Service Use

Andersen's Model of Health Service Use (Andersen, 1968, 1995) is one of the more commonly used theories that explores people's health care use. Andersen originally developed the model in 1960s to help understand why families use health services, to assess and describe equitable access to health care, and to help guide policy development to promote equitable access to health care (Andersen, 1968). The model has progressed with time, with the most frequently used version (Andersen, 1995) placing more emphasis on contextual and individual characteristics that impact health service use, and a later version (Andersen & Davidson, 2007) that focuses more on community and contextual variables. The different versions of the model have been used in research studies to explore how different characteristics, divided into predisposing (such as demographics, religion and education), enabling-(such as income and wealth, employment and health insurance), and needs (such as physical and mental health statuses and self-perceived or evaluated health) reflect on people's views about their own wellbeing, the (health) conditions of their community, and eventually their health service use (Babitsch, Gohl, & von Lengerke, 2012). The interaction between the different characteristics and views about health service use is illustrated in Figure 1-3. As it currently stands it is difficult to determine which characteristics have the most power to determine health service use.

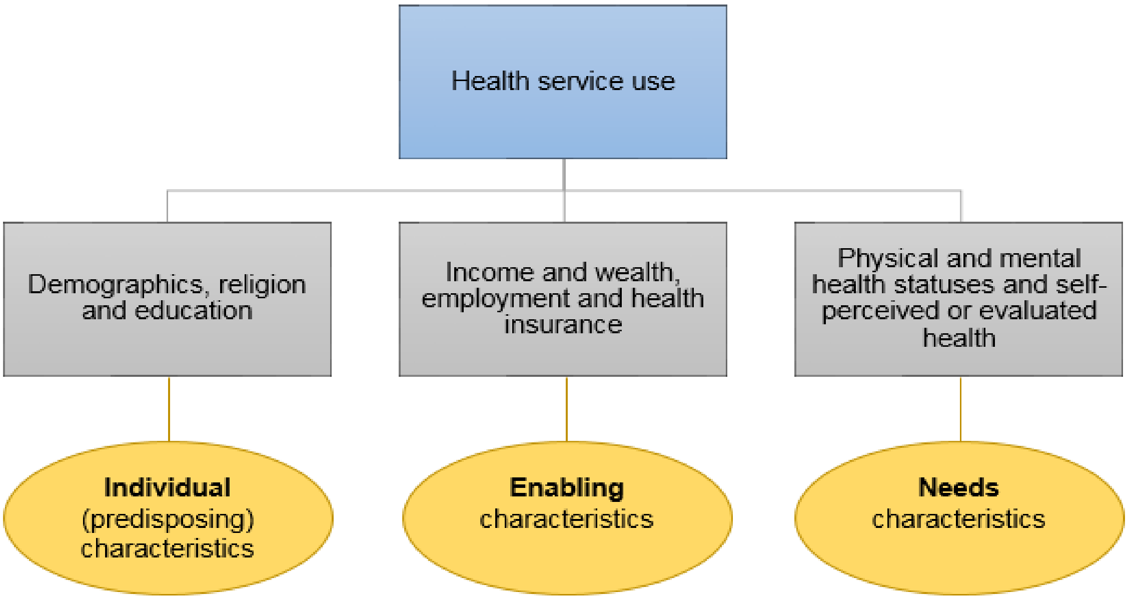


Figure 1-3 Illustration of the Andersen's Model of Health Service Use

1.1.7.2 Health Belief Model

Health Belief Model (Hochbaum et al., 1952) is a theory commonly used in health education and promotion. It was originally developed to help understand why people failed to participate in public health disease prevention and detection programs (Hochbaum, 1958). The concept underlying the model is that health behaviour is determined by personal beliefs or perceptions about a health condition and the strategies available to decrease its occurrence (Hochbaum, 1958). The model proposes that personal perception about a health condition, such as dementia, is influenced by a range of factors related to a person, such as belief in one's own ability to do something about the condition (Hochbaum, 1958). In other words, a person's awareness and attitude about a health condition and the strategies they believe they have available to decrease its impact determines how one manages their health (condition). This theory would suggest that people who are more knowledgeable about health conditions, such as dementia, are more likely to seek information about diagnosis and healthcare services. Poor knowledge about dementia (or other conditions) would be related to a lower rate of timely diagnosis and subsequent treatment (Rahja, Laver, Comans, & Crotty, 2018). Figure 1-4 illustrates the flow of the Health Belief Model. The model is often used to motivate people to take positive health actions to avoid negative consequences, and is often used as theory in prevention programs (Sugg Skinner, Tiro, & Champion, 2015). As the model focuses on personal responsibility, little emphasis is placed on emotional aspects that may impact health related behaviour (Sugg Skinner et al., 2015).

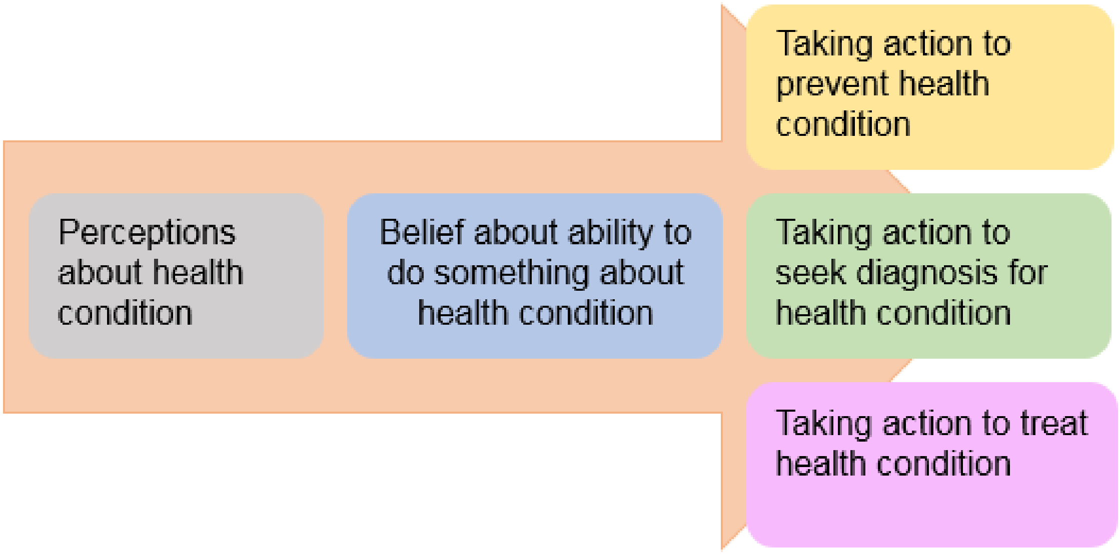


Figure 1-4 Illustration of the Health Belief Model

1.1.7.3 Transtheoretical Model and stages of behavioural change

The Transtheoretical Model (Prochaska, 1979) is an integrative model used to explore health related behaviour through stages of change. The model integrates principles of change from multiple, popular, theories and describes the processes that lead to a change in a person's health related behaviour (Prochaska & DiClemente, 1983). Overall, the model proposes that people's health-related behaviour is rooted in their readiness to change (for example, if a person is ready to accept help to remain at home following a diagnosis of dementia). The model characterises this readiness through stages (pre-contemplation, contemplation, preparation, action and maintenance; Figure 1-5) that a person reaches while changing their health behaviour (Prochaska, 1979). Change processes such as increasing awareness about causes and consequences of health related (in)action, weighing up the benefits and costs of changing behaviour, and confidence in one's ability to change their health-related behaviour are reflected in each stage (Prochaska, 1979). The model is often used in studies that aim to make changes in habitual behaviour, such as smoking cessation, and explore the actions taken by people who successfully adopted the change in health behaviour, including maintenance of the behaviour changes (Rimer & Brewer, 2015). This type of model of readiness to change has also been used in studies around engaging caregivers of people with dementia in interventions. Chee, Dennis, and Gitlin (2005) described caregivers' readiness through these stages and suggested that there are different approaches to how to work with a caregiver though these stages. This includes, for example, beginning with simple education about the disease at 'pre-contemplation' stage, or teaching about different strategies to help the person with dementia engage in activities at 'action' stage.

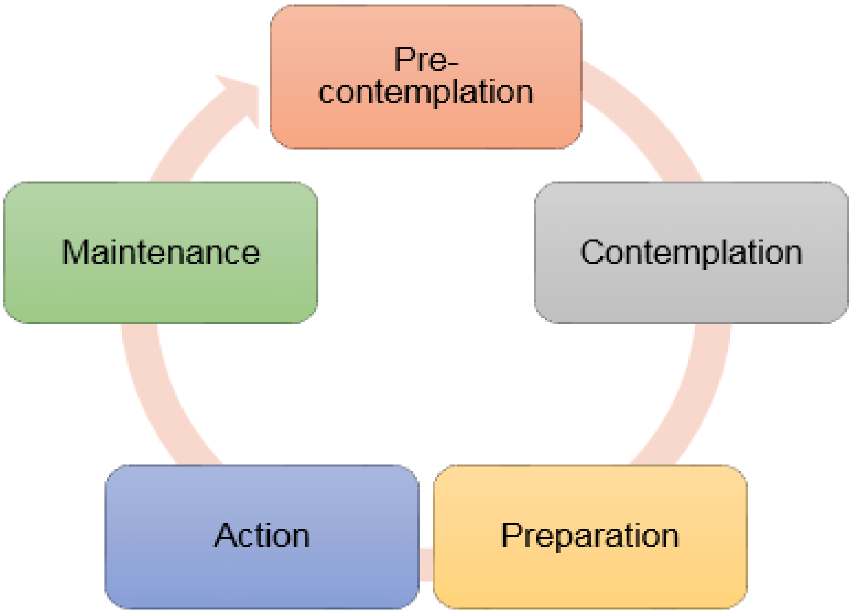


Figure 1-5 Illustration of the Stages of Behavioural Change

1.1.7.4 Theory of Planned Behaviour

A theory used to explain motivational factors related to health behaviour is the Theory of Planned Behaviour (Ajzen, 1985; Fishbein & Ajzen, 1975). Theory of Planned Behaviour is an extension of the Theory of Reasoned Action (Fishbein, 1967) that was developed to help understand the relationships between attitudes, intentions and behaviours. The core concept underlying this theory is that intention is the best predictor of changes in behaviour and that intention is grounded in attitudes and common social perceptions about the behaviour. Further, a person's perceived control over their performance of the desired behaviour and the likelihood of the behaviour resulting in certain health outcomes is accounted for in this theory. In other words, if and how a person adopts a health-related behaviour, such as engagement in a new program, is dependent on their attitudes and ultimately the perceived value of engaging in that behaviour. The relationship is illustrated in Figure 1-6. In health research this theory is typically used in cross-sectional studies to explain variances in intention and predicted health behaviour. While intentions are an important step towards behavioural change in health service use, and adoption of new healthcare interventions, they do not always translate to changes in behaviour (Rimer & Brewer, 2015).

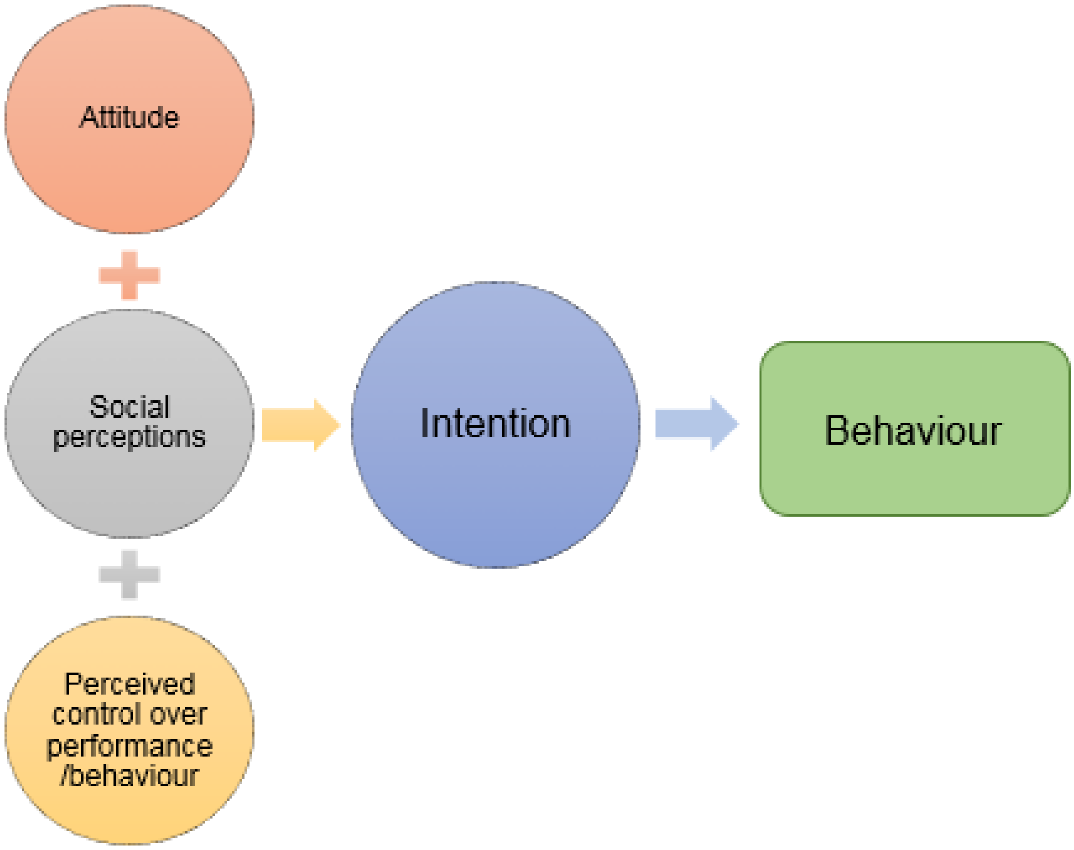


Figure 1-6 Illustration of the Theory of Planned Behaviour

Table 1-2 Theories used to explore health related decision making and their applicability to this thesis

Theory (Author, year)	**Relevance to health care decision making**	**Main concept(s)**	**Application to aged and / or dementia care**	**How theory may be applied in this thesis** ***Chapter(s) applied in***
Andersen's Model of Health Service Use (Andersen, 1968, 1995)	Developed to understand why health services are used. Assesses and describes (people's) access to health care and can be used to guide policy development.	Explains how different predisposing, enabling and needs characteristics reflect health services use and views about health.	To explore type and purpose of services currently used by a person, including interval/time period; To explore how characteristics such as age and gender, or different funding schemes available may impact health services accessed.	To explore how different characteristics can reflect views about health services and their use; To explore participant characteristics and engagement in the COPE program; To explore funding schemes available to access the COPE program. *Chapters 3, 4, 6 and 7*
Health Belief Model (Hochbaum, 1958; Hochbaum et al., 1952)	Developed to help understand people's decisions to use (or not use) preventive services offered by public health departments.	People will take health related action if they feel that a health condition can be avoided, they can successfully undertake the recommended health action, and by taking an action they can avoid a negative health condition.	To investigate behaviour around health concerns that are asymptomatic, related to illness or injury prevention, or risk reduction; To explore and understand primary reasons for health service use (or lack thereof).	To explore people's knowledge and perceptions of interventions that can improve outcomes for dementia and if this impacts their readiness to take action to seek such interventions. *Chapter 3, 4 and 6*

Theory **(Author, year)**	**Relevance to health care decision making**	**Main concept(s)**	**Application to aged and / or dementia care**	**How theory may be applied in this thesis** ***Chapter(s) applied in***
Transtheoretical Model and Stages of Behavioural Change (Prochaska, 1979)	Used to understand changes in habitual behaviour (e.g. smoking or alcohol and drug abuse), including actions, or steps, taken to make desired changes.	Describes health behaviour, or readiness to change health behaviour as stages (pre-contemplation, contemplation, preparation, action and maintenance). A person progresses through these stages as they change their health related behaviour.	To determine consumers' readiness to accept services and / or supports; To tailor interventions or health promotion campaigns at an appropriate level of readiness.	To evaluate caregivers and / or people with dementia's readiness to engage in the COPE program; To explore how the COPE program can be implemented depending on different levels of readiness. *Chapter 6*
Theory of Planned Behaviour (Ajzen, 1985; Fishbein & Ajzen, 1975)	Used to explore relationships between people's attitudes, intentions and behaviours, as well as perceived control over performance of the wanted or targeted behaviour.	Motivation predicts health related behavioural change and is grounded in a person's attitudes and societal expectations towards the behaviour.	To separate and understand attitudes towards engaging in a health-related behaviour and beliefs about the possible outcomes of a behaviour; To identify key influencers (such as peers or specific health professionals) that may promote engagement in health related behaviour.	To explore initial attitudes and feelings towards dementia reablement programs, or engagement in research studies; To understand participants' beliefs regarding possible outcomes from engaging in the COPE program and; To explore how the COPE program could be promoted to wider audience in the community. *Chapters 3, 4 and 6*

1.2 Rationale for thesis

This chapter has described some of the economic and societal implications of dementia (worldwide and in Australia). The chapter has also outlined that the Australian government has called for improvements in the support provided to people living with dementia. Programs exist that are aimed at improving functional independence and reducing caregiver impact, but only a few have been translated to real-world settings. The chapter has introduced the implementation of an evidence-based occupational therapy program, Care of People with dementia in their Environments (COPE), in the existing Australian health context. The ultimate goal of the COPE program implementation is to change the current dementia care practice in Australia. In order to reach this goal, a number of different outcomes related to the program implementation, services and clients need to be evaluated. The combination of these outcome evaluations can help inform policy and future program implementation. The purpose of this thesis is to evaluate outcomes related to the COPE program implementation in Australia.

1.2.1 Aims

Five aims were identified that contribute to the evaluation of outcomes presented in this thesis. These aims were:

1. To establish the costs and outcomes of different occupational therapy approaches for people with cognitive and/or functional decline and/or their caregivers.
2. To understand the Australian general public's current level of knowledge about treatments for dementia and about occupational therapy for older people.
3. To evaluate the current approaches to delivering occupational therapy services for older people with dementia in the community.
4. To understand the experiences of people with dementia and their family caregivers of participating in the COPE program.
5. To identify the costs and benefits of including the COPE program in the existing Australian health context from different perspectives.

Six inter-related projects addressing these aims were completed as part of this work. The flow of these projects is illustrated in Figure 1-7. The first step was to conduct a systematic review to identify costs and outcomes of different occupational therapy approaches for people with age related cognitive/functional decline (chapter 2). The next steps were to identify the Australian' public's level of knowledge about treatments for dementia (chapter 3) and of occupational therapy services for older people (chapter 4). These studies were completed in order to provide background to assist with the evaluation of how programs, such as COPE, can be promoted to the wider population based on the population's current level of knowledge and beliefs. The next study (chapter 5) assessed the gap between research evidence on occupational therapy intervention approaches to delivering services for people with dementia in the community and current practice. Recommendations were made to address gaps that exist.

Next, to assist with implementation recommendations and ensure that that the COPE program is appropriate to meet the needs of people with dementia and their caregivers, chapter 6 discusses a qualitative study that sought to understand and describe participant experiences of being part of the COPE program. Chapter 7 synthesises the costs and benefits of including the COPE program in the existing Australian health context and includes a detailed cost-benefit analysis of the program implementation. Lastly, the implications of overall results and key considerations for researchers and decision-makers are deliberated in chapter 8. Opportunities for future research in this area are also identified.

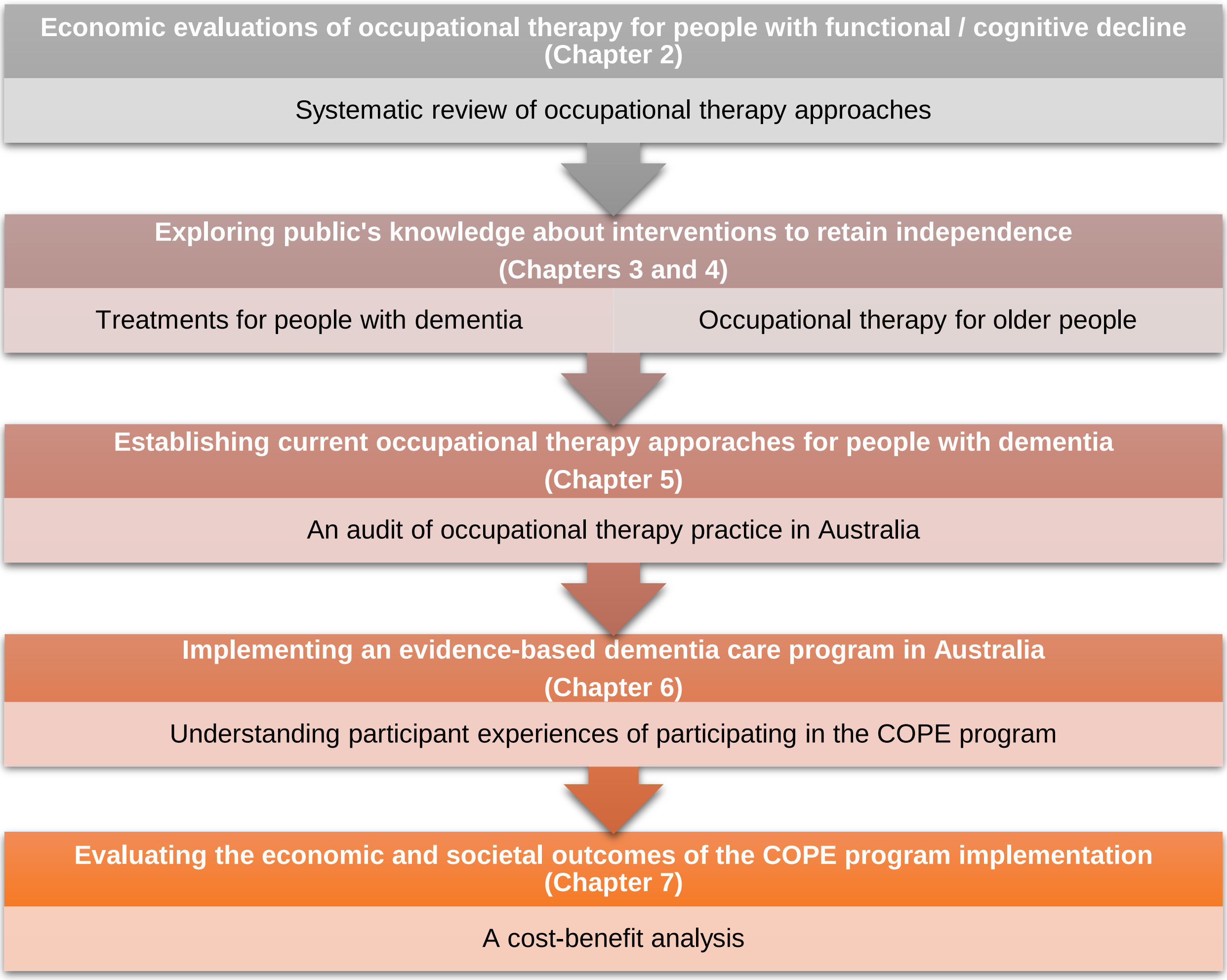


Figure 1-7 Thesis flow

1.2.2 Original contribution to research

My original contribution to research is the evaluation of the COPE program implementation as identified in the aims above. The practical and policy implications of the research completed are:

- A foundation about the Australian public's knowledge about treatments for dementia. This foundation can be used to inform campaigns aimed at increasing awareness and reducing stigma.

- A clearly defined evidence-practice gap in services delivered by occupational therapists supporting community dwelling people with dementia in Australia. The knowledge about this gap can be used to evaluate future uptake of interventions identified as best practice, as well as to make recommendations for service improvements.

- A significant addition to the policy perspective in reablement programs for people with dementia in Australia.

This introductory chapter has provided background and rationale to this thesis. The following chapters proceed to discuss the six projects undertaken to inform the final outcomes and implications of this thesis. Each chapter that contains published research material includes a statement in the prologue about the publication and contribution of the candidate. The next chapter presents a systematic review of economic evaluations of occupational therapy approaches for people with age related cognitive and/or functional decline.

CHAPTER 2: ECONOMIC EVALUATIONS OF OCCUPATIONAL THERAPY APPROACHES FOR PEOPLE WITH COGNITIVE AND/OR FUNCTIONAL DECLINE: A SYSTEMATIC REVIEW

This chapter answers Aim 1 of the thesis: “to establish the costs and outcomes of different occupational therapy approaches for people with cognitive and/or functional decline and / or their caregivers”. This chapter describes a systematic review conducted and is adapted with minor changes for thesis formatting and consistency from the published article in *Health and Social Care in the Community* (Rahja, Comans, Clemson, Crotty, & Laver, 2018b).

The review was completed to gauge if there is potential for occupational therapy interventions for people with age related decline, such as dementia, to be cost effective. It was also important (for the candidate) to understand the types of economic evaluations completed in current literature in order to determine a suitable approach to evaluating costs and outcomes related to the COPE Australia project.

As the main author for the publication, the candidate’s contribution was 80% of this chapter. The candidate constructed the research question, and completed and registered the study protocol with the International Prospective Register of Systematic Reviews (PROSPERO). The candidate also liaised with a medical librarian regarding search terms and strategy, completed data collection and screening, as well as analysis and the writing of results. Co-authors and supervisors TC and KL assisted with refining the study question. TC also provided guidance in identifying data extraction tools and interpretation of the economic outcomes. All authors were involved in editing and proof-reading the final manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

2.1 Rationale

As described in chapter 1, ageing is associated with a number of changes that affect a person’s daily function; these changes are characterised by decline in cognition or function that are typically associated with frailty, non-communicable diseases or other degenerative neurological conditions such as dementia (World Health Organization, 2015b). Impaired cognition and physical function often coexist and studies have reported cognitive decline is associated with poorer physical function and ability to perform activities required to live independently (Auyeung et al., 2008; Rosano et al., 2005). Common implications of cognitive and functional decline include reduced quality of life and increased health and social care costs (World Health Organization, 2015b). Thus, while this thesis evaluates the implementation of a dementia care program, dementia exhibits as decline in cognitive skills and functional ability that impact a person’s ability to participate in everyday activities. It is, therefore, important to include interventions that address age related decline related to both cognition and function in this review.

Chapter 1 also identified that for people with age related cognitive and/or functional decline, occupational therapy can lead to positive effects in functional ability (Steultjens et al., 2004; Steultjens, Dekker, Bouter, Leemrijse, & van den Ende, 2005; Wilkins, Jung, Wishart, Edwards, & Norton, 2003), independence (Beswick et al., 2008) and reduced caregiver burden (Laver, Milte, Dyer, & Crotty, 2016). Yet, there is no single way of delivering occupational therapy for people experiencing cognitive and/or functional decline; the approaches to intervention delivery vary depending on client needs, resources available and organisational demands (Dow & McDonald, 2007; Steultjens et al., 2004). It has been recommended that studies investigate different approaches to delivering interventions to further determine the effectiveness of occupational therapy for various population groups (Steultjens et al., 2004).

With the economic impact of the ageing population, governments and health service providers are becoming increasingly concerned with resource allocation and the cost effectiveness of interventions (Brown et al., 2017; Detsky & Laupacis, 2007). Economic evaluations of healthcare interventions provide critical information for policy makers and other clinicians about the cost effectiveness of interventions and their feasibility to be included in standard care provision (Detsky & Laupacis, 2007). There are different methods for conducting economic evaluations; often described as full or partial economic evaluations. Full economic evaluations include cost-effectiveness analyses, cost-utility analyses, and cost-benefit analyses (Joanna Briggs Institute, 2011). Cost-effectiveness analyses compare the relative costs and outcomes for different interventions used to achieve the same health outcome. Cost-effectiveness is typically expressed as the average cost per unit of effectiveness, often described as an incremental cost-effectiveness ratio (ICER). A limitation of this approach is that it focuses solely on health outcomes, programs with different types of outcomes cannot be compared, and it is dependent on the quality of data collected and evaluated (Joanna Briggs Institute, 2011). Cost-utility analyses are similar to cost-effectiveness analyses, but they are used to determine costs and effects in terms of utilities, a measured used to describe a person’s health state. The most commonly used utility measure is Quality Adjusted Life Years (QALYs) (Joanna Briggs Institute, 2011). A limitation to a cost-utility analysis is that it can be difficult to place a value on a health state or on an improvement in health state as perceived by different people. Cost-benefit analyses place monetary value on all costs and outcomes, and are typically used to assess the worthwhileness of an intervention in order to help decision-makers appraise options, and decide whether to implement them (Department of Treasury and Finance, 2013). The challenge of a cost-benefit analysis is that it can be difficult to identify, quantify and predict all costs and benefits related to intangible items (Campbell & Brown, 2015). Cost analysis studies, cost-description studies, cost-outcome descriptions, and cost minimisation studies are described as partial economic evaluations.

Economic evaluations of occupational therapy services are limited. While some randomized controlled trial studies have conducted economic evaluations alongside measuring the clinical effectiveness of an intervention, little is still known about the overall cost effectiveness of occupational therapy in supporting people with cognitive and/or functional decline. Preliminary evidence suggests that occupational therapy may be cost effective in supporting people with dementia (Knapp, Iemmi, & Romeo, 2013) or older people (Nagayama, Tomori, Ohno, Takahashi, & Yamauchi, 2016). However, this evidence is still weak and comes from reviews that have evaluated a combination of interventions, or occupational therapy provided as part of a multidisciplinary team intervention.

In order to justify the value of occupational therapy in supporting people who experience age related decline, the (potential) cost effectiveness needs to be evaluated. To our knowledge, no systematic reviews of economic evaluations have been conducted that includes occupational therapy specific interventions for people experiencing cognitive and/or functional decline. Thus, the purpose of this review is to identify and synthesise the best available evidence on resource use and costs involved in occupational therapy for people with cognitive and/or functional decline (and/or their caregivers). The review examines if and how occupational therapy can be a cost effective service for these people. The question posed for this review was:

> What are the costs and outcomes of occupational therapy for people with cognitive and/or functional decline and/or their caregivers?

Secondary questions were:

1. Are there differences in costs for providing occupational therapy intervention in the community compared to residential care for people with cognitive and/or functional decline?
2. How have the costs and outcomes of occupational therapy services for people with cognitive and/or functional decline been assessed in economic evaluations?

2.2 Methods

2.2.1 Protocol and registration

The protocol for this systematic review was developed ‘a priori’ and the review was registered with PROSPERO International Prospective Register of Systematic reviews on 28th September 2016;

registration number CRD42016046491. The protocol includes full details of the methods used and is also included as an Appendix B. There were no changes made to the protocol during the review.

2.2.2 Eligibility Criteria

Population: Studies including people with cognitive and/or functional decline and/or their caregivers were included in this review. This included people with degenerative neurological conditions and degenerative conditions related to ageing such as mild cognitive impairment, dementia, multiple sclerosis, Parkinson's disease, Huntington's disease, motor neurone disease, arthritis, frailty, falls, and hip fracture. As the aim of the review was to investigate occupational therapy intervention approaches for conditions that have a gradual onset, are progressive and are more commonly seen in the ageing population, conditions (such as traumatic brain injury and stroke) that occur with sudden onset and have different trajectories compared with the gradual onset conditions were not included. Chapter 1 also identified that nearly half of (informal) caregivers of people with dementia are employed in the workforce and are required to reduce work hours leading to higher economic impact on society due to indirect costs such as forgone earnings (Brown et al., 2017). This was the reason why interventions aimed at caregivers were also included in the following review.

Intervention: Studies were included if people living with cognitive and/or functional decline were receiving occupational therapy services and costs related to accessing such services were evaluated in accordance to the above inclusion criteria. We also included studies where the caregiver was involved in the intervention (for example, the caregiver was involved in problem solving or education). Where intervention was multidisciplinary in nature, studies were excluded unless at least 70% of the intervention was provided by an occupational therapist.

Occupational therapy intervention in the context of this review was conceptualised as an intervention that promotes health and wellbeing by improving independence, daily function and participation, and may contain caregiver education on care provision (World Federation of Occupational Therapists, 2012). This may include: environmental assessment and modification that aids independent functioning; prescription of assistive technology and; tailored intervention that promotes independence in activities of daily living such as problem solving, task simplification, and education and skills training of caregivers and family members (Laver, 2016; Wilkins et al., 2003).

Comparator: Quantitative studies that encompassed full economic evaluation studies (i.e. cost-effectiveness analyses, cost-utility analyses, cost-benefit analyses); partial economic evaluations (i.e. cost analyses, cost-description studies, cost-outcome descriptions, cost minimisation studies); randomized trials reporting more limited information, such as estimates of resource use or costs associated with intervention(s) and comparator(s) and; studies with pre and post intervention cost comparators were included in this review.

Studies with partial economic evaluations with no comparator (e.g. outcome description studies, cost-description studies, cost-outcome descriptions, unless they are pre and post studies) and studies using financing models were excluded from this review.

Outcome: The primary outcome of interest was the cost effectiveness of occupational therapy interventions.

2.2.3 Search strategy and study selection

Ten electronic databases were searched on the 23rd September 2016 and the search was updated on 20th April 2017. These databases were: MEDLINE; PsycINFO; EconLit; CINAHL; ProQuest (Health & Medicine; Social Science subsets only); Cochrane Central Register of Controlled Trials (CENTRAL): Issue 8 of 12, August 2016; Health Technology Assessment Database: Issue 3 of 4, July 2016; NHS Economic Evaluation Database (NHS EED): Issue 2 of 4, April 2015 and issue 4 of 12, April 2017 in the subsequent search; ALOIS database and; EMBASE. American, Canadian, Australian, UK, and New Zealand Occupational therapy association web pages; websites of large organisations interested in ageing (Australian Association of Gerontology and National Institute of Health and Ageing) and; government research bodies [National Health and Medical Research Council (Australia), National Health Services and The National Institute for Health and Care Excellence (United Kingdom) and Agency for Healthcare Research and Quality (USA)] were searched for grey literature. Reference lists of included studies were also scanned. No date limits were imposed on the search strategy. A medical sciences librarian with expertise in systematic reviews assisted with the development of the search strategies. The search strategy was developed for Medline using medical subject headings (MeSH) and text words, and then adapted for use with the other databases. The strategy combined terms relating to occupational therapy, economics, people with cognitive and/or functional decline, and caregiver. The search strategies have been included as Appendix C of this thesis.

Two people (the candidate and a research assistant) independently screened titles and abstracts based on the inclusion criteria detailed in the review protocol. Differences between reviewers' results were resolved by discussion and when necessary in consultation with a second review author (KL). Full copies of studies identified by the title/abstract screen as having met the inclusion criteria were obtained. Reasons for excluding studies were documented.

2.2.4 Data extraction

The candidate (MR) extracted data using a modified version of the Joanna Briggs Institute Data Extraction Form for Economic Evaluations (Joanna Briggs Institute, 2011). The extraction tool was shortened, and detail related to economic and clinical effectiveness outcomes were combined in the modified version to allow for ease of comparison of the two outcomes. Items related to modelling used, indirect costs and statistical analysis used were not directly collected as these were not the primary aim of this review. Yet, this information were sought in the papers if they were considered relevant. The extraction form has been included in Appendix D. Another review author (KL) crosschecked the data extracted. The data extracted included descriptive data about the study method, evaluation design, participants, intervention used, comparator, outcomes, prices and currency used for costing, time period of analysis, setting, tools used to measure outcomes, and authors' conclusions.

2.2.5 Risk of bias assessment

EVERS checklist (Evers, Goossens, de Vet, van Tulder, & Ament, 2005) was used for a critical appraisal of the studies. The checklist covers study population, competing alternatives, study question, study design, timing of costs, study perspective, comparison of alternatives, units of cost, accuracy, credibility and identification of costs and outcomes, incremental analysis, sensitivity analysis, coherence, generalizability of results, conflict of interest and ethical implications. The appraisal was conducted independently by the candidate and a research assistant trained on the use of the checklist. Any disagreements were discussed, and another review author (TC or KL) was consulted as necessary.

2.3 Results

2.3.1 Study selection

Figure 2-1 depicts the PRISMA flow diagram describing the study selection process. The initial search resulted in a total of 13,584 citations. After removing duplicates, 8,782 titles and abstracts were reviewed. One hundred and thirteen full text reviews were completed and 11 papers met the inclusion criteria. An additional two studies were added through searching the reference lists and grey literature search, resulting in a total of 13 included studies. Two cost effectiveness studies (Smith & Widiatmoko, 1998; Zingmark & Bernspång, 2011) were excluded from the review as they were based on assumptions and used decision analytic models to reach outcomes.

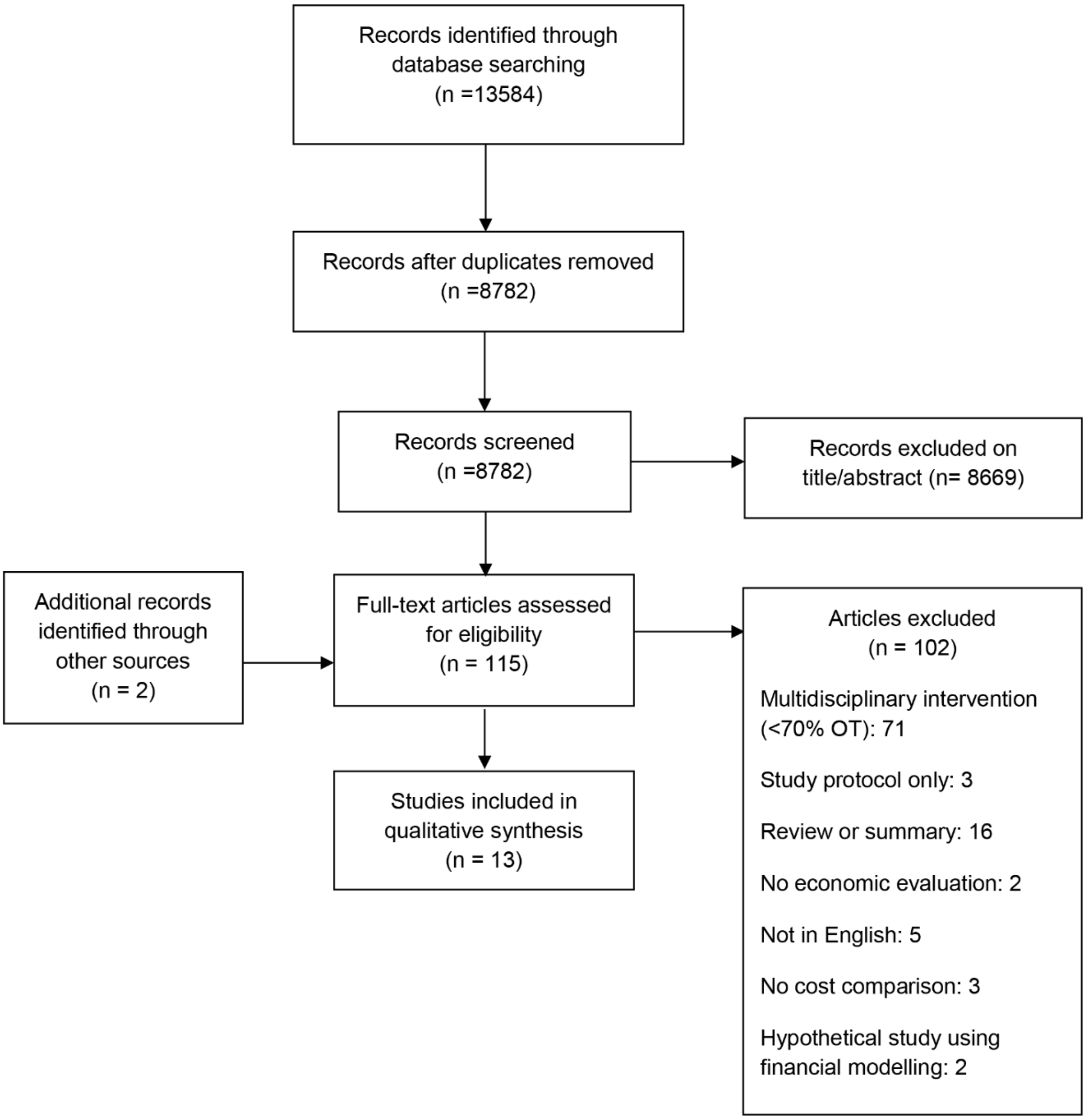


Figure 2-1 PRISMA flow diagram

2.3.2 Overview of studies

Table 2-1 outlines the characteristics of the studies included in this review. Nine of the included studies were full economic analyses. These included six cost effectiveness studies (Campbell et al., 2005; Gitlin, Hodgson, Jutkowitz, & Pizzi, 2010; Graff et al., 2008; Hay et al., 2002; Jutkowitz, Gitlin, Pizzi, Lee, & Dennis, 2012; Salkeld et al., 2000) two cost utility analysis (Flood et al., 2005; Sturkenboom et al., 2015) and one cost benefit analysis (Carande-Kulis, Stevens, Florence, Beattie, & Arias, 2015). Four studies involved partial economic analysis. Two of these were cost comparison studies (Bendixen, Levy, Olive, Kobb, & Mann, 2009; Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999), one involved a cost analysis of implementing occupational therapy services in a residential home (Schneider, Duggan, Cordingley, Mozley, & Hart, 2007) and the final study (Sheffield, Smith, & Becker, 2013) was an informal evaluation comparing the intervention to usual care reporting pre and post intervention care plan costs, intervention related costs and then measuring intervention effectiveness using the occupational therapists’ professional judgment to assess care needs following intervention.

Six studies (Bendixen et al., 2009; Flood et al., 2005; Jutkowitz et al., 2012; Mann et al., 1999; Schneider et al., 2007; Sheffield et al., 2013) counted costs related to delivering the intervention (including travel time, home modification or equipment prescription), staff training, and health service use, and were evaluated from a health service perspective. Flood et al. (2005) also included a patient perspective evaluating the cost of services used by the participants. Five studies (Campbell et al., 2005; Graff et al., 2008; Hay et al., 2002; Salkeld et al., 2000; Sturkenboom et al., 2015) were evaluated from a societal perspective, including data from the health system, intervention set up, patient and caregiver costs. One study (Gitlin et al., 2010) used an individual perspective evaluating time spent “doing things” and “on duty”, and one study (Carande-Kulis et al., 2015) used a third-party payer perspective; an approach used to aid health care funders and other organisations to select interventions that can provide a positive return on investment.

Table 2-1 Characteristics of included studies

Source, Country Study acronym (where applicable)	Target population	Study description Intervention VS comparator	Type of economic analysis	Perspective, time period and currency used	Source of effectiveness data	Costs included
Gitlin (2010), United States “TAP”	Dementia	RCT Eight sessions (6 home / 2 telephone) to identify and prescribe activities tailored to patients’ capabilities, roles, habits and interests delivered by an OT over a period of 4 months VS No OT for people with dementia and their caregivers.	Incremental cost effectiveness analysis for time spent "doing things", and "on duty" pre and post intervention.	Individual caregiver perspective 4 months, *USD*	Caregiver Vigilance Scale of National Institute of Health Resources for Enhancing Alzheimer's Caregiver Health	Therapist training and supervision, caregiver time in intervention sessions, assessments materials, intervention supplies, therapist time spent delivering intervention (including travel)
Graff (2008), Netherlands “COTiD”	Dementia	RCT Ten x 1hr OT sessions over a period of 5 weeks. Consisted of assessment and goal defining and then patient skills building and caregiver training VS Usual care that did not include OT.	Incremental cost effectiveness analysis as the difference in mean total care costs per successful treatment	Societal perspective 3 months, *Euro*	Successful treatment defined as a clinically relevant improvement in participants and caregivers on the AMPS, IDDD and SCQ combined over a three month period.	Therapist time spent delivering intervention, therapist additional hours (travel administration, report writing); other healthcare services used by participants; caregiver healthcare service utilisation; nursing, domestic or other day care provided at home; other services used (meal on wheels); days of illness; hospital and nursing home stays.

Source, Country Study acronym (where applicable)	**Target population**	**Study description Intervention VS comparator**	**Type of economic analysis**	**Perspective, time period and currency used**	**Source of effectiveness data**	**Costs included**
Sturkenboom (2015), Netherlands “OTiP”	Parkinson’s Disease	RCT Ten weeks (maximum of 16 hours) of OT focusing on improving performance in daily activities selected and prioritised by the patient, and provided at the patient's home VS No OT.	Cost utility analysis conducted by comparing observed and estimated mean cost differences between intervention and control groups.	Societal perspective 6months, *Euro*	EQ5D Cost differences and cost utility analysed using linear mixed models and presented as the next monetary benefit for WTP values per QALY gained.	Intervention delivery, participant healthcare and resource use (including home care, aids and adaptations, institutional care), and caregiver informal care hours, absence from work and healthcare consults.
Hay (2002), United States	People aged 60 and over	RCT Weekly OT group focusing on healthy lifestyle and meaningful activity engagement VS (Active) generalised social activity group program, and (passive) no treatment.	Incremental cost effectiveness analysis as the difference in included participant costs divided by the incremental difference in participant QALYs between intervention and treatment groups.	Societal perspective 9 months, *USD*	SF-36	Intervention delivery (contact, travel and preparation time), healthcare (physician visits, hospital in and outpatient visits, and health professional home visits), caregiver expenses (paid and unpaid in-home support)

Source, Country Study acronym (where applicable)	Target population	Study description Intervention VS comparator	Type of economic analysis	Perspective, time period and currency used	Source of effectiveness data	Costs included
Jutkowitz (2012), United States “ABLE”	People aged 70 and over, cognitively intact	RCT Five OT contacts to address client-identified functional difficulties, performance goals, and home safety (four 1.5-hour visits and one telephone contact) and one 1.5-hour physiotherapy home visit over the first six months, and another three brief OT telephone contact and final home visit during second six months VS No intervention contact – home safety booklet only.	Incremental cost effectiveness calculated as difference between the intervention and control divided by the difference in survival benefit between the two using two models. Model 1: base case of delivering intervention in a home care agency. Model 2: base case + 10% to account for a potential variation in the cost of delivering intervention in a real world setting.	Service provider perspective 12 months, *USD*	No utility instruments used. Life Years Saved analysed using Kaplan-Meier method to calculate additional cost to bring about one additional year of life.	Intervention delivery including home and telephone sessions, staff training, intervention materials, therapist travel, and home modifications (ordering, installing and quality control).
Sheffield (2013), United States	Community dwelling older adults	RCT Up to four visits of occupational therapy home assessment, assistance with ADL, AD/EI, medication management increased safety and compensatory strategies VS Usual care.	Cost analysis based on OT judgement on participant’s need for assistance in community pre and post intervention.	Health service perspective 3 months, *USD*	No utility instrument used for economic analysis. Cost analysis conducted by taking the average care plan cost prior to intervention minus average intervention cost and subsequent need for continued assistance as assessed by the OT.	Intervention delivery, equipment and home modification.

Source, Country Study acronym (where applicable)	Target population	Study description Intervention VS comparator	Type of economic analysis	Perspective, time period and currency used	Source of effectiveness data	Costs included
Bendixen (2009), United States "LAMP"	Older people with chronic health conditions	Retrospective matched comparison study LAMP Tele-rehabilitation program coordinated by OT that uses traditional and advanced technologies to promote independence and maintenance of skills to remain living at home safely VS Treatment as usual. Number of OT consultation sessions unclear.	Cost comparison of national data extracts from Veterans Health Administration and actual costs of in- and out- patient encounters.	Health service perspective 24 months, *USD*	No utility instrument used for economic analysis. Economic outcomes calculated using differences-in-differences approach including hospitalisation, clinic visit, emergency visit, and nursing home care unit costs.	Hospital BDOC, clinic visits, emergency room visits and NHCU
Mann (1999), United States	Frail older people	RCT Comprehensive functional assessment and evaluation of home environment by an OT with recommendation and provision of AD/EI, training and follow up VS Standard care. A mean of 8.9 visits conducted by study OT.	Cost comparison conducted calculating differences in healthcare costs for intervention and control groups.	Health service perspective 18 months, *USD*	No utility instrument used for economic analysis. Mann Whitney U statistical test used to compare differences in healthcare costs.	AT/EI intervention delivery (including equipment, staff training, set up and follow up) cost of in-home personnel (e.g. nurses), institutional costs (e.g. hospitalisation).

Source, Country Study acronym (where applicable)	**Target population**	**Study description Intervention VS comparator**	**Type of economic analysis**	**Perspective, time period and currency used**	**Source of effectiveness data**	**Costs included**
Carande-Kulis (2015), Varied based on intervention (United States, Australia, New Zealand)	Falls prevention programs for older people	RCT "Stepping on" OT led falls prevention program consisting of seven weekly three -hour sessions conducted in community setting VS Otago Exercise Program or Tai Chi: Moving for Better Balance.	Cost benefit analysis where effects were calculated as probability for intervention to reduce falls and calculation of net benefit and ROI for each intervention relevant to a healthcare funder.	Third party payer perspective (secondary analysis) 12-14 months, *AUD , USD, NZD*	No utility instrument used for economic analysis. ROI for each dollar invested based on assumptions used for estimating the net benefit from averting falls related medical costs minus the average intervention costs.	Intervention therapist training, post-intervention follow up, therapist wage for delivering intervention, estimation of average expected medical costs resulting from a fall in intervention and control groups.
Salkeld (2000), Australia	Older adults who had experienced a recent fall	RCT OT home hazard reduction program to identify and educate client regarding environmental hazards and supervision of recommended home modifications VS Routine care after discharge with no occupational therapy.	Incremental cost effectiveness calculated as difference is costs in intervention and control group divided by difference in falls prevented in the two groups.	Societal perspective 12 months, *AUD*	No utility instrument used for economic analysis. Calculated by diving the difference in costs between control and intervention groups and difference in number of falls prevented in the groups.	Healthcare resource use in hospital, other healthcare provided as outpatient or at home, other health services used, informal caregiving, and expenses related to home modification (e.g. price of goods and labour)

Source, Country Study acronym (where applicable)	**Target population**	**Study description Intervention VS comparator**	**Type of economic analysis**	**Perspective, time period and currency used**	**Source of effectiveness data**	**Costs included**
Campbell (2005), New Zealand	People aged 75 and over with poor vision	RCT OT home safety assessment and modification program to identify hazards, provide education about items, behaviour or lack of equipment that could lead to falls, and a follow up visit to sign off equipment installed VS Exercise program to reduce falls.	Incremental cost of implementing the intervention program per falls prevented by the intervention.	Societal perspective 6 months, *NZD*	No utility instrument used for economic analysis. Cost effectiveness measured as the ratio between incremental cost and incremental effect where the measures of change were resources used and number of falls following intervention.	Therapist training (including transport and materials), program delivery (including transport, materials, administration), services and equipment installed, and overhead expenses.
Schneider (2007), United Kingdom	Older people residing in residential homes	RCT Hiring full time OT for individual and group therapy to evaluate the effect of OT on depression and quality of life VS Usual care.	Cost analysis	Health service perspective 12 months, *GBP*	No utility instruments used. Cost effectiveness measured with Mann Whitney U statistical test comparing differences in health and social services used pre and post intervention.	Intervention delivery computed by published unit cost with adjustments for travel, equipment and methods of program delivery.

Source, Country Study acronym (where applicable)	**Target population**	**Study description Intervention VS comparator**	**Type of economic analysis**	**Perspective, time period and currency used**	**Source of effectiveness data**	**Costs included**
Flood (2003), United Kingdom	Older people (not otherwise specified)	RCT OT assessment of older people's independence and quality of life ("the single assessment process; SAP") VS SW led assessment as above.	Cost utility analysis conducted comparing costs and consequences of intervention using utility instruments.	Health service and patient perspective. 8 months, *GBP*	CDI, EQ5D	Intervention delivery, healthcare resource use (inpatient and outpatient), expenses bared by health services and local authority (e.g. equipment, pharmaceuticals, laboratory use), expenses bared by participant and their caregivers.

Abbreviations used: OT – occupational therapy; RCT – Randomised Controlled Trial; AMPS - Assessment of Motor and Process Skills process scale; IDDD - Interview of Deterioration in Daily activities in Dementia performance scale; SCQ - Sense of Competence Questionnaire; EQ5D - Euroqol 5 Dimensions; SF-36 – Short Form 36; QALY – Quality Adjusted Life Years; WTP – Willingness to Pay; SW- social work; ADL – Activities of Daily Living; AD/EI - Assistive Devices/Environmental Interventions; ROI – Return on Investment; MCG - Matched Control Group; BDOC – Bed Days of Care; NHCU – Nursing Home Care Unit; CDI - Community Dependency Index

Most (12/13) studies described an evaluation embedded within a randomised controlled trial. However, the target participant groups varied. Three of the randomised controlled studies evaluated the cost effectiveness of fall prevention programs (Campbell et al., 2005; Carande-Kulis et al., 2015; Salkeld et al., 2000). Two studies (Jutkowitz et al., 2012; Sheffield et al., 2013) evaluated the effectiveness of occupational therapy intervention for older people with functional difficulties. One study was aimed at older people with poor vision (Campbell et al., 2005), one for otherwise frail older people (Mann et al., 1999), and one study (Hay et al., 2002) evaluated the effectiveness of an intervention that focused on promoting healthy lifestyle. One randomised controlled trial (Flood et al., 2005) evaluated the economic effects of a once off assessment of independence and quality of life, and one (Schneider et al., 2007) the effect of occupational therapy on quality of life and depression for older people in residential care. The other randomised controlled studies involved occupational therapy interventions aimed at supporting people living with dementia and their caregivers (Gitlin et al., 2010; Graff et al., 2008), and people living with Parkinson’s disease (Sturkenboom et al., 2015). The final study by Bendixen et al. (2009) drew on national data extracts to conduct retrospective matched comparison of occupational therapy coordinated tele-rehabilitation program.

Six of the studies were conducted in the USA (Bendixen et al., 2009; Gitlin et al., 2010; Hay et al., 2002; Jutkowitz et al., 2012; Mann et al., 1999; Sheffield et al., 2013), two in the UK (Flood et al., 2005; Schneider et al., 2007), two in the Netherlands (Graff et al., 2008; Sturkenboom et al., 2015), one in Australia (Salkeld et al., 2000) and one in New Zealand (Campbell et al., 2005). One study compared interventions trialled in Australia, New Zealand and the USA (Carande-Kulis et al., 2015).

The secondary aims of this review were to compare the costs of occupational therapy interventions delivered in community and residential care settings and to examine how the costs and outcomes of occupational therapy services have been assessed in economic evaluations. Only one study (Schneider et al., 2007) evaluated the cost of occupational therapy in a residential setting, thus analysis of differences in results was not possible. The methods of assessing costs and outcomes varied; no two studies used the same methods. Eight studies (Bendixen et al., 2009; Campbell et al., 2005; Carande-Kulis et al., 2015; Jutkowitz et al., 2012; Mann et al., 1999; Salkeld et al., 2000; Schneider et al., 2007; Sheffield et al., 2013) measured intervention effectiveness by comparing differences in resource use and costs in the intervention and control groups following intervention, and did not use utility instruments to evaluate economic outcomes. Five studies (Flood et al., 2005; Gitlin et al., 2010; Graff et al., 2008; Hay et al., 2002; Sturkenboom et al., 2015) employed different utility instruments to reach their findings. The preference based Euroqol 5 Dimensions (EQ5D; Barton et al., 2008) was used in two studies, while the non-preference based Short Form 36 (SF-36; Hays, Sherbourne, & Mazel, 1993) was used in one study. The other utility instruments used were the Caregiver Vigilance Scale of National Institute of Health Resources for Enhancing Alzheimer's Caregiver Health (Mahoney et al., 2003), Assessment of Motor and Process Skills process scale (AMPS; Fisher, 2003), Interview of Deterioration in Daily activities in Dementia performance scale (IDDD; Teunisse & Derix, 1997), Sense of Competence Questionnaire (SCQ; Vernooij-Dassen, Persoon, & Felling, 1996) and the Community Dependency Index (CDI; Eakin & Baird, 1995). Table 2-1 includes further detail about how intervention effectiveness was measured.

Due to the range of study characteristics it was not possible to group studies and therefore a narrative synthesis of the results is presented.

2.3.3 Methodological quality

Table 2-2 summarises the methodological quality of the studies included in this review. Studies by Graff et al. (2008) and Salkeld et al. (2000) are examples of the higher methodological quality analyses using societal viewpoint including all relevant information on healthcare and resource utilisation, absence from work, informal care hours, and intervention costs. Other studies did not identify all relevant costs and outcomes for the alternatives chosen (Campbell et al., 2005), convert costs to single year (Sturkenboom et al., 2015), conduct a sensitivity analysis, and discuss generalizability and distributional implications to varying contexts and populations (Hay et al., 2002). Four studies (Bendixen et al., 2009; Mann et al., 1999; Schneider et al., 2007; Sheffield et al., 2013) did not clearly state the perspective chosen, and were also limited in methodological quality.

Table 2-2 EVERS Checklist; methodological quality of studies

Source	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19
Gitlin (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No
Graff (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sturkenboom (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Hay (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No
Jutkowitz (2012)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Sheffield (2013)	Yes	Yes	Yes	No	Yes	No	No	No	No	No	No	No	No	No	No	Yes	No	No	Yes
Bendixen (2009)	Yes	No	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes	Yes	Yes
Mann (1999)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
Carande-Kulis (2015)	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Salkeld (2000)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Campbell (2005)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Schneider (2007)	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Flood (2004)	No	No	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Q1	Is the study population clearly described
Q2	Are competing alternatives clearly described?
Q3	Is a well-defined research question posed in answerable form?
Q4	Is the economic study design appropriate to the stated objective? †
Q5	Is the chosen time horizon appropriate to include relevant costs and consequences?
Q6	Is the actual perspective chosen appropriate? ‡
Q7	Are all important and relevant costs for each alternative identified?
Q8	Are all costs measured appropriately in physical units?
Q9	Are costs valued appropriately?
Q10	Are all important and relevant outcomes for each alternative identified?
Q11	Are all outcomes measured appropriately?
Q12	Are outcomes valued appropriately?
Q13	Is an incremental analysis of costs and outcomes of alternatives performed?
Q14	Are all future costs and outcomes discounted appropriately? §
Q15	Are all important variables, whose values are uncertain, appropriately subjected to sensitivity analysis?
Q16	Do the conclusions follow from the data reported?
Q17	Does the study discuss the generalizability of the results to other settings and patient/ client groups?

Q18	Does the article indicate that there is no potential conflict of interest of study researcher(s) and funder(s)?
Q19	Are ethical and distributional issues discussed appropriately?

† Economic study design only ticked “yes” if full economic evaluation, ‡Perspective ticked yes if perspective chosen clearly stated and justification for choosing this perceptive was given, § future costs and outcomes discounted appropriately required if study expands over a year.

2.3.4 Synthesis of economic evaluations

Table 2-3 provides a summary and a visual representation of the effectiveness and economic outcomes pertaining to the occupational therapy interventions evaluated. The table also presents reported and adjusted economic outcomes for the included studies rounded to the closest dollar. The OECD consumer price indices and purchasing power parities (Organisation for Economic Co-operation and Development, 2016) were used to standardise the presented costs for each study into a single currency (USD) and year (2012) that presented most frequently in the studies. The type and duration of occupational therapy interventions varied in the included studies. Most common were multicomponent interventions that lasted for three months or longer. They consisted of a systematic intervention approach that was delivered over a number of sessions and had a focus on independence, function or fall prevention. Those interventions with multiple sessions comprised of problem identification, goal setting, and skills building for the person (and their caregiver). The home safety interventions consisted of a joint problem solving assessment with the client and consultation around behavioural and environmental adaptations to prevent falls. Other studies evaluated the (cost) effectiveness of occupational therapy in residential care and as a once off needs assessment.

Table 2-3 Summary of economic results

Source	Target population	Effectiveness	Costs	Economic outcome	Adjusted economic outcome to USD in 2012	Explanation of key economic results
Gitlin (2010)	Dementia	↑	↑	Intervention caregivers saved an extra hour per day in "doing things" at a cost of $2.37/day and one extra hour per day in "being on duty" at a cost of $1.10/day.	Intervention caregivers saved an extra hour per day in "doing things" at a cost of $2.53/ day and one extra hour per day in "being on duty" at a cost of $1.17/day.	If shadow price is applied, there is a net economic benefit of the intervention to caregivers.
Graff (2008)	Dementia	PwD ↑ CG ↑	PwD ↓ CG ↓	The OT intervention cost €1,183/dyad (CI €1,128-€1239). The economic evaluation resulted in a total of €1,748 (CI €4,244-€748) lower costs per participant and caregiver dyad for the intervention group. Largest cost savings were recorded in informal care.	At a cost of $1,808/dyad the OT intervention produced a cost saving of $2,672/dyad.	At a cost of about €1200, the intervention is dominant as it saved an average of €1748 in other healthcare costs over a period of three months.
Sturkenboom (2015)	Parkinson's Disease	PD ↑ CG ↑	PD O CG ↓	Mean total costs for intervention group compared with control were €125 (CI -€1,651-€1401) lower for participant, €29 (CI -€172-€114) lower for caregiver groups, and €122 (CI -€1,483-€1,727) higher for participant-caregiver dyad. Costs for institutional care were significantly lower in intervention compared to control group. If society was willing to pay €20,000 per QALY gained, the benefit of intervention for caregiver is positive. The mean total costs for institutional care for people in intervention group were €1,458 (CI -€2,825-€91) lower than in control group.	The mean total cost for OT intervention participant was $1,931 lower than in control group. The mean total intervention costs were $166 lower for participants, $38 lower for caregivers, and $162 higher for caregiver participant dyad. However, the benefit of intervention for caregiver would be positive if the society was willing to pay $26,494 per QALY gained.	While there is no significant impact on total costs compared with usual care, at €20,000 WTP threshold the OT intervention can be cost effective for caregivers of people living with Parkinson's disease.

Source	Target population	Effectiveness	Costs	Economic outcome	Adjusted economic outcome to USD in 2012	Explanation of key economic results
Hay (2002)	People aged 60 and over	↑	HC ↓ CG ↑ TOT ↓	Costs for a 9 month program averaged $548/ participant. Post intervention healthcare costs were lower for the OT group ($967, SD +/- $1,808) than active ($1,726, SD +/- $3,253) passive ($3,334, SD +/- $7,435), or a combination of the control groups ($2,593, SD +/- $5,918). There was a 4.5% QALY differential in intervention vs combined control. Cost per QALY estimated for intervention group was $10,666, CI $6,747/QALY - $25,430/QALY.	The 9 month OT program cost an average $826. The post intervention costs were lower in the OT group at a cost of $1,457, and the cost of QALY for OT intervention group was $16,068.	A cost effectiveness ratio of $10,666 is considered cost effective, meaning preventative OT is cost effective. Significant savings in healthcare costs during follow up suggests preventative OT intervention is also cost effective in the long term.
Jutkowitz (2012)	People aged 70 and older, cognitively intact	↑	↓	Total cost of intervention per participant was $942 (Model 1), and $1,036 (Model 2). The intervention group had a survival rate of 94% versus 87% for control group. Incremental cost per additional year of life gained was $13,179 (Model 1) or $14,800 (Model 2).	Based on model 2, accounting for costs in real world, the cost of intervention per participant was $1,091. This led to an incremental cost per life year gained of $15,854.	Under the assumptions of Model 2, the intervention is cost effective over 50% of the time if the purchaser is willing to pay more than $14,800 for one additional year of life.
Sheffield (2013)	Community dwelling older adults	↑	↓	The average cost for intervention equipment and home modifications was $205/ client, therapy costs were $940/ client, and the mean total intervention cost $1,145/ client. Intervention resulted in 39% (2.36hr/ week, 0.44SD) reduction in recommended hours of care by OT.	The average intervention cost was $1,206/client.	At a cost of $1,145 / client the intervention can produce a cost saving for health service providers due to reduced demand (39%) for personal care needs in older people.

Source	Target population	Effectiveness	Costs	Economic outcome	Adjusted economic outcome to USD in 2012	Explanation of key economic results
Bendixen (2009)	Older people with chronic conditions	O	O	The intervention clinic visits increased by 4167 visits and $890,000 in cost (preventative medicine, rehabilitation and use of allied health services, assistive devices). Clinic visits decreased for MCG by 157 (increase of $220,000). NHCU days spent for intervention group decreased by 116 days (reduction of $42,000) and for MCG reduced by 4 days amounting to cost saving of $15,000.	The total cost of clinic visits in the intervention group increased to $1,110,391, however there was a reduction of $52,400 in nursing home care unit.	Uncertain cost-effectiveness. The intervention led to an increase in cost for preventative clinic visits, with a decrease in cost for post-intervention hospital and nursing home stays.
Mann (1999)	Frail older people	↑	O	The intervention group expended more than control group on AT/EI ($2,620 VS $443). There was no significant difference for overall total costs, but effect size for total overall costs measured were large (d=0.56) with intervention group expanding mean of $14,173 (SD $13, 761) versus control group $31,610 (SD $42 239).	The intervention group expended $3,044 more than control group on AT/EI.	The intervention led to increased costs in acquiring AT/EI, but resulted in reduced expenditure in institutional care and other health professional visits.
Carande-Kulis (2015)	Falls prevention programs for older people	↑	↓	For every dollar spent Stepping on had 64% ROI.	The average cost of stepping on intervention was $137/participant, The expected benefit of the program was estimated as $225, and the net benefit was estimated as $87.	Stepping on program is cost effective. Policy makers and healthcare service organisations can expect to cover intervention costs and receive a positive return on their investment if they were to implement the program.
Salkeld (2000)	Older adults who had experience	↑	NF ↑	Participants in the intervention group consumed $1,805 more ($10,084 VS $8,279) on average in resources. The incremental cost per fall prevented was	Following sensitivity analysis and after removing outliers, the	The intervention is likely to be more cost effective for people with a history of falls, but may

Source	Target population	Effectiveness	Costs	Economic outcome	Adjusted economic outcome to USD in 2012	Explanation of key economic results
	d a recent fall		FH ↓	$4,986 for all subjects. Following sensitivity analysis and removing outliers, incremental cost effectiveness per fall prevented was $1,921 for all subjects.	incremental cost per fall prevented was $1,884.	not be cost saving for people with no falls history.
Campbell (2005)	People aged 75 and over with poor vision	↑	↓	The OT home program cost $325/person (SD $292). The incremental cost per fall prevented was $650/person (ranging from $460 – $1,569) for different cost scenarios.	The OT intervention cost $270/person, and led to an incremental cost per fall prevented of $540/ person.	Cost saving. It would be worthwhile investing in an OT home safety assessment and modification program to reduce falls in older people with visual impairment.
Schneider (2007)	Residential homes	↑	↑	The provision of OT service came at a cost of £16/resident/week. This led to a significant increase in using social services in the intervention homes.	At a cost of $28/resident/week of OT services, the use of other social services increased.	At a cost of £16, OT can increase other social care costs due to identifying unmet care needs for people living in residential homes.
Flood (2003)	Older people (not otherwise specified)	O	O	Mean total cost of care for OT group was £4379 and SW group £3837. The difference in mean cost per case was £542 (CI £434-£1,519). The cost to public sector was 87% of overall cost for OT and 84% of overall cost for SW.	Mean total care for OT group was $1,008 higher at $8,140 for OT compared to $7,133 for SW group.	There is no significant difference in costs between SW or OT to conduct the assessments to ensure older people stay in community.

Abbreviations used: OT – Occupational therapy; PWD - Person with dementia; CG – caregiver; PD – Person with Parkinson’s Disease; HC – healthcare consumer; QALY – Quality Adjusted Life Year; TOT – Total; NF – People with no falls history; FH – People with falls history; SW- social work; MCG – Matched Control Group; NHCU- Nursing Home Care Unit; AT/EI - Assistive Technology/Environmental Interventions.
Effectiveness: ↑ intervention is more effective than comparator, intervention is equally effective 0, or ↓ intervention is less effective
Costs: ↑ the intervention is more expensive, 0 the intervention and comparator’s costs are the same, or ↓ the intervention is less expensive

2.3.4.1 *Systematic occupational therapy interventions delivered over a number of consultations*

Eight studies evaluated the effects of various occupational therapy programs delivered over a number of consultations. Three studies assessed the cost effectiveness of occupational therapy for older people by focusing on healthy lifestyle and meaningful activity engagement (Hay et al., 2002), reducing functional difficulties (Jutkowitz et al., 2012) and evaluating home assessment, assistance with activities of daily living, prescription of assistive devices and environmental modification (Sheffield et al., 2013).Two studies evaluated the cost effectiveness of tailored multicomponent community based occupational therapy programs for people with dementia and their caregivers (Gitlin et al., 2010; Graff et al., 2008), and one study examined occupational therapy for people with Parkinson’s disease (Sturkenboom et al., 2015). One study assessed the provision of assistive devices and environmental interventions in maintaining independence and reducing home care costs in community dwelling frail older people (Mann et al., 1999) and the final study used a retrospective matched comparison approach to conduct a cost comparison of Low Activities of daily living Monitoring (LAMP) tele-rehabilitation program (Bendixen et al., 2009).

The occupational therapy interventions in these multicomponent studies incorporated comprehensive environmental or home safety assessment to aid independent function at home, prescription of assistive technologies, tailored individualised programs, caregiver education and ongoing skills training, at least four consultation sessions and/or followed a systematic approach of delivering the intervention. Five of the studies (Gitlin et al., 2010; Graff et al., 2008; Jutkowitz et al., 2012; Sheffield et al., 2013; Sturkenboom et al., 2015) reported cost effectiveness of the intervention, although Gitlin et al. (2010) applied shadow pricing to demonstrate the net economic benefit of the intervention. Sturkenboom et al. (2015) found significant cost effectiveness for the caregivers of people with Parkinson’s disease, but the intervention was not significantly different overall. Hay et al. (2002) found that preventative occupational therapy was cost effective for older people, however they concluded that the intervention was not cost effective for caregivers (Hay et al., 2002).

In the studies by Bendixen et al. (2009) and Mann et al. (1999) the groups receiving occupational therapy intervention expended more on healthcare costs related to primary and preventative medicine, rehabilitation and assistive devices. However, costs related to secondary care such as hospitalisation or nursing home care were lower in the intervention groups in both studies. Furthermore, Mann et al. (1999) reported that while the intervention group expended more than the control group on assistive devices and environmental interventions, the control group expended significantly more for institutional care, nurse visits and case manager visits. Additionally, while the effect size for total overall costs measured was reported to be large (d=0.56), Mann et al. (1999) reported no significant difference for the mean total costs between the groups with treatment group expending a mean of $14,173 (SD $13,761 USD) vs control $31,610 (SD $42,239 USD).

2.3.4.2 Systematic occupational therapy intervention with specific focus on home safety and fall prevention

Three studies assessed the cost effectiveness of systematic occupational therapy interventions with specific focus on fall prevention in community-dwelling adults (Carande-Kulis et al., 2015; Salkeld et al., 2000) and people aged 75 and over with poor vision (Campbell et al., 2005). Two of the three studies, which were home safety interventions, used an incremental cost effectiveness to conduct their evaluation approaching the costs from a societal viewpoint (Campbell et al., 2005; Salkeld et al., 2000). Carande-Kulis et al. (2015) conducted a cost benefit analysis from a third party payer perspective comparing the ‘Stepping on’ fall prevention program to single factor ‘Otago exercise’ and ‘Tai Chi: Moving for better balance’ programs.

The home safety interventions consisted of home safety assessment (identification of environmental hazards and behaviours that may lead to falls at home) and problem solving solutions to reduce fall hazards and increase fall safety awareness, with follow up to provide and /or install prescribed equipment following the assessment if required. The ‘Stepping on’ program was a group based multicomponent fall prevention program led by an occupational therapist and conducted over seven sessions, a follow up home visit and a 3-month booster session. All studies reported positive effects with fewer falls, less hospitalisations and improved quality of life. Two of the three studies reported positive economic outcomes for the fall prevention program (Campbell et al., 2005; Carande-Kulis et al., 2015). The remaining study by Salkeld et al. (2000) found that while the intervention led to a reduction in falls, there was an increase in healthcare costs. However, following a sensitivity analysis where they assessed outlier effects and removed 15 subjects whose total costs were more than three standard deviations above the group mean and/or had reported more than 50 falls in a year, Salkeld et al. (2000) concluded that a single factor home hazard reduction program can be a cost saving amongst older people with history of falls in the previous 12 months.

2.3.4.3 Occupational therapy in residential care

One study (Schneider et al., 2007) evaluated costs and effects of occupational therapy in residential care. The intervention consisted of employing full time occupational therapists to provide individual and group therapy at residential homes. The aim of this was to improve mood and quality of life for the residents (Schneider et al., 2007). The study reported significant reduction in secondary health care costs (such as hospitalisation) in the occupational therapy intervention group and found that occupational therapy can be feasible and have positive impact on caregivers, residents and staff in residential homes. However, they reported an increase in referrals to other primary care services, thus increasing the costs of health care (Schneider et al., 2007).

2.3.4.4 *Once off occupational therapy needs assessment*

One study (Flood et al., 2005) evaluated the effectiveness of occupational therapy assessment of older people's independence and quality of life compared to social worker led assessment. The assessment completed by both professions was standardised for the evaluation and planning of care needs in the United Kingdom, called ‘the single assessment process’ (Flood et al., 2005). The study reported a lack of difference in occupational therapy and social work assessment, and found increases in referrals to other primary care services, thus increasing the costs of health care for the occupational therapy intervention group (Flood et al., 2005). It was also noted that 82% of the occupational therapy interventions in the study were not completed at the time of cost utility analysis, thus this may have affected the outcomes that were measured using the community dependency index (Flood et al., 2005).

2.4 Discussion

This chapter investigated the cost effectiveness of occupational therapy in care of people with cognitive and/or functional decline and/or their caregivers through a systematic review. Thirteen studies were included. The review found evidence supporting the cost effectiveness of systematic occupational therapy interventions over a number of consultations, or with specific focus on home safety and fall prevention. There are trends towards better economic outcomes for occupational therapy interventions that include tailored multiple components and/ or the provision of home safety assessments and environmental modifications to enhance independence and participation in activities of daily living for people who experience cognitive and/or functional decline. The economic benefits of these interventions were evident for supporting people with dementia and their caregivers, the caregivers of people with Parkinson’s disease, community dwelling people aged 60 or over experiencing functional decline due to ageing, people with vision impairment, and for those with a history of falling. Due to lack of studies, there was insufficient evidence to support occupational therapy in aged care homes.

This review adds to other reviews that have explored the cost effectiveness of interventions to support people with dementia (Knapp, Iemmi, & Romeo, 2013), their informal caregivers (Jones, Edwards, & Hounsome, 2012; Vandepitte et al., 2016), and older people living in the community (Nagayama, Tomori, Ohno, Takahashi, & Yamauchi, 2016; Steultjens et al., 2004). For example, Knapp et al. (2013) reported that out of non-pharmacologic interventions used to support people with dementia, a number are more economically beneficial than usual care. These include occupational therapy, cognitive stimulation therapy (CST; a form of therapy that aims to improve cognitive abilities and memory through themed activities) and tailored activities (TAP; a programme that provides individuals with activities tailored to their cognitive and functional abilities). Interestingly, CST and TAP are also usually provided by occupational therapists. Similar to this review, Knapp et al. (2013) also found economic benefits for interventions to support caregivers of people with dementia; interventions that focused on support and psychosocial wellbeing were found to produce better economic outcomes. However, these findings are in contrast to a review by Jones et al. (2012) who found little evidence to support that non-pharmacological interventions may result in better economic outcomes for caregivers of people with dementia. However, it should be noted that the review (Jones et al., 2012) evaluated a combination of interventions and was not limited to occupational therapy. As such, it would be worthwhile to conduct a thorough comparison of occupational therapy and other intensive interventions that are used to support people with cognitive dysfunction, complex neurological diseases such as Parkinson’s disease, functional difficulties and/or frailty. Such comparison could determine the relative cost-effectiveness of occupational therapy compared with other interventions.

The review also found better economic outcomes from interventions that were aimed at reducing falls in community dwelling elderly, specifically for people aged 75 or older, with poor vision, or with history of falls. In particular, interventions that consisted of a thorough home safety assessment by an occupational therapist, included joint problem solving with the client, and incorporated behavioural and environmental adaptations resulted in positive outcomes. These findings add to earlier reviews that included fall prevention programs for community dwelling older people aged 65 or over (Corrieri, Heider, Riedel-Heller, Matschinger, & König, 2011) and aged 80 or over (Davis et al., 2010). While Corrieri et al. (2011) found no conclusive results for cost effectiveness of interventions, Davis et al. (2009) reported that two single factor interventions: home-based exercise for women over 80 and a home safety assessment by occupational therapists, produced cost savings. The later study by Carande-Kulis (2015) also provides support for multicomponent programs for fall prevention with positive results found in the multicomponent ‘Stepping On’ program as well as other single factor programs.

This review also included occupational therapy interventions aimed at informal caregivers of those with cognitive and/or functional decline. Four studies (Gitlin, Hodgson, et al., 2010; Graff et al., 2008; Hay et al., 2002; Sturkenboom et al., 2015) included in this review considered caregivers in their evaluation of effectiveness and cost effectiveness. Three out of the four studies (Gitlin, Hodgson, et al., 2010; Graff et al., 2008; Sturkenboom et al., 2015) reported cost savings from reduced need for informal care in the occupational therapy intervention group. The study by Hay et al. (2002) reported non-significantly higher costs for caregivers from the occupational therapy intervention, but did not expand on this outcome in further detail. Additionally, our findings add to those of Nagayama et al. (2016) that suggest tailored occupational therapy interventions may be cost effective for older people. The differences in these two reviews were that the outcomes in this review were reported from interventions that were aimed at people who experience cognitive and/or functional decline and where the primary approach to intervention in the included studies consisted of at least 70% of occupational therapy intervention.

Many randomised trials have been conducted in the field of occupational therapy. However, economic evaluations are still uncommon in research studies examining the effectiveness of these interventions. Furthermore, the quality of the studies that have evaluated the economic outcomes of occupational therapy interventions is varied. This review builds on the work of Green and Lambert (2017), who appraised the quality of nine economic evaluation studies of occupational therapy and multidisciplinary interventions. The review by Green and Lambert (2017) did not report on the economic outcomes of the included studies and the economic effectiveness of occupational therapy remained unexplored. The current review also consisted of a critical appraisal of the methodological quality of the studies included. In particular, we utilised the EVERS checklist (Evers et al., 2005) that enabled our reviewers to discuss the nature and transparency of information sharing of the included studies in more detail. We noted that the quality of the included studies varied considerably. Differences were noted in providing enough information on study background, methods used and costs included. For example, higher quality studies (e.g. Gitlin, Hodgson, et al., 2010; Graff et al., 2008; Jutkowitz et al., 2012; Salkeld et al., 2000) provided adequate detail on justification for viewpoint chosen, included all relevant costs, used a sensitivity analysis and provided consideration for time horizon. The poorer quality studies (e.g. Bendixen et al., 2009; Mann et al., 1999; Sheffield et al., 2013) lacked such detail from their reporting.

Substantial diversity was apparent in the collection and reporting of costs and outcomes in the included studies. Some studies reported health related costs only, whereas others included costs related to social care, including informal caregiving. Incorporating intervention implementation costs, healthcare costs, other healthcare resource use, and participant (and caregiver, if applicable) opportunity costs is the most comprehensive approach to health economic evaluation and should be adopted when possible (Davis, Robertson, Comans, & Scuffham, 2011). However, this may not always be suitable, for example due to the research question, in which case justification should be provided for the appropriateness of the perspective chosen and costs included.

Quality of life (QoL) has been recognised as an amalgamation of person and environment specific factors that contribute to a person's well-being and capacity to participate in meaningful activities (Bulamu, Kaambwa, & Ratcliffe, 2015; WHOQOL Group, 1993). As such, preference-based Health Related Quality of Life (HRQOL) instruments are recommended for evaluation as they allow for a broader evaluation of intervention outcomes (Bulamu et al., 2015; Makai, Brouwer, Koopmanschap, Stolk, & Nieboer, 2014) . These instruments provide the utility estimates to allow calculation of Quality Adjusted Life Years (QALYs) for Cost Utility Analysis. (Bulamu et al., 2015). For example, three of the included studies (e.g. Flood et al., 2005; Hay et al., 2002; Sturkenboom et al., 2015) used generic HRQOL instruments such as the EQ5D (Barton et al., 2008) and the SF-36 (Hays, Sherbourne, & Mazel, 1993) to evaluate the intervention effects on the participants' well-being. However, eight studies conducted their economic analysis without utility instruments and did not provide justification of the alternative outcomes used. Outcomes of such studies are not easily comparable to other studies and should be interpreted with more caution. Thus, to provide more consistent and high-quality economic evaluations of occupational therapy interventions, current guidelines such as the CHEERS checklist (Husereau et al., 2013) or falls economic guidelines (Davis et al., 2011) should be followed that enable a more consistent form of analysing and reporting economic outcomes of occupational therapy interventions.

2.5 Strengths and limitations

This review has a number of strengths. First, it included a thorough search with assistance from a librarian who has extensive experience in literature searches. Second, studies in other languages were considered, however based on the screened abstracts these did not meet the set inclusion criteria. Third, the screening process was conducted by two independent reviewers. Lastly, the review captured interventions that included informal caregiving as occupational therapists often work with family members in supporting people with various health conditions. The inclusion of caregiver data of economic evaluations may yield more accurate outcomes of the intervention under study. This is important as excluding informal caregiving may alter the cost-effectiveness of assessments (Goodrich, Kaambwa, & Al-Janabi, 2012). It is therefore recommended that more studies should include caregiver data when evaluating the cost effectiveness of occupational therapy interventions.

One of the limitations of the review is the limited number of included studies which makes it difficult in making conclusive recommendations about the cost effectiveness of occupational therapy in care of people with cognitive and/or functional decline. This is particularly complex as the studies used various models and perspectives for analysis. Thus this review can only suggest trends for the economic benefit of occupational therapy. There is also a gap in evidence from countries outside of North America, Europe, Australia and New Zealand. This is important to consider as the countries from non-western cultures may have different approaches to healthcare.

2.6 Direction for future research

The economic impact of people who experience age related cognitive and/or functional decline cannot be ignored. It is therefore imperative that healthcare professionals can provide information to policy makers and other clinicians about the effectiveness and cost effectiveness of their services. It is recommended that future studies of occupational therapy interventions should include a cost evaluation of the service and its delivery. A societal viewpoint that incorporates healthcare use, informal care and intervention costs is the most comprehensive approach to evaluating intervention costs in health economics. However, the authors of this review recognise that this may not always be suitable and therefore recommend that when conducting a health economic evaluation, researchers provide a clear justification for the appropriateness of the perspective chosen for their evaluation.

The review discussed in this chapter has highlighted how the economic impact of occupational therapy is a scarcely studied topic. No study has evaluated the economic impact of occupational therapy for people with dementia living in Australia. Also, only a few studies have incorporated comprehensive and high quality economic aspects into their evaluation of intervention effectiveness. However, the findings of this review suggest that there are trends towards the economic benefit of systematic, or multicomponent, occupational therapy interventions for people experiencing cognitive and/or functional decline. Interventions that combined a number of consultation sessions and focused on improving the home environment, the ability of the person and the skills of their caregiver were most dominant in being effective and less costly. To determine the feasibility and acceptability of occupational therapy in care of people with cognitive and/or functional decline, further economic evaluations should be conducted of the service and its delivery. The planned economic evaluation for the COPE project should, therefore, be a valuable contribution to literature about occupational therapy for people with dementia in Australia and worldwide. The findings from this review will be re-visited again in chapter 8 once the costs and outcomes from the COPE program implementation have been established (in chapter 7).

This review has also identified that occupational therapy can deliver better functional and economic outcomes for people with dementia and older people with other age-related decline. However, and as discussed in chapter 1, this does not guarantee the uptake of interventions. Factors, such as heath literacy, can impact engagement in programs (such as those delivered by occupational therapists) that can improve well-being. The next chapter moves on to explore the public’s knowledge about treatments for people with dementia, and the subsequent chapter continues to explore the public’s knowledge about occupational therapy for older people. The purpose of the next two chapters is to assist with the ongoing implementation of the COPE program in Australia, specifically as it relates to the acceptability and uptake of the program.

CHAPTER 3: WHAT DOES THE AUSTRALIAN GENERAL PUBLIC KNOW ABOUT TREATMENTS FOR DEMENTIA? A POPULATION SURVEY

This chapter answers the first part of Aim 2 of the thesis: “to understand the Australian general public’s current level of knowledge about treatments for dementia and about occupational therapy for older people”. This chapter presents a population survey about the Australian general public’s knowledge about treatments for dementia and is adapted with minor changes for thesis formatting and consistency from the published article in *Gerontology and Geriatric Medicine* (Rahja, Laver, et al., 2018). The survey was completed to guide the COPE program implementation and to understand how the COPE program can be promoted to the Australian public.

As the main author for the publication, the candidate’s contribution was 85% of this chapter. Together with authors KL and MC the candidate constructed the study questions. The candidate was responsible for completing the ethics application for the study and liaising with a third party company to complete the survey. The candidate was also responsible for data collection, analysis, as well as the writing of results. Co-authors and supervisors TC and KL provided guidance for statistical methods used in data analysis and all authors were involved in editing and proof-reading the final manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

3.1 Introduction

The previous chapter identified occupational therapy approaches that may improve health and economic outcomes for people with dementia. Yet as per chapter 1.1.7, some (people) may not take action to seek programs that can improve their health outcomes. This chapter delves into this concept in more detail and incorporates aspects of the Health Belief Model (HBM) described in section 1.1.7.2.

The Australian Government has recognised that people with dementia, their families and caregivers need to be better supported, and there is a need to act to reduce the economic and societal impact of the condition (Brown et al., 2017). Yet, one of the biggest challenges in dementia care is timely and accurate diagnosis (World Health Organization, 2012). Many people with dementia never receive a diagnosis or delay seeking help (Phillips, Pond, & Goode, 2011). Estimates suggest that over 50% of dementia cases go undiagnosed (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Valcour, Masaki, Curb, & Blanchette, 2000). Potential barriers to receiving an early or timely diagnosis of dementia have been identified on consumer, primary care provider, health system, and service context level (Bradford et al., 2009). Examples of these barriers are financial and time constraints, attitudes, communication difficulties, and limited knowledge among health care providers, people with dementia and their caregivers (Bradford et al., 2009). Yet, there are interventions that can delay cognitive and/or functional decline, or assist with the management of symptoms (Brasure, Desai, Davila, & et al., 2018; Guideline Adaptation Committee, 2016; Livingston et al., 2017).

Knowledge about an illness corresponds to health behaviour (Hochbaum, 1958). In other words, how one manages their health condition is determined by a person's awareness and attitude about the condition and the strategies available to reduce its impact (Hochbaum, 1958). This would suggest that people with symptoms of dementia and their caregivers who are more knowledgeable about dementia are more likely to seek information about diagnosis and healthcare services. Poor knowledge about dementia (and related treatment) can, therefore, be associated with inactivity in pursuing additional information as people may not believe there are effective treatments (Bradford et al., 2009). The Global Action plan on Dementia (World Health Organization, 2017) encourages countries to implement campaigns to raise awareness about dementia, including the development of "evidence-based, user friendly information and training tools concerning dementia and available services to allow timely diagnosis and enhance the continued provision of long-term care" (World Health Organization, 2017, p. 25). Campaigns in Australia aimed at improving knowledge about dementia already exist. These include: Your Brain Matters (https://yourbrainmatters.org.au/); Dementia Awareness Month; Dementia Stigma Reduction (DESeRvE) Program by Dr Sarang Kim (http://science.anu.edu.au/news-events/news/award-anu-dementia-researcher), and the Community Radio Dementia Awareness Project that has developed audio messages about dementia for remote and/or Indigenous communities (https://www.cbaa.org.au/about-community-education-programs-new/community-radio-dementia-awareness-project). However, these campaigns focus on prevention or stigma, rather than treatments.

Chapter 1 identified how the Australian Government has committed over $200 million to dementia research (Commonwealth of Australia, 2014) and is currently undertaking a reform of dementia services including the re-design of support services for people with dementia (Commonwealth of Australia, 2016). In order to enhance accessibility and uptake of programs and services it is vital to understand the public's current level of awareness and attitudes towards dementia, including signs and symptoms, risk reduction, and treatment. Such understanding means that initiatives can be promoted and provided in a way that is compatible with consumer knowledge. The public should be made aware of how they can access these programs, how the programs can help them reach their care needs or goals, the estimated costs involved and the effects of accessing such programs.

A systematic review that included 36 international studies (Cahill, Pierce, Werner, Darley, & Bobersky, 2015) found that the majority of the population has only fair to moderate knowledge and understanding about dementia. For example, a study conducted in South Korea found that half of the participants (n=2189) had an incorrect understanding regarding the curability of some types of dementia and about 20% did not know that drug treatment can be useful for dementia symptom management (Seo, Lee, & Sung, 2015). A more recent systematic review (Cations, Radisic, Crotty, & Laver, 2018) explored the public's understanding about prevention and treatment for dementia. The review (Cations et al., 2018) found that while the belief that there are effective treatments for dementia has increased over time, overall there is still poor knowledge about the potential for treatments. The two Australian studies included within the review failed to report on knowledge about treatments available (Cations et al., 2018). Only a few studies in Australia have explored people's knowledge and understanding about dementia (Garvey et al., 2011; Low & Anstey, 2009; Smith, Ali, & Quach, 2014). These studies have focused on exploring the participants' understanding about cause, signs, symptoms and risk reduction, and indicate that there is a limited understanding in the Australian public regarding reducing the risk of dementia (Garvey et al., 2011; Low & Anstey, 2009; Smith et al., 2014). To our knowledge there are no Australian studies that have examined the current level of knowledge about treatments available for dementia. Such information could assist in forming recommendations for action about how to promote evidence-based services to reduce the societal impact of the condition in view of current beliefs and perceptions. The purpose of this survey was to identify what the Australian general public knows about treatments for dementia.

3.2 Methods

This survey was approved by the Flinders University Social and Behavioural Research Ethics committee (project 7626).

3.2.1 Participant recruitment

A cross-sectional online survey was administered through a consumer panel provider PureProfile (https://www.pureprofile.com/au/). The company specialises in online survey programming to distribute surveys to a nationally representative sample. For a fee, researchers can program surveys that are distributed to a panel (participants) of approximately 250,000 members of the general public who have volunteered and registered with the organisation to complete surveys for a small monetary reimbursement for their time. The registered participants are aged 18 and over, and live in Australia. As part of this service, PureProfile initially launches a pilot survey and provides the researcher with approximately 100 responses from the participants. This enables the research team to review and modify (if required) their survey. Following confirmation, the survey is formally launched to the panel. Once the agreed number of responses (n=1000) has been reached, PureProfile provides the researcher with a data file containing responses. Each survey also collects pre-defined demographic detail including gender, age group (18-24 years, 25-34 years, 35-44 years, 45-54 years, 55-64 years, and 65+ years), and state or territory of residence (including postcode).

3.2.2 Data collection

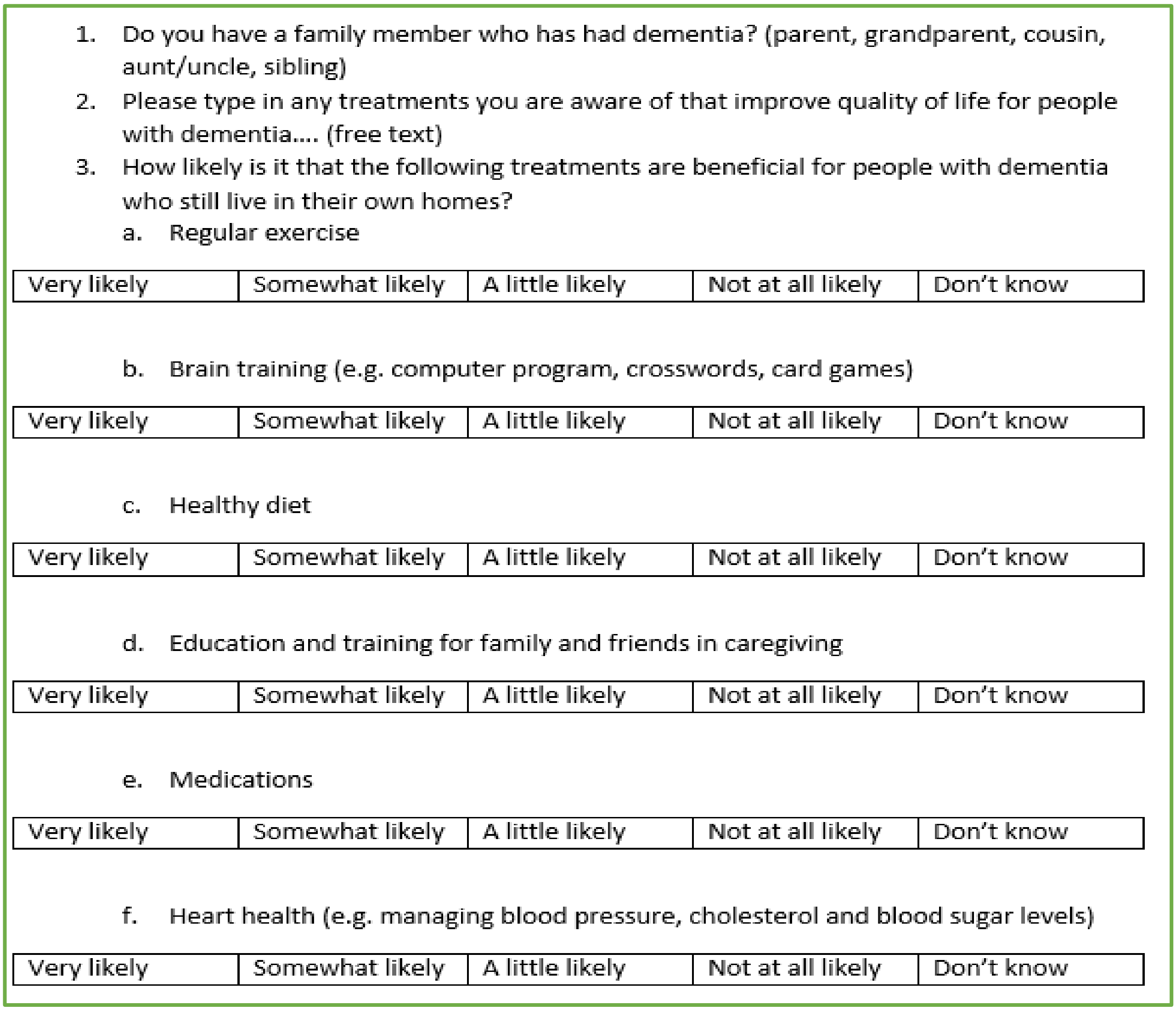
A pilot survey was distributed on 19th May 2017, formally launched on 23rd May 2017 and data collection was completed on 26th May 2017. Data was collected from the first 1000 participants who responded to the questions. Data collected included: gender, age group, place of residence (including post code), family connections to dementia, knowledge of any treatments for dementia (free text space), and awareness of the benefits of existing treatments for people with dementia living at home (five point Likert scale) (Likert, 1932). The scores for the Likert scale ranged from 1 = 'very likely', 2= 'somewhat likely', 3 = 'a little likely', 4 = 'not at all likely', and 5 = 'I don't know'. The questions posed in the survey were chosen based on recommendations for treatment and care for people with dementia as outlined by the Clinical Practice Guidelines in Australia (2016). For the purpose of the survey, some of the terms were simplified to cater for lower health literacy levels. Figure 3-1 depicts the survey questions.

3.2.2.1 Socioeconomic status

The Index of Relative Socio-economic Advantage and Disadvantage (IRSAD; Australian Bureau of Statistics, 2013) was used to measure socioeconomic status based on the area of residence of the participants. The IRSAD is part of the Socio-Economic Indexes for Areas (SEIFA) (Australian Bureau of Statistics, 2011) classification and includes measure of income, employment, education and living circumstances (Australian Bureau of Statistics, 2013). The participants were allocated to one of five SEIFA categories from the lowest quintile (areas having the most disadvantage) to the highest quintile (areas having the most advantage). The lowest quintile (quintile 1) comprises 20% of areas ranked by socioeconomic status as the most disadvantaged; the highest quintile (quintile 5) comprises 20% of areas ranked by socioeconomic status as the most advantaged. The IRSAD has been identified as an appropriate index for use in analysis when comparing the entire range of socioeconomic areas rather than focusing on disadvantaged areas only (Australian Bureau of Statistics, 2013).

3.2.3 Data analysis

Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corporation, 2013) was used for quantitative data analysis. Descriptive statistics were used to summarise sociodemographic data and participants' understanding of treatments that have been reported beneficial for people with dementia who still live in their own homes. Logistic regression was used to ascertain the effects of age, gender, socioeconomic status (SEIFA IRSAD score in quintiles) and having a relative with dementia on the likelihood that participants had better knowledge about available treatments for dementia. Odds ratios, confidence intervals, significance and Wald Chi-Square were reported. The scores for the Likert scale were reverse coded for ease of interpretation and ‘I don’t know’ responses were treated as missing data. QSR NVivo software version 10 (QSR International Pty Ltd, 2018) was used to aid data analysis from free text responses and to create an audit trail. This included memo writing to record ideas and justify codes used during data analysis.



1. Do you have a family member who has had dementia? (parent, grandparent, cousin, aunt/uncle, sibling)
2. Please type in any treatments you are aware of that improve quality of life for people with dementia.... (free text)
3. How likely is it that the following treatments are beneficial for people with dementia who still live in their own homes?
   a. Regular exercise

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

   b. Brain training (e.g. computer program, crosswords, card games)

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

   c. Healthy diet

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

   d. Education and training for family and friends in caregiving

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

   e. Medications

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

   f. Heart health (e.g. managing blood pressure, cholesterol and blood sugar levels)

Very likely	Somewhat likely	A little likely	Not at all likely	Don’t know

Figure 3-1 Survey questions

3.3 Results

The number of responses received was 1001. Table 3-1 summarises the demographic characteristics of the participants. The Table also presents the distribution of gender ratios and age groups in the Australian population for point of comparison. Data for this was derived from the

Australian Bureau of Statistics estimates of resident populations as at June 2016 (Australian Bureau of Statistics, 2017). About half of the study participants were female, and this percentage closely matches the general population in Australia (50.4%). The age groups represented within our sample were approximately even. These percentages vary from the population statistics, as we did not collect data from people aged under 18 years. All Australian states and territories were represented. Again, closely matching the distribution of the general population (Table 3-1). Less than a third of participants identified that they had a family member who has or has had dementia.

Table 3-1 Participant characteristics

		Study (n= 1001) n (% of n)	**Australia (N = 24,210,809)† N (% of N)**
Gender	Female	511 (51.0%)	12,198,963 (50.4%)
Age	18-24 years	131 (13.1%)	2,305,576 (9.5%)
	25-34 years	186 (18.6%)	3,614,747 (14.9%)
	35-44 years	184 (18.4%)	3,236,348 (13.4%)
	45-54 years	175 (17.5%)	3,157,138 (13.0%)
	55-64 years	150 (15.0%)	2,783,662 (11.5%)
	65+ years	175 (17.5%)	3,673,511 (15.2%)
State / Territory§	NSW	316 (31.6%)	7,739,274 (32.0%)
	VIC	253 (25.3%)	6,179,249 (25.6%)
	QLD	203 (20.3%)	4,848,877 (20.0%)
	SA	74 (7.4%)	1,713,054 (7.1%)
	WA	105 (10.5%)	2,558,951 (10.6%)
	ACT	17 (1.7%)	403,468 (1.7%)
	TAS	23 (2.3%)	517,588 (2.1%)
	NT	10 (1.0%)	245740 (1.0%)
SEIFA quintile ‡	Quintile 1	137 (13.7%)	
	Quintile 2	156 (15.6%)	
	Quintile 3	237 (23.7%)	
	Quintile 4	211 (21.1%)	
	Quintile 5	257 (25.7%)	
A family member who has had dementia?	Yes	294 (29.4%)	
Who is the closest relative to you who has dementia?	Parent	104 (35.4%)	
	Grandparent	142 (48.3%)	
	Cousin	6 (2.0%)	
	Aunt/Uncle	32 (10.9%)	
	Sibling	10 (3.4%)	

† A total population of 24,210,809 includes other Territories comprising Jervis Bay Territory, Christmas Island, the Cocos (Keeling) Islands and Norfolk Island (ABS, 2017). ‡ Based on SEIFA index of Socioeconomic Advantage and Disadvantage 2011. Three participants came from areas that have low populations or high levels of non-response in census and thus received no SEIFA score.

3.3.2 Knowledge about treatments for dementia

When asked: “Please type in any treatments you are aware of that improve quality of life for people with dementia”, more than half (n= 636, 63.5%) of the participants initially responded that they did not know of any treatments that improved outcomes. Of treatments that were recorded in this question ‘brain training’ and ‘keeping the mind busy’ were most commonly considered to improve outcomes (n=166, 17%) and many considered games effective. Some participants (n=74, 7%) reported that exercise and being fit improved outcomes for people living with dementia. Other responses for this question included music therapy (n=51, 5%), pharmacological therapies (n=45, 4%) and social support and participation (n=45, 4%).

Table 3-2 depicts participant attitudes towards treatments that are frequently evaluated in research trials for people with dementia. Brain training was considered to be ‘very likely’ to be beneficial by approximately half of the participants, followed by education and training for family members and caregivers and healthy diet. Many considered these interventions to be ‘somewhat likely’ to be beneficial.

Ordinal logistic regression analyses found that out of the independent factors (age, gender, socioeconomic status and having a relative with dementia), age and gender had a statistically significant effect on the prediction if a treatment was considered to be effective for people with dementia. The results from the logistic regression are presented in Table 3-3. Males were significantly less likely to agree that the treatments were likely to be beneficial aside from medication (p = 0.052). Older people were more likely to agree that most of the treatments were likely to be beneficial. Again, there was no statistically significant effect of age on the odds of considering medication to be an effective treatment (p = 0.885).

Table 3-2 Perceptions about evidence-based treatment effectiveness

	Very likely	**Somewhat likely**	**A little likely**	**Not at all likely**
	n (% of n)	n (% of n)	n (% of n)	n (% of n)
Brain training (e.g. computer program, crosswords, card games)	468 (49.4%)	330 (34.8%)	126 (13.3%)	23 (2.4%)
Education and training for family and friends in caregiving	439 (46.2%)	359 (37.7%)	129 (13.6%)	24 (2.5%)
Healthy diet	434 (43.4%)	336 (35.5%)	144 (15.2%)	32 (3.4%)
Regular exercise	372 (40.4%)	347 (37.7%)	167 (18.1%)	35 (3.8%)
Heart health (e.g. managing blood pressure, cholesterol and blood sugar levels)	321 (34.7%)	361 (39.1%)	195 (21.1%)	47 (5.1%)
Medications	295 (31.6%)	405 (43.4%)	190 (20.3%)	44 (4.7%)

Note: ‘I don’t know’ responses were treated as missing data, hence numbers (n) do not total to 1001.

Table 3-3 Logistic regression predicting likelihood of agreeing that treatments are beneficial for people with dementia

		B	SE	Wald	DF	p	Odds ratio	95% C.I. for Odds Ratio	
								Lower	**Upper**
Regular exercise	Male	-0.39	0.12	9.91	1	**0.002***	**0.68**	0.53	0.86
	Yes - Family member with dementia	-0.02	0.13	0.03	1	0.865	0.98	0.75	1.27
	Age	0.17	0.04	21.06	1	**0.000***	**1.19**	1.10	1.28
	SEIFA Quintile	0.08	0.05	2.85	1	0.091	1.08	0.99	1.18
Brain training	Male	-0.41	0.13	10.75	1	**0.001***	**0.66**	0.52	0.85
	Yes - Family member with dementia	-0.25	0.14	3.37	1	0.066	0.78	0.60	1.02
	Age	0.13	0.04	11.23	1	**0.001***	**1.14**	1.05	1.22
	SEIFA Quintile	0.01	0.05	0.02	1	0.886	1.01	0.92	1.10
Healthy diet	Male	-0.52	0.12	17.33	1	**0.000***	**0.60**	0.47	0.76
	Yes - Family member with dementia	-0.11	0.13	0.71	1	0.401	0.89	0.69	1.16
	Age	0.14	0.04	13.44	1	**0.000***	**1.15**	1.07	1.23
	SEIFA Quintile	0.04	0.05	0.76	1	0.383	1.04	0.95	1.14
Education	Male	-0.79	0.13	39.23	1	**0.000***	**0.45**	0.36	0.58
	Yes - Family member with dementia	0.16	0.14	1.30	1	0.254	1.17	0.89	1.52
	Age	0.08	0.04	4.23	1	**0.040***	**1.08**	1.00	1.16
	SEIFA Quintile	-0.02	0.05	0.28	1	0.600	0.98	0.89	1.07
Medication	Male	-0.24	0.12	3.79	1	0.052	0.79	0.62	1.00
	Yes - Family member with dementia	-0.08	0.13	0.36	1	0.551	0.92	0.71	1.20
	Age	0.01	0.04	0.02	1	0.885	1.01	0.94	1.08
	SEIFA Quintile	0.04	0.04	0.66	1	0.416	1.04	0.95	1.13
Heart health	Male	-0.51	0.12	16.89	1	**0.000***	**0.60**	0.47	0.77
	Yes - Family member with dementia	0.04	0.13	0.08	1	0.783	1.04	0.80	1.35
	Age	0.11	0.04	8.68	1	**0.003***	**1.12**	1.04	1.20
	SEIFA Quintile	-0.02	0.04	0.15	1	0.702	0.98	0.90	1.07

*p<0.05

3.4 Discussion

The findings of this survey have provided valuable insight into the Australian public's knowledge regarding treatments available for people living with dementia. Overall there is limited awareness of treatments that can improve outcomes for this population group. Of the treatments that are frequently evaluated in research trials, less than half of the participants considered these very likely to be effective. For example, exercise was initially only nominated by 7% of respondents as an effective method to improve outcomes for people with dementia. There is scope to educate the Australian public about the treatments available and their effectiveness to improve the trajectory of people living with dementia.

This survey builds on earlier studies conducted in Australia about dementia related topics (Garvey et al., 2011; Low & Anstey, 2009; Smith et al., 2014). While the earlier studies examined the knowledge about cause, signs, symptoms, and risk reduction of dementia, the focus of this study was on attitudes about treatments for dementia. The findings presented in this survey are consistent with findings from other Australian studies that report gender (being female) (Low & Anstey, 2009; Smith et al., 2014) and older age (Garvey et al., 2011) are associated with better awareness about dementia and related topics. Dementia is still not recognised as a health priority by many young Australians (Smith et al., 2014). The current survey also found that younger people were less likely to identify treatments as effective compared with older Australians, suggesting that they may have a limited understanding of the implications of a diagnosis.

While knowledge describes a person's awareness or understanding of a fact or situation, attitudes describe the person and their approach to a situation. Attitudes influence thoughts and actions, and are associated with beliefs and behaviours towards an issue or topic. Attitude is measured using direct or indirect methods (McLeod, 2009). A direct measure involves participants rating an issue or topic on a standard set (such as Likert scale) allowing for quantification and a more objective measure of an attitude than an indirect method, which provides more qualitative information about how a person interprets information given to them (McLeod, 2009). While these sets have been designed to present a valid measure of a particular attitude, their results can be biased due to participants adjusting their replies to be more socially desirable (McLeod, 2009). Culture, demographic variables, perceived stigma, exposure to media or advertising, individual differences and personal experiences have been reported as causes for attitudes and respective behaviour (Fishbein & Yzer, 2003). For example, the relationship between attitude and behaviour has been studied by many (Glasman & Albarracín, 2006). It appears that attitudes can predict behaviour, such as seeking diagnosis or treatment if a person has direct experience with dementia. This association between an attitude and behaviour is also considered stronger if formed on the basis of behaviour-relevant information, such as knowledge about treatments (Glasman & Albarracín, 2006).

Contrary to surveys conducted in other countries that have reported the public's knowledge about the benefits of treatments for dementia (Roberts, McLaughlin, & Connell, 2014; Wortmann, Andrieu, Mackell, & Knox, 2010), we did not find a significant association between socioeconomic status or having a relative with dementia and knowledge about effective treatments for dementia. This was unexpected as studies in other countries have found socioeconomic status to be associated with better knowledge about cause, signs and symptoms, risk reduction, and treatment of dementia (Cahill et al., 2015). The lower socioeconomic status may refer to people living in poverty, which may not be represented in our study sample.

Information regarding the public's awareness may assist in developing research and health education interventions; raising the public's awareness regarding effective treatments available is crucial for improving the quality of care for people with dementia (Rimmer, Wojciechowska, Stave, Sganga, & O'Connell, 2005). Improved knowledge about treatments available for dementia can lead to an increased ability to seek appropriate support (Low & Anstey, 2009). It can also reduce stigma (Mukadam & Livingston, 2012), caregiver burden (Jorm, 2012) and the societal impact of dementia (World Health Organization, 2012). However, similar to other surveys (Jones, Mackell, Berthet, & Knox, 2010), this study found that the public may not know or believe that there are effective treatments for dementia. This limited awareness and attitude needs to be considered when developing research and health education programs. While it may be unclear what the enablers and barriers to improving dementia awareness are, the public needs to be made aware of the benefits (and possible barriers) of available treatments (Hochbaum et al., 1952). This includes educating the public about the positive effects that treatments can have on a person's daily functioning, mobility and independence (Hochbaum et al., 1952). There may also be beliefs about effective treatments being costly, time consuming and inconvenient. Any misconceptions should be addressed through health education and research as there are a number of interventions that are cost effective and can improve outcomes for people with dementia (Jones et al., 2012; Knapp et al., 2013; Rahja, Comans, et al., 2018b).

3.5 Strengths and limitations

This is the first survey to report on the Australian public's awareness and attitudes about treatments available for people with dementia. The survey used a nationally representative sample which included all states and territories from within Australia. The findings from this study suggest that there is a need to improve the awareness of available treatments for people living with dementia. A limitation of this survey is that it may underrepresent people from the lowest socioeconomic areas. It may also be that people participating in online surveys are likely to be higher users of technology and therefore they would be more exposed to information about dementia and treatments. The survey also does not evaluate different cultural groups and it is unclear to what extent Indigenous Australians were represented in the sample. This is particularly important as the prevalence of dementia in Indigenous populations in Australia is up to five times higher than that of the non-Indigenous population (Smith et al., 2008). Additionally, beliefs about dementia in the Indigenous people can be different to people from non-indigenous background. The term dementia is not used in some cultures and the concept of well-being is embedded in a diversity of beliefs, traditions, law, language and the land (Smith et al., 2007).

3.6 Implications

An understanding of the public's knowledge regarding treatments for dementia is important; such knowledge can help guide future health education and service development campaigns that are aimed at reducing the societal impact of the condition. The survey presented in this chapter found that many Australians are still unfamiliar with treatments available for people with dementia and still have a limited understanding of the benefits of treatments that have been proven effective in clinical trials. This chapter has also discussed factors, including age and gender, that may contribute to this lack of knowledge. These factors were identified as 'predisposing' factors to health related behaviour in chapter 1.1.7, and were discussed as a way of exploring or understanding health related behaviours.

The discussion in this chapter has identified and made recommendations for the need to better educate the public about effective treatments available. These recommendations can help guide the promotion of the COPE program in order to assist with program implementation and uptake. The *how* to educate the public about treatments available is discussed in further in chapter 8 of this thesis.

Lastly, the findings described in this chapter present a challenge for the COPE program implementation. COPE is delivered by occupational therapists, yet the responses in this chapter do not make references to occupational therapy. Thus, in order to assist with promotion of the program, it may also be worthwhile to investigate the public's understanding of occupational therapy. This will inform effective methods of promotion. The next chapter will delve into this challenge in more detail.

CHAPTER 4: WHAT DOES THE AUSTRALIAN PUBLIC KNOW ABOUT OCCUPATIONAL THERAPY FOR OLDER PEOPLE? A POPULATION SURVEY

This chapter answers the second part of Aim 2 of this thesis: “to understand the Australian general public’s current level of knowledge about treatments for dementia and about occupational therapy for older people”. This chapter discusses the findings from a study: *“What does the Australian public know about occupational therapy for older people? A population survey”*. The study was published in the *Australian Occupational Therapy Journal* (Rahja & Laver, 2019), and is adapted with minor changes for thesis formatting and consistency from the published article. The study builds on the survey presented in the previous chapter and, as previously, was completed to help guide the COPE program implementation and to understand how the COPE program can be promoted to the Australian public based on their current level of knowledge.

As the main author for the publication, the candidate’s contribution was 90% of this chapter. Together with the co-author (KL) the candidate constructed the study question. As in the previous chapter, the candidate was responsible for completing the ethics application for the study and liaising with a third-party company to complete the survey. The candidate was also responsible for data collection, analysis, as well as the writing of results. KL provided guidance and was involved in editing and proof-reading the final manuscript. The co-author (KL) has provided permission to use this work in the thesis as per the submission of thesis form.

4.1 Introduction

The previous chapter found that Australians have limited understanding of the benefits of treatments for people with dementia. These findings raised a concern that the Australian public may not seek occupational therapy services as these services may not be recognised as beneficial. This could also mean that people with dementia and/or their caregivers may not seek to engage in programs such as COPE as they may not be aware of the scope of services, or programs, that are delivered by occupational therapists. This chapter delves in to this concern further.

This thesis has already described how occupational therapists work with people of all ages and abilities, and occupational therapy is concerned with improving participation in everyday activities taking into consideration physical and mental capacities (Occupational Therapy Australia, 2019). The purpose is to find ways that can help maintain or improve a person’s mental and functional independence, quality of life and social participation (Steultjens et al., 2005). In 2016, 14,126 registered occupational therapists worked as clinicians in Australia, with 16.8% (n=2,673) therapists reporting aged care as their principal scope of practice in their principal role (third most popular area of practice after rehabilitation (19.4%, n=3,083) and paediatrics (18.7%; n =2,971)) (National Health Workforce Dataset, 2018). More therapists work in the public (44.1%; n=7,020) than the private sector (43.0%; n=6,849), and the last years have seen an increase in services provided from private practices (National Health Workforce Dataset, 2018).

The introductory chapter of this thesis gave background to the reform of the Australian Aged care sector and introduction of the Consumer Directed Care model (Department of Health Australia, 2012). The chapter explained that while there are various types of Consumer Directed Care programs across the world, the concept behind each is to give consumers and/or their representatives more choice and control over the delivery of their care services than in traditional programs where decisions about service delivery are made by professionals (e.g. Da Roit & Le Bihan, 2010). In Australia, consumers (care recipients and their caregivers) receive individualised budgets (allocated based on independently assessed care needs) and are expected to inform their care provider of their service preferences based on their self-identified care needs (Department of Health Australia, 2012).

An emerging body of research about Consumer Directed Care in Australia suggests that older consumers value the choice of care and service provider, flexibility in the services provided and control over managing their own budgets (Healthdirect Australia, 2018; McCaffrey et al., 2015). Yet, there is still unfamiliarity among consumers around what types of supports and services one can access through these packages (Gill, Bradley, Cameron, & Ratcliffe, 2018). Many older people have reported that finding information regarding available services can be time-consuming and difficult; they would like more information about available services and support with identifying what services to choose (Gill et al., 2018). A survey completed by a research consultancy commissioned to measure older consumers' satisfaction and experiences with their Home Care Packages (in Australia) found that the most common services received were domestic support (such as cleaning) and transport, with only 10% receiving physiotherapy or occupational therapy services; the least frequently accessed services among those who were receiving them (Healthdirect Australia, 2018). It appears that the potential to improve health outcomes at older age through allied health professions, such as occupational therapy, remains ill-understood and largely unseen (Philip, 2015). For example, occupational therapists have reported that there is poor community awareness regarding the profession (Van't Leven et al., 2012) and therapists often find it difficult to explain their profession to others (Polatajko, Creek, Davis, Cameron, & Sinclair, 2018). There is a lack of research about Australian occupational therapists' perceptions about how their profession is viewed by the community or other health professionals.

A few international studies have explored awareness about occupational therapy and reported that other health professionals have limited understanding of the scope of assessments and interventions that occupational therapists provide (Bonsall, Mosby, Walz, & Wintermute, 2016; Patel & Shriber, 2001; Tariah, Abulfeilat, & Khawaldeh, 2012). In Australia, two studies have explored how occupational therapists are perceived (Aguilar, Stupans, Scutter, & King, 2014; Smith & Mackenzie, 2011). Aguilar et al. (2014) explored how Australian occupational therapists and physiotherapists understood each other's professional values, and Smith & Mackenzie (2011) reported findings from interviews conducted with seven nurses in an in-patient mental health setting. Limited awareness about occupational therapy has also been reported in the general population in Jordan (Darawsheh, 2018). To our knowledge, no studies have investigated the public's level of knowledge of occupational therapy in Australia and specifically the public's knowledge about the profession's role in supporting older Australians remains unknown. Such knowledge means that the profession and its role in supporting older people can be promoted in a way that is compatible with the current level of understanding. The aim of this study was to ascertain what the general public in Australia knows about occupational therapy services for older people.

4.2 Methods

This study was approved by Flinders University Social and Behavioural Research Ethics Committee (ID: 7993).

4.2.1 Participant recruitment

A cross-sectional cohort study was administered in form of an online survey through a consumer panel provider PureProfile (https://www.pureprofile.com/au/). The company specialises in online survey programming and distributes weekly surveys, called 'omnibus', to a nationally representative sample. Researchers are able to have questions included in the omnibus for a fee. Once the omnibus has been completed (with the required number of respondents) the company provides the researcher with a data file containing responses from approximately 1000 respondents. Each omnibus collects pre-defined demographic details including gender, age group (18-24 years, 25-34 years, 35-44 years, 45-54 years, 55-64 years, and 65+ years), and state or territory of residence (including postcode). The panel consists of approximately 250,000 members of the general public (participants) aged 18 and over living in Australia who have volunteered and registered with the organisation, to complete surveys for a small monetary compensation for their time.

4.2.2 Data collection

The survey was launched on 10th May, 2018 and data collection was completed on 14th May, 2018. Data was returned from the first 1000 participants who responded to the question. All participants were asked to write a free text response to one question: "What is your understanding of occupational therapy, and do you believe it has a role in supporting older people (people aged 65 and over)?".

4.2.3 Data analysis

Data were analysed using both quantitative and qualitative methods. Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corporation, 2013) was used to aid quantitative data analysis. Descriptive statistics were used to summarise sociodemographic data. Chi-square test for independence was used to explore associations between gender, age (group), place of residence and knowledge about occupational therapy for older people.

QSR NVivo software version 12 (QSR International Pty Ltd, 2018) was used to aid analysis for the free-text responses and to generate an audit trail. Thematic analysis of responses was used as described by Braun and Clarke (2006). The candidate read all of the responses first to gain a general understanding of the type of responses received. Then the candidate re-read the responses making initial codes by identifying patterns to the posed question regarding participants' understanding about occupational therapy and its role in supporting older people. For example, noting responses that clearly stated they did not have knowledge about the profession, or had not responded to the question. The candidate continued to re-read the responses and developed codes to capture key concepts, such as responses that the profession was 'helping to bring people back to work' or 'exercise training'. These codes were then adjusted into themes by revisiting the responses to ensure that they shaped a clear pattern that fitted the suggested theme, for example, 'keeping older people active'. Lastly, with consultation from the second author (KL) the candidate continued to analyse each response and to identify the themes that are presented in this study as the level of understanding of occupational therapy.

4.3 Results

A total of 1004 responses were received for this survey. The demographic characteristics of the participants are summarised in Table 4-1. The distribution of gender ratios and age groups in the Australian population is also presented in the table for point of comparison. This data was retrieved from the Australian Bureau of Statistics of Resident Populations as at December, 2017 (Australian Bureau of Statistics, 2018a). Approximately half of the participants were female, closely matching the gender ratios in Australia (50.4%; Table 4-1). About one fifth were aged 65 or over (age ratios differ from the population statistics as we did not collect data from people aged under 18 years). All Australian states and territories were represented to the similar proportion as the population statics (Table 4-1). Thus, the study sample can be described as representative of the general population in Australia.

Table 4-1 Participant characteristics

		Study (n = 1004) n (% of n)	Australia (N = 24,597,528)† N (% of N)
Gender	Female	511 (50.9%)	12,395,691 (50.4%)
Age group	18-24 years	115 (11.5%)	2,334,895 (9.5%)
	25-34 years	184 (18.3%)	3,681,765 (15.0%)
	35-44 years	180 (17.9%)	3,264,387 (13.3%)
	45-54 years	169 (16.8%)	3,183,493 (12.9%)
	55-64 years	154 (15.3%)	2,838,185 (11.5%)
	65+ years	202 (20.1%)	3,791,528 (15.4%)
State / Territory	NSW	323 (32.2%)	7,915,069 (32.2%)
	VIC	254 (25.3%)	6,385,849 (26.0%)
	QLD	200 (19.9%)	4,965,033 (20.2%)
	WA	107 (10.7%)	2,584,768 (10.5%)
	SA	70 (7.0%)	1,728,053 (7.0%)
	TAS	21 (2.1%)	524,677 (2.1%)
	ACT	19 (1.9%)	415,916 (1.7%)
	NT	10 (1.0%)	246,726 (1.0%)

† A total population of 24,597,528 includes also other Territories comprising Jervis Bay Territory, Christmas Island, the Cocos (Keeling) Islands and Norfolk Island (ABS, 2018). Australian population age was taken at June, 2017

4.3.1 Understanding of occupational therapy

Table 4-2 provides a summary of the six themes that were identified from the data analysis. Examples of responses included in each theme have been included in Table 4-3. Over half of the participants had some, but limited knowledge about the profession with responses including general, physical or workplace health related descriptions. General responses in this category included brief detail about rehabilitation, wellbeing, getting better, recovery, function, or quality of life.

> *Promote health and wellbeing, rehabilitation, yes I believe it has a role in supporting older people, I think it would be very effective. (Participant: 25)*

Table 4-2 Summary of results

Theme	n (% of N)
No knowledge or has not responded to the question	332 (33.1%)
Some, but limited knowledge about occupational therapy with general health focus	275 (27.4%)
Some, but limited knowledge about occupational therapy with physical focus	140 (13.9%)
Good or advanced knowledge about occupational therapy	109 (10.9%)
Some, but limited knowledge about occupational therapy with workplace focus	99 (9.9%)
Has provided a description with exact word matches with an internet search	49 (4.9%)
Total	1004 (100.0%)

Table 4-3 Example responses to questions (participant ID)

Example responses to questions (participant ID)	n (% of N)
No knowledge or has not responded to the question	332 (33.1%)
- I know nothing about occupational therapy (383)	
- I have absolutely no idea what occupational therapy is (454)	
- Trying to keep them safe (235)	
Some, but limited knowledge about occupational therapy with general health focus	275 (27.4%)
- Aids to help your health and wellbeing (22)	
- Concerned with living facilities at the family home (527)	
- Doing stuff to help overcome problems (931)	
Some, but limited knowledge about occupational therapy with physical focus	140 (13.9%)
- I understand occupational therapy is beneficial for older people to assist them to stay active (238)	
- Exercise to improve mobility (394)	
- Do they help people like a physiotherapist (139)	
Good or advanced knowledge about occupational therapy	109 (10.9%)
- Assisting people of all ages and abilities to do the things they need and want to in all aspects of life, such as taking care of oneself and others, working, volunteering, and participating in hobbies, interests and social activities. Also help people to manage and live with long-term (chronic) health conditions, like arthritis, diabetes, cancer, etc. Most DEFINITELY as assist older people to remain active and mobile to take care of themselves and live in their own home longer. (251)	
- It helps people with everyday issues, like how to manage cutlery when they have trouble with their hands and fingers. Also teachers people to use limbs if they had an injury with arms and legs. It can be anything that people have had a loss or injury that needs help to use again. It is extremely important for older people to get occupational therapy, as when we age we could have trouble with doing things we take for granted. Older people can use as much as help as possible, when things stop working. (735)	
- They help older people to be able to function at home. They provide equipment older people might need to help them do day to day tasks.(95)	
Some but limited knowledge about occupational therapy with workplace focus	99 (9.9%)
- Basically therapy, physical or otherwise, aimed at getting a person fit to work (369)	
- Helping people know what work they are best able to do (50)	
- It helps people who have work related injury's (561)	
Has provided a description with exact word matches with an internet search	49 (4.9%)
- It's the use of particular activities as an aid to recuperation from physical or mental illness. (641)	
- Occupational therapy (OT) is the use of assessment and intervention to develop, recover, or maintain the meaningful activities, or occupations, of individuals, groups, or communities. It is an allied health profession performed by occupational therapists. (343)	
- Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.(328)	
Total	**1004 (100.0%)**

Many considered occupational therapy to be "…a type of physical therapy for causes brought upon by working environments" (Participant: 808) or is "…to do with physical therapy for workplace injuries and is very relevant to older people too" (Participant: 108). Physical and movement related activities were frequently mentioned with references to 'keeping active'.

> *I think it is a form of physical assistance and exercise training. It would be helpful to older people to keep them physically fitter and in better condition as their bodies age. (Participant: 576)*

Other responses identified occupational therapy to be workplace related treatment.

> *Occupational therapy is the treatment of problems sustained in the working environment. This has a very important role with regards to the older people in the workplace. (Participant: 425)*

Approximately one in every 10 participants provided a description that captured detail regarding client-centeredness and/or promotion of independence or participation in everyday/meaningful activities through modifying activities or environments; a description that includes some of the core principles of the profession as described by the World Federation of Occupational Therapists (2012).

> *My understanding of occupational therapy is when therapists help older people aged 65 & over perform daily tasks that may be a struggle. They may show them a simpler or easier way to perform the task. It may even be that an injury has stopped them from performing such a simple task that the therapists will be able to help them make a full recovery to be able to do it again. (Participant: 917)*

Figures 4-1 and 4-2 provide a visual representation of responses provided by age group and place of residence, respectively. A chi-square test of independence found a significant association between age groups and level of knowledge about occupational therapy ($\chi 2(25) = 60.365, p < 0.001$). Of the 202 participants aged 65 or older, a quarter (25.2%) had no knowledge or did not respond to the question. Good or advanced level description of the profession was provided by 17 (8.4%) of the (202) older participants. Of the youngest age group (aged 18-24 years, n= 115), almost half (n= 52, 45.2%) reported no knowledge or did not respond to question, and 40.9% (n=47) had some, good or advanced knowledge about occupational therapy and its role in supporting older people.

A chi-square test for independence found a significant association between gender and knowledge about occupational therapy (χ2(1) = 15.695, p <0.001). Females had a better understanding of the profession, responding to the question with good knowledge (14.7%, n=511, p <0.001) compared to males from whom 6.9% responded to the question with good knowledge. Of the male respondents (n=493), 43.2% reported they did not have knowledge about the profession (p <0.001). A chi-square test of independence found no significant association between place of residence (state or territory) and level of knowledge about occupational therapy (χ2(35) = 41.161, p = 0.219).

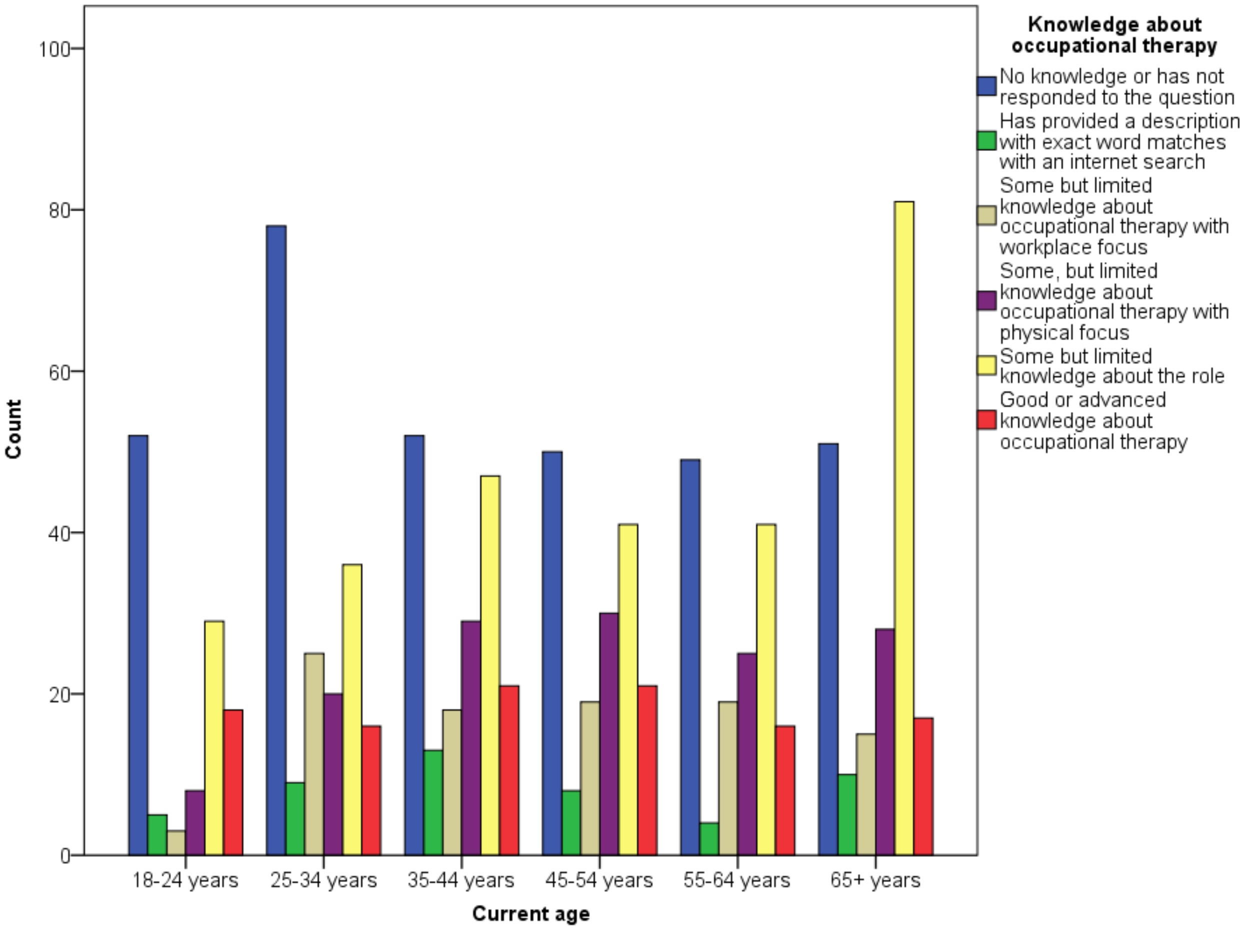


Figure 4-1 Knowledge about occupational therapy by age

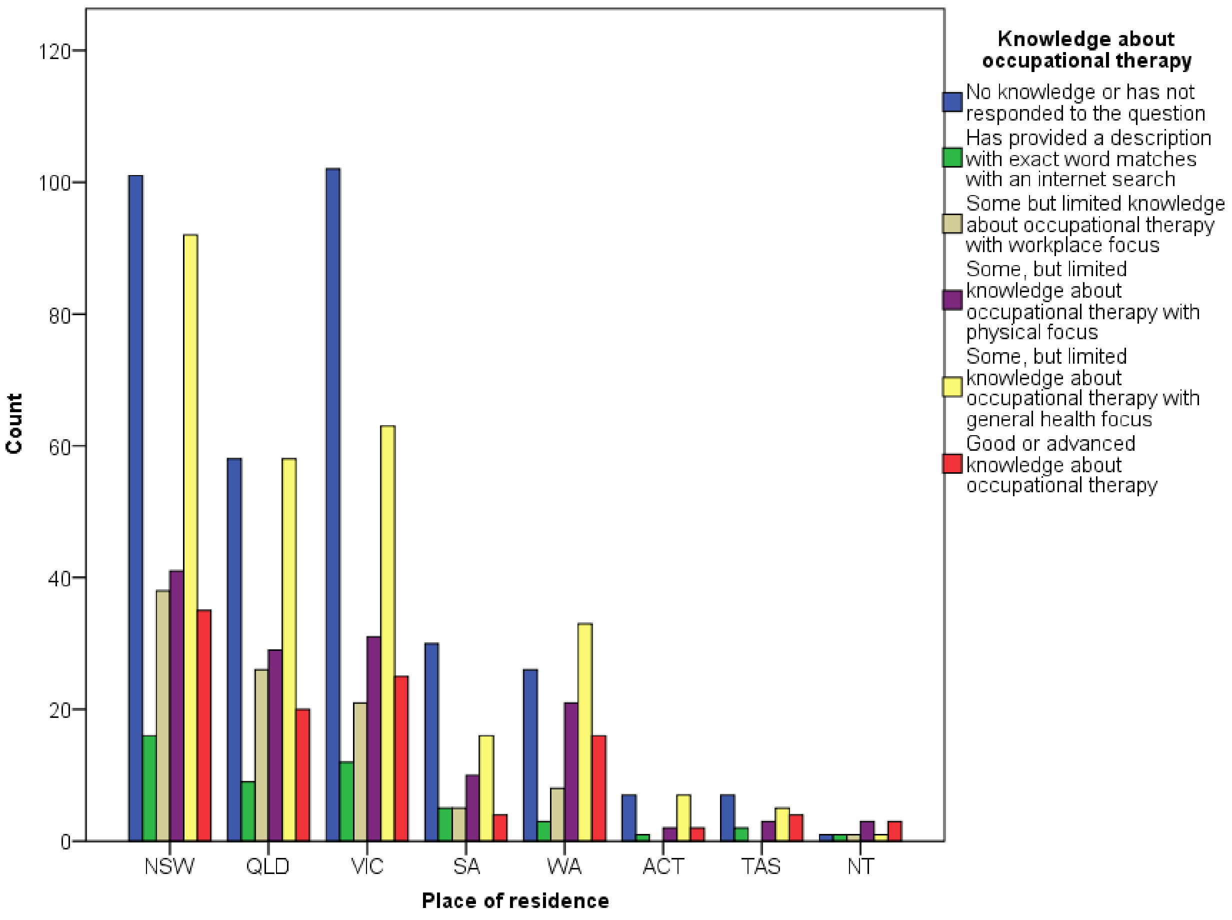


Figure 4-2 Knowledge about occupational therapy by place of residence

4.4 Discussion

This study provides valuable insight into the Australian general public's knowledge about occupational therapy. Little is still known amongst the general public about the core principles of the profession and its role in supporting older people. Many believe the profession has a general health and rehabilitation focus, provides physical or movement related care, or is concerned with workplace related matters. There is scope to educate the Australian public about the profession and its role in promoting health and wellbeing through meaningful engagement in activities related to the person's abilities and life situation.

The findings from this study echo the limited understanding and misconceptions that have been reported in other studies examining knowledge about occupational therapy (Bonsall et al., 2016; Darawsheh, 2018; Smith & Mackenzie, 2011). For example, in Australia, Smith and Mackenzie (2011) reported that the role of occupational therapists is not fully understood by mental health nurses. This study also found that while people may not know what occupational therapy is or what therapists do, they seem to accept that 'anything can help older people'. In Jordan, many believe the profession is solely concerned with people with disabilities or is simply focused on upper limb treatment or physiotherapy (Darawsheh, 2018). A similar misconception, that the profession was a type of physical therapy was evident in this study.

In its broader form, health literacy has been recognised as an amalgamation of person specific factors such as knowledge, motivation and ability to apply health related information to make well informed decisions regarding health and health related care (Australian Commission on Safety and Quality in Health Care, 2014). Low levels of health literacy mean that a person “may not be able to effectively exercise their choice or voice when making healthcare decisions” (ACSQHC, 2014, p. 8). As such, level of health literacy may contribute to the person’s ability to make informed decisions about which healthcare services to choose. For example, gender inequalities have been reported in health and health literacy (Department of Health Australia, 2010). It has also been identified that males’ health related behaviour may be driven by different needs, wants and goals than females’ (Peerson & Saunders, 2009). This study found that the females appeared to be more knowledgeable about occupational therapy, providing significantly more advanced level descriptions of the profession than males. While the reasons for this may vary, it is worthwhile noting that females are typically the primary providers of informal care for family members (who may have also had a reason to use the services of an occupational therapist). Females are also more likely to be an occupational therapists; with 90.8% of therapists in Australia being female (National Health Workforce Dataset, 2018). However, our findings, would suggest that, if suitable, females may be more likely to seek occupational therapy services to assist with their healthcare needs and goals than males, as they tend to have a better understanding of the benefits of the profession. Similar gaps in health related knowledge between gender have been reported in other studies in Australia (Low & Anstey, 2009; Smith et al., 2014), suggesting people may not seek diagnosis or treatment as they do not know that there are ways to improve their health outcomes.

Awareness of the public’s understanding could assist in guiding the promotion of many evidence-based occupational therapy interventions that have the potential to improve functional independence, quality of life and social participation for (older) people in light of the current awareness and beliefs. Considering the recent changes in the aged care sector (discussed in section 1.1.2), specifically the shift in decision making power from health professionals to consumers, healthcare providers need to make themselves visible to these consumers. For example, in view of the principles of Consumer Directed Care, consumers should to be educated on how to access occupational therapy services under this scheme. Occupational therapists ought to also communicate with the public and other health care providers effectively about their unique services, provide evidence that service recipients are offered best value for their investment, and identify and promote the costs and effects of choosing their specific services.

While this study reinforces the need to raise awareness about occupational therapy, a number of campaigns already exist. For example, from September to December 2017, select trains in Sydney and Melbourne carried signs about occupational therapy to coincide with the ‘OT week’ to build awareness and launch a consumer website about occupational therapy in Australia (http://aboutoccupationaltherapy.com.au/). The campaign also encouraged social media followers to spread the message about the profession. However, in light of the findings from this study, it may be useful for future campaigns to consider the current level of knowledge about the profession and focus on addressing the common misconceptions that the public has about occupational therapy. As it currently stands, consumers may believe that occupational therapy is irrelevant without knowing the benefits that the service may provide.

Lastly, awareness campaigns to foster better service engagement may not be possible without the support from our therapists and the members of the occupational therapy association. Each member strengthens the voice of the association, providing more scope and value for the profession (https://www.otaus.com.au/about/why-join-ota). The larger the association, the greater the presence in the community. This power in numbers also means that there are more resources available to advocate for the profession in order to ensure that occupational therapy services are recognised and used to their fullest potential (for example by aged care consumers). Therapists are encouraged to become members of their country specific occupational therapy associations to support this advocacy for the profession.

4.4.1 Strengths and limitations

This is the first survey to report on the Australian general public’s awareness about occupational therapy. The survey used a nationally representative sample and all states and territories from within Australia were represented. A limitation of this survey is that people who participate in online surveys may be more advanced users of technology, thus they may be more exposed to information about occupational therapy. This is particularly as some responses were direct quotations from internet searches to questions such as: what is occupational therapy? While it may be that these participants had an understanding of occupational therapy, literature about attitudes suggest that participants may adjust their replies to be more socially desirable (McLeod, 2009) and therefore copied their response from the internet. Participant responses may also be influenced by factors such as perceived stigma, cultural or demographic variables, and previous experiences (Fishbein & Yzer, 2003). The survey also does not delve into knowledge amongst different cultural groups, such as Indigenous Australians. Such information would be particularly important as the perceptions about healthcare service access and use may be different in these communities (Stedman & Thomas, 2011). Similarly, given the structured methods of the online panel service (i.e. demographic data provided by PureProfile), there was limited opportunity to collect additional information about the participants, such as their highest level of education, if they had met or knew someone who had received occupational therapy, or if they had seen the profession advertised. Such knowledge could assist with interpreting the findings. For example, prior encounter may impact responses regarding awareness questions. Finally, the posed question was phrased in two parts, consisting of both open and closed ended questions, and may have been difficult to interpret for some participants. Thus, the responses may have been a reflection of education levels or knowledge of English, rather than thoughts about occupational therapy. Additionally, closed questions can elicit deceptive responses as saying ‘no’ provides an easy way to end the enquiry (and enable reimbursement), while ‘yes’ assumes knowledge about occupational therapy and an expectation that the participant writes what they know about the profession, giving them more work (than saying ‘no’).

4.4.2 Implications

There is scope to educate the Australian public about the varied and unique skills that occupational therapists have to support older people to remain involved and active in their chosen environments. Younger people and men appear to know less about the profession and how it can help older people. The findings from this survey have implications for occupational therapists and healthcare service providers that support older Australians. First, there is a need to address the misconception that the profession is exclusively concerned with physical therapy or only has to do with supporting people to ‘return to work’. Second, occupational therapists should be confident in explaining their role to others and include detail about the core concepts such as client-centeredness, everyday activities, meaningful tasks, participation and social engagement, functional ability and independence in their description of the profession. The use of case stories may be useful to assist with generating better understanding in the public. Third, both occupational therapists and organisations offering their services should be forward in their thinking and engage in up to date social media, blogging, press releases and other public relations strategies to advocate, educate and market the profession. Finally, future promotional campaigns should consider the current level of knowledge about occupational therapy to address the common misconceptions that the public has about the profession.

This chapter has identified that occupational therapists’ role in supporting older people is poorly understood in Australia. The chapter also described how understanding the general public’s knowledge regarding occupational therapy can be used to inform awareness campaigns and address misconceptions about the profession’s role in supporting older people (and people with dementia). This is particularly important to note for the COPE program implementation and future promotion. Many Australians, especially younger people and men, are not aware of the unique knowledge and skills that occupational therapists have to promote healthy ageing and enable older people to remain engaged and active in their chosen environments.

This chapter has also explored how the newly introduced Consumer Directed Care model (that was also discussed in section 1.1.3) has changed the way consumers access services, and identified that there is a need to better educate the public about occupational therapy in order to facilitate service use. The chapter highlighted the need to consider the current level of knowledge about occupational therapy in future promotional campaigns to address the common misconceptions that the public has about the profession. These implications are revisited again in chapter 8 of this thesis, during discussion of the practical implications of the overall findings.

Thus far, this thesis has discussed the current recommendations for occupational therapy practices in order to improve functional outcomes for people with dementia living in the community. The thesis has identified that occupational therapy approaches that are individualised, consist of multiple components, and include evaluation of the home environment to support independence and participation in activities of daily living tend to deliver better economic and functional outcomes. However, while the potential for occupational therapy to improve outcomes for people with dementia exist, the scope of occupational therapy practice remains largely unknown in the general public. Additionally, the general public seems to have a poor knowledge about treatments that can improve the wellbeing of people with dementia that have been proven effective in research studies.

While this thesis has begun to highlight the need to educate the public about the potential benefits of interventions that can improve outcomes for people living with dementia, there is also a need to ensure that these interventions are provided to the public. In other words, it is expected that therapists deliver intervention approaches that align with the recommendations for improved outcomes. If these interventions were not delivered, there needs to be a clear way of recognising where the evidence-practice gaps are, and how these gaps could be addressed. For this reason, the next chapter moves on to explore current occupational therapy practices delivered in the community for people living with dementia.

CHAPTER 5: ARE THERE MISSED OPPORTUNITIES FOR OCCUPATIONAL THERAPY FOR PEOPLE WITH DEMENTIA? AN AUDIT OF PRACTICE IN AUSTRALIA

This chapter addresses Aim 3 of the thesis: “to evaluate the current approaches to delivering occupational therapy services for older people with dementia in the community”. This chapter discusses a case note audit completed as part of the COPE implementation project. The purpose of the study was to determine the current occupational therapy practices in care of people with dementia in the community The study is adapted with minor changes for thesis formatting and consistency from the published article in the *Australian Occupational Therapy Journal* (Rahja, Comans, Clemson, Crotty, & Laver, 2018a).

As the main author for the publication, the candidate’s contribution was 80% of this chapter. The audit chart was constructed prior to the commencement of candidature. The data collection was completed by staff at the participating sites, due to ethical requirements of the sites. De-identified data was then provided to the COPE research team for analysis and writing. The candidate was responsible for training and liaising with local staff about data collection. The COPE Australia project manager assisted with data collection with participating organisations that were located interstate. The candidate was responsible for data analysis and the writing of results. KL provided guidance for statistical methods used in data analysis. All authors were involved in editing and proof-reading the final manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

5.1 Introduction

Thus far the work in this thesis has explored how occupational therapy for community dwelling people with dementia in Australia is provided through government, not-for-profit and private organisations (Department of Health Australia, 2016a). For example, care within a person’s home (usually funded by the Commonwealth Government) is delivered via the recently introduced Consumer Directed Care scheme (Department of Health Australia, 2012). In this model, consumers must choose and pay for occupational therapy from their allocated funds. Occupational therapy is also provided within acute and sub-acute services funded by state governments or the Commonwealth. The capacity to which occupational therapy is utilised within the differing service contexts remains unknown.

Current literature suggests a significant gap between the care recommended in clinical practice guidelines and usual care. Few evidence-based dementia care interventions have been implemented (Morrow-Howell et al., 2013). Surveys of occupational therapists who work with people with dementia suggest that occupational therapists spend most of their time on assessment at the expense of intervention (Bennett, Shand, & Liddle, 2011; Swinson et al., 2016). The surveys also reveal that occupational therapists may not feel competent in treating older people with dementia at home (Van't Leven et al., 2012), pay limited attention to occupational participation (McGrath & O'Callaghan, 2014) and are restricted by time and organisational structures to provide recommended services (Bennett et al., 2011; Gately & Trudeau, 2017; McGrath & O'Callaghan, 2014). Client factors such as changed behaviours and difficulty following treatment procedures have also been identified as barriers to service delivery (Gately & Trudeau, 2017).

While surveys have explored occupational therapists' perceptions of care provided, they may be subject to self-reporting bias and lack an objective approach to providing feedback on current practices that can help improve accountability (Ivers et al., 2012). One way in which we can understand current practice is by conducting case note audits (Holmboe, 2008). Audits can be used to quantify the evidence-practice gap; that is, the gap between what is recommended in clinical guidelines and what occurs in clinical practice (Bennett & Bennett, 2000) and to feedback information about current practice to staff. In many cases audit and feedback has been shown to result in improvements in service delivery (Ivers et al., 2012). To our knowledge, no case note audits have been conducted of occupational therapy interventions in providing services to people with dementia in Australia. The aim of this audit was to determine: What are the assessment and intervention approaches used by occupational therapists working with people with dementia living in the community?

5.2 Methods

This audit was approved by University of Sydney Human Research Ethics Committee (ID: 2016/292), Northern Sydney Local Health District Ethics Committee (ID: HREC/16/HAWKE/283 and Southern Adelaide Clinical Human Research Ethics Committee (ID: HREC/16/SAC/173).

5.2.1 Eligibility criteria

This audit is part of a larger scale study registered with the Australian New Zealand Clinical Trials Registry (ID: ACTRN12617000238370). Case notes were audited from different service contexts in New South Wales and South Australia. These services were community geriatric services managed by Local Health; intensive home based rehabilitation services; services provided by a private organisation where patients use government funded home care packages to purchase services for themselves and; a centre based rehabilitation service. Case notes were included if a person had a diagnosis of dementia, or cognitive decline suggesting probable dementia, and if the person had been referred to occupational therapy and subsequent assessment(s) and/or intervention(s) performed by an occupational therapist were documented. No restrictions were placed on duration of service or number of referrals.

5.2.2 Data extraction

Case notes from the included sites were audited sequentially dating backwards from 31st December 2016 to 1st January 2015 in order to capture recent data. Guidelines for conducting clinical audits do not provide prescriptive information regarding sample sizes but suggest including 10 cases (charts) per variable of interest (Gearing, Mian, Barber, & Ickowicz, 2006). The aim for this audit was to include a total of 100 case notes and we selected five different sites of interest to reflect the different contexts in which occupational therapy is delivered in the community (hence, we required 20 case notes from each site). Furthermore, based on the number of people with dementia seen at each site and the similarities between sites in terms of population (community dwelling people with dementia) and traditional nature of the occupational therapy role at each site, we established that 20 notes from each service would provide information that could be generalizable to other settings (Dixon & Pearce, 2011). Data extraction was completed by independent auditors (not treating occupational therapists), trained in the use of the data collection tool. The data collection tool was specifically developed for this study and included the following variables: age, gender, living situation, formal cognitive assessment tools used, duration of occupational therapy service, number of face to face and telephone consultations, assessments undertaken and intervention approaches used. The variables were included in the tool in order to facilitate comparison between the differences in assessments and interventions used. The data extraction tool had space for recording formal cognitive assessments and occupational therapy assessment methods used. Findings from earlier research (Bennett et al., 2011; McGrath & O'Callaghan, 2014) were used to create a list of the most commonly used occupational therapy interventions in care of people with dementia. The data extraction tool used is included in Appendix E.

5.2.3 Data analysis

All data were entered into SPSS Version 22 (IBM Corporation, 2013). Descriptive statistics were used to summarise sociodemographic data and service characteristics as well as to describe assessment and intervention approaches used. Two sub-groups (based on age and living situation) were defined to explore differences in assessment and interventions used. Age sub-groups were defined as under 70 years, 70-84 years, and 85 or older. The age cohorts of particular interest were under 70 years and 85 or older. These cohorts were defined based on the prevalence of dementia among senior Australians from less than 3% of under 70 year olds to over 28% of centenarians (Australian Institute of Health and Welfare, 2012). Living situation was defined as ‘living alone in the community’ and ‘living with others’.

Chi-square test of two proportions was used to determine if interventions received by the sub-groups were similar. Fisher's exact test for determining the statistical significance was reported when there were insufficient numbers of participants in sub-groups to use the test of two proportions. The null hypothesis for the test was that the difference between the sub groups was equal to 0 (zero), $p < 0.05$ was considered significant.

5.3 Results

A total of 87 case notes from four different service contexts were included in the analysis. Two of the sites were unable to identify the expected number of notes meeting the inclusion criteria. Sixty notes were audited from South Australia and 27 from New South Wales. Case notes were included from non-government organisations, community health services delivered by Local Health Networks, community rehabilitation services and outpatient day rehabilitation services. Characteristics of the included participants are presented in Table 5-1. The mean age of participants was 81.8 years (range 43 – 101 years) and approximately half were female. Just over half of the participants lived with a spouse or other caregiver. A formal cognitive assessment conducted with a health professional was present in the notes most of the time (63 out of 87, 72.4%). The most commonly used cognitive assessment was the Montreal Cognitive Assessment, followed by the Mini Mental State Examination.

5.3.1 Service delivery

The median length of the occupational therapy intervention was one month, ranging from a single consultation to a service offered over 14 months. The average number of face to face visits per referral was 2.1 visits, and the maximum number of visits recorded was 11. An average of 3.4 telephone contacts, were recorded with a maximum of 39 phone calls recorded within a referral. Almost half of the services offered continued for less than one full month (n = 44, 48.4%). All services offered by a non-government organisation comprised once-off consultations that consisted of home assessment and environmental modification and/or assistive device prescription. The number of visits and service length varied between the other service contexts.

Table 5-1 Participant characteristics

		N = 87
Participant Age	Mean	81.8 years, SD = 9.77
	Range	43-101 years
Participant Gender	Female	44 (50.6%)
	Male	43 (49.4%)
Participant living situation†	With spouse	42 (48.3%)
	Alone	36 (41.4%)
	With other family (child, relative etc.)	5 (5.7%)
	Private caregiver	2 (2.3%)
Formal cognitive assessment (conducted by a health professional) present in the notes ‡		63 (72.4%)
Montreal Cognitive Assessment		38 (43.7%)
Mini Mental State Examination		28 (32.2%)
Frontal Assessment Battery		18 (20.7%)
Rowland Universal Dementia Assessment Scale		3 (3.4%)
Six Item Screener		3 (3.4%)
Psychogeriatric Assessment Scale		2 (2.3%)

†Two case notes were missing detail about living situation, hence answers do not total 100%; ‡More than one cognitive assessment was conducted with some participants, hence answers may not total 100%. Abbreviations: SD - Standard Deviation.

5.3.2 Assessments

Table 5-2 summarises the type and frequency of assessments conducted. Overall, the four most commonly used assessments were home, fall risk, functional and cognitive assessments. A comparison of the number of assessments conducted on younger (under 70 years) and older (aged 85 years and over) people with dementia as well as their living situation found that the most commonly used assessments (in all groups) were home and fall risk assessments (Table 5-2). However, cognitive and money management assessments tended to be used more with people living alone in the community, whereas home functional assessments were more commonly used for those living with other caregivers.

5.3.3 Interventions

Table 5-3 depicts the different intervention approaches used. Overall, the most common approaches were referral to other services, environmental modification advice and prescription of assistive devices or equipment, with over half of the participants receiving these interventions. The use of strategies to enhance memory were more commonly used interventions for people who were younger (under the age of 70) ($p < 0.01$), whereas this participant group was rarely prescribed assistive devices or equipment (p = 0.01). Around two-thirds of older people (aged 85 and over) received assistive devices (p = 0.033). Case management (p = 0.024) and psychosocial support (p = 0.029) were more commonly used interventions for participants who lived alone in the community.

Table 5-2 Type and frequency of assessments conducted

	Overall	**Living situation†**		**Age group**		
	N = 87	Alone (n=36)	With others (n = 49)	<70 (n = 9)	70-84 (n = 39)	≥ 85 (n = 39)
	n (% of total)	n (% of total)	n (% of total)	n (% of total)	n (% of total)	n (% of total)
Home assessment	42 (48.3%)	17 (47.2%)	25 (51.0%)	3 (25.0%)	19 (48.7%)	20 (51.3%)
Falls risk assessment	29 (33.3%)	11 (30.6%)	18 (36.7%)	4 (33.3%)	11 (28.2%)	14 (35.9%)
Functional assessment	18 (20.7%)	4 (11.1%)	14 (28.6%)	1 (8.3%)	8 (20.5%)	9 (23.1%)
Cognitive assessment	14 (16.1%)	9 (25.0%)	4 (8.2%)	2 (16.7%)	8 (20.5%)	4 (10.3%)
Home functional assessment	12 (13.8%)	7 (19.4%)	5 (10.2%)	0 (0.0%)	4 (10.3%)	8 (20.5%)
Money management assessment	10 (11.5%)	9 (25.0%)	0 (0.0%)	1 (8.3%)	8 (20.5%)	1 (2.6%)
Health and safety assessment	6 (6.9%)	5 (13.9%)	0 (0.0%)	1 (8.3%)	3 (7.7%)	2 (5.1%)
Pressure risk	4 (4.6%)	1 (2.8%)	3 (6.1%)	0 (0.0%)	2 (5.1%)	2 (5.1%)
Personal care assessment	2 (2.3%)	0 (0.0%)	2 (4.1%)	0 (0.0%)	0 (0.0%)	2 (5.1%)
Depression scale	1 (1.1%)	1 (2.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.6%)
Upper limb assessment	1 (1.1%)	1 (2.8%)	0 (0.0%)	0 (0.0%)	1 (2.6%)	0 (0.0%)

† Two participants were missing data on living situation.

NOTE: More than one assessment was conducted with some participants, hence answers do not total 100%

Table 5-3 Interventions used

	Overall	Living alone or with others†		Age group		
	N = 87	Alone (n = 36)	With others (n = 49)	< 70 (n = 9)	70-84 (n = 39)	≥ 85 (n = 39)
		n (% of n)	n (% of n)	n (% of n)	n (% of n)	n (% of n)
Referral to other services	52 (59.8%)	23 (63.9%)	28 (57.1%)	5 (55.6%)	24 (61.5%)	23 (59.0%)
Environmental modification advice	48 (55.2%)	19 (52.8%)	29 (59.2%)	3 (33.3%)	20 (51.3%)	25 (64.1%)
Prescription of assistive devices or equipment	47 (54.0%)	20 (55.6%)	27 (55.1%)	**1 (11.1%)***	20 (51.3%)	**26 (66.7%)***
Case management	35 (40.2%)	**19 (52.8%)***	14 (28.6%)	1 (11.1%)	19 (48.7%)	15 (38.5%)
Compensatory strategies for ADLs and IADLs	31 (35.6%)	15 (41.7%)	16 (32.7%)	4 (44.4%)	11 (28.2%)	16 (41.0%)
Carer coping strategies	28 (32.2%)	11 (30.6%)	16 (32.7%)	1 (11.1%)	15 (38.5%)	12 (30.8%)
Placement/respite processes	24 (27.6%)	10 (27.8%)	12 (24.5%)	2 (22.2%)	11 (28.2%)	11 (28.2%)
Aged Care Assessment applications	19 (21.8%)	9 (25.0%)	9 (18.4%)	2 (22.2%)	9 (23.1%)	8 (20.5%)
Education (for the person with dementia or their caregiver)	15 (17.2%)	7 (19.4%)	8 (16.3%)	1 (11.1%)	8 (20.5%)	6 (15.4%)
Use of strategies to enhance memory	11 (12.6%)	3 (8.3%)	8 (16.3%)	**5 (55.6%)***	3 (7.7%)	3 (7.7%)
Rehabilitation for comorbidities (e.g. falls)	11 (12.6%)	6 (16.7%)	5 (10.2%)	3 (33.3%)	3 (7.7%)	5 (12.8%)
Behavioural management approaches	7 (8.0%)	3 (8.3%)	3 (6.1%)	0 (0.0%)	4 (10.3%)	3 (7.7%)
Driving cessation advice/transport options	7 (8.0%)	3 (8.3%)	4 (8.2%)	1 (11.1%)	4 (10.3%)	2 (5.1%)
Social and leisure	6 (6.9%)	1 (2.8%)	5 (10.2%)	1 (11.1%)	3 (7.7%)	2 (5.1%)
Psychosocial support (e.g. counselling)	5 (5.7%)	**4 (11.1%)***	0 (0.0%)	0 (0.0%)	3 (7.7%)	2 (5.1%)
Teaching compensatory strategies for community activities	3 (3.4%)	2 (5.6%)	1 (2.0%)	0 (0.0%)	2 (5.1%)	1 (2.6%)
Assisting clients choice and use of meaningful activities	2 (2.3%)	1 (2.8%)	1 (2.0%)	1 (11.1%)	1 (2.6%)	0 (0.0%)
Functional mobility training	1 (1.1%)	0 (0.0%)	1 (2.0%)	0 (0.0%)	1 (2.6%)	0 (0.0%)
Cognitive retraining	1 (1.1%)	0 (0.0%)	1 (2.0%)	1 (11.1%)	0 (0.0%)	0 (0.0%)
Reality orientation	1 (1.1%)	1 (2.8%)	0 (0.0%)	0 (0.0%)	1 (2.6%)	0 (0.0%)

† Two participants were missing data on living situation; *p < 0.05 chi-square test of homogeneity or Fisher's exact test where number of participants in sub group was too small. Null hypothesis was set as no difference between the earlier defined study sub-groups (age group and living situation) and interventions received.

Abbreviations: ADLs – Activities of Daily Living; IADLs – Independent Activities of Daily Living

NOTE: More than one intervention was provided with some participants, hence answers do not total 100%. There were no entries recorded for the following interventions: Reminiscence therapy, Validation therapy, Creative media (dance, drama, music, art), Outings (eg museum, clubs), Exercise/tai chi/yoga, Perceptual retraining, Stress management/relaxation training and Snoezelen.

5.4 Discussion

The findings of this audit suggest that evidence-based dementia-specific treatment programs which are comprehensive, provided over a number of consultations and address the individual dementia specific concerns of the person and caregiver are underutilised. A limited number of consultations are provided for people with dementia and there were only a few occasions in which caregivers were engaged in education, problem solving and skills building interventions. Thus, there is scope for more comprehensive intervention approaches to be used by occupational therapists with this population.

There is a lack of evidence supporting the use of some interventions that are currently provided in clinical practice for people with dementia, suggesting more research is required to determine efficacy. There are only a few small studies (Tchalla et al., 2013; Wesson et al., 2013) which have investigated the efficacy of different fall prevention programs for people with dementia, and there is still a lack of information about the best fall prevention approach for this population. There is also a lack of research into the effectiveness of case management for people with dementia (Reilly et al., 2015), including efficacy for costs and resource use (Pimouguet, Lavaud, Dartigues, & Helmer, 2010). The effects of home assessment and environmental modification (the more common intervention approaches used) are also still relatively unknown for this population group. Stark, Keglovits, Arbesman, and Lieberman (2017) found evidence that single and multicomponent interventions that included home assessment and modification can improve function and help reduce risk of falls among older people. However, their review only reported effectiveness of intervention outcomes for caregivers of people with dementia (Stark et al., 2017).

This study is consistent with other studies that have described the nature of occupational therapy interventions as short in duration. Specifically, earlier surveys regarding barriers to occupational therapists providing services to people with dementia suggest that therapists may be restricted with time (Bennett et al., 2011), may not feel confident in their level of knowledge of current evidence about occupational therapy in dementia care (Bennett et al., 2011) and may not have the adequate skills to support this population (McGrath & O'Callaghan, 2014; Van't Leven et al., 2012). Such information regarding the therapists' knowledge and skills may assist with understanding the short service duration, why referrals are often made to other services, and the limited amount of interventions offered.

The opportunity to offer evidence-based interventions may also be limited by the service context, including the role of occupational therapy within the service. Most services provide programs that are short-term in nature and there is pressure to discharge clients in a timely manner (Dow & McDonald, 2007). Location of service provision may also be an issue. For example, when occupational therapy is offered in hospital clinics, therapists may have limited ability to conduct home safety assessments and make recommendations for improving the home environment. Alternatively, when referrals are made for the purpose of home assessment and environmental modification, falls prevention, or functional assessment, limited opportunities exist to provide interventions that address problem solving and caregiver coping strategies (Bennett et al., 2011). Other restrictions experienced may also be related to limited understanding of occupational therapy and its potential with older clients, or clients with dementia, as was described in chapter 4.

Current evidence supports longer-term multicomponent occupational therapy interventions with one review (Laver et al., 2014) showing effective interventions to reduce the behavioural symptoms of dementia provided an average of eight visits (range 3-17). Box 5-1 includes examples of such occupational therapy intervention programs found to be effective with community dwelling people with dementia. There is insufficient evidence at present to reach conclusions about whether short-term (one or two session) interventions are effective. While this does not necessarily mean that current approaches are not beneficial, research to demonstrate this has not yet been conducted. Only one German study (Voigt-Radloff et al., 2011) has compared short-term occupational therapy intervention effectiveness to the multi-session approach to care; reporting that a multi-session community occupational therapy program (involving 10 consultations over five weeks) was no more effective than a once-off occupational therapy consultation. However, it should be noted that the participants presented with low level need for assistance at the beginning of the study and therefore the study outcomes may have been different had the participant care needs been higher (Voigt-Radloff et al., 2011).

Box 5-1 Examples of occupational therapy intervention programs found to be effective with community dwelling people with dementia

Examples of occupational therapy intervention programs found to be effective with community dwelling people with dementia

Care Of People with dementia in their Environments (COPE; Gitlin, Winter, et al., 2010):

- Up to 10 home or telephone contacts from occupational therapist over 4 months;
- Assessment of participant capabilities and deficits;
- Complimented by nurse intervention (2 consults) for medical management;
- Caregiver education and skills building about home safety, simplifying activities, and stress reduction.

Tailored Activity Programme (TAP; Gitlin et al., 2008):

- Eight sessions (6 home / 2 telephone) over a period of 4 months
- Identification and prescription of activities tailored to patients’ capabilities, roles, habits and interests

Community Occupational Therapy in Dementia (COTiD; Graff et al., 2006):

- Ten 1 hour sessions over a period of 5 weeks;
- Assessment and goal setting;
- Participant skills building and caregiver training.

5.4.1 Strengths and limitations

A strength of this audit is that it describes actual services provided and therefore helps remove biases that may be prevalent in self-reporting (Holmboe, 2008). A variety of service contexts were also included, giving a broader understanding of the overall occupational therapy practice in care of people with dementia in Australia. However, while case notes were audited from two different states in Australia, the number of notes audited was relatively small and they were from services in metropolitan areas. Thus, interventions and assessments used in regional and rural Australia remain unclear. Such information is particularly important as two of five people with dementia live in regional or rural towns and communities Australia (Brown et al., 2017) and dementia care provision in regional and rural areas of Australia is different to care in metropolitan areas (Hansen, Robinson, Mudge, & Crack, 2005). Finally, case notes do not always provide sufficient detail regarding the content of intervention. Limited time and space in medical records and poor therapist recall of detail mean that not all aspects of assessment and intervention are recorded in the case notes. For example, therapists may have spent more time identifying concerns and collaboratively problem solving with caregivers but the collaborative approach to care was not apparent from reading the notes (Pierre, 2001).

5.4.2 Implications for future practice and research

There is scope for more comprehensive occupational therapy intervention to support people with dementia in clinical practice; the gap between evidence-based practice and usual care needs closing. The findings from this audit have implications for occupational therapists as well as organisations offering services to people with dementia (and their caregivers). Firstly, this study is a call for action for dementia care service providers to facilitate evidence-based occupational therapy through resources, training and role definition. Such care has been shown to improve outcomes for people with dementia and their caregivers. Secondly, the audit highlights the (potential) need for occupational therapists to further their knowledge and skills in providing care for people with dementia. Multiple courses exist that specialise in training occupational therapists to work with this population group. Thirdly, the authors encourage those interested and/or confident in supporting people with dementia to promote their knowledge and skills within their services and networks, for example via newsletters. Finally, if no changes are made to the current practice approach, there is a need to evaluate if the current approach (one or two visit intervention with a focus on short-term service delivery) is an effective method to support people with dementia, and if so, for whom and at what stage in the disease process.

To summarise, occupational therapists have the potential to improve functional capacity, quality of life and leisure participation for people with dementia. Therapists can also provide education to caregivers around coping skills, including managing with changes in behaviours attributable to dementia. However, this chapter has highlighted that the current focus appears to be on short-term risk management and there is a gap between evidence and current occupational therapy practice in provision of services for people living with dementia in Australia. Following on from the final remarks in the previous chapter, while there is a need to educate the public about the potential benefits of engaging people with dementia in interventions delivered by occupational therapists, it appears that the current approaches do not reflect those recommended by the guidelines. The evidence-practice gap identified in this chapter includes: small number of consultation sessions currently delivered compared to the recommended minimum number of sessions; limited engagement of caregivers in interventions such as education; limited approaches used to address areas of behavioural concern that are attributable to dementia and; limited assistance for the person with dementia to engage in meaningful activities.

As identified in chapter 1, the COPE Australia project seeks to upskill occupational therapists working with people with dementia in Australia. The aim is to address the evidence-practice gap in current service delivery. The project has trained occupational therapists in New South Wales and South Australia to deliver the COPE program to people with dementia living in the community. The next two chapters move on to explore some of the outcomes following the training of therapists and the delivery of the COPE program. The next two chapters also begin to describe if it is possible to close the evidence-practice gap described in this chapter, and explore the service delivery and client satisfaction related outcomes related to the COPE program implementation. First, participant experiences of participating in the COPE program is explored.

CHAPTER 6: A SECOND CHANCE: EXPERIENCES OF PEOPLE WITH DEMENTIA AND THEIR FAMILIES PARTICIPATING IN THE COPE PROGRAM

This chapter addresses Aim 4 of the thesis: "to understand the experiences of people with dementia and their family caregivers of participating the COPE program". It is clear by now that the COPE program is different compared to the current occupational therapy approaches provided to community dwelling people with dementia in Australia. Chapter 1 identified different 'outcome levels' that were evaluated as part of the COPE program implementation; these were related to implementation, service, and client level outcomes. One way of evaluating client level outcomes is to understand how the program is experienced by the clients. Thus, the purpose of this chapter is to describe participant experiences when participating in the COPE program. The study described in this chapter is under peer review for a special issue about 'Knowledge translation and dementia' in *Brain Impairment*, 2019. The chapter is adapted for thesis formatting and consistency from the submitted manuscript.

As the main author for the publication, the candidate's contribution was 80% of this chapter. The COPE project manager (SD) was in charge of overall data collection for the COPE project and therefore was aware of the circumstances of each project participant. The project manager (SD), therefore, assisted with identifying potential participants for this study. The candidate was responsible for contacting occupational therapists and subsequent participant recruitment as described in the chapter below. The candidate was responsible for data collection, analysis and the writing of manuscript. All authors were included in regular updates following interviews. Co-author (JC) completed one interview, as well as reviewed and confirmed coding of interviews (data analysis). All study authors were involved in final editing and proof-reading the manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

6.1 Introduction

The thesis so far has established that care of people with dementia comes with significant societal and economic impact (Brown et al., 2017; Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Wimo et al., 2011). Indirect costs, such as lost productivity, of both people with dementia and their informal caregivers in the workforce, account for 38% of the total cost (which is A$14.25 billion) of dementia in Australia (Brown et al., 2017). Most (over 70%) people with dementia live in the community and informal caregivers (such as family members) are in a key position to enable them to remain at home (Australian Institute of Health and Welfare, 2012; Brown et al., 2017).

Informal care is used by the majority of (85.1%) people with dementia living in the community (Michalowsky et al., 2016). Yet, caring for a person with dementia comes with responsibilities such as managing changes in a person's communication and behaviour, ensuring safety at home (for the person with dementia), finding additional supports and services, and engaging the person with dementia in daily activities (Edwards, 2015; Jennings et al., 2015). Stress and sense of burden amongst caregivers is common due to factors such as severity of changes in behaviour and functional impairment for the person with dementia, available social support networks for both the person with dementia and their caregiver, length of care provided by the caregiver, and lack of time to look after caregiver's personal health needs (Gaugler et al., 2011; Hughes et al., 2014). Informal care comes with other intangible costs that are more difficult to monetise and are often described in interviews. These intangible costs include stress, pain, emotional hardship, and challenges in personal and family relationships; these 'costs' add to the societal and economic impact of dementia (Gaugler et al., 2011; Hughes et al., 2014). The amalgamation of these factors often leads to an eventual move from home to residential care for the person with dementia (Gitlin & Hodgson, 2015). Thus, the economic benefits of informal care are significant (Brown et al., 2017; Hurd et al., 2013).

This thesis has described how evidence from randomised controlled studies suggest that dyadic interventions (that is interventions that involve a person with dementia and their caregiver) are more effective than pharmacological therapies in delaying functional decline in people with dementia (Laver, 2016) and reduce caregiver burden (Etters, Goodall, & Harrison, 2008). However, to date, access to such interventions has been poor (Jennings et al., 2015; Maslow, 2012). In their global action plan, the World Health Organization (2017) called for implementation of evidence-based interventions that enhance function and capability in people with dementia. This means using strategies to adopt an intervention and change the culture of practice within specific health systems or settings (National Institute of Health, 2009). Reablement is a term used to describe a suite of strategies that work to maintain or improve a person's functional capability and independence (Poulos et al., 2017). This is done by maximizing the person's cognitive and functional capacities and optimising environmental features that impact on the person's participation. In dementia care reablement adopts a collaborative approach to care with the person with dementia and their caregiver (when appropriate). The purpose is to maintain the person with dementia's function, regain lost function where possible, and adjust to lost function that cannot be regained (Poulos et al., 2017).

To re-iterate, Care Of People with dementia in their Environments (COPE) is a dyadic intervention (designed in the United States) that supports physical and cognitive function and quality of life for people with dementia, and the wellbeing of their caregiver (Gitlin, Winter, et al., 2010). The COPE program draws on the unique skills of occupational therapists and nurses to work collaboratively with the person with dementia and their caregiver. Collaboration with the caregiver seeks to identify areas of concern and problem solve different approaches around modifying caregiver communication and the home environment, and encouraging the person with dementia to participate in valued activities. A nurse provides education and advice around health needs (such as medication, hydration, pain or continence). A randomised controlled trial found COPE to be effective in reducing functional dependence and dependence in instrumental activities of daily living for the person with dementia, as well as improving engagement for the person and wellbeing of their caregiver (Gitlin, Winter, et al., 2010). The program is now being translated into practice in the United States (Fortinsky et al., 2016) and Australia (Clemson et al., 2018).

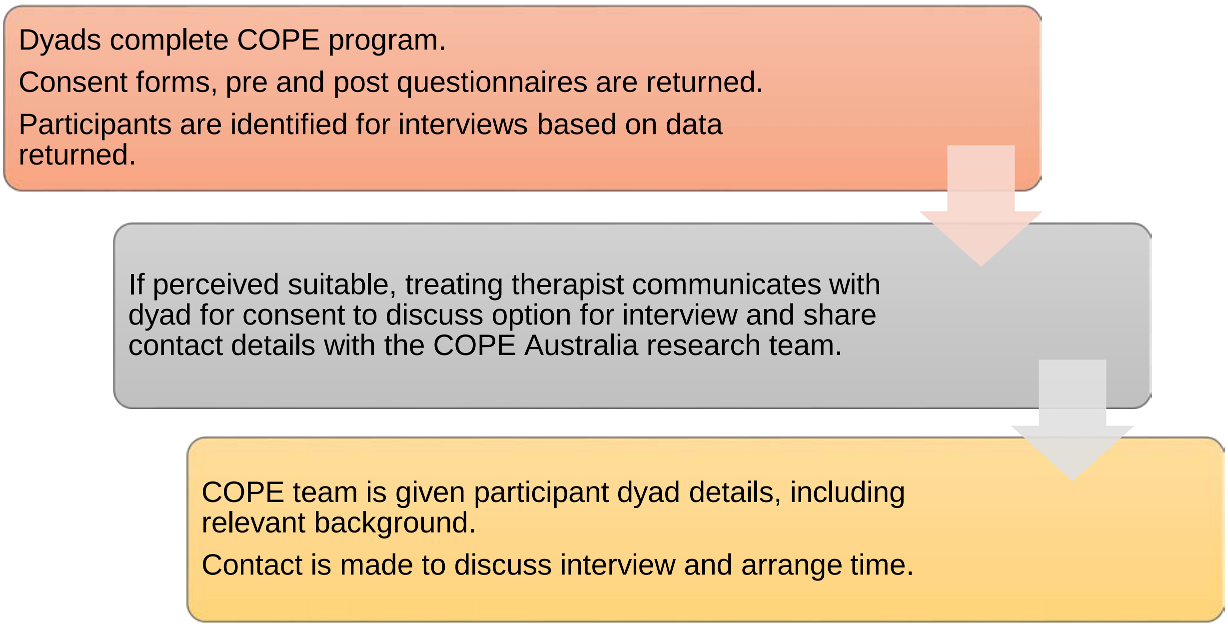
Published evidence about COPE has described the quantitative outcomes of the program, but little is known about how or why it is effective. Qualitative interviews with participants would enable an in-depth understanding of their perception of the program and can be used to explain quantitative outcomes, thus informing future practice. Such knowledge can ensure that interventions used to address care needs of people with dementia are appropriate (Skladzien, Bowditch, & Rees, 2011). The purpose of this study is to understand and describe participant experiences of participating the COPE program in Australia.

6.2 Methods

This qualitative study was part of an implementation research project funded by the (Australian) National Health and Medical Research Council (ID: ACTRN12617000238370). Ethical approval was obtained from University of Sydney Human Research Ethics Committee (ID: 2016/834), Northern Sydney Local Health District Ethics Committee (ID: HREC/16/HAWKE/283) and Southern Adelaide Clinical Human Research Ethics Committee (ID: HREC/16/SAC/173). Semi-structured interviews were used to explore the participants’ experiences with the program as well as how the person with dementia and their family are managing after program completion.

6.2.1 Participant recruitment

Participants were recruited as per the protocol described elsewhere (Clemson et al., 2018). Of the 85 dyads (person with dementia and their caregiver) who completed the COPE program, purposeful sampling was used to identify and recruit ten dyads to participate in the interviews. The criteria used for identifying these dyads were: received the COPE program through different services (e.g. local health, private therapist); differences in caregiver – person with dementia relationship (e.g. spouses, parent – child); location (e.g. New South Wales, South Australia as well as metropolitan and regional areas); differences captured by the pre and post questionnaires completed as part of the project evaluation (e.g. no change, improved or worsened outcomes in reported perceived caregiver wellbeing and/ or engagement activities for the person with dementia). Figure 6-1 displays the flow of recruitment process. Participants were provided with an honorarium in recognition of the time spent participating in the interview.



Dyads complete COPE program.
Consent forms, pre and post questionnaires are returned.
Participants are identified for interviews based on data returned.

If perceived suitable, treating therapist communicates with dyad for consent to discuss option for interview and share contact details with the COPE Australia research team.

COPE team is given participant dyad details, including relevant background.
Contact is made to discuss interview and arrange time.

Figure 6-1 Participant recruitment process

6.2.2 Data collection

The candidate completed semi-structured interviews with the person with dementia and their caregiver to explore expectations about and experiences with the COPE program. Nine interviews were conducted face-to-face and one over the telephone. The participants were asked questions such as 'What did you hope to gain from the program?'; What were the things that really stood out to you [about COPE]?' and "How are things going after participating the program?" and they were prompted to provide examples. At the end of the interview the participants were asked to rate their satisfaction with COPE on a four-point Likert scale (Likert, 1932). The scores for the scale ranged from 1 = 'Not Valuable, 2= 'Somewhat Valuable, 3 = 'Valuable', 4 = 'Very Valuable'. The interview guide has been included as Appendix F. The interviews lasted between 28 – 72 minutes and were completed between March and December, 2018 (within one month and nine months from the cessation of the program). Each participant provided written consent prior to commencing the interviews. All interviews were audio recorded and transcribed verbatim by a third-party transcription company.

6.2.3 Data analysis

An inductive thematic approach was used to analyse the data and thus the coding was based on naturally occurring themes from the interviews (Braun & Clarke, 2006). The candidate completed the coding and subsequent analysis by first listening to the interviews and reading the transcripts to gain an initial understanding of each interview; then re-reading the transcripts and making initial codes to capture developing concepts. The responses were initially coded to represent thoughts, experiences and expectations about COPE; for example, responses that highlighted 'education for caregiver', 'at risk of going to aged care facility' or 'problem solving together'. The candidate then organised these codes into themes that summarised the key messages behind the initial codes; for example, 'learning new ways for caring', 'trying to stay home as long as possible' or 'they are helping at home'. This process of re-reading the transcripts and refining codes continued in order to capture key messages; for example thoughts about how the COPE program has provided the caregiver confidence to continue look after the person with dementia at home. To enhance rigour, a second study author (JC) also independently read and coded all the transcripts. The authors held regular meetings to discuss data and themes that were identified from the interviews. These team meetings enabled consideration of multiple viewpoints for the interpretation of the data and a wider exploration of the responses. Field notes to record observations and initial thoughts during and after each interview were also completed. The candidate also used memo writing to note ideas or questions that came to mind while listening to the interviews and reading transcripts. QSR NVivo software version 12 (QSR International Pty Ltd, 2018) was used to aid this data analysis and to create an audit trail. Pseudonyms are used to ensure confidentiality of the participants. Words in [brackets] have been added for contextual clarity.

6.3 Results

Table 6-1 summarises participant characteristics. Of the 10 interviews, five had both caregiver and person with dementia present (total of 15 participants). Six of the dyads were spouses or partners, four were other family relationships. Three dyads came from culturally and linguistically diverse backgrounds, identifying as Indian or Russian. Of the 15 participants, 13 rated the program. Two people with dementia left the session prior to the end of the interview. The average satisfaction score (as measured on the Likert Scale) was 3.8/4 (range 3-4), suggesting COPE was considered mostly very valuable by the participants.

Table 6-1 Participant characteristics

	Number of participants (N = 15)
Caregivers (n)	10
Female	8
Average age (range)	66.9 years (39 – 89 years)
From CALD background	3
Relationship to participant	8
Partner or spouse	6
Other family	4
Lives with participant	8
Average satisfaction score with COPE	3.8/4
Person with dementia (n)	5
Female	1
Average age (range)	82.8 years (74 -89 years)
From CALD background	1
Average satisfaction score with COPE	3.7/4

Abbreviations used: CALD – Culturally and Linguistically Diverse; COPE – Care of People with dementia in their Environments (i.e. the program).

Overall, coping with stress was reported to be a concern by all caregivers. They reported they were committed to keeping the person with dementia at home.

> *I made a promise I wouldn't put her [person with dementia] into a [nursing] home. So that's the hard thing, keeping her home, keeping her in her own environment. [Mary – Caregiver]*

Caregivers reported that their decision to become involved with COPE "was a matter of whatever will make it easier for both of us" [Bob – Caregiver]. Three key messages regarding experiences with the COPE program were identified from the interviews: 'empowering the caregivers' 're-engaging in roles and activities' and; 'given a second chance'.

6.3.1 Empowering the caregivers

Caregivers wanted to ensure the person with dementia was safe at home, but felt concerned and unsure of how to facilitate this. Learning ways to support the person with dementia (to complete activities successfully) was considered important.

> *Um, frustration because there's a real balance that I had to learn, which was about while she's got dementia, she also needs to have her own independence, but … I didn't want her to fail, if that makes sense. [Karen – Caregiver]*

The role of caregiving was considered stressful, often leading to thoughts of panic and anxiety about not being able to manage. However, the focus of the COPE program on caregiver stress management and teaching problem-solving strategies around common concerns, empowered caregivers to feel they were able to take action to address their concerns.

> *I mean, I don't have any choice about it. (laughs) I've got to problem solve anything that comes up at the moment. And, and, I think [therapist] helped me calm down and, and not think, I can't do this. [Louise – Caregiver]*

Caregivers acknowledged that the therapists built on strategies they may have already attempted on their own. This was considered useful in helping the caregivers feel confident in their own problem solving skills and ability to use similar approaches later, if needed.

> *[Therapist] sort of built on what we were doing, I think that was the- the good part from our point of view… for instance, the bath, bath situation was a good example of that one, and building on, um, what we were trying to do, and- and suggesting alternatives that make it easier for her and for me, um, in the long run... [Daniel – Caregiver]*

Considered together, these empowerments and reinforcements were invaluable. Caregivers reported they learned the skills required to help navigate through the journey together with the person with dementia.

> *[COPE] taught me how to give him, give a dementia person the care and you know accompany him on his journey to being independent. [Vicki – Caregiver]*

6.3.2 Re-engaging in roles and activities

Caregivers reported that prior to engaging in the program they felt unsure if the person with dementia should (or could) continue taking part in activities at home or in the community. They wondered if engaging in these activities would still mean anything for the person.

> *My questions at that stage were, well, can I leave him at home alone? Is he going to be safe near stoves, things like that? [Laura – Caregiver]*

However, continuing to engage in activities at home and in the community was considered important by the people living with dementia as they felt that they had valuable contributions to make. There was a sense that they wanted to be useful around the house and take on roles that would assist in day to day activities.

> *Yes it worries me that he's not, that he spends such a long time looking after me. I can't, you know I'd suggest, "Can I help you, can I do anything?" …I've gotta do something, there's gotta be something I can do. [Jane – Person with dementia]*

Therapists were in a key position to educate caregivers about the importance of including people with dementia in routines around the house. This inclusion in day to day activities meant that the caregivers received some 'help' around the house and also appeared to improve the person with dementia's mood.

> *I didn't think it mum at this age should be helping me…. But then, [therapist] said, "Let her do something." So, I said all right, I'll try that. …I let her [help with cooking]... And get the clothes from outside, um, after drying, she'll fold them up… I thought, this is great! You know, because at least for, what, 10 minutes, she's knows that she's contributing and therefore she's happy… [Tina – Caregiver]*

Therapists were also educating the caregivers about the importance of engaging the person in other (meaningful) activities.

> *[Therapist] was saying just that activities are important so just to make sure that every day you do somewhat… we have been doing that since, you know, mixing*

> *things up, and he [person with dementia] seems to, in some ways, be improving. In some ways his decline is you know, he's less mobile, but he seems a lot happier, my dad. Like a lot calmer as well. [Jenny – Caregiver]*

It appeared that using the COPE program to identify preserved capabilities of the person with dementia, and then engaging them in activities targeted to their level of abilities, fostered wellbeing through participation.

6.3.3 Given a second chance

Giving people with dementia a chance to remain at (or return to) home appeared to be a powerful feature of the COPE program. Caregivers perceived it was giving them ‘a second chance’ to do things differently. Jenny [caregiver] reflected how they had been “pressured to put [person with dementia] in a nursing home” almost a year prior to the interview being completed. However, following participating in COPE, caregivers reported that they were managing better at home now than they had before. For example, Paul [person with dementia] and Ellen [caregiver] discussed how they were managing after participating in COPE.

> *Ellen: I apply these things [stress management and problem solving strategies learned through COPE] and I think we're living together more normally, it gets more normal all the time, doesn't it?*
>
> *Paul: Yes, yes.*
>
> *Ellen: I don't think it gets harder. I think it gets more normal.*

Tina [caregiver] also reflected on how she was “so desperate early 2016”, yet months after participating in COPE she stated “now that I have understood what it is, give me a chance to make it good” [Tina – Caregiver].

As the program progressed, the people with dementia were re-engaging in routine activities at home. These activities included participating in cooking, cleaning and other household duties including attending to home maintenance tasks they used to complete. It appeared that they were doing this without relying on as much assistance from caregivers.

> *But he's been doing well now. He's getting back into being comfortable in the home. This wouldn't have happened if they weren't on that program. You know gets up and makes tea. And then he will you know, do certain things that I can't do, where height is needed or strength is needed. And he never did that before. [Vicki – Caregiver]*

There was a sense that the dyads were given a second chance to continue, in some way, their respective roles at home and in the community.

6.4 Discussion

This qualitative study has provided insight into ten participant dyads' experiences of participating in an evidence-based reablement program, COPE, in two different states in Australia. To our knowledge, this is the first time that a systematic multicomponent nurse and occupational therapy program (that consists of a step by step approach to care and up to 12 sessions) has been delivered to persons with dementia living in the community in Australia. Until now, occupational therapy services have been limited to one or two sessions and often consist of risk management through home modification advise and prescription of assistive devices, rather than reablement approach to care (Rahja, Comans, et al., 2018a).

This study found that participation in the COPE program enabled caregivers to feel empowered to continue provide care at home through learning strategies around stress management, problem solving, and articulating effective strategies around key challenges. The findings highlight how identifying a person's capabilities and using these to engage the person in day to day activities (that are modified to their abilities) can result in improved mood and sense of belonging. This, in turn, led to feelings of having received a second chance to continue participate in a person's chosen roles and activities.

Experiences about participating in reablement programs for people with dementia are scantly reported. In the United Kingdom, people with dementia and their caregivers have expressed willingness to engage in occupational therapy programs that could assist them to remain independent at home (Hynes et al., 2016). Yet, only one qualitative study (Corvol, Netter, Campeon, & Somme, 2018) has described experiences about participating in such programs. The study was conducted in France and reported experiences of people with dementia and their caregivers following the implementation of 'Specialised Alzheimer Teams' that were set up as part of the country's initiative to implement strategies to better support people with mild to moderate dementia living at home (Corvol et al., 2018). The outcomes from the interviews in the study also suggested that the program had helped improve quality of life for the person with dementia and empowered caregivers to continue in their caring roles (Corvol et al., 2018). The authors were unable to find other studies that reported participant experiences of participating in programs such as COPE in the community.

Programs such as COPE depend on the caregiver to implement strategies. Yet, caregivers have differences in their approach and readiness to provide care (Gitlin & Hodgson, 2015). Studies of dyadic programs have described caregiver readiness in stages (pre-contemplation,

contemplation, preparation, action and maintenance) and how different stages of readiness can guide collaboration with the caregiver (e.g. Gitlin & Rose, 2014). Caregivers in this study reported they were committed to keeping the person with dementia at home and volunteered to participate in the program. This would suggest that they were ready to learn and implement strategies offered, and were more likely in the preparation and action stage of readiness. However, caregivers at earlier stages of readiness may initially benefit from education about dementia and related symptoms (Gitlin & Rose, 2014). Thus, time should be invested in understanding caregiver readiness when engaging them in dyadic interventions.

The findings from this study support multicomponent interventions aimed at upskilling caregivers (of people with dementia) through approaches such as stress management, problem solving, and support in implementing strategies; a useful addition to current evidence about these types of programs (Laver et al., 2017). Caregivers in this study reported improved ability and confidence in continuing with their caregiving roles, with reports also suggesting that COPE had enabled the person with dementia to remain at home longer. However, while multicomponent programs can reduce caregiver impact and delay functional decline for people with dementia (Laver et al., 2017), there is a gap in literature about the explanatory detail about how or why these programs are effective.

Lastly, evidence about positive outcomes of occupational therapy for people with dementia is accumulating. This is particularly for interventions that consist of multiple consultations and a step by step approach to care that upskills caregivers in areas such as problem solving (Laver et al., 2014; Rahja, Comans, et al., 2018b). Occupational therapists are unique as their models of practice are grounded in reablement approaches (Poulos et al., 2017). Reablement programs, such as COPE, fit with the Australian policy of enabling people with dementia live well, in the community, independently and/or with caregiver support, for as long as they want (Poulos et al., 2017). In care of people with dementia, through programs such as COPE, occupational therapists can enable people with dementia remain engaged and active in their chosen environments. This is achieved for example by teaching compensatory strategies and remediation, modifying or simplifying activities, and educating and up-skilling caregivers and; is supported by the nurse role through management of medical issues such as pain or incontinence that may impact on day-to-day behaviour. However, as it currently stands (in Australia) there is poor knowledge about treatments for dementia (Cations et al., 2018; Rahja, Laver, et al., 2018) and little is known by the public about the scope of occupational therapy and their services to support older people (such as people with dementia) (Rahja & Laver, 2019). People with dementia and/or their caregivers may not seek support from occupational therapists to access reablement programs such as COPE as they may not believe or know that effective interventions exist. A person can live over 20 years following a diagnosis of dementia, the average is between seven and 10 years (Brodaty et al., 2012). Programs such as COPE have the potential to bring quality to those years.

6.4.1 Strengths and limitations

The inclusion of both caregivers and people with dementia who received the program (COPE) is a strength of this study. Another strength is that this is one of the first studies that describes participant experiences from participating in dyadic interventions, such as COPE, to support people with dementia and their caregivers particularly in Australia. Including the perceptions from these key stakeholders helps with understanding the authentic outcomes of an intervention and is more likely to lead to changes in care for people with dementia. Another strength of this study is that it included participants from culturally and linguistically diverse backgrounds. Given the cultural diversity of Australia, including this population group in research studies is important as their perceptions about health (including conditions such as dementia) and service use may be different to the native Australians'. However, a limitation is that the study did not have participants who identified as Indigenous Australians. Dementia can be up to five times more prevalent in Indigenous populations in Australia than the non-Indigenous population (Smith et al., 2008). Again, the beliefs about dementia in Indigenous people can be different to people from non-indigenous backgrounds. The study also did not have detail, and therefore it was unable to report, on the severity of dementia symptoms experienced by the participants. Such knowledge could assist in further interpretation of the outcomes, as it may be that symptom severity affected the manner the program was experienced and/or caregiver readiness.

As part of the COPE program, up to two sessions are completed with a nurse who provides advice around medical management (that are based on the person's health needs). It was noted that while the COPE program includes this nurse component, the level and extend of nurse involvement did not stand out, or was not delved into, in the interviews and outcomes presented in this study. This may have also been because the nurse involvement with the participating dyads was limited, or did not differ from usual care.

Another limitation is that the voices of people with dementia in the current study were limited. Five people with dementia took part in the interviews, two asked to excuse themselves mid-way. The interviews were conducted jointly with the caregiver and while the candidate encouraged the person with dementia to share their experiences with the COPE program, they mostly listened in to the interview and/or provided short responses. This was, for example, due to difficulty with word finding or in recalling detail about the program. Similar outcomes have been reported in other studies that have included interviews with people with dementia (e.g. Quinn, 2017).

Lastly, while the study included participants from two different states in Australia, the study sample was relatively small (10 dyads – a total of 15 participants) and some interviews were completed within a month from the dyad completing the COPE program. Thus, while we have reported positive outcomes related to COPE, it is difficult to determine the long-term sustainability of these effects and/ or generalise these findings to larger populations. It would, therefore, be important to continue explore experiences with programs such as COPE to determine their long-term effects..

6.4.2 Implications

Continuing to remain at home (for person with dementia) provides significant societal (and economic) benefits. This study has shown that the COPE program has the potential to enable people with dementia to continue to participate in meaningful roles and activities in their chosen environments. This study has given examples of how through learning stress management techniques and problem-solving strategies caregivers feel empowered to continue with their caring roles. This study has also discussed how the COPE program is an opportunity for occupational therapists, and organisations that provide occupational therapy services, to lift their profile in supporting people with dementia.

This thesis has identified that work is required to increase the uptake of reablement interventions, such as the COPE program, in standard care. The thesis has also argued that there is a need to educate consumers and healthcare organisation about benefits of these types of programs in reducing the societal impact of dementia. This chapter has provided a narrative description of the client satisfaction outcomes related to the COPE program implementation and; demonstrated the value that the COPE program implementation can bring to families who have been impacted by dementia. Thus, the findings reported here could be used to educate the public and health service organisations about the potential benefits of engaging in these types of programs.

6.4.3 Epilogue

The next chapter builds on to the findings presented thus far. The thesis began with identifying the 'cost' of dementia for Australia; many direct, indirect, and intangible costs are associated with the disease. These costs have been discussed throughout this work. However, as with any initiative that seeks to integrate programs into existing health systems at a national level, there is a need to understand the costs and consequences of the program implementation. In other words, programs exist that can improve outcomes for people (living with dementia). However, including these programs in care systems can be costly, and sometimes the costs may offset the potential benefits of these programs. In such cases these programs may not be worthwhile for the country to implement. There is, therefore, a need to evaluate if it is economically feasible to implement these programs. The decision about if the COPE program should be made available to Australians with dementia also depends, and is guided by, the costs and benefits related to the program implementation. A detailed cost-benefit analysis of the COPE program implementation is presented in the next chapter. The analysis uses a cost-benefit analysis framework that is familiar to governments and decision makers. The chapter draws on some of the findings presented in the thesis thus far, for example the current approaches to dementia care by occupational therapists described in chapter 5 and improved wellbeing outcomes for people with dementia and their caregivers following participating in the COPE program described in this chapter.

CHAPTER 7: IMPLEMENTING THE COPE PROGRAM IN THE AUSTRALIAN HEALTH CONTEXT: A COST-BENEFIT ANALYSIS

This chapter answers Aim 5 of the thesis: “to identify the costs and benefits of including the COPE program in the existing Australian health context from different perspectives”. The study in this chapter describes a cost-benefit analysis completed as part of the COPE implementation project. The described analysis is currently under peer review in *Health and Social Care in the Community,* 2019, and is adapted with minor changes for thesis formatting and consistency.

This chapter includes a substantial supplementary document that was used to complete the cost-benefit analysis described. The document includes a detailed description of the work-up completed and it has been included in Appendix G of this thesis. The detail was included as an appendix so that readers who are more interested in the calculations of the outcomes could refer to this document.

As the main author for the publication, the candidate’s contribution was 75% of this chapter. The plan for health economic evaluation for the COPE program was constructed prior to commencement of the candidature. However, the evaluation approach was left for the candidate to decide together with authors TC and KN. Under the guidance of KN the candidate built the worksheets for the evaluation. The data entry and evaluation was completed by the candidate and KN checked/confirmed these for accuracy. TC was consulted throughout. The candidate was responsible for the writing of results and TC/KN provided additional feedback. All authors were involved in final editing and proof-reading the manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

7.1 Introduction

Chapter 1 identified that in 2016 dementia cost Australia A$14.25 billion (Brown et al., 2017). This was made up of direct and indirect costs; 62% were attributable to direct costs such as hospitalisation, practitioner consultations and medications. The rest (38%) was made up of indirect costs such as lost productivity for people with dementia and their caregivers in the workforce (Brown et al., 2017).

There are over 400,000 people living with dementia in Australia and over 70% (over 280,000) of these people live in the community (Australian Institute of Health and Welfare, 2012; Brown et al., 2017). Approximately 85% (that is over 238,000) of the people with dementia who live in the community rely on family or friends to provide informal care that enables them to remain at home (Brown et al., 2017; Michalowsky et al., 2016).

Chapter 6 began to explore the stressors of informal caregiving. These included the need to find appropriate supports and services, ensure the person is safe at home, and engage the person with dementia in everyday activities (Edwards, 2015; Jennings et al., 2015). Caregiver stress was identified as a common implication of informal care, and is amplified by factors such as changes in behaviour for the person with dementia, lack of social support networks, and overall length of care provided (Gaugler et al., 2011; Hughes et al., 2014). These stress and emotional hardship add to the societal and economic impact of dementia, but are more difficult to 'monetise'. Chapter 6 identified these stressors as 'intangible costs' of dementia (Gaugler et al., 2011; Hughes et al., 2014). The build-up of these intangible costs can become a struggle for the caregivers. They may reduce or stop providing care, leading to an eventual move from home to residential care for the person with dementia (Gitlin & Hodgson, 2015). Thus, the economic benefits of informal care are significant. Without informal care, it would be difficult to meet the needs of people with dementia living in the community, and far more residential care options would be required (Brown et al., 2017; Hurd et al., 2013). The Australian Government is grappling with how to best reduce the societal and economic impact of dementia.

This thesis has discussed how 'Care Of People with dementia in their Environments' (COPE) (Gitlin, Winter, et al., 2010) is an example of a reablement program that works with both the person with dementia and their caregiver (known as a dyad). The program has already been described in detail in this thesis. COPE uses a systematic approach to care by an occupational therapist in enabling functional outcomes (up to 10 sessions) and is complemented by up to 2 nurse sessions for medical management. Programs such as COPE have been found to be effective in delaying functional decline and improving caregiver wellbeing (Etters et al., 2008; Laver, 2016), but they are not routinely implemented in occupational therapy practice (Jennings et al., 2015; Maslow, 2012). Chapter 5 (Rahja, Comans, et al., 2018a) identified that therapists currently focus on risk management, and intervention duration is short (two consultation sessions).

In 2016, the COPE Australia implementation project began to bridge the evidence-practice gap in services provided by occupational therapists for people with dementia, with the aim of changing current dementia care practice (Clemson et al., 2018). The project established partnerships with government, non-government and private health care service providers in New South Wales and South Australia. Therapists who provided their services through community geriatric services, home based rehabilitation services, short-term transitional care programs, and privately through the Government funded home care packages (see chapter 1.1.3 for further detail) were trained to deliver the COPE program to people with dementia and their caregivers. The purpose of the project was to inform policy through translation and implementation of the COPE program in standard dementia care provision (Clemson et al., 2018).

Chapter 1 also highlighted that in order to inform policy, there is a need to provide decision makers with information about the societal, economic and environmental impact of proposed programs. Cost-benefit analysis (CBA) is a preferred approach (Department of Treasury and Finance, 2013). By identifying, evaluating and comparing costs and benefits of a project, researchers and/or deciding bodies can appraise who gains from a program and who bears the costs from multiple perspectives (including society as a whole, service providers and/or effected individuals) (Campbell & Brown, 2015). A positive overall net benefit (where the benefits outweigh the costs), signifies an economic gain. This means, in theory, that parties who gain from the program could compensate for the parties who pay and the society is still better off. The main characteristic of a cost-benefit analysis is that monetary value is assigned for all costs and outcomes using recognised methodologies (Campbell & Brown, 2015). To allow a decision to be made on whether the COPE program should be made available to Australians with dementia and their caregivers, a cost-benefit analysis is warranted.

The primary aim of this study was to identify the costs and benefits of implementing the COPE program in the existing Australian health context from different perspectives. The secondary aim was to assist policy makers in appraising the program potential for more widespread adoption.

7.2 Methods

This cost-benefit analysis was completed in conjunction with the COPE implementation project which is registered with the Australian National Health and Medical Research Council (ID: ACTRN12617000238370). Ethical approval was obtained from the University of Sydney Human Research Ethics Committee (ID: 2016/834), Northern Sydney Local Health District Ethics Committee (ID: HREC/16/HAWKE/283 and Southern Adelaide Clinical Human Research Ethics Committee (ID: HREC/16/SAC/173).

7.2.1 Cost benefit analysis approach

The approach used was a cost-benefit analysis framework developed by Campbell and Brown (2015) and information was evaluated from four different analytical perspectives; market (or project), private, efficiency and referent group. The four perspectives are described below and their relationship is illustrated in Figure 7-1. Four distinct stakeholder groups were identified for the evaluation: 1) the COPE project team; 2) partner organisations with therapists delivering the COPE intervention (such as aged care organisations, hospitals and private therapists); 3) people with dementia and their caregivers (i.e. clients paying for the intervention) and; 4) the Australian health and social care system.

The different analyses included market and/or non-market (also known as shadow or efficient) prices. Market prices measure the benefits of all project outputs (and inputs) in actual monetary value. This means that any aspect that contributes to the economic outcome of the project is traded ‘in a market’ and a real exchange of currency occurs. However, this rarely happens as outputs such as health or informal care provided by familial caregiver are not/cannot be traded in a market. In these instances (when a market price does not reflect an accurate measure of the marginal cost or benefit) a shadow price is used. Shadow prices can be estimated, or sourced, for example though ‘contingent valuation’; by exploring people’s preferences for their willingness to pay or willingness to accept measures of a good or commodity (Boardman, Greenberg, Vining, & Weimer, 2017). For example, this can be done through studies that seek to identify individuals’ “willingness to pay” (WTP) to avoid negative consequences (such as adverse effects of medications) or to pay for positive consequences (such as reducing pain) (Boardman et al., 2017). This method is typically applied when there is no market price or a market price is not appropriate for the outcomes or impact of interest. Other methods to obtain shadow prices are through publicly available data, for example through the Bureau of Statistics or Government funding bodies. In a cost-benefit analysis adjustments through applying shadow prices are completed to reflect social costs and benefits (Campbell & Brown, 2015).

Market (project) analysis

This perspective considers all project related in- and outputs at actual (market) prices and calculates if the program is effective from a market perspective (Area A + B in Figure 7-1).

Private analysis

Private analysis for a cost-benefit analysis evaluates the costs and benefits of the program from the implementing organisation’s perspective, and is shown as Area B in Figure 7-1.This cost-benefit analysis considers two private organisations: the COPE project team, and the service providers (with COPE trained therapists). Private analysis only considers the costs and benefits related to the organisation to calculate the profit (or the net benefit). Market prices are used to calculate the two separate private analyses for the analysis for this project. Private analysis is familiar to most organisations as it is commonly used in developing business cases.

Efficiency analysis

Area A + B + C (Figure 7-1) represents the net efficiency, or social benefits. This approach is similar to market analysis, with the exception that shadow prices are used when applicable. An example of shadow price use is the ‘value’ placed on the Quality of Life (QoL) for the caregivers and/or people with dementia who receive the COPE program. As there is no market for Quality of Life, its ‘value’ cannot be included in the project analysis. Yet, Quality of Life can be included in the efficiency analysis using shadow prices.

The efficiency analysis determines if the COPE program is economically efficient between all stakeholders. The analysis draws from standard economic theory in welfare economics where the impact of a good, or program, to social welfare is determined by deducting social costs from gross social benefits; resulting in net social benefits (Heijman, 1998). The Kaldor-Hicks criterion is further applied to this analysis (Campbell & Brown, 2015). This criterion means that if the monetised net benefits for all parties affected by the program could compensate for the parties that are adversely affected by the program (where costs outweigh the benefits) and the society is still better off, the program is an economically efficient method of applying scarce resources across all stakeholders involved (Campbell & Brown, 2015).

Referent group analysis

Referent group analysis considers stakeholders relevant to the decision-maker and clarifies the distribution of the program net benefits; that is who benefits from the COPE program and who endures the costs. This analysis explores alternative program features and / or policy recommendations and therefore allows for greater transparency than a conventional cost-benefit analysis. Additionally, referent group analysis ensures that the costs and benefits incurred by different stakeholders are readily available for further appraisal in the separated groups (Campbell & Brown, 2015). Since the funding agency is the decision maker for the COPE program, we included the COPE project team, health service providers and occupational therapists delivering the COPE program, and people with dementia and their caregivers in the referent group.

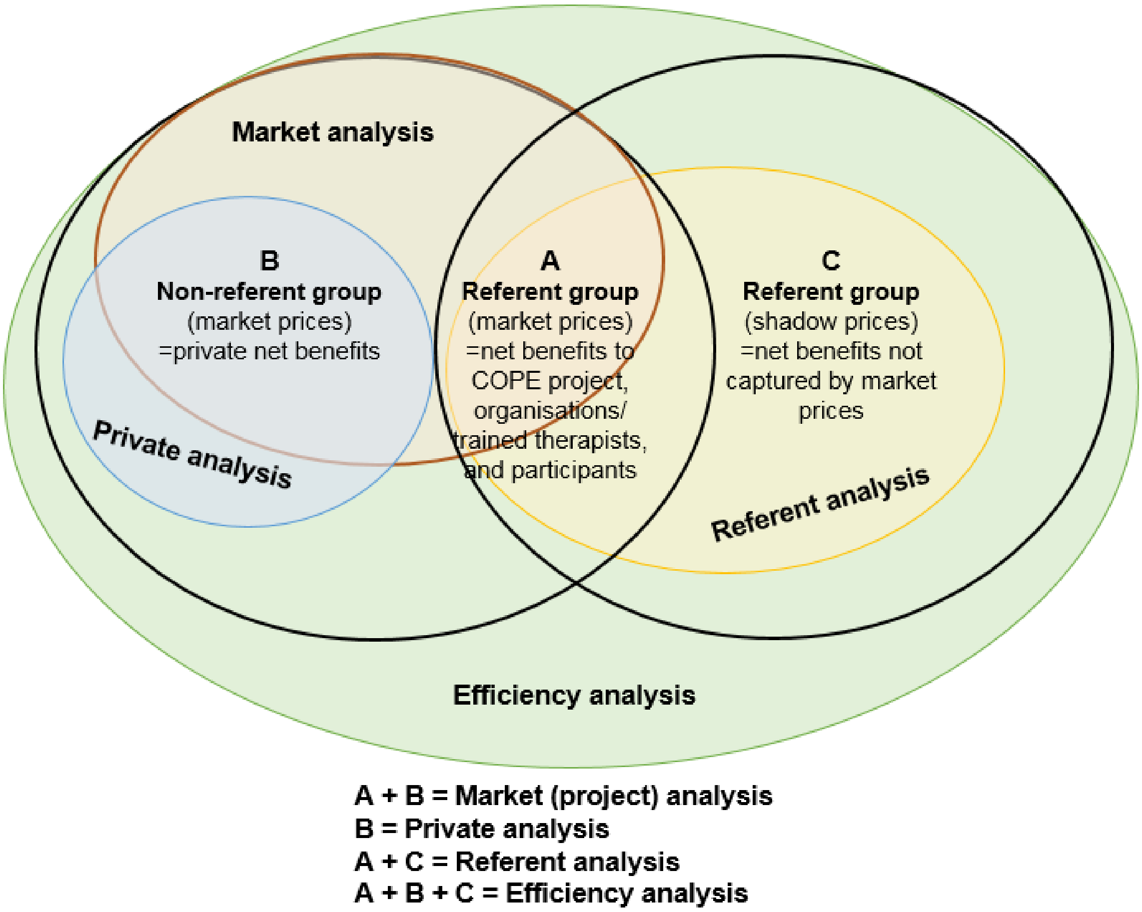


Figure 7-1 Relationship between the Market, Private, Efficiency and Referent Group analysis. Adapted from Campbell and Brown (2015).

7.2.2 Key variables

The program funding began in 2016 and implementation with participating organisations continued until 2019. A projection for the program adoption was completed until 2024 to reflect the implementation of the program in Australia. In other words, the application of COPE in standard care. In general, the projection period should be long enough to capture the potential costs and benefits of including COPE in standard care provision. Yet, as with any cost-benefit analysis, uncertainty exists about the expected project outcomes and care should be taken when predicting for future (or long term) impacts (Office of Best Practice Regulation, 2016). A five year projection period beyond the research study was used for this project.

7.2.2.1 Discounting

The yearly costs and benefits (cash flows) for each of the four types of analysis described above were calculated from the beginning of the project funding (2016), through the project implementation (2017-2019), and adoption period (2020- 2024). These cash flows were discounted to the value of 2019 (A$) to reflect the year of the evaluation (not the initial project commencement year as indicated by the study protocol) (Clemson et al., 2018). A discount rate reflects a time preference where future costs and benefits have a stronger rating than current (costs and benefits). Three different discount rates were tested 2%, 5% and 7%, with 5% being the recommended rate for health economic evaluations in Australia (Department of Health Australia, 2016b). Other sensitivity analyses were also completed as part of this analysis in order to explore alternative scenarios. This was done by adjusting the cell entries in our worksheets (Campbell & Brown, 2015). Overall, and all other things considered equal, implementation of the COPE program will be considered worthwhile if the discounted net benefit (that is benefits minus costs) is positive.

The project team's plans for program roll-out and basic design is outlined in Table 7-1. Two 'master trainers' will deliver ongoing training in different cities in Australia three times a year. The training is planned as two-day intensive (face-to-face) workshop as per the original training structure during implementation phase. The cost for the program was derived from current continuing professional development programs for occupational therapists in Australia (retrieved 24 February, 2019 from https://www.otaus.com.au/professional-development). Further detail is outlined in Appendix G; Supplementary file.

Table 7-1 Program basic design

COPE program basic design parameters	Unit
Number of training sessions (per year)	3
Number of participants per training session (target)	20
Number of days per training session (days)	2
Number of hours per training day (hours)	7
Number of hours preparation for training (hours)	7
Number of coaching sessions for an occupational therapist	3
Number of coaching calls planned a year	6
Price of COPE for therapist (training certification, 3 coaching sessions)	$ 900.00

As with any cost-benefit analysis, this study was completed using assumptions and estimations based on data collected during the project and from published literature. As part of the project, the participant dyads (i.e. people with dementia and their caregivers) were asked about their health service use with a revised (Lite) version of the Resources Use in Dementia instrument (RUD; Wimo, Jonsson, & Zbrozek, 2010; Wimo & Winblad, 2003). The questionnaire has been validated for assessing care accessed in community dwelling people with dementia in Sweden (Wimo et al., 2010). A copy of the questionnaire is attached as Appendix H. Actual data were used from 84 participant dyads who completed the questionnaires. Paired mean pre- and post-program differences for health service use were calculated to assess health service use outcomes for each dyad. SPSS statistical software package (IBM Corporation, 2013) was used to aid the calculations. Grey literature (e.g. Department of Health Australia, 2017a; Independent Hospital Pricing Authority, 2019) around health service use related costs were used to calculate (the change in) value of services accessed.

Actual data (including salaries) from partner organisations on therapist and/or nurse involvement time were used to complete the analysis. Therapist and/or nurse time to attend program specific training was recorded and each completed service records of time spent with participant dyads (Appendix I). The records included detail about average total minutes spent delivering a session (including travel, one-on-one, documentation and follow up time), resources provided, and consultation related charges to the dyad (if applicable). We estimated the number of therapists available for training (National Health Workforce Dataset, 2018) and used audit findings from Chapter 5 (Rahja, Comans, et al., 2018a) to inform changes in therapist intervention delivery.

For key variables regarding informal caregivers, we used national averages (Australian Bureau of Statistics, 2018b) to evaluate costs related to changes in employment and the value of informal care provided (accessed 20th April, 2018 through https://www.payscale.com/research/AU/Job=Home_Care_Worker/Hourly_Rate). All pre-modelled variable inputs for the analyses are further detailed in the work-up (Appendix G).

7.2.3 Costs

Costing of items was completed by using information provided about actual costs from participating organisations and publicly available data regarding the cost of healthcare use. Two primary cost components were included in this analysis; the initial investment and ongoing costs. Initial investment costs were derived from the actual expenditure data and included detail related to the four rounds of occupational therapist training provided (two in both New South Wales and South Australia); trainer related salary, travel and accommodation, partner related travel, catering and all training related material provided (Initial set up and implementation years 2016-2017).

The ongoing costs were related to the COPE project team, organisations/ therapists and participant dyads. The estimated project specific ongoing costs (2020-2024) were calculated using actual training related costs and program design plan (Table 7-1). Shadow price was applied to training venue hire in the efficiency analysis as the venue was originally provided at no cost by the hosting university. By applying a shadow price, the opportunity cost of a hire fee, if the university was to hire this space out, was included in the analysis.

Organisation and/or therapist specific ongoing costs were calculated using actual and estimated data at market prices. The projection of number of therapists trained (and how many remain delivering COPE) is presented in Table 7-2. Detailed work-up is included in the supplementary document (Appendix G). Specifically, Table S7-4 demonstrates the drop off assumptions for retaining trained therapists, and Table S7-5 depicts the calculations for number of trained and retained therapists. The numbers were based on actual data; 38 occupational therapists (33 from public and 5 from private sectors) were initially trained over four training sessions. Of the 38 trained therapists, 26 delivered at least one program by 2019. The variances in therapists delivering the program was tested in the sensitivity analysis.

Table 7-2 Projection of COPE trained therapists retained at the end of each adoption year

Year	(n) trained new	(n) trained accumulated	(n) retained newly trained	(n) left delivering COPE
Year 1 (2020)	38	38	26	54
Year 2 (2021)	60	98	41	69
Year 3 (2022)	60	158	41	78
Year 4 (2023)	60	218	41	85
Year 5 (2024)	60	278	41	91

Costs and estimates related to delivery of the COPE program were calculated in market prices using actual data from therapist logs. Table 7-3 provides a breakdown of the costs and estimates related to annual COPE program delivery based on the data. Costs related to total number of programs delivered for each of the program adoption years were calculated using the estimated numbers in Tables 7-2 and 7-3. Our data contained significant variance in regards to program delivery due to the different settings in which implementation occurred (private, government and non-government aged care organisations).

As can be seen in Table 7-3 therapist logs showed that the average time spent in each session was 169 minutes (inclusive of travel and documentation time). We modelled a minimum and maximum time spent per session by subtracting and adding (respectively) 30% to the total average time spent per session per dyad (including travel and documentation). The therapist logs also did not separate detail about time spent completing research related consent and questionnaires with participants. We estimated that research related time consisted of 30 minutes during the first session (to complete consent and pre study questionnaires), and 15 minutes during final session (to complete post questionnaire). We also calculated a total average time spent delivering each session without these research related items (line D, Table 7-3). The minimum time spent delivering each COPE consultation was calculated as 85 minutes (line E, Table 7-3). This was counted as the average face-to-face time only taken to deliver the program. Sensitivity analysis was used to explore these variances in program delivery.

Table 7-3 Costs and estimates related to annual COPE program delivery

Per occupational therapist (including nursing hours)	**Average**	**Minimum**	**Maximum**
A)Number of clients per therapist per year	5	3	10
B)Number of sessions per client	7	3	10
C)Total time spent delivering a session in minutes (includes: travel, 1:1, documentation, follow up) – *with* project documentation	169	118†	219‡
D)Total time spent delivering a session in minutes (includes: travel, 1:1, documentation, follow up) – *without* project documentation	157§	Not modelled	Not modelled
E)Total time spent delivering a session in minutes (includes: 1:1 time only)	85	Not modelled	Not modelled
F)Occupational therapist wage per hour (weighted average of public and private)	A$ 70.91	A$ 56.25	A$ 153.00
G)Nurse wage per hour	A$ 68.76		
H)Standard number of occupational therapy sessions per COPE package	10	1	10
I)Number of nursing sessions per COPE package	1	0	2
J)Client fee per session	A$ 181.30	A$ 102.73	A$ 250.00
K)COPE caregiver guide book	A$ 30.00		

† Minimum session time calculated as average total session time -30%
‡ Maximum session time calculated as average total session time +30%
§ Average session time counted without research related documentation

Dyad specific (ongoing) costs were related to accessing the COPE program. These were derived from actual charges reported in therapist logs (Table 7-3, and Appendix I). Based on findings from the study in chapter 5 (Rahja, Comans, et al., 2018a) regarding therapists' intervention focus, COPE was considered to be a new service delivered by occupational therapists. Therefore, 10 sessions were included in the calculated total revenue from programs delivered to the dyads. The sensitivity analysis examined variances in number of programs delivered and time spent delivering the program.

7.2.4 Benefits

Whilst occupational therapists acquire a new skill following COPE training, an assumption was made that this does not warrant an increase in industry award rate (salary). However, an increase in quality of services delivered to people with dementia was expected. This was specifically in the number of consultation sessions delivered. For the participant dyads the expected benefits from participating in the program were related reduction in informal care provided and health services accessed.

The benefits of COPE on a person's function and quality of life (QoL), as well as caregiver wellbeing have been reported in earlier studies evaluating participant outcomes following participating in the COPE program (Fortinsky et al., 2016; Gitlin, Winter, et al., 2010). We, therefore, expected benefits around time spent providing informal care related to activities of daily living (ADLs), instrumental activities of daily living (IADLs) and supervising the person with dementia. We also collected data and assessed benefits related to time spent away from paid employment for caregivers. However, we did not collect data to directly evaluate changes in Quality of Life for this project. In general, Quality of Life consists of a number of personal and environmental factors that contribute to one's well-being and ability to participate in meaningful activities (Bulamu et al., 2015; WHOQOL Group, 1993). A number of disease (e.g. QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999), generic (e.g. EQ-5D; Rabin & de Charro, 2001) and caregiver specific (e.g. CWS; Quirk et al., 2012) instruments can be used to evaluate the program effects on the participants' Quality of Life. Such tools allow for calculation of Quality Adjusted Life Years (QALYs) that are commonly used in cost-utility analyses. We assumed a 0.01 improvement in a person's health state, less than the minimum important change if using the EQ-5D to measure change in health utility (Coretti, Ruggeri, & McNamee, 2014). Published data (A$60,000 per QALY gained) was used to place monetary value for the change in health state estimates for the participants (Shiroiwa et al., 2010). This change in Quality of Life was also tested in the sensitivity analysis.

Based on earlier reports regarding the benefits of multicomponent occupational therapist delivered interventions on health service use (Graff et al., 2008), it was expected that there would be a reduction in health service use costs for the person with dementia. This included more nights spent at home instead of hospital, long-term or respite care. Other expected benefits included less presentations to emergency department or ambulance attendances at home, as well as reduced use of home care services, and less healthcare services accessed in the community. It should be noted that due to the nature of the project partners, some participants received the COPE program directly following hospitalisation, through transitional care programs. It is assumed that the rates of hospitalisation prior to accessing the COPE program for these participants would have been higher than those accessing the program through other avenues, such as home care packages. This variation was included in the sensitivity analysis.

7.3 Results

The main results and discounted net benefits for each four analyses (market, private, efficiency and referent group) are summarised at a discount rate of 5% in Table 7-4. Table 7-5 displays the distribution of the net benefits to the referent group (the COPE project team; health service providers and occupational therapists delivering the COPE program and; participant dyads) with the same discount rate (5%). Each (Table) includes the base case scenario and subsequent univariate sensitivity analysis.

The program incurred a net cost of over A$2.4 million from a market (project) perspective. The main expenses were related to cost of therapists delivering and participant dyads paying for the intervention. The private analysis found gains for both the COPE project team (A$249,017) and the service providers adopting and delivering the COPE program (A$405,064) at market prices.

If shadow prices are used to appraise the project, almost A$6.2 million societal gain is presented (as shown in the efficiency analysis). The gains are most prominent from reduced use of hospital and long-term care services, as well as reduced healthcare service use in the community. Other noticeable gains were improved Quality of Life for the participant dyads, and reduction in time spent caregiving and away from paid employment (see Table 7N in supplementary file: Appendix G for more detail about breakdown of benefits). The societal benefit more than doubles, if the number of programs delivered doubles (sensitivity analysis, Table 7-4). Smaller improvements in societal gains are made if the time spent delivering the program, or number of sessions delivered to a dyad is reduced (sensitivity analysis, Table 7-4). These improvements included the removal of time spent with participant dyads in completing research related documentation (30 minutes during first session and 15 minutes during last session). A conservative estimate, as in no improvement, in Quality of Life as well as variance to accessing the program directly following hospitalisation also showed that the program could maintain a net gain for the society.

The distribution of the costs and benefits of the program to relevant stakeholders are expressed in the referent group analysis in Table 7-5. People with dementia and their caregivers endure most of the ongoing costs, regardless of the variance in program set up and scenarios. Reduced fees to access the program and increased Quality of Life value reduced the costs endured by the participants. Most variance in costs and benefits (as in changes in net benefits) was evident for organisations (and therapists) delivering the program.

The non-referent group analysis showed that the Australian health and social care system benefits the most out of the program implementation and adoption (approximately A$8.1 million). The univariate sensitivity analysis indicated that number of programs delivered in a year and hospital stays prior to program entry were the key components affecting efficiency gains.

Table 7-4 Base case and univariate sensitivity analysis (5% discount rate)

	Project	Private	Efficiency	Referent group	Non-referent group
Base case	**(-$2,438,073)**	**$654,081**	**$6,189,249**	**(-$1,890,317)**	**$8,079,567**
Number of therapists left delivering COPE (+10%)	(-$2,492,108)	$667,633	$6,334,254	(-$1,921,912)	$8,256,166
Number of therapists left delivering COPE (-10%)	(-$2,384,038)	$640,530	$6,044,245	(-$1,858,723)	$7,902,968
Number of programs delivered by therapists per year (3)	(-$1,449,211)	$406,082	$3,535,618	(-$1,312,122)	$4,847,740
Number of programs delivered by therapists per year (10)	(-$4,910,228)	$1,274,080	$12,823,329	(-$3,335,805)	$16,159,133
Therapist time spent delivering COPE (mean total time -30%, 118 minutes)	(-$1,746,761)	$1,345,393	$6,880,561	(-$1,199,005)	$8,079,567
Therapist time spent delivering COPE (mean total time +30%, 219 minutes)	(-$3,127,671)	(-$35,516)	$5,499,652	(-$2,579,915)	$8,079,567
Therapist time spent delivering COPE without research related data collection during first (30min) and last (15min) visits, 157 minutes	(-$2,277,025)	$815,130	$6,350,298	(-$1,729,269)	$8,079,567
Therapist time spent delivering COPE (mean 1:1 time, 85 minutes)	(-$1,291,693)	$1,800,462	$7,335,630	(-$743,937)	$8,079,567
Number of sessions delivered to a dyad (minimum: 3)	(-$1,094,554)	$1,997,600	$7,532,768	(-$546,798)	$8,079,567
Number of sessions delivered to a dyad (maximum: 10)	(-$3,337,197)	(-$245,043)	$5,290,125	(-$2,789,441)	$8,079,567
Client fee for accessing program (minimum A$102)	(-$2,438,073)	(-$613,400)	$6,189,249	(-$1,890,317)	$8,079,567
Client fee for accessing program (maximum A$259)	(-$2,438,073)	$1,921,562	$6,189,249	(-$1,890,317)	$8,079,567
Participant Quality of Life improvement (0.03)	(-$2,438,073)	$654,081	$8,124,991	$45,424	$8,079,567
Participant Quality of Life improvement (nil: 0)	(-$2,438,073)	$654,081	$5,221,379	(-$2,858,188)	$8,079,567
Variation in hospital stay prior to accessing COPE (-50%)	(-$2,438,073)	$654,081	$1,971,269	(-$1,890,317)	$3,861,587

Table 7-5 Distribution of net benefits to referent group, base case and univariate sensitivity analysis (5% discount rate)

	COPE project team	Organisations delivering COPE	Participant dyads
Base case	**$135,363**	**$39,806**	**(-$2,065,486)**
Number of therapists left delivering COPE (+10%)	$135,363	$53,358	(-$2,110,633)
Number of therapists left delivering COPE (-10%)	$135,363	$26,254	(-$2,020,340)
Number of programs delivered by therapists per year (3)	$135,363	(-$208,194)	(-$1,239,292)
Number of programs delivered by therapists per year (10)	$135,363	$659,805	(-$4,130,973)
Therapist time spent delivering COPE (mean -30%, 118 minutes)	$135,363	$731,118	(-$2,065,486)
Therapist time spent delivering COPE (mean +30%, 219 minutes)	$135,363	(-$649,792)	(-$2,065,486)
Therapist time spent delivering COPE without research related data collection during First (30min) and last (15min) visits, 157 minutes	$135,363	$200,854	(-$2,065,486)
Therapist time spent delivering COPE (minimum 85 minutes)	$135,363	$1,186,186	(-$2,065,486)
Number of sessions delivered to a dyad (minimum: 3)	$135,363	$1,383,325	(-$2,065,486)
Number of sessions delivered to a dyad (maximum: 10)	$135,363	(-$859,318)	(-$2,065,486)
Client fee for accessing program (minimum A$102)	$135,363	(-$1,227,675)	(-$798,006)
Client fee for accessing program (maximum A$259)	$135,363	$1,307,287	(-$3,332,967)
Participant Quality of Life improvement (0.03)	$135,363	$39,806	(-$129,745)
Participant Quality of Life improvement (nil: 0)	$135,363	$39,806	(-$3,033,357)
Variation in hospital stay prior to accessing COPE (-50%)	$135,363	$39,806	(-$2,065,486)

7.4 Discussion

This is the first study to report on the costs and benefits of including an evidence-based dementia reablement program, COPE, in the existing health and aged care context in Australia. Almost A$6.2 million societal gain was found to result from including the program in standard dementia care provision.

The findings from this cost-benefit analysis have implications for the Australian health and aged care sector. As it currently stands, the health care system is the main gainer from the program, with approximately A$8.1 million benefit presented in the non-referent group analysis. However, people with dementia and their caregivers are the bearers of the costs due to out-of-pocket payments for accessing the program. Thus, in order to improve social welfare, there is a need to implement strategies to address the costs currently incurred by people with dementia to ensure uptake of the program.

The findings presented in this study add to evidence base about ‘dyadic’ interventions (i.e. interventions that work with both people with dementia and their caregivers). A recent review by the Australian Government's independent research and advisory body, the Productivity Commission, found that current interventions to support caregivers were not “appropriate for adoption” in preventing or delaying entry into residential care for people with dementia (SCRGSP, 2018, p. 2). Of the 44 interventions included in the review, only two (Brodaty, Gresham, & Luscombe, 1997; Brodaty, Mittelman, Gibson, Seeher, & Burns, 2009) included participants in Australia. Furthermore, only three interventions were high quality and effective (in preventing or delaying entry into residential aged care facilities); two included counselling and the other case management (SCRGSP, 2018). This study has provided evidence to support dyadic interventions that consist of education and skills building for caregivers of people with dementia. The study has demonstrated a decline in hospital and long-term care services accessed as well as gains in caregiver impact (supplementary file includes further detail of outcomes). The current intervention and evaluation were also completed within the existing health context in Australia, suggesting that adoption of the COPE program in Australia is possible.

Lastly, conservative estimates for training (and retaining) of occupational therapists to deliver the program for people with dementia were used; the actual 32% drop off rate for initial year and 50%, 30% and 10% drop off rates for subsequent years. The outcomes reported in this study are based on an assumption that 91 therapists continue to deliver the program at the end of 2024. In 2016, 14,126 registered therapists worked in Australia (National Health Workforce Dataset, 2018). Of these, 2,673 worked in the aged care sector (National Health Workforce Dataset, 2018). This means that only 3% of therapists working in aged care would need to adopt and deliver COPE in their ongoing practice to produce the societal gains presented in this study. This percentage (of therapists delivering the COPE program) is in line with what Rogers (1995) describes as ‘innovators’; first individuals to adopt a new innovation relative to current knowledge. Therapists who are forward in their thinking, intrigued about new programs (and seek) to improve their own practice, consider themselves as opinion leaders, and are supported by their contextual factors (such as organisational demands) exemplify the ‘innovators’ who may initially engage in training and subsequent delivery of the COPE program (Greenhalgh, 2005).

7.4.1 Strengths and limitations

A strength of this study is that it applied a well-recognised economic methodology that is familiar to governments and decision makers. The costs and benefits were evaluated from four different perspectives: market, private, efficiency (social) and referent group (key stakeholders). The breakdown of net benefits related to key stakeholders in the referent group analysis allowed for greater transparency. Using different perspectives to evaluate the size and distribution of the net benefits is particularly important as it allows for the examination of who benefits from the program and who endures the costs. This is important in evaluations of programs that have multiple stakeholder groups (Campbell & Brown, 2005). This study also demonstrated the impact of different scenarios regarding the implementation of the COPE program using the different sensitivity analyses. This was particularly useful as the COPE project seeks to establish how the program fits the existing Australian heath context. Additionally, the inclusion of the referent group analysis added depth to this analysis that a more traditional cost-benefit analysis may have missed (Campbell & Brown, 2015).

A limitation of this study is that the outcomes were only calculated using a program adoption, or ‘with-or-without’, scenario. The study did not compare the net benefits to an alternative intervention aimed at supporting functional independence for people with dementia. Thus, it is difficult to ascertain if including the COPE program as per the evaluation completed in this thesis is the ‘best’ scenario for program (or intervention) uptake. Another limitation is that the analysis was completed with data collected before and immediately after participating in the program (pre and post). This may have biased results towards the net benefit for the COPE program as some participants access the program at the point of crisis, for example immediately following an acute hospitalisation for health condition that may or may not be attributable to their dementia. Therefore, items such as reporting reduction in health service use may have been impacted. At this stage no data for long-term outcomes (for example 12 months post intervention) are available. Future research should include evaluation of longer-term outcomes following participating in COPE or similar programs.

Lastly, the analysis was completed using data collected with an instrument that has been validated for the collecting detail about informal care and health service use with people with dementia (Wimo et al., 2010; Wimo & Winblad, 2003). Although the instrument has been modified with time to increase accuracy and precision to reflect current health service use, the instrument was not designed, developed, or validated in Australia. As such, it was difficult to collect detail about how and to what extent the participants accessed health services at home or in the community under the different Government subsidised schemes (such as the home care packages discussed in section 1.1.2) that are available for aged care consumers in Australia.

7.4.2 Implications for practice

The COPE reablement program has the potential to reduce the societal and economic impact of dementia in Australia, especially through reduction in healthcare service utilisation, informal care burden and improved quality of life of people with dementia. Decision makers can be reassured that the uptake and inclusion of the program in standard care provision in Australia would represent value. This study is a call for action to enable the shift in current occupational therapy practice in care of people with dementia from a short-term approach to a multi-session one, such as the COPE program, that considers individualised concerns and upskilling caregivers to continue to provide informal care. Ongoing therapist training has been planned for Australia and any occupational therapist working in the aged care sector is encouraged to seek training and engage in subsequent program implementation. Health service providers (including Government, non-government and private) are encouraged to be innovators and adopters of initiatives such as COPE. Organisations are encouraged to use their own financial departments to establish breakeven points for adopting and delivering the program.

Lastly, this cost-benefit analysis presents an archetypal example of a preventative social care program that can improve the wellbeing of people with dementia and their caregivers. Economic evidence now exists that it is worthwhile, and the society can be better off. This study has demonstrated how the health and social care system is the biggest beneficiary of the program. The direct users of the program are the bearers of the costs. There is a need to plan and provide subsidies (or incentives) that assist people with dementia and their caregivers to engage in these programs. Funding bodies are urged to recognise the potential societal benefits that can be achieved from participating in reablement programs such as COPE.

This chapter has evaluated the costs and benefits of implementing the COPE program in Australia. The chapter has provided reassurance that implementing the COPE program can be worthwhile and the program should be made available (and accessible) for Australians living with dementia.

Considered together, the research studies presented in this thesis have added knowledge to guide the development of the final ‘blueprint’ for the ongoing implementation of the COPE program in Australia. The chapters presented so far have evaluated aspects that contribute to the COPE implementation; specifically related to feasibility, uptake, costs, service delivery, and client satisfaction. The thesis now moves on to synthesising the findings presented. The next chapter re-visits the aims for this thesis and includes a discussion about the strengths and limitations of the overall work completed. As the purpose of this thesis is to evaluate the COPE program implementation, the next chapter also re-states the candidate's original contribution to research, including a discussion about the implications for practice and future research arising from the work completed.

CHAPTER 8: GENERAL DISCUSSION

The World Health Organization in their global action plan for dementia (2017) identified that translation of research into daily practice as crucial for improving the lives of people living with dementia. The Organisation called on member states, including Australia, to “develop, implement and monitor the realisation of a national research agenda on prevention, diagnosis, treatment, and care of people with dementia” (World Health Organization, 2017, p. 33). In Australia, the National Health and Medical Research Council (NHMRC) had already funded the Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (or the Cognitive Decline Partnership Centre; CDPC). The CDPC engages in research and knowledge exchange in order to improve health and health care related to cognitive and associated functional decline in older people, including people with dementia. When the Australian Federal Government provided A$200 million for the Boosting Dementia Research Initiative (Commonwealth of Australia, 2014), the NHMRC established the National Institute for Dementia Research (NNIDR); an umbrella institute that focuses on translating dementia research evidence to practice with the vision to produce improved outcomes for people with dementia, their caregivers, and the Australian community (NHMRC National Institute for Dementia Research, 2017). A number of ‘programs’, including the CDPC began operating under this umbrella (NHMRC NNIDR, 2017). In 2016, the CDPC funded the ‘COPE Australia project’. The project aimed to change current dementia care practice in Australia and inform policy through implementation of the COPE program in standard dementia care provision (Clemson et al., 2018).

The purpose of this thesis was to evaluate the implementation of the COPE program in the Australian health context. The implementation outcomes of interest for this thesis were related to feasibility, acceptability, uptake, costs, service delivery, and client satisfaction. The studies described in this thesis (chapters 2-7) have each contributed to the evaluation of these outcomes and each has included discussion about the findings related to the study described. This chapter will re-visit and build on to the dialogue already had. Five aims were identified for this thesis. These aims are re-visited below. After, a discussion about the strengths and limitations of this thesis is included through synthesis of the findings from the included studies. Lastly, a discussion about implications for practice and future research is presented, and final remarks about the COPE program implementation in Australia are made.

Aim 1: To establish the costs and outcomes of different occupational therapy approaches for people with cognitive and/or functional decline and /or their caregivers

A narrative systematic review identified the costs and outcomes of occupational therapy for people with cognitive and/or functional decline and/or their caregivers. Thirteen studies with diverse range of occupational therapy interventions were included in the review. The intervention approaches in the included studies varied, ranging from one-off assessment through to systematic multicomponent programs. The participant characteristics also varied and included people with Parkinson's disease or dementia, older people who were cognitively intact, had visual impairment or other chronic health conditions. Results suggested that structured occupational therapy interventions which comprised of multiple consultations and engaged caregivers delivered better functional and economic outcomes. No study included economic evaluations of occupational therapy for people with dementia in Australia, highlighting the unique contribution of the work presented in chapter 7 of this thesis. The review was published in *Health and Social Care in the Community* (Rahja, Comans, et al., 2018b).

Aim 2: To understand the Australian general public's current level of knowledge about treatments for dementia and about occupational therapy for older people

Two online population surveys were completed using a consumer panel provider PureProfile. The first survey concerning the public's knowledge about treatments for dementia found that dementia specific treatments proven effective in randomised trials may not be recognised as effective by the general population in Australia. The study also identified that health education and research programs need to focus on educating Australians about the effectiveness of treatments for dementia in order to reduce the societal impact of the condition. The study was published in *Gerontology and Geriatric Medicine* (Rahja, Laver, et al., 2018).

The second study asked the general public about their knowledge of occupational therapy for older people. The study was published in the *Australian Occupational Therapy Journal* (Rahja & Laver, 2019). The three take home messages from the study were that: 1) the Australian public has limited understanding of the scope of occupational therapy in supporting older people; 2) the misconceptions that occupational therapy is only concerned with workplace or physical health need to be addressed and; 3) future advertising campaigns should consider the current level of knowledge about occupational therapy.

Both studies provided insight into the public's current level of knowledge and beliefs that can assist with promotion of the COPE program to the wider population in Australia. This was particularly important to achieve because an understanding of the public's knowledge regarding treatments available can guide future health education and service development campaigns in a way that is compatible with the current level of understanding.

Aim 3: To evaluate the current approaches to delivering occupational therapy services for older people with dementia in the community

A total of 87 occupational therapy case notes were audited from different service contexts in two states in Australia. The case notes were reviewed against criteria that included duration of service, assessments conducted, and interventions used. With the median length of the intervention being 1 month, and an average of 2.1 consultations per referral, the services tended to be short-term. The most common assessments were related to home safety, falls risk and function. Intervention most commonly focussed on referrals to other services, environmental modification advice and prescription of assistive technologies. The audit revealed that current occupational therapy practice for people with dementia focusses on assessment and management of risk. The audit highlighted that occupational therapy practice in dementia care does not reflect occupational therapy interventions which have been shown to be effective in randomised trials. Furthermore, steps are needed to increase the time and number of consultations offered and to shift the focus from assessment (and risk management) to interventions which focus on promoting independence and addressing changed behaviours. The audit was published in the *Australian Occupational Therapy Journal* (Rahja, Comans, et al., 2018a).

The audit findings can be used to evaluate the uptake of longer-term occupational therapy intervention approaches in the future. For example, uptake of interventions that focus on improving engagement in day to day activities for people with dementia and educating caregivers on strategies to address changes in behaviours attributable to dementia. The findings were also used to evaluate change in care provision by occupational therapists in the cost-benefit analysis described in this thesis.

Aim 4: To understand the experiences of people with dementia and their family caregivers of participating in the COPE reablement program.

Ten interviews with the COPE program participants were completed to describe their experiences of participating in the program. The overall experience was mostly rated very valuable by the participants. Themes from the interviews highlighted that caregivers found the ongoing collaboration with a therapist in addressing dementia related areas of concern empowering. The findings from the interviews also validated that programs such as COPE are helpful and desired by consumers. A therapeutic relationship between the family and health professional together with individualised intervention approaches tailored to needs and readiness of the participants fostered positive experiences and confidence. The COPE program also promoted participation in everyday activities for the person with dementia and was considered to give them a ‘second chance’ to remain in their own homes and communities.

The findings from the interviews also reported benefits of the COPE program that are difficult to capture quantitatively. For example, the way in which COPE had helped delay entry to residential care homes for the participants. The findings also highlighted how the COPE program is an opportunity for occupational therapists and organisations that provide occupational therapy services to lift their profile in supporting people with dementia. The study has been submitted for peer review for a special issue (knowledge translation and dementia) in *Brain Impairment* (2019).

Aim 5: To identify the costs and benefits of implementing the COPE program in the existing Australian health context from different perspectives.

A well-used and reliable methodology familiar to governments and decision makers was applied to evaluate the costs and benefits of implementing the COPE program in Australia. Four different perspectives: market, private, efficiency (social) and referent group (key stakeholders) were considered in the evaluation. A social cost-benefit analysis presented almost A$6.2 million societal gain. The referent group analysis demonstrated that people with dementia and their caregivers are the bearers of the costs and that the Australian health and social care system gains the most from the program implementation. The findings emphasised the need to plan and provide subsidies or other financial incentives to assist people with dementia and their caregivers to engage in programs such as COPE. Funding bodies and decision makers were reassured, and urged to recognise the potential societal benefits that can be achieved from participating in programs such as COPE. The study has been submitted for peer review in *Health and Social Care in the Community,* 2019.

8.1 Strengths

A strength of this work is the mixed methods approach used to complete the included studies. Each study has contributed to the evaluation of the implementation of the COPE program in Australia. For example, the use of PureProfile for the two population surveys was a contemporary approach to reach people across Australia who may not be otherwise available to occupational therapy researchers. No such method has been used in occupational therapy literature in Australia before and the findings provided insight into how the COPE program may be promoted to the public. The audit described actual services provided and quantified the evidence-practice gap in occupational therapy interventions currently delivered to people with dementia. The participant interviews about their experiences with the program added explanatory detail about how or why programs such as COPE can be effective, and the cost-benefit analysis applied an approach familiar to governments and decision makers that can be used to inform policy.

The review of literature (chapter 2) established that systematic multicomponent occupational therapy interventions that consist of improving the home environment, the ability of the person and the skills of their caregiver can be cost effective for people experiencing cognitive and/or functional decline. Evidence of the economic benefits was found for supporting community dwelling people with dementia and their caregivers, the caregivers of people with Parkinson’s disease, and people aged 60 and over (Rahja, Comans, et al., 2018b). The review highlighted that only a few studies have incorporated detailed economic aspects into their evaluation of intervention effectiveness for older people with cognitive and/or functional decline. Only two studies (Carande-Kulis et al., 2015; Salkeld et al., 2000) in the review included participants from Australia. Carande-Kulis et al. (2015) compared the costs and benefits of a falls prevention program for older people (led by an occupational therapist) to an exercise and a Tai Chi program. Salkeld et al. (2000) calculated the incremental cost effectiveness of an occupational therapist delivered home hazard reduction program for older adults who had experienced a recent fall. Additionally, only two studies (Gitlin, Hodgson, et al., 2010; Graff et al., 2008) evaluated occupational therapy interventions for people living with dementia. One study was conducted in the United States (Gitlin, Hodgson, et al., 2010) and the other in the Netherlands (Graff et al., 2008). To date, no study has evaluated the economic impact of occupational therapy interventions for people with dementia in Australia (Rahja, Comans, et al., 2018b).

The current cost-benefit analysis adds to the evidence about economic evaluations of occupational therapy approaches for people with cognitive and/or functional decline in Australia, and worldwide. The analysis reported almost A$ 6.2 million in social gains from the COPE program implementation until 2024 using shadow prices. The current analysis considered four different perspectives in the evaluation and also provided a breakdown of the costs and benefits of the program to different stakeholder groups. Of the two studies included in the systematic review in this thesis, Gitlin, Hodgson, et al. (2010) applied shadow price in their evaluation and reported a net economic benefit of the occupational therapist delivered Tailored Activities Program (TAP). They used an incremental cost effectiveness analysis and reported that the caregivers saved an extra hour per day in "doing things" at a cost of $2.37/day and one extra hour per day in "being on duty" at a cost of $1.10/day if engaging in the program (Gitlin, Hodgson, et al., 2010). Graff et al. (2008) also used an incremental cost effectiveness analysis and found that the Community Occupational Therapy intervention for people with Dementia (COTiD) produced the largest cost savings in informal care. At a cost of about €1200, the intervention saved an average of €1748 in other healthcare costs over a period of three months.

It is important to note that the content of the COPE program has similarities with the interventions evaluated in the two dementia specific studies included in the review (Gitlin, Hodgson, et al., 2010; Graff et al., 2008). The three interventions (COPE, COTiD and TAP) consist of multiple components, are tailored to the needs of the person with dementia, their caregiver, and are between 8 to 10 sessions long. They are examples of occupational therapy intervention approaches that have been recognised as best practice to reduce behavioural symptoms for people with dementia living in the community (Laver et al., 2014). Examples were provided in Box 5.1, chapter 5. Overall, all three programs have shown to produce better functional and economic outcomes, and the findings from the current cost-benefit analysis support the use of multicomponent occupational therapy approaches to improve the well-being of people with dementia living in the community.

The inclusion of people with dementia-caregiver dyads in the interviews (with participants who received the COPE program in chapter 6) is another strength. Including the perceptions from these key participants (or stakeholders) helps with understanding the authentic outcomes of an intervention and is more likely to lead to changes in care of people with dementia. Furthermore, the interviews about participant experiences with COPE (chapter 6) together with the cost-benefit analysis (chapter 7) provide information that builds onto the report from the Productivity Commission that was described in chapter 7 (SCRGSP, 2018). The report found that of 44 interventions that were assessed for their effectiveness in preventing or delaying entry into residential care for people with dementia, only two (2) (Brodaty et al., 1997; Brodaty et al., 2009) included participants in Australia. Only three high quality interventions that consisted of either counselling or case management were identified as effective in preventing or delaying entry into residential care for people with dementia, and no existing interventions aimed at caregivers of people with dementia were considered suitable for adoption in Australia (SCRGSP, 2018). The findings from the current two chapters (6 and 7) support multicomponent interventions aimed at upskilling caregivers through approaches such as problem solving, stress management and articulating effective strategies around areas of concern. The findings from the included studies demonstrated that the COPE program can be adopted in care practices in Australia, and there are net societal gains to be made from the program implementation in standard care. The outcomes also suggest improved ability and confidence in caregivers to continue with their caregiving roles; re-engagement in activities at home for people with dementia and; enablement for the person with dementia to remain at home longer, suggesting delayed admission to residential care facilities.

8.2 Limitations

One of the limitations of these studies is the lack of Indigenous Australians representation in the included studies. The two population surveys (chapters 3 and 4) were unable to identify the extent to which Aboriginal and Torres Strait Islander people were represented in the responses. The representation was also not evident in the case note audit (chapter 5). Neither of the studies about participant experiences with COPE and cost-benefit analysis included detail about the representation of Indigenous Australians (chapters 6 and 7). As already discussed in chapters 3 and 4, the prevalence of dementia in Indigenous people in Australia is up to five times the rate of the non-Indigenous population (Smith et al., 2008) and their voices should be heard. This is particularly important as understanding and beliefs about dementia amongst Indigenous people can be different to people from non-indigenous background. Chapters 3 and 4 also gave an example of how the term dementia is not used in some cultures, and how beliefs, traditions, law, language and the connection to the land symbolise the concept of well-being (Smith et al., 2007).

The number of people with dementia represented in chapters 6 and 7 is another limitation to this work. Consent and returned questionnaires were received from 85 participant dyads (people with dementia and their caregivers); 84 were included in the cost-benefit analysis as one dyad did not return details of health service use. There are over 400,000 people with dementia and almost

200,000 informal caregivers living in Australia (Brown et al., 2017). The studies related to the COPE program implementation outcomes also only included participants from New South Wales and South Australia. Thus, it can be difficult to generalise findings to residents in other states, especially given the size of Australia and differences in health services in rural and remote areas of the country. Conducting research studies, such as the current project, come with challenges. These challenges include financial and time constraints, as well as small sample sizes. Yet, as this thesis has identified, reablement programs that are aimed at people with dementia and their caregivers are not available in standard care practice in Australia. It would, therefore, be important to continue evaluate the outcomes of engaging in programs such as COPE to determine the long-term effects of these interventions.

8.3 Original contribution

This thesis has described findings from six research studies which have each shown originality in their contribution to knowledge. The first chapter outlined that my original contribution to research was to evaluate particular aspects of implementation. I described three ways in which my work was going to further knowledge in the field and have an impact on dementia care in Australia. These are re-iterated below.

1) A foundation about the Australian public’s knowledge about treatments for dementia. This foundation can be used to inform campaigns aimed at increasing awareness and reducing stigma.

2) A clearly defined evidence-practice gap in services delivered by occupational therapists supporting community dwelling people with dementia in Australia. The knowledge about this gap can be used to evaluate future uptake of interventions identified as best practice, as well as to make recommendations for service improvements.

3) A significant addition to the policy perspective in reablement programs for people with dementia in Australia.

The implications for practice and research of these contribution are now outlined.

8.3.1 Implications for practice

The cost-benefit analysis presented in chapter 7 displays a classic example of a preventative social care program that can improve the wellbeing of people with dementia and their caregivers. Implementation of the COPE program in Australia can produce almost A$6.2 million in social gains to the country. These gains can be achieved through reduction in healthcare service use, informal caregiver burden and improved Quality of Life for people with dementia. To the health and social care system alone, the gains were over A$8 million. Thus, the cost-benefit analysis demonstrated that the Australian health and social care system gains the most out of the program implementation. The analysis also showed that the people with dementia and their caregivers (i.e. the direct users of the COPE program) are the bearers of the costs due to payments for accessing the program. Thus, the study in chapter 7 highlighted the need to implement strategies to address the costs incurred by people with dementia to ensure uptake and sustainability of the COPE program implementation. Chapter 1.1.3 discussed funding schemes currently available for older Australians accessing supports and services in the community. Other schemes also exist but are not within the scope of this study. In summary, short-term services can be accessed through Commonwealth Home Support Program (CHSP) and transitional care programs (TCP). Ongoing services for more complicated care needs can be further accessed through schemes such as the newly introduced home care packages (HCP) guided by the Consumer Driven Care reform. Department of Veterans' Affairs (DVA) are also available for eligible older people. All these schemes were used by the participants in the COPE program as described in chapter 7. In the future, these schemes may be used to access the COPE program delivered by appropriately trained and certified occupational therapists. However, work is required to enable access to these funding schemes for people with dementia and their caregivers in order to facilitate program uptake and limit out-of-pocket costs.

A key objective of the Australian Government's home-based care schemes is to enable older people to remain at home (Nous Group & Department of Health, 2018). These schemes can be used to access reablement and wellness programs that support this objective. The COPE program is in line with the current objectives around reablement of people with dementia. However, challenges exist in encouraging organisations to pursue delivering home based reablement programs such as COPE. For example, not all home care package providers consider or expect to deliver reablement programs under Consumer Directed Care (Nous Group & Department of Health, 2018). Organisations have also expressed concern about a lack of financial incentives to pursue wellness and reablement approaches as these approaches can be difficult to reconcile within existing business models. This concern is also explained in the current cost-benefit analysis. The referent group analysis (chapter 7, Table 7-5, sensitivity analysis) showed vast variances in net benefits (range -A$859,318 to A$1,186,186) for organisations. The variances were related to the number of programs delivered and occupational therapist time spent delivering the COPE program. Organisations would need to consider their approaches to delivering COPE to ensure feasibility for the business.

This thesis has also argued that reablement programs, such as COPE, should be recognised and given more prominence in health policy. The interview outcomes described in chapter 6 and cost-benefit evaluation completed in chapter 7 add to evidence about 'dyadic' interventions (that is, interventions that work with both people with dementia and their caregivers). As described earlier, the findings from this thesis support dyadic interventions to support caregivers of dementia to continue to provide informal care that can delay entry to residential care homes. Funding incentives and recognition for providers who demonstrate commitment to wellness and reablement approaches is also warranted. Further guidelines and incentives for organisations to adopt and implement programs such as COPE is required in order to maintain with the key objectives of the Government funded home-based care schemes.

As already explained, it was possible to embed COPE in existing healthcare systems. Chapters 6 and 7 identified that the program was delivered by occupational therapists working in different service contexts, including government funded geriatric community services, short-term transitional care programs (TCP) or Commonwealth Home Support Programs (CHSP). Some participants also accessed the COPE program through non-government organisations and private therapists, for example by using their Home Care Packages (HCP) or Veteran's Affairs allowances (DVA). Metropolitan and regional areas in the two participating states (New South Wales and South Australia) were also covered by the program. Positive experiences and outcomes were reported by participants accessing COPE across all involved schemes and geographical areas. Thus, it is possible to embed COPE in a range of service contexts and service areas to enable people with dementia live in their chosen environments.

However, work is required to embed programs such as COPE in routine occupational therapy practice in Australia. Chapter 5 identified that current practice does not reflect interventions shown to be effective in randomised trials (Rahja, Comans, et al., 2018a). Yet, despite the current occupational therapy practice being short-term and limited to one or two sessions (chapter 5), therapists were able to adopt and deliver COPE over an average of seven sessions (chapter 7). These findings suggest that with appropriate support and reinforcement, COPE can be accepted and adopted by occupational therapy practitioners and/or their respective organisations. Chapter 5 made relevant recommendations that should be considered by occupational therapists and organisations offering services to people with dementia and their caregivers. These recommendations included: a call for action for dementia care service providers to facilitate evidence-based occupational therapy through resources, training and role definition; the need for occupational therapists to further their knowledge and skills in providing care for people with dementia and; the encouragement for occupational therapists interested and/or confident in supporting people with dementia to promote their knowledge and skills within their services and networks.

Despite the lack of knowledge about treatments for dementia (chapter 3) and occupational therapy (chapter 4) in the general population in Australia, the program was well accepted by the participants in the study. For example, the overall rating regarding the experience of participating in COPE was 3.8 out of 4 (range 3-4) as described in chapter 6. Chapter 1.1.7 discussed theories that can be used to explain how and why people may (not) take action to engage in programs such as COPE to improve their health. Health literacy was described as a person's ability to make informed decisions about their health that is structured around their knowledge about health and health-care systems (Kickbusch & Maag, 2008). Health related behaviour was recognised as the actions and the causes, correlates and consequences of those actions such as improved quality of life and coping skills (Parkerson et al., 1993). The issue of the public's health literacy has been the subject of previous academic work, as well as the two population surveys included in this thesis. The two chapters identified that younger people and men were less knowledgeable about treatments for dementia and the scope of occupational therapy. Both chapters also identified that health education and research programs need to focus on educating Australians about the effectiveness of treatments that can improve functional outcomes for older people and people with dementia in order to reduce the societal impact of the ageing population and the condition. Health related behaviour was further examined in chapters 6 and 7. For example, the study in chapter 6 asked about the participants' reasons for engaging in the COPE program and identified that caregiver readiness may contribute to the approaches taken by therapists to deliver the COPE program and the subsequent outcomes from engaging in the program. Chapter 7 included a discussion about the enabling factors, such as the different healthcare schemes in Australia that can aid people with dementia to access programs such as COPE. A further description of how the theories described in chapter 1.1.7 can be applied to the findings from chapters presented in this thesis is included in Table 8-1.

Chapter 4 made recommendations about how to make occupational therapy services more visible for consumers. These recommendations are also relevant to promoting access to programs such as COPE. For example, there is a need to educate consumers on how to access occupational therapy services (and programs such as COPE) within the current healthcare schemes (such as Home Care Packages under the new Consumer Driven Care model). The public and other health care providers should be made aware of the unique services occupational therapists can deliver. Therapists and organisations offering their services were encouraged to be forward in their thinking and engage in up to date promotional strategies such as social media, blogging, press releases and other public relations strategies to advocate for the profession. Therapists were also encouraged to provide evidence that service recipients are offered best value for their investment, as well as identify and promote the costs and effects of choosing their specific services. The use of case stories of people participating in programs such as COPE was identified as a useful way of improving the public's level of understanding of program related outcomes. For example, stories about participants' experiences with the COPE program are freely available through the COPE Australia website (Accessed 5 June, 2019: https://copeprogram.com.au/cope-stories/). This thesis has also outlined a number of costs and benefits related to participating in the COPE program that can be used to demonstrate the value of engaging in such programs.

Table 8-1 Applying health related decision-making theories to thesis findings

Theory (Author, year)	Chapter and application to practice
Andersen's Model of Health Service Use (Andersen, 1968, 1995)	*Chapters 3 and 4:* 'Predisposing factors' such as age and gender may impact if and how programs such as COPE are accessed. *Chapter 6:* "Need factors' such as difficulty managing, but the willingness to keep the person with dementia at home may encourage participation in programs such as COPE. *Chapter 7:* 'Enabling factors' such as Government healthcare funding schemes can impact the access to health services and programs such as COPE.
Health Belief Model (Hochbaum, 1958; Hochbaum et al., 1952)	*Chapters 3 and 4:* Attitudes towards dementia reablement programs such as COPE can impact engagement in such programs. Same applies to engaging with occupational therapy. Current level knowledge should be considered in future advertising and promotional activities in order to increase uptake. *Chapter 6:* Understanding about the participants' reasons for engaging in the COPE program can assist in future promotion of programs. Participant experiences with the program can further help change people's beliefs about how to improve wellbeing for people with dementia and their caregiver.
Transtheoretical Model and Stages of Behavioural Change (Prochaska, 1979)	*Chapter 6:* The level of caregiver readiness, including willingness to accept help and implement strategies learned though the COPE program may shape the way COPE is delivered and the subsequent outcomes.
Theory of Planned Behaviour (Ajzen, 1985; Fishbein & Ajzen, 1975)	*Chapters 3 and 4:* Current level of knowledge can be used to guide how to develop programs that are based on the current level of knowledge and perceptions of interventions that can improve outcomes for dementia and if this impacts their readiness to take action to seek such intervention. *Chapter 6:* Motivation and socially desirable outcomes can be used to help engage people with programs such COPE. Using examples of participant experiences such as empowering caregivers, re-engaging the person with dementia in activities and giving a second chance to remain at home can be powerful motivators to engage people in programs such as COPE.

Another way of enhancing the public's knowledge could be via platforms such as Massive Open Online Courses (MOOCs). These are online educational platforms that are free for the public and can be accessed anywhere in the world. MOOCs are becoming increasingly popular with health practitioners as well as the general public. MOOCs about understanding and preventing dementia already exist. For example, the Wicking Dementia Research and Education Centre's Understanding Dementia MOOC (2018) had over 20,000 people enrolled in the course in 2016, and over 29,000 in 2017 (Eccleston et al., 2019). It may be worthwhile investing in developing a MOOC about "living well with dementia", or a similar course that specifically focuses on life after diagnosis of dementia. Such a course could enhance the public's knowledge about treatments available, as well as the role of different health professionals in supporting people with dementia.

8.3.2 Implications for research

As the first study to evaluate the implementation of an evidence-based reablement program in Australia, this thesis has made a significant contribution to dementia care literature in this country. However, there is a need to investigate the long-term outcomes of engaging in programs such as COPE in Australia. A follow-up would, therefore, be useful to explore whether the benefits achieved from participating in the COPE intervention and the changes in health service use are sustained in longer-term.

The Australian Government is grappling to identify services and supports that can reduce the economic impact of dementia, and the ageing population. Health economic evaluations ultimately inform health policy. However, choosing tools to calculate health economic outcomes may impact the way in which the outcomes are collected and reported. Chapter 7 evaluated the costs associated with delivery of the COPE program and assessed changes in resource use of people with dementia before and after participating in the intervention, including informal care provided. The instrument used to collect data related to the participants' health service use was the revised version of the Resources Use in Dementia instrument (RUD-Lite; Wimo & Winblad, 2003). The RUD instrument has been validated for assessing care accessed and resources used by community dwelling people with dementia in Sweden, and is widely used across the globe (Wimo et al., 2013; Wimo et al., 2010). The RUD collects detail about the informal caregivers' level of care contribution, as well as the time they spent delivering care related to activities of daily living (ADLs), instrumental activities of daily living (IADLs) and supervising the person with dementia. Although the RUD instrument has been modified over time to increase accuracy and reflect current health service use, it has not been designed, developed, or validated in Australia.

Chapter 7 identified that it was difficult to ascertain how, and to what extent, health services were used by the participants in the community through the different Government subsidised schemes such as the home care packages (discussed in chapter 1.1.3). Other instruments can also be used to measure health service use, including services used by people with dementia (e.g. Leggett et al., 2016; Yang, Dawes, Leroi, & Gannon, 2018). Examples of these instruments include the Client Service Receipt Inventory (CSRI; Beecham & Knapp, 1992), Resource Use Inventory (RUI; Sano et al., 2006) and other cost diaries and surveys. The CSRI includes 30 questions and consists of five domains: background, living situation, employment status including income and other benefits, and detail about services accessed and informal care received (Beecham & Knapp, 1992). The instrument was originally developed to collect detail about service use of residents who had moved from long-stay hospitals to community (PSSRU, 2019), but has been adapted to suit different populations of interest, including people with dementia (e.g. Panca et al., 2019; Yang et al., 2018). The instrument has also been validated for evaluating health service use for treatment of adults with deliberate self-harm (Byford et al., 2007). The Resource Use Inventory (RUI; Sano et al., 2006) was developed to capture formal (paid) and informal (unpaid) care use, as well as loss of paid and volunteer employment in healthy elderly (Sano et al., 2006). The RUI includes nine questions related to hospitalisation, outpatient clinic visits and medical tests, non-medical care accessed, source and type of informal care, and time use related to employment or volunteer activities (Sano et al., 2006). The instrument has also been used to evaluate health service use of people with cognitive impairment (e.g. Zhu et al., 2013). Other cost diaries and surveys have also been used (e.g. Koopmanschap, van Exel, van den Berg, & Brouwer, 2008), but it is unknown if any of these instruments have been validated to assess service use by people with dementia.

Currently there is no instrument that has been specifically designed to capture the Australian health care context and health service use. Instruments that capture the nature of different health care funding schemes accessed in Australia may yield more accurate outcomes of health service use in studies evaluating economic outcomes of interventions in the country. Therefore, future research should investigate adapting one of the earlier described instruments, or developing a new instrument that captures the nature of Australia's health care system in health economic evaluations. Such measurement would enable more rigorous and standardised economic evaluations to be completed in Australia to guide future funding initiatives.

Lastly, another area for further investigation is to understand how older people, and people with dementia, choose home care services under the new Consumer Directed Care model in Australia. Such knowledge could help guide future healthcare practice by identifying the services consumers accessing home care packages prefer and why, as well as how consumers accessing community aged care packages make decisions about their package spending. This knowledge could further assist occupational therapists and organisations in deciding which services and staff are used by consumers and why in order to better meet consumers' needs. To this end, a study is currently underway (Rahja, Laver, Crotty, & Comans, 2019).

CONCLUSIONS

Evidence-based reablement programs for people with dementia and their caregivers exist, but are not routinely implemented in practice. Randomised controlled studies have shown these programs to be effective in terms of delaying functional decline and improving caregiver wellbeing. However, less is known about the implementation of these programs in standard care practice, including feasibility, acceptability, costs and outcomes. The COPE Australia project is one of the first implementation projects in Australia aimed at improving the lives of people living with dementia by adapting and implementing an occupational therapist-delivered evidence-based reablement program, COPE, in standard care provision. The evaluation presented in this thesis has contributed to the implementation of the COPE program within the Australian health and aged context.

The work presented in this thesis proposes that implementing the COPE program in Australia can produce societally and economically positive outcomes. This thesis has described how implementing the program in the existing health and aged context has the potential to advance current dementia care practice, including upskilling occupational therapists to deliver evidence-based reablement programs in the community. This thesis has also established that the COPE program has potential to reduce the societal and economic burden of dementia through reduction in healthcare service utilisation, informal care burden and improved quality of life for people with dementia. However, the suite of studies completed in this thesis also suggest that engagement and adoption of programs such as COPE can be difficult. This is, for example, due to the public's limited knowledge about effective interventions available to treat dementia. Suggestions to improve the public's knowledge were made. Lastly, in order to increase uptake of programs such as COPE, this thesis made a call to give reablement programs more prominence in funding schemes available to people living with dementia. Work is still required to embed evidence-based reablement programs, such as COPE, for people with dementia and their families within clinical practice in Australia.

REFERENCES

Abdin, E., Subramaniam, M., Achilla, E., Chong, S. A., Vaingankar, J. A., Picco, L., . . . McCrone, P. (2016). The Societal Cost of Dementia in Singapore: Results from the WiSE Study. *Journal of Alzheimer's Disease, 51*(2), 439-449. doi:10.3233/JAD-150930

Access Economics. (2003). The dementia epidemic: Economic impact and positive solutions for Australia.

Aguilar, A., Stupans, I., Scutter, S., & King, S. (2014). Exploring how Australian occupational therapists and physiotherapists understand each other's professional values: implications for interprofessional education and practice. *Journal of Interprofessional Care, 28*(1), 15-22. doi:10.3109/13561820.2013.820689

Ajzen, I. (1985). From intentions to actions: A theory of planned behavior. In J. Kuhl & J. Beckmann (Eds.), *Action control: From cognition to behavior* (pp. 11-39). Berlin, Heidelber, New York: Springer-Verlag.

Allen, C. (1985). *Occupational therapy for psychiatric diseases: Measurement and management of cognitive disabilities*. Boston, United States: Little, Brown and Company.

Alzheimer's Disease International. (2013). *Policy Brief for G8 Heads of Government. The global impact of dementia 2013-2050.* Retrieved from London: https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf

Alzheimer Society of Canada. (2010). *Rising Tide: The impact of dementia on Canadian society*. Retrieved from Toronto, Canada: https://alzheimer.ca/en/suroit/Get-involved/Advocacy/Latest-info-stats/Rising-Tide

Alzheimer's Disease International. (2015). *The global impact of dementia: An analysis of prevalence, incidence, cost and trends*. Retrieved from London: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupation Therapy, 62*, 625-683. doi:10.5014/ajot62.6.625

Andersen, R. M. (1968). *Families' use of health services: A behavioural model of predisposing, enabling and need components.* Purdue University, West Lafayette, IN. USA. Retrieved from http://docs.lib.purdue.edu/dissertations/AAI6902884

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1-10. doi:10.2307/2137284

Andersen, R. M., & Davidson, P. (2007). Improving access to care in America: Individual and contextual indicators. In R. M. Andersen, T. Rice, & G. Kominski (Eds.), *Changing the U.S. health care system: Key issues in health services policy and management* (pp. 3-31). San Francisco, CA, US: Jossey-Bass.

Australian Bureau of Statistics. (2011). Census of Population and Housing: Socio-Economic Indexes for Areas, Australia, 2011. Retrieved from http://www.abs.gov.au/ausstats/

Australian Bureau of Statistics. (2013). Technical paper: Socio-Economic Indexes for Areas (SEIFA), 2011. Retrieved from http://www.abs.gov.au/ausstats/

Australian Bureau of Statistics. (2017). Australian demographic statistics, Mar 2017. Retrieved from http://www.abs.gov.au/

Australian Bureau of Statistics. (2018a). Australian demographic statistics, June 2017. Retrieved from http://www.abs.gov.au/

Australian Bureau of Statistics. (2018b). Characteristics of Employment, Australia, August 2018. *6333.0.* Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/mf/6333.0

Australian Commission on Safety and Quality in Health Care. (2014). Health literacy: Taking action to improve safety and quality. Retrieved from www.safetyandquality.gov.au/

Australian Institute of Health and Welfare. (2012). *Dementia in Australia. Cat. No. AGE 70*. Retrieved from Canberra: https://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents

Australian Institute of Health and Welfare. (2017). Older Australia at a glance. Retrieved from http://www.aihw.gov.au/

Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen’s Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *GMS Psycho-Social-Medicine, 9*. doi:10.3205/psm000089

Barton, G. R., Sach, T. H., Doherty, M., Avery, A. J., Jenkinson, C., & Muir, K. R. (2008). An assessment of the discriminative ability of the EQ-5Dindex, SF-6D, and EQ VAS, using sociodemographic factors and clinical conditions. *The European Journal of Health Economics, 9*(3), 237-249. doi:10.1007/s10198-007-0068-z

Beecham, J., & Knapp, M. (1992). Costing psychiatric interventions. In G. Thornicroft, C. R. Brewin, & J. J. Wing (Eds.), *Measuring mental health needs (pp.).* (pp. 163-183). London, England: Gaskell/Royal College of Psychiatrists.

Bendixen, R. M., Levy, C. E., Olive, E. S., Kobb, R. F., & Mann, W. C. (2009). Cost effectiveness of a telerehabilitation program to support chronically ill and disabled elders in their homes. *Telemedicine Journal & E-Health, 15*(1), 31-38. doi:10.1089/tmj.2008.0046

Bennett, S., & Bennett, J. (2000). The process of evidence-based practice in occupational therapy: Informing clinical decisions. *Australian Occupational Therapy Journal, 47*(4), 171-180. doi:10.1046/j.1440-1630.2000.00237.x

Bennett, S., Shand, S., & Liddle, J. (2011). Occupational therapy practice in Australia with people with dementia: A profile in need of change. *Australian Occupational Therapy Journal, 58*(3), 155-163. doi:10.1111/j.1440-1630.2011.00930.x

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . . Viswanathan, M. (2011). Health literacy interventions and outcomes: An updated systematic review. *Evid Rep Technol Assess (Full Rep),* (199), 1-941. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4781058/

Beswick, A. D., Rees, K., Dieppe, P., Ayis, S., Gooberman-Hill, R., Horwood, J., & Ebrahim, S. (2008). Complex interventions to improve physical function and maintain independent living in elderly people: A systematic review and meta-analysis. *The Lancet, 371*(9614), 725-735. doi:10.1016/S0140-6736(08)60342-6

Boardman, A. E., Greenberg, D. H., Vining, A. R., & Weimer, D. L. (2017). *Cost-benefit analysis: Concepts and practice* (4th ed.): Cambridge University Press.

Bonsall, A., Mosby, A., Walz, M., & Wintermute, K. (2016). Health care professionals' knowledge of occupational therapy. *American Journal of Occupational Therapy, 70*(4_Supplement_1), 7011510189p7011510181-7011510189p7011510181. doi:10.5014/ajot.2016.70S1-PO1060

Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Dis Assoc Disord, 23*(4), 306-314. doi:10.1097/WAD.0b013e3181a6bebc

Brasure, M., Desai, P., Davila, H., & et al. (2018). Physical activity interventions in preventing cognitive decline and alzheimer-type dementia: A systematic review. *Annals of Internal Medicine, 168*(1), 30-38. doi:10.7326/M17-1528

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Brodaty, H., & Cumming, A. (2010). Dementia services in Australia. *International Journal of Geriatric Psychiatry, 25*(9), 887-995. doi:10.1002/gps.2587

Brodaty, H., Gresham, M., & Luscombe, G. (1997). The Prince Henry Hospital dementia caregivers' training programme. *Int J Geriatr Psychiatry, 12*(2), 183-192.

Brodaty, H., Mittelman, M., Gibson, L., Seeher, K., & Burns, A. (2009). The effects of counseling spouse caregivers of people with Alzheimer disease taking donepezil and of country of residence on rates of admission to nursing homes and mortality. *American Journal of Geriatric Psychiatry, 17*(9), 734-743. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2738999/

Brodaty, H., Seeher, K., & Gibson, L. (2012). Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *International Psychogeriatrics, 24*(7), 1034-1045. doi:10.1017/s1041610211002924

Brown, L., Hansnata, E., & La, H. A. (2017). Economic cost of dementia in Australia 2016-2056. Canberra: National Centre for Social and Economic Modelling & Alzheimer's Australia. Retrieved from www.fightdementia.org.au.

Bulamu, N., Kaambwa, B., & Ratcliffe, J. (2015). A systematic review of instruments for measuring outcomes in economic evaluation within aged care. *Health Qual Life Outcomes, 13: 179*. doi:10.1186/s12955-015-0372-8

Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J. (2009). Translating the REACH Caregiver Intervention for Use by Area Agency on Aging Personnel: The REACH OUT Program. *Gerontologist, 49*(1), 103-116. doi:10.1093/geront/gnp012

Burns, A., & Iliffe, S. (2009). Dementia. *BMJ, 338*, b75. doi:10.1136/bmj.b75

Byford, S., Leese, M., Knapp, M., Seivewright, H., Cameron, S., Jones, V., . . . Tyrer, P. (2007). Comparison of alternative methods of collection of service use data for the economic evaluation of health care interventions. *Health Economics, 16*(5), 531-536. doi:10.1002/hec.1175

Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Dis Assoc Disord, 29*(3), 255-275. doi:10.1097/wad.0000000000000102

Campbell, A., Hale, L., Jacobs, R., Kerse, N., La Grow, S., Robertson, M., . . . Sharp, D. (2005). Randomised controlled trial of prevention of falls in people aged = or > 75 with severe visual impairment: The VIP trial. *British Medical Journal, 331*(7520), 817-820. doi:10.1136/bmj.38601.447731.55

Campbell, H., & Brown, R. (2005). A multiple account framework for cost–benefit analysis. *Evaluation and Program Planning, 28*(1), 23-32. doi:10.1016/j.evalprogplan.2004.05.001

Campbell, H., & Brown, R. (2015). *Cost-benefit analysis: Financial and economic appraisal using spreadsheets* (2nd ed.). London: Taylor and Francis.

Carande-Kulis, V., Stevens, J. A., Florence, C. S., Beattie, B. L., & Arias, I. (2015). A cost-benefit analysis of three older adult fall prevention interventions. *Journal of Safety Research, 52*, 65-70. doi:10.1016/j.jsr.2014.12.007

Cations, M., Radisic, G., Crotty, M., & Laver, K. (2018). What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. *PLoS One, 13*(4), e0196085. doi:10.1371/journal.pone.0196085

Chee, Y. K., Dennis, M., & Gitlin, L. (2005). Provider assessment of interactions with dementia caregivers. *Clinical Gerontologist, 28*(4), 43-59. doi:10.1300/J018v28n04_04

Chen, M. L. (2016). The growing costs and burden of family caregiving of older adults: A review of paid sick leave and family leave policies. *Gerontologist, 56*(3), 391-396. doi:10.1093/geront/gnu093

Cheung, K. S.-L., Lau, B. H.-P., Wong, P. W.-C., Leung, A. Y.-M., Lou, V. W. Q., Chan, G. M.-Y., & Schulz, R. (2015). Multicomponent intervention on enhancing dementia caregiver well-being and reducing behavioral problems among Hong Kong Chinese: A translational study based on REACH II. *International Journal of Geriatric Psychiatry, 30*(5), 460-469. doi:10.1002/gps.4160

Chong, M. S., Tan, W. S., Chan, M., Lim, W. S., Ali, N., Ang, Y. Y., & Chua, K. C. (2013). Cost of informal care for community-dwelling mild-moderate dementia patients in a developed

Southeast Asian country. *International psychogeriatrics / IPA, 25*(9), 1475-1483. doi:10.1017/S1041610213000707

Clemson, L., Laver, K., Jeon, Y.-H., Comans, T., Scanlan, J. N., Rahja, M., . . . Gitlin, L. (2018). Implementation of an evidence-based intervention to improve the wellbeing of people with dementia and their carers: Study protocol for 'Care of People with dementia in their Environments (COPE)' in the Australian context. *BMC Geriatr, 18*(1), 108. doi:10.1186/s12877-018-0790-7

Commonwealth of Australia. (2013a). My Aged Care. Retrieved from https://www.myagedcare.gov.au/

Commonwealth of Australia. (2013b). National Disability Insurance Scheme Act 2013. No20, 2013. Retrieved from https://www.legislation.gov.au/Details/C2013A00020

Commonwealth of Australia. (2014). Budget Paper No. 2: Budget Measures. *Boosting Dementia Research.* Retrieved from http://www.budget.gov.au/2014-15/content/bp2/html/bp2_expense-14.htm

Commonwealth of Australia. (2016). New national approach to dementia support. Retrieved from http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2016-ley25012016.htm?OpenDocument&yr=2016&mth=01

Coretti, S., Ruggeri, M., & McNamee, P. (2014). The minimum clinically important difference for EQ-5D index: A critical review. *Expert Rev Pharmacoecon Outcomes Res, 14*(2), 221-233. doi:10.1586/14737167.2014.894462

Corrieri, S., Heider, D., Riedel-Heller, S., Matschinger, H., & König, H. (2011). Cost-effectiveness of fall prevention programs based on home visits for seniors aged over 65 years: A systematic review. *International Psychogeriatrics, 23*(5), 711-723. doi:10.1017/S1041610210002280

Corvol, A., Netter, A., Campeon, A., & Somme, D. (2018). Implementation of an occupational therapy program for Alzheimer's disease patients in France: Patients' and caregivers' perspectives. *Journal of Alzheimer's Disease, 62*(1), 157-164. doi:10.3233/jad-170765

Cummings, J. (2001). Treatment of Alzheimer's disease. *Clinical Cornerstone, 3*(4), 27-39. doi:10.1016/S1098-3597(01)90046-8

Czaja, S. J., Lee, C. C., Perdomo, D., Loewenstein, D., Bravo, M., Moxley, P., Jerad H, & Schulz, R. (2018). Community REACH: An implementation of an evidence-based caregiver program. *Gerontologist, 58*(2), e130-e137. doi:10.1093/geront/gny001

Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: Cash-for-care in six European countries' long-term care policies. *Milbank Q, 88*(3), 286-309. doi:10.1111/j.1468-0009.2010.00601.x

Darawsheh, W. B. (2018). Awareness and knowledge about occupational therapy in Jordan. *Occup Ther Int, 2018*. doi:10.1155/2018/2493584

Davis, J. C., Robertson, M. C., Ashe, M., Liu-Ambrose, T., Khan, K., & Marra, C. A. (2010). Does a home based strength and balance programme in people aged ≥ 80 years provide the best value for money to prevent falls?: A systematic review of economic analyses of falls prevention interventions. *Br J Sports Med, 44*(2), 80-89. doi:10.1136/bjsm.2009.060988

Davis, J. C., Robertson, M. C., Comans, T., & Scuffham, P. A. (2011). Guidelines for conducting and reporting economic evaluation of fall prevention strategies. *Osteoporosis International, 22*(9), 2449-2459. doi:10.1007/s00198-010-1482-0

Department of Health Australia. (2010). National male health policy: Building on the strengths of australian males.   Retrieved from https://www.health.gov.au/internet/main/publishing.nsf/Content/male-policy

Department of Health Australia. (2012). Living longer. Living better.   Retrieved from https://apo.org.au/node/29086

Department of Health Australia. (2016a). Ageing and aged care.   Retrieved from https://agedcare.health.gov.au

Department of Health Australia. (2016b). Guidelines for preparing a submission to the Pharmaceutical Benefits Advisory Committee (Version 5).   Retrieved from https://pbac.pbs.gov.au/information/printable-version-of-guidelines.html

Department of Health Australia. (2017a). Medicare Benefits Schedule Book. Category 1.   Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/downloads

Department of Health Australia. (2017b). Your guide to commonwealth home support programme.   Retrieved from www.myagedcare.gov.au

Department of Treasury and Finance. (2013). *Economic evaluation for business cases technical guidelines*. Melbourne, Australia Retrieved from https://www.dtf.vic.gov.au/investment-lifecycle-and-high-value-high-risk-guidelines/technical-guides.

Detsky, A. S., & Laupacis, A. (2007). Relevance of cost-effectiveness analysis to clinicians and policy makers. *JAMA, 298*(2), 221-224. doi:10.1001/jama.298.2.221

Dixon, N., & Pearce, M. (2011). *Guide to ensuring data quality in clinical audits*. Retrieved from Healthcare Quality Improvement Partnership: https://www.hqip.org.uk/resources/hqip-guide-to-ensuring-data-quality-in-clinical-audits/

Dopp, C. M., Graff, M. J., Teerenstra, S., Olde Rikkert, M. G., Nijhuis-van der Sanden, M. W., & Vernooij-Dassen, M. J. (2015). Effectiveness of a training package for implementing a community-based occupational therapy program in dementia: A cluster randomized controlled trial. *Clin Rehabil, 29*(10), 974-986. doi:10.1177/0269215514564699

Dow, B., & McDonald, J. (2007). The invisible contract: Shifting care from the hospital to the home. *Australian Health Review, 31*(2), 193-202. doi:10.1071/AH070193

Drame, M., Lang, P. O., Jolly, D., Narbey, D., Mahmoudi, R., Laniece, I., . . . Novella, J. L. (2012). Nursing home admission in elderly subjects with dementia: Predictive factors and future challenges. *J Am Med Dir Assoc, 13*(1), 83.e17-20. doi:10.1016/j.jamda.2011.03.002

Eccleston, C., Doherty, K., Bindoff, A., Robinson, A., Vickers, J., & McInerney, F. (2019). Building dementia knowledge globally through the Understanding Dementia Massive Open Online Course (MOOC). *npj Science of Learning, 4*(1), 3. doi:10.1038/s41539-019-0042-4

Edwards, M. (2015). Family caregivers for people with dementia and the role of occupational therapy. *Physical & Occupational Therapy in Geriatrics, 33*(3), 220-232. doi:10.3109/02703181.2015.1031926

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *20*(8), 423-428. doi:10.1111/j.1745-7599.2008.00342.x

Evers, S., Goossens, M., de Vet, H., van Tulder, M., & Ament, A. (2005). Criteria list for assessment of methodological quality of economic evaluations: Consensus on Health Economic Criteria. *Int J Technol Assess Health Care, 21*(2), 240–245. doi:10.1017/S0266462305050324

Fishbein, M. (1967). *Readings in attitude theory and measurement*. Oxford, England: Wiley.

Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.

Fishbein, M., & Yzer, M. C. (2003). Using theory to design effective health behavior interventions. *Communication Theory, 13*(2), 164-183. doi:10.1111/j.1468-2885.2003.tb00287.x

Fitzpatrick, A. L., Kuller, L. H., Lopez, O. L., Kawas, C. H., & Jagust, W. (2005). Survival following dementia onset: Alzheimer's disease and vascular dementia. *J Neurol Sci, 229-230*, 43-49. doi:10.1016/j.jns.2004.11.022

Flood, C., Mugford, M., Stewart, S., Harvey, I., Poland, F., & Lloyd-Smith, W. (2005). Occupational therapy compared with social work assessment for older people. An economic evaluation alongside the CAMELOT randomised controlled trial. *Age Ageing, 34*(1), 47-52. doi:10.1093/ageing/afh232

Flood, E., Rousculp, M., Ryan, K., Beusterien, K. M., Divino, V. M., Toback, S. L., . . . Mahadevia, P. J. (2010). Parents' decision-making regarding vaccinating their children against influenza: A web-based survey. *Clin Ther, 32*(8), 1448-1467. doi:10.1016/j.clinthera.2010.06.020

Fortinsky, R., Gitlin, L., Pizzi, L., Piersol, C., Grady, J., Robison, J., & Molony, S. (2016). Translation of the Care of Persons with Dementia in their Environments (COPE) intervention in a publicly-funded home care context: Rationale and research design. *Contemp Clin Trials, 49*, 155-165. doi:10.1016/j.cct.2016.07.006

Garvey, G., Simmonds, D., Clements, V., O'Rourke, P., Sullivan, K., Gorman, D., . . . Beattie, E. (2011). Making sense of dementia: Understanding amongst indigenous Australians. *International Journal of Geriatric Psychiatry, 26*(6), 649-656. doi:10.1002/gps.2578

Gately, M., & Trudeau, S. (2017). Occupational therapy and advanced dementia: A practitioner survey. *Journal of Geriatric Mental Health, 4*(1), 48-53. doi:10.4103/jgmh.jgmh_41_16

Gaugler, J. E., Wall, M. M., Kane, R. L., Menk, J. S., Sarsour, K., Johnston, J. A., . . . Newcomer, R. (2011). Does caregiver burden mediate the effects of behavioral disturbances on nursing home admission? *Am J Geriatr Psychiatry, 19*(6), 497-506. doi:10.1097/JGP.0b013e31820d92cc

Gearing, R. E., Mian, I. A., Barber, J., & Ickowicz, A. (2006). A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 15*(3), 126-134. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2277255/

Gill, L., Bradley, S., Cameron, I., & Ratcliffe, J. (2018). How do clients in Australia experience Consumer Directed Care? *BMC Geriatr, 18*(1), 148. doi:10.1186/s12877-018-0838-8

Gitlin, L., & Hodgson, N. (2015). Caregivers as therapeutic agents in dementia care: The context of caregiving and the evidence base for interventions. In J. E. Gaugler & R. L. Kane (Eds.), Family caregiving in the new normal (pp. 305-353). San Diego: Academic Press. Retrieved from http://www.sciencedirect.com/science/article/pii/B9780124170469000179. doi:10.1016/B978-0-12-417046-9.00017-9

Gitlin, L., Hodgson, N., Jutkowitz, E., & Pizzi, L. (2010). The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: The Tailored Activity Program. *American Journal of Geriatric Psychiatry, 18*(6), 510-519. doi:10.1097/JGP.0b013e3181c37d13

Gitlin, L., Jacobs, M., & Earland, T. (2010). Translation of a dementia caregiver intervention for delivery in homecare as a reimbursable medicare service: Outcomes and lessons learned. *Gerontologist, 50*(6), 847-854. doi:10.1093/geront/gnq057

Gitlin, L., Winter, L., Burke, J., Chernett, N., Dennis, M., & Hauck, W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. *American Journal of Geriatric Psychiatry, 16*(3), 229-239. doi:10.1097/JGP.0b013e318160da72

Gitlin, L., Winter, L., Dennis, M., Hodgson, N., & Hauck, W. (2010). A biobehavioral home-based intervention and the well-being of patiend with dementia and their caregivers: The COPE randomized trial *Journal of American Medical Association, 304*(9), 983-991. doi:10.1001/jama.2010.1253

Gitlin, L. N., & Rose, K. (2014). Factors associated with caregiver readiness to use nonpharmacologic strategies to manage dementia-related behavioral symptoms. *International Journal of Geriatric Psychiatry, 29*(1), 93-102. doi:10.1002/gps.3979

Glanz, K., & Rimer, B. (1995). *Theory at a glance: A guide for health promotion practice*. Bethesda, MD: National Cancer Institute.

Glanz, K., Rimer, B., & Viswanath, K. (2015a). The scope of health behaviour. In K. Glanz, B. Rimer, & K. Viswanath (Eds.), *Health Behavior: Theory, Research, and Practice* (pp. 3-22). New York: New York, NY: John Wiley & Sons, Incorporated.

Glanz, K., Rimer, B., & Viswanath, K. (2015b). Theory, research and practice in health behaviors. In K. Glanz, B. Rimer, & K. Viswanath (Eds.), *Health Behavior : Theory, Research, and Practice* (pp. 23-42). New York: New York, NY: John Wiley & Sons, Incorporated.

Glasgow, R., & Emmons, K. (2007). How can we increase translation of research into practice? Types of evidence needed. *Annual Review of Public Health, 28*(1), 413-433. doi:10.1146/annurev.publhealth.28.021406.144145

Glasman, L. R., & Albarracín, D. (2006). Forming attitudes that predict future behavior: A meta-analysis of the attitude–behavior relation. *Psychological bulletin, 132*(5), 778-822. doi:10.1037/0033-2909.132.5.778

Goodrich, K., Kaambwa, B., & Al-Janabi, H. (2012). The inclusion of informal care in applied economic evaluation: A review. *Value in Health, 15*(6), 975-981. doi:10.1016/j.jval.2012.05.009

Graff, M. J., Adang, E. M., Vernooij-Dassen, M. J., Dekker, J., Jonsson, L., Thijssen, M., . . . Rikkert, M. G. (2008). Community occupational therapy for older patients with dementia and their care givers: Cost effectiveness study. *BMJ, 336*(7636), 134-138. doi:10.1136/bmj.39408.481898.BE

Graff, M. L., Vernooij-Dassen, M., Thijssen, M., Dekker, J., Hoefnagels, W., & Rikkert, M. (2006). Community based occupational therapy for patients with dementia and their care givers: Randomised controlled trial. *BMJ, 333*(7580), 1196. doi:10.1136/bmj.39001.688843.BE

Green, S., & Lambert, R. (2017). A systematic review of health economic evaluations in occupational therapy. *British Journal of Occupational Therapy, 80*(1), 5-19. doi:10.1177/0308022616650898

Greenhalgh, T. (2005). *Diffusion of innovations in health service organisations: A systematic literature review*. Malden, Mass.: Malden, Mass. : Blackwell.

Guideline Adaptation Committee. (2016). Clinical practice guidelines and principles of care for people with dementia. Sydney, Australia: Guideline Adaptation Committee.

Guideline Committee. (2018). *Dementia: Assessment, management and support for people living with dementia and their carers. NICE Guideline 97. Methods evidence and recommendations*. Retrieved from United Kingdom: https://www.nice.org.uk/guidance/ng97/evidence/full-guideline-pdf-4852695709

Gustavsson, A., Jonsson, L., Rapp, T., Reynish, E., Ousset, P. J., Andrieu, S., . . . Group, I. S. (2010). Differences in resource use and costs of dementia care between European countries: Baseline data from the ICTUS study. *J Nutr Health Aging, 14*(8), 648-654. doi:10.1007/s12603-010-0311-7

Hansen, E., Robinson, A., Mudge, P., & Crack, G. (2005). Barriers to the provision of care for people with dementia and their carers in a rural community. *Australian Journal of Primary Health, 11*(1), 72-79. doi:10.1071/PY05010

Hay, J., LaBree, L., Luo, R., Clark, F., Carlson, M., Mandel, D., . . . Azen, S. P. (2002). Cost-effectiveness of preventive occupational therapy for independent-living older adults. *Journal of the American Geriatrics Society, 50*(8), 1381-1388.

Hays, R., Sherbourne, C., & Mazel, R. (1993). The RAND 36-item Health Survey 1.0. *Health Economics, 2*(3), 217-227. doi:10.1002/hec.4730020305

Healthdirect Australia. (2018). Home Care Package Research. Retrieved from https://agedcare.health.gov.au/sites/default/files/documents/02_2018/home_care_package_research_report.pdf

Heijman, W. J. M. (1998). Welfare economics and cost-benefit analysis *The economic metabolism* (pp. 51-60). Dordrecht: Springer Netherlands.

Hochbaum, G. (1958). Public participation in medical screening programs: A socio-psychological study *Issue 572 of Public Health Service publication*. Washington, DC: United States Public Health, Service Division of Special Health Services.

Hochbaum, G., Rosenstock, I., & Kegels, S. (1952). *Health belief model*: United States Public Health Service.

Holmboe, E. S. (2008). Practice audit, medical record review, and chart-stimulated recall. In E. S. Holmboe & R. E. Hawkins (Eds.), *Practical guide to the evaluation of clinical competence* (pp. 60-74). Philadelphia, USA: Mosby Elsevier.

Hughes, T., Black, B., Albert, M., Gitlin, L., Johnson, D., Lyketsos, C., & Samus, Q. (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: Influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics, 26*(11), 1875-1883. doi:10.1017/S1041610214001240

Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine, 368*, 1326–1334. doi:10.1056/NEJMsa1204629

Husereau, D., Drummond, M., Petrou, S., Carswell, C., Moher, D., Greenberg, D., . . . Loder, E. (2013). Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement. *BMJ, 346*, f1049. doi:10.1136/bmj.f1049

Hynes, S. M., Field, B., Ledgerd, R., Swinson, T., Wenborn, J., di Bona, L., . . . Orrell, M. (2016). Exploring the need for a new UK occupational therapy intervention for people with dementia and family carers: Community Occupational Therapy in Dementia (COTiD). A focus group study. *Aging Ment Health, 20*(7), 762-769. doi:10.1080/13607863.2015.1037243

IBM Corporation. (2013). IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corporation.

Independent Hospital Pricing Authority. (2018). National Hospital Cost Data Collection, Public Hospitals Cost Report, Round 20 (Financial year 2015-16). Retrieved from https://www.ihpa.gov.au/publications/national-hospital-cost-data-collection-public-hospitals-cost-report-round-20-financial

Independent Hospital Pricing Authority. (2019). National Hospital Cost Data Collection, Public Hospitals Cost Report, Round 21 (Financial year 2016-17). Retrieved from https://www.ihpa.gov.au/sites/default/files/publications/national_hospital_cost_data_collection_australian_public_hospitals_cost_report_round_21_2016-17.pdf

Ivers, N., Jamtvedt, G., Flottorp, S., Young, J. M., Odgaard-Jensen, J., French, S. D., . . . Oxman, A. D. (2012). Audit and feedback: Effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews*(6). doi:10.1002/14651858.CD000259.pub3

Jackson, C. L., Janamian, T., van Weel, C., & Dunbar, J. A. (2014). Implementation research - its importance and application in primary care. *Med J Aust, 201*(3 Suppl), S42-S43. doi:10.5694/mja14.00063

Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., . . . Wenger, N. S. (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *J Am Geriatr Soc, 63*(2), 282-289. doi:10.1111/jgs.13251

Jensen, M., Agbata, I. N., Canavan, M., & McCarthy, G. (2015). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry, 30*(2), 130-143. doi:10.1002/gps.4208

Jeon, Y.-H., Clemson, L., Naismith, S., Szanton, S. L., Simpson, J. M., Low, L.-F., . . . Brodaty, H. (2017). Optimising independence of older persons with cognitive and functional decline: Interdisciplinary home-based reablement program (I-HARP). *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 13*(7), P1157. doi:10.1016/j.jalz.2017.06.1691

Joanna Briggs Institute. (2011). Joanna Briggs Institute Reviewers’ Manual. Adelaide, Australia: The University of Adelaide.

Jones, C., Edwards, R. T., & Hounsome, B. (2012). A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. *International Psychogeriatrics, 24*(1), 6-18. doi:10.1017/S1041610211001207

Jones, R. W., Mackell, J., Berthet, K., & Knox, S. (2010). Assessing attitudes and behaviours surrounding Alzheimer's disease in Europe: Key findings of the Important Perspectives on Alzheimer's Care and Treatment (IMPACT) survey. *J Nutr Health Aging, 14*(7), 525-530. doi:10.1007/s12603-010-0263-y

Jorm, A. F. (2012). Mental health literacy: Empowering the community to take action for better mental health. *American Psychologist, 67*(3), 231-243. doi:10.1037/a0025957

Jutkowitz, E., Gitlin, L., Pizzi, L., Lee, E., & Dennis, M. (2012). Cost effectiveness of a home-based intervention that helps functionally vulnerable older adults age in place at home. *Journal of Aging Research, 2012*(2). doi:10.1155/2012/680265

Kenigsberg, P. A., Aquino, J. P., Berard, A., Gzil, F., Andrieu, S., Banerjee, S., . . . Robert, P. (2016). Dementia beyond 2025: Knowledge and uncertainties. *Dementia (London), 15*(1), 6-21. doi:10.1177/1471301215574785

Khdour, M. R., Hawwa, A. F., Kidney, J. C., Smyth, B. M., & McElnay, J. C. (2012). Potential risk factors for medication non-adherence in patients with chronic obstructive pulmonary disease (COPD). *Eur J Clin Pharmacol, 68*(10), 1365-1373. doi:10.1007/s00228-012-1279-5

Kickbusch, I., & Maag, D. (2008). Health Literacy. In H. K. Heggenhougen (Ed.), *International Encyclopedia of Public Health* (pp. 204-211). Oxford: Academic Press.

Knapp, M., Iemmi, V., & Romeo, R. (2013). Dementia care costs and outcomes: A systematic review. *International Journal of Geriatric Psychiatry, 28*(6), 551-561. doi:10.1002/gps.3864

Koopmanschap, M. A., van Exel, N. J. A., van den Berg, B., & Brouwer, W. B. F. (2008). An overview of methods and applications to value informal care in economic evaluations of healthcare. *Pharmacoeconomics, 26*(4), 269-280. doi:10.2165/00019053-200826040-00001

Kripalani, S., Yao, X., & Haynes, R. (2007). Interventions to enhance medication adherence in chronic medical conditions: A systematic review. *Acrhives of Internal Medicine, 167*(6), 540-549. doi:10.1001/archinte.167.6.540

Ku, L. J., Pai, M. C., & Shih, P. Y. (2016). Economic impact of dementia by disease severity: Exploring the relationship between stage of dementia and cost of care in Taiwan. *PLoS One, 11*(2), e0148779. doi:10.1371/journal.pone.0148779

Laver, K. (2016). Evidence-based occupational therapy for people with dementia and their family: What clinical practice guidelines tell us and implications for practice. *Australian Occupational Therapy Journal, 64*(1), 3-10. doi:10.1111/1440-1630.12309

Laver, K., Clemson, L., Bennett, S., Lannin, N., & Brodaty, H. (2014). Unpacking the evidence: Interventions for reducing behavioral and psychological symptoms in people with dementia. *Physical & Occupational Therapy in Geriatrics, 32*(4), 294-309. doi:10.3109/02703181.2014.934944

Laver, K., Milte, R., Dyer, S., & Crotty, M. (2017). A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers of people with dementia. *J Aging Health, 29*(8), 1308-1349. doi:10.1177/0898264316660414

Leggett, L., Khadaroo, R., Holroyd-Leduc, J., Lorenzetti, D., Hanson, H. M., Wagg, A. S., . . . Clement, F. (2016). Measuring resource utilization: A systematic review of validated self-reported questionnaires. *Medicine, 95*(10), e2759-e2759. doi:10.1097/MD.0000000000002759

Likert, R. (1932). A technique for the measurement of attitudes. *Archives of Psychology, 140*, 1-55.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Mukadam, N. (2017). Dementia prevention, intervention, and care. *Lancet, 390*(10113), 2673-2734. doi:10.1016/s0140-6736(17)31363-6

Logsdon, R. G., Gibbons, L., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21-32.

Low, L.-F., & Anstey, K. J. (2009). Dementia literacy: Recognition and beliefs on dementia of the Australian public. *Alzheimer's & Dementia, 5*(1), 43-49. doi:10.1016/j.jalz.2008.03.011

Low, L.-F., White, F., Jeon, Y.-H., Gresham, M., & Brodaty, H. (2013). Desired characteristics and outcomes of community care services for persons with dementia: What is important according to clients, service providers and policy? *Australasian Journal on Ageing, 32*(2), 91-96. doi:10.1111/j.1741-6612.2012.00625.x

Makai, P., Brouwer, W. B. F., Koopmanschap, M. A., Stolk, E. A., & Nieboer, A. P. (2014). Quality of life instruments for economic evaluations in health and social care for older people: A systematic review. *Social Science & Medicine, 102*(Supplement C), 83-93. doi:10.1016/j.socscimed.2013.11.050

Mann, W., Ottenbacher, K. J., Fraas, L., Tomita, M., & Granger, C. (1999). Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. *Archives of Family Medicine, 8*(3), 210-217. Retrieved from https://clockss.org/triggered-content/archives-of-family-medicine/

Martindale-Adams, J., Tah, T., Finke, B., LaCounte, C., Higgins, B. J., & Nichols, L. O. (2017). Implementation of the REACH model of dementia caregiver support in American Indian and Alaska Native communities. *Translational Behavioral Medicine, 7*(3), 427-434. doi:10.1007/s13142-017-0505-1

Maslow, K. (2012). *Translating innovation to impact: Evidence based interventions to support people with Alzheimer's disease and their caregivers at home and in the community.* Retrieved from https://www.agingresearch.org/publications/view/18#.WSvFOmiGM2w

McCaffrey, N., Gill, L., Kaambwa, B., Cameron, I., Patterson, J., Crotty, M., & Ratcliffe, J. (2015). Important features of home-based support services for older Australians and their informal carers. *Health Soc Care Community, 23*(6), 654-664. doi:10.1111/hsc.12185

McClaren, A., LaMantia, M., & Callahan, C. (2013). Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging and Mental Health, 17*(6), 655-666. doi:10.1080/13607863.2013.781121

McGrath, M., & O'Callaghan, C. (2014). Occupational therapy and dementia care: A survey of practice in the Republic of Ireland. *Australian Occupational Therapy Journal, 61*(2), 92-101. doi:10.1111/1440-1630.12081

McLaren, A. N., LaMantia, C. M., & Callahan, M. (2013). Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging & Mental Health, 17*(6), 655-666. doi:10.1080/13607863.2013.781121

McLeod, S. A. (2009). Attitude Measurement. Retrieved from www.simplypsychology.org/attitude-measurement.html

Michalowsky, B., Thyrian, J. R., Eichler, T., Hertel, J., Wucherer, D., Flessa, S., & Hoffmann, W. (2016). Economic Analysis of Formal Care, Informal Care, and Productivity Losses in Primary Care Patients who Screened Positive for Dementia in Germany. *Journal of Alzheimer's Disease, 50*(1), 47-59. doi:10.3233/jad-150600

Moore, M. J., Zhu, C. W., & Clipp, E. C. (2001). Informal costs of dementia care: Estimates from the national longitudinal caregiver study. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 56*(4), S219-S228. doi:10.1093/geronb/56.4.s219

Morrow-Howell, N., Proctor, E., Gitlin, L., Stevens, A., Mausbach, B., Cardenas, V., . . . editors. (2013). Accelerating translation of knowledge to community practices for older adults workshop series: Family caregiving to persons with dementia. The Gerontological Society of America Annual Scientific Meeting. New Orleans, Louisiana.

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: Approaches and goals. *Aging Health, 8*(4), 377-386. doi:10.2217/ahe.12.42

Nagayama, H., Tomori, K., Ohno, K., Takahashi, K., & Yamauchi, K. (2016). Cost-effectiveness of occupational therapy in older people: Systematic review of randomized controlled trials. *Occup Ther Int, 23*(2), 103-120. doi:10.1002/oti.1408

National Health Workforce Dataset. (2018). Occupational Therapists 2016. Retrieved from http://hwd.health.gov.au

National Institute of Health. (2009). Dissemination and implementation research in health Retrieved from https://grants.nih.gov/grants/guide/pa-files/par-10-038.html

NHMRC National Institute for Dementia Research. (2017). NNIDR strategic roadmap for dementia research and translation. Retrieved from https://www.nnidr.gov.au/about-institute/strategic-roadmap

Northern Sydney Primary Health Network. (n.d.). Defining Characteristics of Consumer Directed Care (CDC). Retrieved from https://sydneynorthhealthnetwork.org.au/wp-content/uploads/2016/11/Difference-Between-Person-Centred-CDC-Services.pdf

Nous Group, & Department of Health. (2018). *Wellness & Reablement Review: A summary of consultations across the home care sector*. Retrieved from Canberra, Australia: https://agedcare.health.gov.au/programs/wellness-and-reablement-review-summary-of-consultations

Occupational Therapy Australia. (2019). About occupational therapy. Retrieved from http://aboutoccupationaltherapy.com.au

Office of Best Practice Regulation. (2016). Cost-benefit analysis guidance note. Retrieved from https://www.pmc.gov.au/resource-centre/regulation/cost-benefit-analysis-guidance-note

Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., Del Ser, T., . . . Muniz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dement Geriatr Cogn Disord, 30*(2), 161-178. doi:10.1159/000316119

Panca, M., Livingston, G., Barber, J., Cooper, C., La Frenais, F., Marston, L., . . . Hunter, R. M. (2019). Healthcare resource utilisation and costs of agitation in people with dementia living in care homes in England - The Managing Agitation and Raising QUality of LifE in Dementia (MARQUE) study. *PLoS One, 14*(2), e0211953. doi:10.1371/journal.pone.0211953

Papageorgiou, N., Marquis, R., Dare, J., & Batten, R. (2016). Occupational therapy and occupational participation in community dwelling older adults: A review of the evidence. *Physical & Occupational Therapy in Geriatrics, 34*(1), 21-42. doi:10.3109/02703181.2015.1109014

Parkerson, G. R., Jr., Connis, R. T., Broadhead, W. E., Patrick, D. L., Taylor, T. R., & Tse, C. K. (1993). Disease-specific versus generic measurement of health-related quality of life in insulin-dependent diabetic patients. *Medical Care, 31*(7), 629-639. Retrieved from https://www.jstor.org/journal/medicalcare

Patel, A., & Shriber, L. (2001). Nurse practitioners' knowledge of occupational therapy. *Occup Ther Health Care, 13*(2), 53-71. doi:10.1080/J003v13n02_04

Peerson, A., & Saunders, M. (2009). Men's health literacy: Advancing evidence and priorities. *Critical Public Health, 19*(3-4), 441-456. doi:10.1080/09581590902906229

Personal Social Services Research Unit (PSSRU). (2019). Client Service Receipt Inventory (CSRI). Retrieved from https://www.pssru.ac.uk/csri/client-service-receipt-inventory/

Peters, D., Tran, N., & Adam, T. (2013). Implementation research in health: A practical guide Retrieved from http://who.int/alliance-hpsr/alliancehpsr_irpguide.pdf

Philip, K. (2015). Allied health: Untapped potential in the Australian health system. *Aust Health Rev, 39*(3), 244-247. doi:10.1071/AH14194

Phillips, J., Pond, D., & Goode, S. (2011). Timely diagnosis of dementia: Can we do better? A report for Alzheimer’s Australia. Paper 24. Sydney, Australia: Alzheimer’s Australia.

Pierre, B. (2001). Occupational therapy as documented in patients records part iii. Valued but not documented. Underground practice in the context of professional written communication. *Scand J Occup Ther, 8*(4), 174-183. doi:10.1080/110381201317166531

Pimouguet, C., Lavaud, T., Dartigues, J. F., & Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization: A systematic review of randomized controlled trials. *J Nutr Health Aging, 14*(8), 669-676. doi:10.1007/s12603-010-0314-4

Polatajko, H., Creek, J., Davis, J., Cameron, D. J., & Sinclair, K. (2018). *The Debate: Is it time to reconsider framing our work as therapy?* Paper presented at the World Federation of Occupational Therapists Congress, Cape Town, South Africa.

Poulos, C., Bayer, A., Beaupre, L. A., Clare, L., Poulos, R. G., Wang, R. H., . . . McGilton, K. (2017). A comprehensive approach to reablement in dementia. *Alzheimer's & dementia (New York, N. Y.), 3*(3), 450-458. doi:10.1016/j.trci.2017.06.005

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., . . . Salimkumar, D. (2014). Dementia UK, Update. 2nd.

Prochaska, J. (1979). *Systems of psychotherapy: A transtheoretical analysis*. Oxford, England: Dorsey.

Prochaska, J., & DiClemente, C. C. (1983). Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of consulting and clinical psychology, 51*(3), 390-395. doi:10.1037/0022-006X.51.3.390

Proctor, E. K., Landsverk, J., Aarons, G., Chambers, D., Glisson, C., & Mittman, B. (2009). Implementation research in mental health services: An emerging science with conceptual, methodological, and training challenges. *Administration and Policy in Mental Health and Mental Health Services Research, 36*(1), 24-34. doi:10.1007/s10488-008-0197-4

Productivity Commission. (2011a). *Caring for older Australians* (Report No. 53). Retrieved from Canberra: https://www.pc.gov.au/inquiries/completed/aged-care/report

Productivity Commission. (2011b). *Disability care and support* (Report no, 54). Retrieved from Canberra: https://www.pc.gov.au/inquiries/completed/disability-support/report

QSR International Pty Ltd. (2018). Nvivo Qualitative Data Analysis Software. Version 12.

Quentin, W., Riedel-Heller, S. G., Luppa, M., Rudolph, A., & Konig, H. H. (2010). Cost-of-illness studies of dementia: A systematic review focusing on stage dependency of costs. *Acta Psychiatr Scand, 121*(4), 243-259. doi:10.1111/j.1600-0447.2009.01461.x

Quinn, C. (2017). Conducting interviews with people with dementia and their caregivers. *SAGE Research Methods Cases.* doi:10.4135/9781526404855

Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., . . . Andiappan, M. (2012). Development of the carer well-being and support (CWS) questionnaire. *Mental Health Review Journal,, 17*(3), 128-138. doi:10.1108/13619321211287184

Rabin, R., & de Charro, F. (2001). EQ-5D: A measure of health status from the EuroQol Group. *Annals of Medicine, 33*(5), 337-343. doi:10.3109/07853890109002087

Rahja, M., Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018a). Are there missed opportunities for occupational therapy for people with dementia? An audit of practice in Australia. *Australian Occupational Therapy Journal, 65*, 565-574. doi:10.1111/1440-1630.12514

Rahja, M., Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018b). Economic evaluations of occupational therapy approaches for people with cognitive and/or functional decline: A systematic review. *Health Soc Care Community, 26*, 635-653. doi:10.1111/hsc.12553

Rahja, M., & Laver, K. (2019). What does the Australian public know about occupational therapy for older people? A population survey. *Australian Occupational Therapy Journal, 66*(4), 511-518. doi:10.1111/1440-1630.12578

Rahja, M., Laver, K., Comans, T., & Crotty, M. (2018). What does the Australian general public know about treatments for dementia? A population survey. *Gerontology and Geriatric Medicine, 4*. doi:10.1177/2333721418793442

Rahja, M., Laver, K., Crotty, M., & Comans, T. (2019). *How do older Australians choose therapy and home support services? An explorative inquiry into decision making using a 'think aloud' technique*. Paper presented at the Occupational Therapy Australia National Aged Care Symposium, Brisbane, QLD.

Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., & Orrell, M. (2015). Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews, Issue 1. Art. No.: CD008345.* doi:10.1002/14651858.CD008345.pub2

Rimer, B., & Brewer, N. (2015). Introduction to health behavior theories that focus on individuals. In K. Glanz, B. Rimer, & K. Viswanath (Eds.), *Health Behavior: Theory, Research, and Practice* (pp. 67-74). New York: New York, NY: John Wiley & Sons, Incorporated.

Rimmer, E., Wojciechowska, M., Stave, C., Sganga, A., & O'Connell, B. (2005). Implications of the Facing Dementia Survey for the general population, patients and caregivers across Europe. *International Journal of Clinical Practice, 59*, 17-24. doi:10.1111/j.1368-504X.2005.00482.x

Roberts, J. S., McLaughlin, S. J., & Connell, C. M. (2014). Public beliefs and knowledge about risk and protective factors for Alzheimer's disease. *Alzheimer's & Dementia, 10*(5 Suppl), S381-S389. doi:10.1016/j.jalz.2013.07.001

Rogers, E. M. (1995). *Diffusion of innovations*. New York: Free Press of Glencoe.

Salkeld, G., Cumming, R. G., O'Neill, E., Thomas, M., Szonyi, G., & Westbury, C. (2000). The cost effectiveness of a home hazard reduction program to reduce falls among older persons. *Aust N Z J Public Health, 24*(3), 265-271. doi:10.1111/j.1467-842X.2000.tb01566.x

Sano, M., Zhu, C. W., Whitehouse, P. J., Edland, S., Jin, S., Ernstrom, K., . . . Alzheimer Disease Cooperative Study, G. (2006). ADCS prevention instrument project: Pharmacoeconomics: Assessing health-related resource use among healthy elderly. *Alzheimer Dis Assoc Disord, 20*(4 Suppl 3), S191-202. doi:10.1097/01.wad.0000213875.63171.87

Schneider, J., Duggan, S., Cordingley, L., Mozley, C. G., & Hart, C. (2007). Costs of occupational therapy in residential homes and its impact on service use. *Aging Ment Health, 11*(1), 108-114. doi:10.1080/13607860600963349

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*(6), 771-791.

SCRGSP (Steering Committee for the Review of Government Service Provision). (2018). *Interventions to support carers of people with dementia*. Retrieved from Canberra: https://www.pc.gov.au/research/ongoing/report-on-government-services/what-works/dementia-support/dementia-support.pdf

Seo, H. J., Lee, D. Y., & Sung, M. R. (2015). Public knowledge about dementia in South Korea: A community-based cross-sectional survey. *International Psychogeriatrics, 27*(3), 463-469. doi:10.1017/s1041610214001896

Sheffield, C., Smith, C., & Becker, M. (2013). Evaluation of an agency-based occupational therapy intervention to facilitate aging on place. *Gerontologist, 53*(6), 907-918. doi:10.1093/geront/gns145

Shiroiwa, T., Sung, Y., Fukuda, T., Lang, H., Bae, S., & Tsutani, K. (2010). International survey on willingness-to-pay (WTP) for one additional QALY gained: What is the threshold of cost effectiveness? *Health Economics, 19*(4), 422-437. doi:10.1002/hec.1481

Skladzien, E., Bowditch, K., & Rees, G. (2011). *National strategies to address dementia: A report by Alzheimer's Australia. Paper 25*. Retrieved from Alzheimer's Australia: https://www.dementia.org.au/files/20111410_Paper_25_low_v2.pdf

Smith, B., Ali, S., & Quach, H. (2014). Public knowledge and beliefs about dementia risk reduction: A national survey of Australians. *BMC Public Health, 14*, 661. doi:10.1186/1471-2458-14-661

Smith, E., & Mackenzie, L. (2011). How occupational therapists are perceived within inpatient mental health settings: The perceptions of seven Australian nurses. *Australian Occupational Therapy Journal, 58*(4), 251-260. doi:10.1111/j.1440-1630.2011.00944.x

Smith, K., Flicker, L., Lautenschlager, N. T., Almeida, O. P., Atkinson, D., Dwyer, A., & LoGiudice, D. (2008). High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology, 71*(19), 1470-1473. doi:10.1212/01.wnl.0000320508.11013.4f

Smith, K., LoGiudice, D., Dwyer, A., Thomas, J., Flicker, L., Lautenschlager, N. T., . . . Atkinson, D. (2007). ‘Ngana minyarti? What is this?’ Development of cognitive questions for the Kimberley Indigenous Cognitive Assessment. *Australasian Journal on Ageing, 26*(3), 115-119. doi:10.1111/j.1741-6612.2007.00234.x

Smith, R. D., & Widiatmoko, D. (1998). The cost-effectiveness of home assessment and modification to reduce falls in the elderly. *Australian & New Zealand Journal of Public Health, 22*(4), 436-440. doi:10.1111/j.1467-842X.1998.tb01410.x

Stark, S., Keglovits, M., Arbesman, M., & Lieberman, D. (2017). Effect of home modification interventions on the participation of community-dwelling adults with health conditions: A systematic review. *American Journal of Occupational Therapy, 71*(2), 7102290010p7102290011-7102290010p7102290011. doi:10.5014/ajot.2017.018887

Stedman, A., & Thomas, Y. (2011). Reflecting on our effectiveness: Occupational therapy interventions with Indigenous clients. *Australian Occupational Therapy Journal, 58*(1), 43-49. doi:doi:10.1111/j.1440-1630.2010.00916.x

Steultjens, E., Dekker, J., Bouter, L., Jellema, S., Bakker, E., & van den Ende, C. (2004). Occupational therapy for community dwelling elderly people: A systematic review. *Age Ageing, 33*(5), 453-460. doi:10.1093/ageing/afh174

Steultjens, E., Dekker, J., Bouter, L., Leemrijse, C., & van den Ende, C. (2005). Evidence of the efficacy of occupational therapy in different conditions: An overview of systematic reviews. *Clin Rehabil, 19*(3), 247-254. doi:10.1191/0269215505cr870oa

Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: A randomized controlled trial. *Movement Disorders, 30*(8), 1059-1067. doi:10.1002/mds.26217

Sugg Skinner, C, Tiro, J., & Champion, V. (2015). The health belief model. In K. Glanz, B. Rimer, & K. Viswanath (Eds.), *Health Behavior : Theory, Research, and Practice* (pp. 75-94). New York: New York, NY: John Wiley & Sons, Incorporated.

Swinson, T., Wenborn, J., Hynes, S., Orrell, M., Stansfeld, J., Rooks, S., & Ledgerd, R. (2016). Community occupational therapy for people with dementia and their family carers: A national survey of United Kingdom occupational therapy practice. *British Journal of Occupational Therapy, 79*(2), 85-91. doi:10.1177/0308022615624447

Tariah, H. S., Abulfeilat, K., & Khawaldeh, A. (2012). Health professionals' knowledge of occupational therapy in Jordan. *Occup Ther Health Care, 26*(1), 74-87. doi:10.3109/07380577.2011.635184

Tchalla, A. E., Lachal, F., Cardinaud, N., Saulnier, I., Rialle, V., Preux, P. M., & Dantoine, T. (2013). Preventing and managing indoor falls with home-based technologies in mild and moderate Alzheimer's disease patients: Pilot study in a community dwelling. *Dement Geriatr Cogn Disord, 36*(3-4), 251-261. doi:10.1159/000351863

Valcour, V. G., Masaki, K. H., Curb, J., & Blanchette, P. (2000). The detection of dementia in the primary care setting. *Archives of Internal Medicine, 160*(19), 2964-2968. doi:10.1001/archinte.160.19.2964

Van't Leven, N., Graff, M. J. L., Kaijen, M., de Swart, B. J. M., Olde Rikkert, M. G. M., & Vernooij-Dassen, M. J. M. (2012). Barriers to and facilitators for the use of an evidence-based occupational therapy guideline for older people with dementia and their carers. *International Journal of Geriatric Psychiatry, 27*(7), 742-748. doi:10.1002/gps.2782

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K., & Annemans, L. (2016). Effectiveness of Supporting Informal Caregivers of People with Dementia: A

Systematic Review of Randomized and Non-Randomized Controlled Trials. *Journal of Alzheimer's Disease, 52*(3), 929-965. doi:10.3233/jad-151011

Voigt-Radloff, S., Graff, M., Leonhart, R., Schornstein, K., Jessen, F., Bohlken, J., . . . Hull, M. (2011). A multicentre RCT on community occupational therapy in Alzheimer's disease: 10 sessions are not better than one consultation. *BMJ Open, 1*(1), e000096. doi:10.1136/bmjopen-2011-000096

Volpp, K., Loewenstein, G., & Asch, D. (2015). Behavioural economics and health. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health Behavior: Theory, Research, and Practice* (pp. 389-409). New York: New York, NY: John Wiley & Sons, Incorporated.

Wesson, J., Clemson, L., Brodaty, H., Lord, S., Taylor, M., Gitlin, L., & Close, J. (2013). A feasibility study and pilot randomised trial of a tailored prevention program to reduce falls in older people with mild dementia. *BMC Geriatr, 13*(1), 89. doi:10.1186/1471-2318-13-89

WHOQOL Group. (1993). Measuring quality of life: The development of the World Health Organization Quality of Life instrument (WHOQoL). Geneva, Switzerland: World Health Organization.

Wicking Dementia Research and Education Centre. (2018). Understanding Dementia MOOC. Retrieved from http://www.utas.edu.au/wicking/understanding-dementia

Wilkins, S., Jung, B., Wishart, L., Edwards, M., & Norton, S. G. (2003). The effectiveness of community-based occupational therapy education and functional training programs for older adults: A critical literature review. *Canadian Journal of Occupational Therapy, 70*(4), 214-225. doi:10.1177/000841740307000405

Wimo, A., Gustavsson, A., Jonsson, L., Winblad, B., Hsu, M. A., & Gannon, B. (2013). Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimers Dement, 9*(4), 429-435 e417. doi:10.1016/j.jalz.2012.06.008

Wimo, A., Jonsson, L., Gustavsson, A., McDaid, D., Ersek, K., Georges, J., . . . Valtonen, H. (2011). The economic impact of dementia in Europe in 2008-Cost estimates from the Eurocode project. *International Journal Geriatric Psychiatry, 26*(8), 825-832. doi:10.1002/gps.2610

Wimo, A., Jonsson, L., & Zbrozek, A. (2010). The Resource Utilization in Dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. *J Nutr Health Aging, 14*(8), 685-690. doi:10.1007/s12603-010-0316-2

Wimo, A., & Winblad, B. (2003). Resource utilisation in dementia: RUDLite. *Brain Aging, 3*, 48-59. Retrieved from https://rudinstrument.files.wordpress.com/2016/08/rud-3-2-sample.pdf

World Federation of Occupational Therapists. (2012). Definition of occupational therapy. Retrieved from http://www.wfot.org/AboutUs/AboutOccupationalTherapy/DefinitionofOccupationalTherapy.aspx

World Health Organization. (2012). Dementia: A public health priority. Geneva, Switzerland: WHO.

World Health Organization. (2015a). World population ageing (Department of Economic and Social Affairs Population Division, Trans.). New York: WHO.

World Health Organization. (2015b). World report on ageing and health. Retrieved from http://www.who.int/ageing/events/world-report-2015-launch/en/

World Health Organization. (2017). Global action plan on the public health response to dementia: 2017–2025. Retrieved from https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

World Health Organization. (2018). Ageing and health. Retrieved from https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

Wortmann, M., Andrieu, S., Mackell, J., & Knox, S. (2010). Evolving attitudes to Alzheimer's disease among the general public and caregivers in Europe: Findings from the IMPACT survey. *J Nutr Health Aging, 14*(7), 531-536. doi:10.1007/s12603-010-0264-x

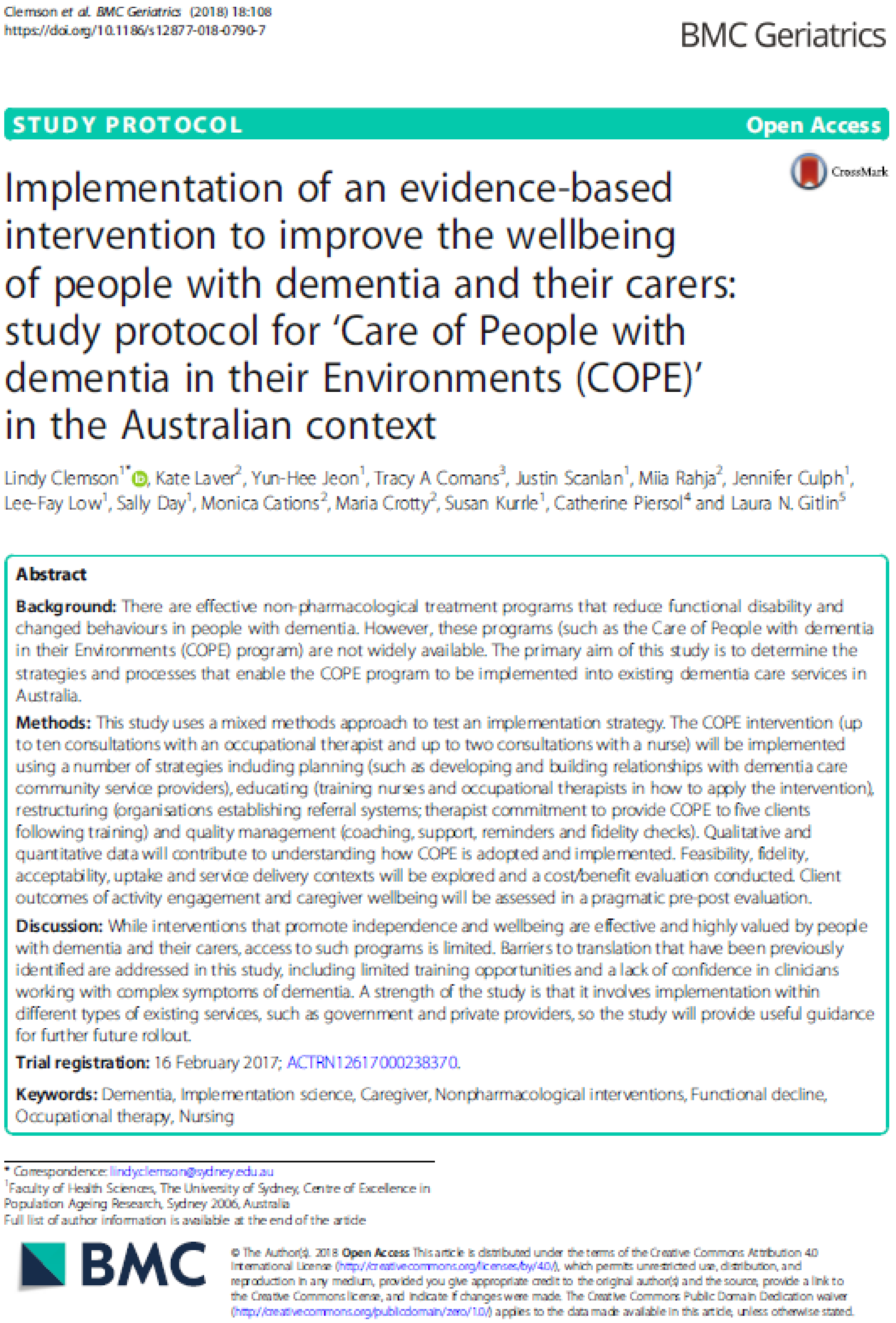
Yang, F., Dawes, P., Leroi, I., & Gannon, B. (2018). Measurement tools of resource use and quality of life in clinical trials for dementia or cognitive impairment interventions: A systematically conducted narrative review. *International Journal of Geriatric Psychiatry, 33*(2), e166-e176. doi:10.1002/gps.4771

Zhu, C. W., Sano, M., Ferris, S. H., Whitehouse, P. J., Patterson, M. B., & Aisen, P. S. (2013). Health-related resource use and costs in elderly adults with and without mild cognitive impairment. *J Am Geriatr Soc, 61*(3), 396-402. doi:10.1111/jgs.12132

Zingmark, M., & Bernspång, B. (2011). Meeting the needs of elderly with bathing disability. *Australian Occupational Therapy Journal, 58*(3), 164-171. doi:10.1111/j.1440-1630.2010.00904.x

APPENDICES

APPENDIX A COPE Australia project; Published study protocol



Clemson *et al. BMC Geriatrics* (2018) 18:108
https://doi.org/10.1186/s12877-018-0790-7

BMC Geriatrics

STUDY PROTOCOL Open Access

Implementation of an evidence-based intervention to improve the wellbeing of people with dementia and their carers: study protocol for 'Care of People with dementia in their Environments (COPE)' in the Australian context

Lindy Clemson[1*], Kate Laver[2], Yun-Hee Jeon[1], Tracy A Comans[3], Justin Scanlan[1], Miia Rahja[2], Jennifer Culph[1], Lee-Fay Low[1], Sally Day[1], Monica Cations[2], Maria Crotty[2], Susan Kurrle[1], Catherine Piersol[4] and Laura N. Gitlin[5]

Abstract

Background: There are effective non-pharmacological treatment programs that reduce functional disability and changed behaviours in people with dementia. However, these programs (such as the Care of People with dementia in their Environments (COPE) program) are not widely available. The primary aim of this study is to determine the strategies and processes that enable the COPE program to be implemented into existing dementia care services in Australia.

Methods: This study uses a mixed methods approach to test an implementation strategy. The COPE intervention (up to ten consultations with an occupational therapist and up to two consultations with a nurse) will be implemented using a number of strategies including planning (such as developing and building relationships with dementia care community service providers), educating (training nurses and occupational therapists in how to apply the intervention), restructuring (organisations establishing referral systems; therapist commitment to provide COPE to five clients following training) and quality management (coaching, support, reminders and fidelity checks). Qualitative and quantitative data will contribute to understanding how COPE is adopted and implemented. Feasibility, fidelity, acceptability, uptake and service delivery contexts will be explored and a cost/benefit evaluation conducted. Client outcomes of activity engagement and caregiver wellbeing will be assessed in a pragmatic pre-post evaluation.

Discussion: While interventions that promote independence and wellbeing are effective and highly valued by people with dementia and their carers, access to such programs is limited. Barriers to translation that have been previously identified are addressed in this study, including limited training opportunities and a lack of confidence in clinicians working with complex symptoms of dementia. A strength of the study is that it involves implementation within different types of existing services, such as government and private providers, so the study will provide useful guidance for further future rollout.

Trial registration: 16 February 2017; ACTRN12617000238370.

Keywords: Dementia, Implementation science, Caregiver, Nonpharmacological interventions, Functional decline, Occupational therapy, Nursing

---

* Correspondence: lindyclemson@sydney.edu.au
[1] Faculty of Health Sciences, The University of Sydney, Centre of Excellence in Population Ageing Research, Sydney 2006, Australia
Full list of author information is available at the end of the article

Background

Functional decline is one of the core features of dementia [1, 2]. As the symptoms of dementia worsen, the person becomes increasingly dependent on others for assistance with activities of daily living. Decline in cognitive and physical function is associated with reduced quality of life in the person with dementia, considerable impact on carers, increased use of health and social care resources and often culminates in the need to move to residential care [3–5].

There is now evidence from multiple randomised controlled trials that functional decline can be delayed in people with dementia [6–11]. Moreover, non-pharmacological interventions that work with both the person with dementia and their carers (dyadic interventions) and include strategies to promote independence and manage symptoms are more effective than pharmacological agents [12] and do not have the associated side effects [13]. Dyadic interventions are associated with a range of other benefits including: reduced carer burden, anxiety and depression, improved carer knowledge, and delayed time to institutionalisation [14–16]. While the ingredients of interventions vary, research suggests that interventions that are tailored and involve multiple components (e.g. carer education plus skills training plus engaging the person with dementia in activities) are most effective [14].

Despite evidence in favour of dyadic interventions and public support for such programs [17], access is limited [18]. Most of the programs found to be effective in research trials have been tested outside of existing care systems therefore the feasibility of providing the programs in routine service delivery is unclear [15]. Implementation is the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings [19]. The need for improved translation of research into practice has been recognised by the World Health Organization who have called for implementation of evidence based interventions that enhance function and capability in people with dementia in their global action plan [20]. The plan also calls for more research to provide information about *how* to translate evidence based programs into action [20].

There are currently few examples of the implementation of evidence based interventions for community dwelling people with dementia and their carers into real-world settings [15, 21] and none of these have taken place in Australia. Of those that do exist, a modified version of the original evidence based treatment has been applied suggesting that some adaptations are required to enhance feasibility in translation [22, 23]. One such program, the Community Occupational Therapy in Dementia (COTiD) project in the Netherlands, involved looking at barriers and facilitators to delivering the intervention as perceived by occupational therapists who had received training in the intervention [24]. COTiD involves ten consultations with an occupational therapist delivered over a shorter time frame (five weeks) and tends to focus mostly on activities of daily living. Focus groups revealed that therapists did not feel competent in implementing the program, had difficulty providing the amount of treatment recommended in the intervention guideline and struggled with the structured nature of the intervention including the amount of documentation associated. Yet, they valued the resources provided within the program, were positive about the evidence supporting the program and benefited from support from their colleagues. Physicians and managers who were involved in the study reported a lack of awareness about the COTiD intervention and referral mechanisms to occupational therapists were not clear or easy to complete. An additional implementation project involving the COTiD intervention, which aimed to address these barriers and facilitators, involved training days, outreach visits, regional meetings and a web based discussion platform. The effectiveness of the implementation strategy was tested in a cluster randomised trial and process evaluation. Results of the study revealed that the referrals to the COTiD program could be increased but adherence to the intervention was not enhanced following the implementation strategies [23, 25].

A second program of implementation conducted in the United States involved implementation of the Environmental Skill-Building Program (ESP; renamed as Skills$_2$Care^R) within a homecare practice [22]. The implementation involved site preparation, training, establishing referral mechanisms and evaluation. A total of 22 therapists were trained to provide the intervention and provided an average of 4.7 sessions; the implementation was considered moderately successful. Fidelity to the intervention was variable and fidelity checks were difficult to conduct within the homecare organisations.

This study examines implementation of the 'Care of People with dementia in their Environments' (COPE) program in the Australian context [26]. COPE is a non-pharmacological intervention designed to reduce functional disability in people with dementia. The program comprises occupational therapy and nursing input (involving 8-10 consultations with an occupational therapist and two consultations with a nurse) delivered over four months. Core elements of the program include: focusing on the capabilities of the person with dementia, prevention and management of changed behaviours and carer support and education. Strategies applied by the therapist and nurse include carer education and strategies to modify communication, tasks and the environment. A large randomised trial ($n = 237$) conducted in the United States found that the program was effective in reducing dependency and increasing engagement of the person with dementia and improving carer wellbeing [26]. At four months carers reported significantly higher levels of wellbeing. At nine months carers in the intervention group reported a "great deal" of improvement in their lives overall, confidence managing changed behaviours and improved ability to keep living at home.

The main research questions for this project are:

(1) How is COPE adopted, implemented and made sustainable within different community health contexts in Australia?
(2) What are the costs associated with delivery of COPE and are there changes in resource utilisation of people with dementia before and after intervention, and

We will also conduct a pragmatic pre-post evaluation to investigate:

When implemented into existing services, does COPE have the same size of effect for activity engagement outcomes for the person with dementia and wellbeing outcomes for the carer as when tested in the randomised controlled trial?

Methods

Design

This implementation research project employs a mixed methods research design [27] to evaluate the process of implementation of the COPE project. According to Curran's classification of effectiveness-implementation hybrid trials, the trial utilises a Type 3 design via testing an implementation strategy and collecting information on the clinical intervention and outcomes [28]. The study seeks to understand what, why and how the COPE intervention will work in the Australian setting within existing programs and resources. The mixed methods design [27] includes collection of qualitative and quantitative data from both health professionals employed by the partner organisations and the people receiving the program (people with dementia and their carers).

An overview of the implementation model used within the project is presented in Fig. 1. The *intervention strategy* is the COPE program, an evidence based dyadic intervention, which has been described briefly above as well as in the original paper published by Gitlin and colleagues [26]. *The implementation strategy* involves a number of components including the development of relationships with existing organisations/service providers who provide services for people with dementia. These organisations include government services, not-for-profit aged care services, and private services; this will allow us to explore the settings in which implementation is most likely to work and will assist with sustainability and scaling up where implementation is successful. Implementation strategies were formed based on known relevant barriers and enablers which are described in Table 1 and possible solutions to these barriers designed by Michie and colleagues and as described in the behaviour change wheel [29].

As portrayed in Fig. 1, our primary *outcome* is related to implementation but we will also measure outcomes at the level of the service and the client.

Study setting and context

Most aged care services in Australia are funded by the state or federal government and are delivered either via a state government health service or a non-government organisation [30]. There are also services offered by private practitioners. Care may be provided for a short period or on an ongoing basis. Short term services include restorative care (early intervention to optimise function and independence) and transition programs (post hospital or illness) which are goal-oriented, time-limited and therapy focussed. Ongoing home care packages are to maintain independent living for as long as possible in one's own home, subsidising a package of care, services and case management depending on need. People with dementia and their carers are also able to access helplines and advisory services which provide education about dementia and advice regarding managing changed behaviours ([31].

In summary, care of community-dwelling people with dementia in Australia is currently fragmented and services are provided in a number of different settings by a range of different health professionals [32]. While there are existing services that provide intervention and care for people with dementia and their carers in the community, care approaches tend to focus on assessment and case management and there are a lack of programs which offer evidence based non-pharmacological treatments to optimise independence and manage the symptoms of dementia [32, 33]. The study is based in two states of Australia: New South Wales (NSW) and South Australia (SA) providing an additional geographical perspective. We aim to recruit a mix of government services, non-government organisations and private practitioners within both of these states.

Participants

Participating organisations

The research team will establish agreements with 10-20 different organisations or individual service providers where there is a fit between the project and the organisation/provider and this is supported by managerial staff. All organisations will provide services for community dwelling people with dementia and will employ occupational therapists. All organisations will either employ nurses or be able to link with community

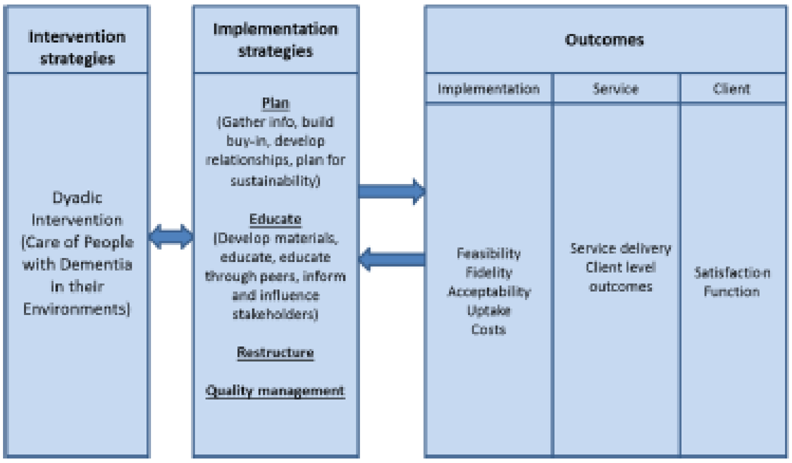


Fig. 1 Implementation model used within the project. This figure depicts an overview of the project using the reporting format recommended by Proctor et al. [47]

nursing services to provide the nursing component of the intervention. As stated, we will deliberately seek to establish agreements with a mix of government and non-government organisations as well as private occupational therapy services in order to examine adoption in different contexts. Each participating organisation will be asked to nominate a team who will be key players in the implementation of COPE comprising someone in a management position, an occupational therapist and a nurse.

Participating occupational therapists and nurses

Occupational therapists and nurses who work at the participating organisations will be nominated to be involved in the study by their participating organisation. These staff will have an existing caseload which includes people with dementia. Participating occupational therapists and nurses will attend training in the intervention and will be asked to consent five dyads (people with dementia and their carer) to participate in the research project. They will deliver the intervention with these five dyads and provide data on these clients for the purposes of the project. Therapists will be provided with certification after attendance at training and upon completion of the program with three dyads. Occupational therapists and nurses will be supported through mentoring and coaching sessions. We will recruit at least 30 therapists which provides considerable allowance for dropout and other circumstances which may prevent therapists from providing the COPE program to five dyads.

Participating people with dementia and their carers (dyads)

The 103 dyads involved in this study will be clients of the participating organisations and more specifically, clients of the participating occupational therapists and

Table 1 Barriers and enablers and possible solutions proposed within the behaviour change wheel [29]

Behaviour Change Wheel components	Barriers and enablers	Possible solutions
Capability	Health professionals have reported limited knowledge regarding best practice dementia care [33]. Working with people with dementia and carers can be complex and requires high level cognitive and interpersonal skills [23]. Therapists tend to provide care-based established patterns and changing therapist behviour is difficult [49].	Education, Training, Enablement
Opportunity	Evidence supports programs delivered over a number of consultations which can be difficult to achieve in the Australian settings [50]. Occupational therapists often receive referrals for home and safety assessments rather than management of the symptoms of dementia	Environmental restructuring, Enablement
Motivation	Therapists report reduced confidence in intervention so may lack confidence that they can make a difference [33]. Therapists tend to work autonomously so they receive little positive reinforcement about their work from within their organisation or from their peers.	Educate, Persuasion, Enablement

nurses. These participants will be identified as having the potential to benefit from the COPE intervention by the participating occupational therapists. Strict inclusion criteria will not be applied but therapists will be made aware of the target client group for whom the intervention was designed: People with a diagnosis of dementia (or probable dementia) or a Mini Mental State Examination score of less than 24 who need help with daily activities and/or have changed behaviours. The participants will live with or nearby someone who takes on a 'carer' role and the carer must report some difficulty in managing symptoms. The client's own therapist will seek their consent to participate in the research study. Whether or not they consent to participate will not impact on the person's ability to access the COPE program or occupational therapy intervention as part of their usual treatment. Participants deemed to be unable to consent will still be included in discussion about the study and verbal assent will be obtained as well as proxy consent.

A diagram of the relationship between the participating organisations, participating occupational therapists and nurses and participating people with dementia and their carers is presented in Fig. 2.

Implementation strategies

We will draw on a number of implementation strategies including planning, education, restructuring, and quality management (presented in Fig. 3). Implementation strategies used within the project are guided by barriers and enablers and proposed solutions suggested using the behaviour change wheel.

Plan

This phase involves establishing relationships with participating organisations and exploration of preparation for change within these organisations. This process will involve sharing of information in order to understand the scope and work of COPE and how this may fit with the implementation of COPE within their organisation and the role of the research team. Discussions with managers and potential interventionists will enable identification of common work, values and goals. This is an iterative process and the ongoing relationship will influence identification of other support strategies to be shared and enacted by the researcher/organisation partnership. Planning for sustainability will be encouraged from the beginning through collection of data to contribute to a business case, formalizing partnerships (with enough partners involved to sustain changes if some withdraw), creation of master trainers and tools and materials for ongoing planning as well as wide promotion of the program for a diverse group of audiences which will raise awareness of the program.

Educate

We will work closely with the primary developers of the COPE program (including author's LNG & CP), establishing the mutable and immutable aspects of the program. Training and manuals originally designed for use in research trials in the United States will be refined for the Australian context to ensure cultural appropriateness. A member of the research team will pilot the modified program with five dyads to ensure applicability to the Australian context and seek informal feedback regarding the utility and content of the program.

Participating occupational therapists and nurses will attend training to understand the theory and application of the intervention. Clinicians will be provided with the intervention manual, documentation and associated resources and taught 'what to do' and 'how to do it'. They will be taught the program structure and content as designed by the original developers of the program (with modifications for the Australian context). Training in delivering the intervention will be provided over two days for occupational therapists and approximately two hours for nursing staff. Training methods have been deliberately designed to build self-efficacy in clinicians by: (a) facilitating mastery through experience (role play), (b) hearing

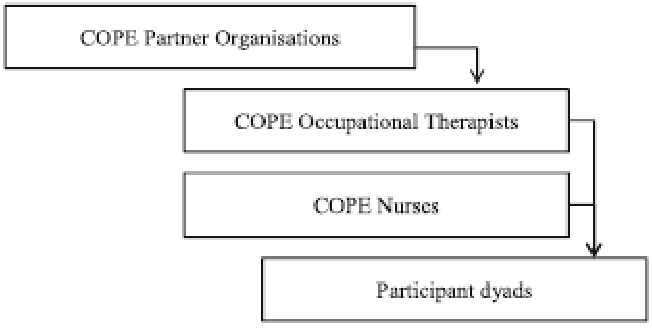
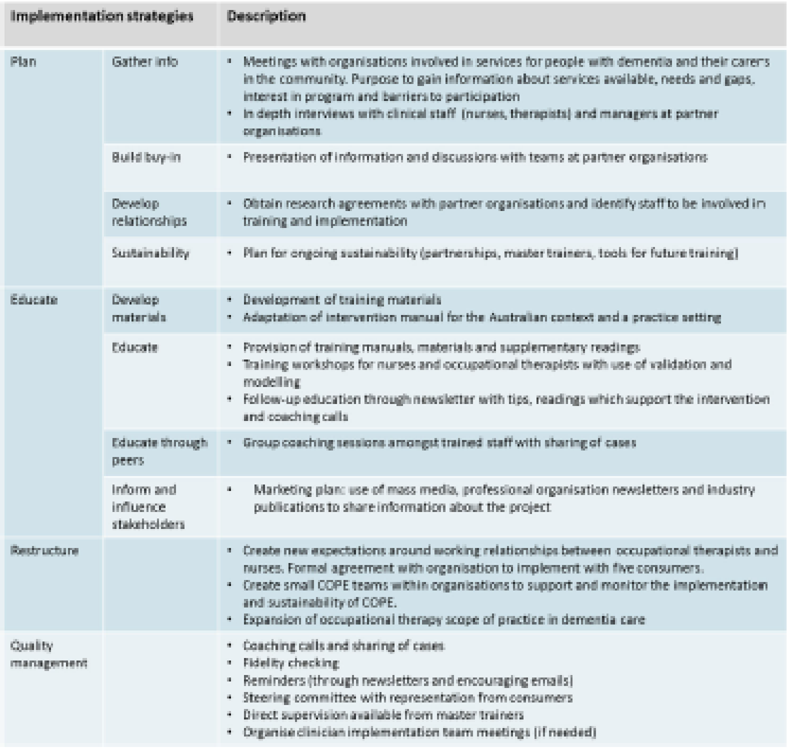


Fig. 2 Study participants



Implementation strategies		Description
Plan	Gather info	• Meetings with organisations involved in services for people with dementia and their carers in the community. Purpose to gain information about services available, needs and gaps, interest in program and barriers to participation • In depth interviews with clinical staff (nurses, therapists) and managers at partner organisations
	Build buy-in	• Presentation of information and discussions with teams at partner organisations
	Develop relationships	• Obtain research agreements with partner organisations and identify staff to be involved in training and implementation
	Sustainability	• Plan for ongoing sustainability (partnerships, master trainers, tools for future training)
Educate	Develop materials	• Development of training materials • Adaptation of intervention manual for the Australian context and a practice setting
	Educate	• Provision of training manuals, materials and supplementary readings • Training workshops for nurses and occupational therapists with use of validation and modelling • Follow-up education through newsletter with tips, readings which support the intervention and coaching calls
	Educate through peers	• Group coaching sessions amongst trained staff with sharing of cases
	Inform and influence stakeholders	• Marketing plan: use of mass media, professional organisation newsletters and industry publications to share information about the project
Restructure		• Create new expectations around working relationships between occupational therapists and nurses. Formal agreement with organisation to implement with five consumers. • Create small COPE teams within organisations to support and monitor the implementation and sustainability of COPE. • Expansion of occupational therapy scope of practice in dementia care
Quality management		• Coaching calls and sharing of cases • Fidelity checking • Reminders (through newsletters and encouraging emails) • Steering committee with representation from consumers • Direct supervision available from master trainers • Organise clinician implementation team meetings (if needed)

Fig. 3 Description of implementation strategies used presented using the framework devised by Powell et al. [48]

descriptions of scenarios in which the program has been delivered and had good results (modelling), (c) hearing descriptions of the supporting evidence and ability for therapists and nurses to make a difference to facilitate belief in the intervention and (d) positive feedback and validation. Clinicians will be informed that the training enables them to deliver the intervention as developed by the team in the US but that in practice, they may need to make some amendments so that the intervention fits within their existing role and resources (for example where they are unable to provide services over four months). We will work with our participating organisations to promote the implementation work within the media, professional organisations and local newsletters or newspapers. The goal of this promotional work is to inform and influence stakeholders (both those who are already participating and other related organisations).

Barriers and enablers to implementation which are identified by the participating health professionals during the implementation phase will be noted and addressed. For example, if clinicians identify that they have trouble explaining the intervention to their colleagues or clients we can provide educational leaflets and strategies to assist with this.

Restructure

Participation in the implementation project involves therapists and nurses delivering the program to five or more dyads. This ensures that the therapist completes the training with the expectation that changes to practice will occur. Furthermore, the expectation that the occupational therapist and nurse will work together to deliver the program may provide the opportunity to create new working relationships in some organisations.

Quality management

Following the training, clinicians will receive support through regular, small group coaching calls (with their peers and a member of the research team) and direct mentoring or supervision if sought. The coaching calls provide the opportunity to share case scenarios and learn from the trainers and their peers. For the 12 months following training we will also provide support in the form of encouragement, reminders and newsletters. If needed, we will visit the site and meet with staff responsible for implementation as well as other people within the organisation who can provide support for implementation, such as managerial staff.

Evaluation

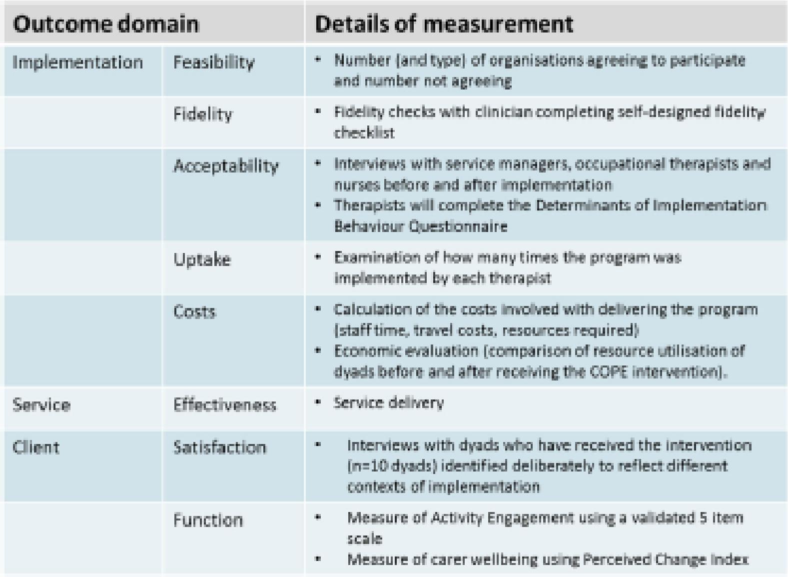
The primary outcome of interest relates to the implementation of the intervention which will be measured in terms of feasibility, fidelity, acceptability, uptake and costs. Evaluation will also determine the efficacy of the COPE intervention when provided by participating organisations. We will assess whether there are beneficial outcomes for the person with dementia and their carer by comparing pre and post measures and then comparing any changes (by effect size) to the effect sizes reported in the original research trial We will also examine similarities and differences within the different service delivery contexts.

Outcomes assessed within the project are presented in Fig. 4.

Implementation

Implementation will be measured by considering the number and type of organisations agreeing to participate. We will also assess uptake of the intervention over time; this information will be recorded by therapists who will provide information regarding on how many occasions they delivered the intervention. In addition, we will chart the duration between attending training and commencing implementation. Interviews with health professionals will be repeated after implementation of COPE and will provide information about acceptability from their perspective. These interviews aim to understand their experience of COPE, perceptions of change (or not) and factors that may have influenced uptake. Normalisation Process Theory can be seen as a framework to identify factors that encourage or impede the implementation of complex interventions. Normalisation Process Theory will be used as a tool in developing the interview guide, as it highlights the work that individuals do to incorporate innovation into the context of their organisational constructs and culture [34]. This information will be supplemented with information from the Determinants of Implementation Behaviour Questionnaire [35] which was developed to measure the behavioural determinants of implementation. The Questionnaire is based on the Theoretical Domains Framework and includes 93 items covering 18 domains including knowledge, skills and social/professional role and identity. Respondents are asked to what degree they agree or disagree with statements such as 'I have the skills to deliver COPE following the guidelines'.

Uptake will also be assessed via a fidelity checklist completed by the occupational therapist providing the intervention. The fidelity check was designed specifically for this study. Fidelity will be assessed primarily in terms of adherence to the duration and content of the intervention provided and how this relates to the duration and content of the original trial. In addition to the number and length of sessions and the assessments conducted therapists are asked to record information about collaboration with the carer, how well the carer was able to use strategies and the perceived level of carer engagement.



Outcome domain		Details of measurement
Implementation	Feasibility	• Number (and type) of organisations agreeing to participate and number not agreeing
	Fidelity	• Fidelity checks with clinician completing self-designed fidelity checklist
	Acceptability	• Interviews with service managers, occupational therapists and nurses before and after implementation • Therapists will complete the Determinants of Implementation Behaviour Questionnaire
	Uptake	• Examination of how many times the program was implemented by each therapist
	Costs	• Calculation of the costs involved with delivering the program (staff time, travel costs, resources required) • Economic evaluation (comparison of resource utilisation of dyads before and after receiving the COPE intervention).
Service	Effectiveness	• Service delivery
Client	Satisfaction	• Interviews with dyads who have received the intervention (n=10 dyads) identified deliberately to reflect different contexts of implementation
	Function	• Measure of Activity Engagement using a validated 5 item scale • Measure of carer wellbeing using Perceived Change Index

Fig. 4 Outcomes assessed

Following establishment of the research agreement between participating organisations and the University of Sydney, participating organisations will be asked to describe the structure of their services including completion of a network map of their organisation. Network maps are useful in examining variables within a context and the complex interactions between them, which may be difficult to describe in an interview [36]. The aim is to develop an understanding about the strength of relationships between different people in the organisation, as well as the perceived source of innovation. We will also conduct in-depth interviews with up to 30 occupational therapists, nurses and service managers within the participating organisations to identify current practices, understand their beliefs about their own capabilities, skills and motivation, gain insight into their organisational culture and structures, explore their previous experiences with innovation and identify the predicted barriers and enablers to the implementation of COPE.

Service: effectiveness, service delivery

Client: We will assess whether outcomes for the carer and person with dementia who received COPE within the study (participating dyads) are similar in terms of effect sizes as those that were demonstrated in the original randomised controlled trial. This evaluation will be a pragmatic pre-post intervention evaluation. Outcomes assessed include activity engagement of the person with dementia using a validated five-item scale in which carers are asked to rate the carer's engagement in leisure and recreational activities from 1 (never) to 3 (often). We will also measure carer wellbeing using the 13 item Perceived Change Index in which carers are asked to rate changes in their wellbeing and coping over the last month. The pre-and-post-intervention dyad questionnaires include a measure of engagement of the person with dementia (a validated five-item scale which demonstrated an effect size of 0.26 (Cohen d) in the earlier trial [26]) and a measure of carer wellbeing, the Perceived Change Index (which had an effect size of 0.30).

Ten of the dyads who have received the program (who will be purposefully identified to represent different settings) will also be asked to participate in an interview. These dyads will be chosen using purposeful sampling, designed to reduce selection bias, and in keeping with the qualitative nature of the inquiry. During this interview, they will be asked a range of questions about how they are managing, how much help they need, and how confident the caregiver feels about providing that care.

Analysis

Quantitative analysis

All quantitative data will be entered into SPSS. Outcome measures relating to impact on outcomes for the person with dementia and carer (engagement and carer wellbeing) will be analysed descriptively. Effect sizes will be calculated and presented using Cohen's d and these will be compared to the effect sizes achieved in the original randomised trial of COPE. We calculate the estimated effect size of 0.26 will give a power of 80% (alpha error probability of.05) testing mean differences of time points using G-power (version 3) software which gave a sample of 93 dyads (before adding the dropout estimate). This is sufficient as the estimate for the 0.30 effect size is 71 dyads. We will recruit a total of 103 to allow for drop out.

A social cost benefit analysis (CBA) will be conducted to synthesise the costs and benefits of including COPE in the existing Australian health context. The CBA framework allows the identification of who bears the cost and who gains from the COPE program from multiple perspectives [37]. Monetary value will be assigned for all costs and outcomes using an established methodology [38] and the net social benefits of the intervention will be calculated. A positive overall net benefit represents an economic gain where theoretically the gainers could compensate the payers and still be better off. Probabilistic sensitivity analysis will be conducted to further interrogate the likelihood of COPE providing a net benefit to healthcare consumers, service providers and the Australian healthcare sector. To inform the analysis, costs relating to the provision of the COPE intervention will be collected. Direct costs include staff time in delivering the interventions (recorded in minutes), travel costs, and the cost of any resources provided (e.g. leaflets, equipment). Therapists providing the intervention will be asked to complete a form for each client which records the information necessary to calculate these costs. Resources will be costed at 2016 prices using actual cost of materials and current award wage rates. All dyads will be asked to complete the Resource Utilisation in Dementia (Lite) questionnaire [39] pre and post intervention. This will provide information on formal and informal care resources which can be used to value the care received.

Qualitative analysis

Interviews with staff and dyads will be audio-recorded, transcribed verbatim and entered into QSR NVivo. Thematic analysis (developing codes) will identify patterns within the study group [40]. A combination of inductive and deductive coding will be used. For participant dyads coding will commence with experience of COPE program and perceptions of change, but will be open to unexpected findings that may contribute to these. For health professionals, frameworks focusing on implementation and organisational culture will assist to synthesise the data gathered in order to build a comprehensive assessment of the barriers and facilitators; and thus informing implementation.

Discussion

Implementation research is the scientific study of methods to promote the integration of research findings and evidence-based interventions into healthcare practice and policy [19]. The importance of implementation science is that it can accelerate the translation of effective interventions. This project is novel in that it is underpinned by theory and includes a broad framework approach that has enabled a focus on multi-component strategies that would best leverage implementation across a range of levels and practice settings, and utilises an iterative mixed method approach to understand the processes, context and complexity of changing practice. We seek to understand at the level of client, occupational therapist, nurse, manager and organisation and contribute to the knowledge base of how evidence-based interventions can be transported to real-world practice settings.

Evidence in favour of dyadic interventions is accumulating. Such interventions have the potential to delay functional decline, reduce carer impact, increase carer knowledge, reduce carer anxiety, reduce carer depression and delay time to institutionalisation [14–16]. Yet, implementation into routine practice has been poor. Surveys suggest that occupational therapists, who could provide these dyadic interventions, tend to focus on assessment and lack confidence in treating people with the symptoms associated with dementia [33]. This research project evaluates the process of implementation of the COPE intervention into a range of different service delivery contexts in Australia.

Strength of this study is its reach to three different types of practice settings which will enable comparison of differences and similarities within and between them. This project confirms the importance of attention to the local context, the engagement of stakeholder organisations, health care delivery settings and the role of individuals in dissemination and implementation [41]. It demonstrates that researchers and stakeholders need to work in partnership, develop working relationships and researchers to be attentive to need and context at individual and organisational levels. We know that elements such as 'packaging' the intervention through development of training, identifying core elements and skills training along with preparation for sustainability are important ([42, 43]) but the kinds of strategies and processes to achieve these are still evolving. In the case of dementia care in the community implementation will require a shift from 'assessment' to 'intervention' focused practice [15, 33]. It will also need to bridge the gap between the potential of empirically proven re-ablement programs, supported in current commonwealth aged care policies [44], to achieve their research aims in real-world settings. This project will provide information about how organisations fit these programs into the funding models they can already access. The extent that this project will impact on policy at the level of organisation, referral pathways and changing landscapes of access to re-ablement programs remains to be seen.

There will be future opportunities to compare cross-cultural implementation issues with another COPE study currently being undertaken in the US [45]. People with dementia who receive services through the Connecticut Home Care Program for Elders will be randomly allocated to receive COPE or usual care. The study aims to look at outcomes for the person with dementia and carer as well as net financial benefit, feasibility and acceptability when delivered within that home care program.

Our implementation study will provide detailed information about the process and outcomes of translation into Australian health contexts with rich qualitative data which will provide understanding about factors influencing implementation. Examining implementation in a range of settings and contexts will help inform the best models of fitting such programs within existing services. Further, challenges in scaling and building sustainability from early stages have received little attention [46]. Learnings from the study will outline strategies and processes for implementation and sustainability and we will better understand how establishing links with policy makers can support ongoing program delivery.

Abbreviations

CBA: Cost benefit analysis; COPE: Care of People with dementia in their Environments; COTiD: Community Occupational Therapy in Dementia

Acknowledgements

Our steering committee plays an integral role in guiding our project, advising on a broad range of issues from how COPE can be framed and marketed to how COPE fits with existing policy and how to disseminate information to the public. We gratefully acknowledge the input of the steering committee members: Danijela Hlis, Glenys Petrie, Jane Thompson, Joan Jackman, John Quinn, Meredith Gresham and Wendy Hudson.

Funding

This study received funding from the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People (grant no. GNT9100000). The funding body peer reviewed and approved the research proposal but has had no role in the design of the study, analysis, interpretation of data or in writing the manuscript.

Authors' contributions

All authors contributed to study conceptualization and contributed to manuscript writing and editing. All authors will be involved in conducting the proposed research: LC, JC, KL, Y-HJ, JS responsible for the qualitative component and KL, LC, MR & K-FL for the quantitative data; TC, KL & MR the Health economic study; MC and SK responsible for policy and scalability; LG, CP, SD & KL for training. All authors gave final approval of the manuscript prior to submission, and agree to be accountable for all aspects of the work described here.

Ethics approval and consent to participate

This study was provided with ethical approval from the University of Sydney 2016-834 and 2016-292 and Northern Sydney RESP/16/188. Participating organisations have signed research agreements with the research team and participating health professionals, people with dementia and their carers have provided written consent to participate.

Competing interests

Laura N Gitlin and Catherine Piersol are the developers of the COPE program. The authors declare that they have no competing interests.

Publisher's Note

Author details

[1]Faculty of Health Sciences, The University of Sydney, Centre of Excellence in Population Ageing Research, Sydney 2006, Australia. [2]Flinders University, Adelaide, Australia. [3]The University of Queensland, Brisbane, Australia. [4]Thomas Jefferson University, Philadelphia, USA. [5]Dexel University, Philadelphia, USA.

Received: 14 February 2018 Accepted: 12 April 2018

References

1. Burns A. Dementia. BMJ. 2009;338:b75.
2. Larson EB, Shadlen M-F, Wang L, McCormick WC, Bowen JD, Teri L, Kukull WA. Survival after initial diagnosis of Alzheimer disease. Ann Intern Med. 2004;140(7):501–9.
3. Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. Health Qual Life Outcomes. 2004;2(1):52.
4. Gustavsson A, Brinck P, Bergvall N, Kolasa K, Wimo A, Winblad B, Jönsson L. Predictors of costs of care in Alzheimer's disease: a multinational sample of 1222 patients. Alzheimers Dement. 2011;7(3):318–27.
5. Mayo AM. Measuring functional status in older adults with dementia. Clin Nurse Specialist. 2008;22(5):212–3.
6. Baines S, Saxby P, Ehlert K. Reality orientation and reminiscence therapy - a controlled crossover study of elderly confused people. Br J Psychiatry. 1987; 151:222–31.
7. Gitlin LN, Corcoran M, Winter L, Boyce A, Hauck WW. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. Gerontologist. 2001;41(1):4–14.
8. Gitlin LN, Winter L, Burke J, Chernett N, Dennis MP, Hauck WW. Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. Am J Geriatr Psychiatr. 2008;16(3):229–39.
9. Gitlin LN, Winter L, Corcoran M, Dennis MP, Schinfeld S, Hauck WW. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. The Gerontologist. 2003;43(4):532–46.
10. Graff MJL, Vernooij-Dassen MJM, Thijssen M, Dekker J, Hoefnagels WHL, Rikkert MGMO. Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. Br Med J. 2006; 333(7580):1196–9.
11. Nobili A, Riva E, Tettamanti M, Lucca U, Liscio M, Petrucci B, Porro GS. The effect of a structured intervention on caregivers of patients with dementia and problem behaviors - a randomized controlled pilot study. Alzheimer Dis Assoc Disord. 2004;18(2):75–82.
12. Laver K, Dyer S, Whitehead C, Clemson L, Crotty M. Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews. BMJ Open. 2016;6(4):e010767.
13. Bond M, Rogers G, Peters J, Anderson R, Hoyle M, Miners A: The effectiveness and cost-effectiveness of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review of Technology Appraisal No 111): a systematic review and economic model. Health Technol Assess 2012. 16(21):1–470.
14. Laver K, Clemson L, Bennett S, Lannin NA, Brodaty H. Unpacking the evidence: interventions for reducing behavioral and psychological symptoms in people with dementia. Phys Occup Ther Geriatr. 2014;32(4):294–309.
15. Maslow K. Translating innovation to impact: evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community. Administration on aging and alliance for aging research. 2012.
16. McLaren AN, LaMantia MA, Callahan CM. Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. Aging Ment Health. 2013;17(6):655–66.
17. Alzheimer's Australia. Alzheimer's Australia National Consumer Summit Communique. Canberra: Alzheimer's Australia; 2016.
18. Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, Chodosh J, Tan Z, Wenger NS. Unmet needs of caregivers of individuals referred to a dementia care program. J Am Geriatr Soc. 2015;63(2):282–9.
19. Dissemination and implementation research in health. [http://grants.nih.gov/grants/guide/pa-files/par-10-038.html].
20. World Health Organization: Draft global action plan on the public health response to dementia. In. Edited by Director-General Rbt. Geneva: World Health Organization; 2016.
21. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. The Gerontologist. 2015;55(2):210–26.
22. Gitlin LN, Jacobs M, Earland TV. Translation of a dementia caregiver intervention for delivery in homecare as a reimbursable medicare service: outcomes and lessons learned. Gerontologist. 2010;50(6):847–54.
23. Döpp CM, Graff MJ, Teerenstra S, Olde Rikkert MG, Nijhuis-van der Sanden MW, Vernooij-Dassen MJ. Effectiveness of a training package for implementing a community-based occupational therapy program in dementia: a cluster randomized controlled trial. Clin Rehabil. 2015;29(10):974–86.
24. Van't Leven N, Graff MJ, Kaijen M, de Swart BJ, Rikkert O, Marcel G, Vernooij-Dassen MJ. Barriers to and facilitators for the use of an evidence-based occupational therapy guideline for older people with dementia and their carers. Int J Geriatr Psychiatry. 2012;27(7):742–8.
25. Dopp CM, Graff MJ, Teerenstra S, Nijhuis-van der Sanden MW, Olde Rikkert MG, Vernooij-Dassen MJ. Effectiveness of a multifaceted implementation strategy on physicians' referral behavior to an evidence-based psychosocial intervention in dementia: a cluster randomized controlled trial. BMC Fam Pract. 2013;14:70.
26. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers the COPE randomized trial. JAMA. 2010;304(9):983–91.
27. Peters DH, Adam T, Alonge O, Agyepong IA, Tran N. Implementation research: what it is and how to do it. Bmj. 2013;347:f6753.
28. Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. Med Care. 2012;50(3):217.
29. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011;6(1):42.
30. My Aged Care. [https://www.myagedcare.gov.au/help-home].
31. Dementia Support Australia. [https://www.dementia.com.au/].
32. KPMG: Analysis of dementia programmes funded by the Department of Social Services. In. 2015; 2015.
33. Bennett S, Shand S, Liddle J. Occupational therapy practice in Australia with people with dementia: a profile in need of change. Aust Occup Ther J. 2011;58(3):155–63.
34. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, Finch T, Kennedy A, Mair F, O'Donnell C, et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC Med. 2010;8(1):63.
35. Huijg JM, Gebhardt WA, Dusseldorp E, Verheijden MW, van der Zouwe N, Middelkoop BJ, Crone MR. Measuring determinants of implementation behavior: psychometric properties of a questionnaire based on the theoretical domains framework. Implement Sci. 2014;9(1):33.
36. Luke DA, Harris JK. Network analysis in public health: history, methods, and applications. Annu Rev Public Health. 2007;28(1):69–93.
37. Campbell HF, Brown RPC. A multiple account framework for cost–benefit analysis. Eval Program Plann. 2005;28(1):23–32.
38. Campbell HF, Brown R. Cost-benefit analysis: financial and economic appraisal using spreadsheets. 2nd ed. London: Taylor and Francis; 2015.
39. Wimo A, Jonsson L, Zbrozek A. The resource utilization in dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. J Nutr Health Aging. 2010;14(8):685–90.
40. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE Publications Ltd; 2006.
41. Gonzalez R, Handley M, Ackerman S, O'Sullivan P. Increasing the translation of evidence into practice, policy, and public health improvements: a framework for training health professionals in implementation and dissemination science. Acad Med. 2012;87(3):271–8.

42. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health Ment Health Serv Res. 2011;38(2):65–76.
43. Kilbourne A, Neumann M, Pincus H, Bauer M, Stall R. Implementing evidence-based interventions in health care: application of the replicating effective programs framework. Implement Sci. 2007;2(42):1–10.
44. The restorative approach. [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/03_2015/chsp_restorative_fact_sheet_0.pdf].
45. Fortinsky RH, Gitlin LN, Pizzi LT, Piersol CV, Grady J, Robison JT, Molony S. Translation of the Care of Persons with dementia in their environments (COPE) intervention in a publicly-funded home care context: rationale and research design. Contemp Clin Trials. 2016;49:155–65.
46. Proctor E, Luke D, Calhoun A, McMillen C, Brownson R, McCrary S, Padek M. Sustainability of evidence-based healthcare: research agenda, methodological advances, and infrastructure support. Implement Sci. 2015;10(1):88.
47. Proctor EK, Landsverk J, Aarons G, Chambers D, Glisson C, Mittman B. Implementation research in mental health services: an emerging science with conceptual, methodological, and training challenges. Adm Policy Ment Health Ment Health Serv Res. 2009;36(1):24–34.
48. Powell BJ, McMillen JC, Proctor EK, Carpenter CR, Griffey RT, Bunger AC, Glass JE, York JL. A compilation of strategies for implementing clinical innovations in health and mental health. Med Care Res Rev. 2012;69(2):123–57.
49. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. Lancet. 2003;362(9391):1225–30.
50. Brodaty H, Cumming A. Dementia services in Australia. Int J Geriatr Psychiatry. 2010;25(9):887–995.

APPENDIX B Systematic review; Published study protocol

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for
Health Research

A systematic review of economic evaluations of occupational therapy services for people with cognitive and/or functional decline and/or their caregivers

Miia Rahja, Kate Laver, Tracy Comans, Lindy Clemson, Maria Crotty

Citation

Miia Rahja, Kate Laver, Tracy Comans, Lindy Clemson, Maria Crotty. A systematic review of economic evaluations of occupational therapy services for people with cognitive and/or functional decline and/or their caregivers. PROSPERO 2016 CRD42016046491 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42016046491

Review question

This systematic review explores the economic impact of occupational therapy services for people with cognitive and/or functional decline and/ or their caregivers. The aim of this review is to identify and summarise the best available evidence on resource use and costs involved in using occupational therapist as support for people with cognitive and/or functional difficulties, and/or their caregivers, and if/how occupational therapy can be a cost effective service for people with cognitive and/or functional decline and/ or their caregivers.The proposed systematic review will answer the following questions:
What are the costs and outcomes of occupational therapy as care option for people with cognitive and/or functional decline (both community dwelling and those in residential care)?
Are there differences in costs for providing occupational therapy intervention in the community compared to residential care for people with cognitive and/or functional decline?
How have the costs and outcomes of occupational therapy services for people with functional and/or cognitive decline been assessed in economic evaluations?

Searches

We will use the following electronic databases:
- Ovid MEDLINE(R) 1946 to Present; Epub Ahead of Print, In-Process & Other Non-Indexed Citations, and Ovid MEDLINE(R) Daily
- PsycINFO (Ovid) 1806-July week 4 2016
- Econlit (Ovid) 1886 to August 2016
- CINAHL (EBSCOhost)
- ProQuest (Health & Medicine; Social Science subsets only)
- Cochrane Central Register of Controlled Trials (CENTRAL): Issue 8 of 12, August 2016
- Health Technology Assessment Database: Issue 3 of 4, July 2016
- NHS Economic Evaluation Database (NHS EED): Issue 2 of 4, April 2015
- ALOIS database
- EMBASE; (1980 onwards)

The search strategies were reviewed by a Medical Sciences Librarian with expertise in systematic review searching. The search strategy was developed for Medline using medical subject headings (MeSH) and text words, and then adapted for use with the other bibliographic databases. The strategy combined terms relating to occupational therapy, economics, people with cognitive and/or functional decline, and caregiver. Only quantitative studies will be sought and reviewed. No study design or date limits will be imposed on the search. The reference lists of included studies will be hand searched.
The search strategy for MEDLINE can be found in the accompanying PDF document (link below).

Search strategy

http://www.crd.york.ac.uk/PROSPEROFILES/46491_STRATEGY_20160828.pdf

Types of study to be included

We will include full economic evaluation studies (i.e. cost-effectiveness analyses, cost-utility analyses, cost-benefit analyses) of [intervention(s) versus comparator(s)]; Partial economic evaluations (i.e. cost analyses, cost-description studies, cost-outcome descriptions, cost minimisation studies) of [intervention(s) and comparator(s)]; Randomized trials reporting more limited information, such as estimates of resource use or costs associated with [intervention(s) and comparator(s)] and; studies with pre and post intervention cost comparators. We will exclude partial economic evaluations with no comparator (e.g. outcome description studies, cost-description studies, cost-outcome descriptions, unless they are pre and post studies). We will also exclude efficacy or effectiveness analyses with no analysis of costs, burden of disease studies, cost-of-illness studies, and aged care financing models.

Condition or domain being studied

The economic impact of occupational therapy services for people with functional and /or cognitive decline and/or their caregivers.

Participants/population

We will include studies examining the economic aspects of occupational therapy services for care of people with functional and/or cognitive decline and/or their caregivers. Studies that include full or partial economic evaluation of occupational therapy for people with cognitive and or functional decline and/or their caregivers. In defining cognitive and/ or functional decline, this review will include occupational therapy interventions aimed at participants with degenerative neurological conditions and degenerative conditions related to aging such as mild cognitive impairment, dementia, multiple sclerosis, Parkinson's disease, Huntington's disease, Creutzfeldt Jakob disease, motor neurone disease, arthritis, frailty, falls, and hip fracture. The review will not include occupational therapy interventions aimed at conditions that may elicit sudden onset of cognitive impairment such as traumatic brain injury or stroke. For the purpose of the review, no specific age will be quantified.

We will exclude systematic reviews, study protocols, conference proceedings, editorials and commentary papers.

Intervention(s), exposure(s)

Interventions will be included which pertain to occupational therapy services for with functional and/or cognitive decline and/or their caregivers (in the community and residential care). Occupational therapy intervention in the context of this review is conceptualised as "intervention that aims to improve independence and functioning, and may include caregiver education on care provision. This may include: environmental assessment and modification that aids independent functioning prescription of assistive technology tailored intervention that promotes independence in activities of daily living (such as problem solving, task simplification, and education and skills training of caregivers and family members) (ICF - WHO, 2001).

Comparator(s)/control

For inclusion, studies must have at least one alternative intervention or control for comparison.

Studies that do not comprise a comparator will be excluded, unless they are pre and post studies.

Context

Studies will be selected for inclusion only if people living with functional and/or cognitive decline and/or their caregivers are receiving occupational therapy services and costs related to accessing such services are evaluated in accordance to our stated study inclusion criteria. There will be no restrictions by region or country. There will be no restriction on care provision setting (i.e. Community or care facility).

If a study intervention consists of a multidisciplinary approach to care, we will only include studies where at last 70% of intervention is provided by an occupational therapist.

Main outcome(s)

The primary outcome of interest is economic evaluation of occupational therapy in care of people with functional and /or cognitive decline and/or their caregivers.

Additional outcome(s)

We will also explore measures of activity and participation, as well as conduct a narrative synthesis of the countries involved in the studies in the review.

Data extraction (selection and coding)

We will extract the data as follow: Two reviewers (MR and KL) will independently screen titles and/or abstracts based on the inclusion criteria detailed in the review protocol. Differences between reviewers' results will be resolved by discussion and when necessary in consultation with a third reviewer, TC. If, after discussion, there is still doubt about the relevance of a study relevance to the review it will be retained.

Full copies will be obtained for all studies identified by the title/abstract screening. A screening tool with inclusion/exclusion criteria as defined in the review protocol will be developed for screening of the full papers in Microsoft Excel. Screening will be conducted independently by two reviewers (MR and KL). Any differences of opinion about inclusion/ exclusion will be resolved by discussion between the two reviewers or by consultation with a third reviewer (TC). Reasons for excluding studies will be documented.
We will use a flow chart to summarise the number of papers included/excluded at each stage of the process. Studies excluded at the full paper screening stage will be listed in the appendix of the review along with the reason for exclusion.
We will use a modified version of the Joanna Briggs Institute Data Extraction Form for Economic Evaluations to extract data from the included studies. The data extracted will cover descriptive data about the: study method, evaluation design, participants, interventions used, comparator, outcomes, prices and currency used for costing, time period of analysis, setting, source of effectiveness data, and authors' conclusions. The primary review author (MR) will extract data independently. The second review author (KL) will check the included articles. Discrepancies will be identified and resolved through discussion, or consultation with a third review author when necessary. Neither the study selection nor the data extraction will be blinded. We will use narrative and table to present findings.

Risk of bias (quality) assessment

Critical appraisal will be undertaken at the study level using the EVERS checklist which covers: study population, competing alternatives, study question, study design, timing of costs, study perspective, comparison of alternatives, units of cost, accuracy, credibility and identification of costs and outcomes, incremental analysis, sensitivity analysis, coherence, generalizability, conflict of interest and ethics.
The appraisal will be conducted independently by two review authors. Any disagreements that arise will be discussed, and a third review author will be consulted if necessary.

Strategy for data synthesis

A quantitative data synthesis is planned. Data extracted from included studies will be analyzed and summarized to answer the stated review objectives using summary tables as well as the Joanna Briggs Institute Dominance Ranking Matrix (DRM), which will classify study results as showing strong dominance, non-dominance or weak dominance for the intervention.
No meta-analysis is planned as it is anticipated that there will be significant heterogeneity of service configurations in the included studies.

Analysis of subgroups or subsets

We will conduct a narrative synthesis of the countries involved in the studies in the review.

Contact details for further information

Miia Rahja
rahj0001@uni.flinders.edu.au

Organisational affiliation of the review

None

Review team members and their organisational affiliations

Ms Miia Rahja. Flinders University
Dr Kate Laver. Flinders University
Dr Tracy Comans. Griffith University
Professor Lindy Clemson. The University of Sydney
Professor Maria Crotty. Flinders University

Type and method of review

Systematic review

Anticipated or actual start date

23 September 2016

Anticipated completion date

31 May 2017

Funding sources/sponsors

The authors gratefully acknowledge funding provided by the National Health and Medical Research Council (NHMRC) Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. The contents of the published materials are solely the responsibility of the Administering Institution, Flinders University, and the individual authors identified, and do not reflect the views of the NHMRC.

Conflicts of interest

None known

Language

English

Country

Australia

Stage of review

Review Completed published

Details of final report/publication(s)

Rahja, M., Comans, T., Clemson, L., Crotty, M., & Laver, K. (2018). Economic evaluations of occupational therapy approaches for people with cognitive and/or functional decline: A systematic review. Health Soc Care Community. doi:doi:10.1111/hsc.12553
https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12553

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Caregivers; Cognition; Cost-Benefit Analysis; Humans; Occupational Therapy

Date of registration in PROSPERO

28 September 2016

Date of publication of this version

02 August 2018

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	**Started**	**Completed**
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Versions

28 September 2016
02 August 2018

APPENDIX C Systematic review; Search strategies used

Ovid MEDLINE(R) 1946 to Present

Includes: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, and Ovid MEDLINE(R) Daily

#	Searches	Results
1	"activities of daily living"/ or neurological rehabilitation/ or occupational therapy/	66224
2	(occupational therap* or "activities of daily living" or ADL or ADLs or IADL or IADLs or self care or selfcare or daily living activit* or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*).tw,kw.	866291
3	1 or 2	902114
4	dementia/ or aids dementia complex/ or alzheimer disease/ or aphasia, primary progressive/ or primary progressive nonfluent aphasia/ or creutzfeldt-jakob syndrome/ or dementia, vascular/ or cadasil/ or dementia, multi-infarct/ or diffuse neurofibrillary tangles with calcification/ or frontotemporal lobar degeneration/ or frontotemporal dementia/ or "pick disease of the brain"/ or huntington disease/ or kluver-bucy syndrome/ or lewy body disease/ or "diffuse cerebral sclerosis of schilder"/	139701
5	parkinsonian disorders/ or parkinson disease/ or parkinson disease, secondary/	63446
6	neurocognitive disorders/ or cognition disorders/ or mild cognitive impairment/	72268
7	delirium/ or Amyotrophic Lateral Sclerosis/ or Motor Disorders/ or Arthritis/ or Frail Elderly/ or Accidental Falls/ or Hip Fractures/	94964
8	multiple sclerosis/ or multiple sclerosis, chronic progressive/ or multiple sclerosis, relapsing-remitting/	49367
9	(dementia or Alzheimer* or progressive aphasia or progressive nonfluent aphasia or creutzfeldt-jakob or cadasil or frontotemporal lobar degeneration or "pick disease*" or "pick’s disease*" or huntington* or kluver-bucy or lewy bod* or Parkinson* or delirious or delirium* or Amyotrophic Lateral Sclerosis or ALS or multiple sclerosis or motor disorder* or arthriti* or frail* or (fall* adj2 prevent*) or (hip* adj2 fracture*)).tw,kw.	531744
10	((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) adj2 (condition* or disease* or disorder* or declin* or impair*)).tw,kw.	219136
11	or/4-10	784869
12	Caregivers/ or (carer or carers or caregiv* or care giv*).tw,kw.	66994
13	or/11-12	836939
14	Economics/	26793
15	"costs and cost analysis"/ or "cost allocation"/ or cost-benefit analysis/ or "cost control"/ or "cost savings"/ or "cost of illness"/ or "cost sharing"/ or "deductibles and coinsurance"/ or medical savings accounts/ or health care costs/ or direct service costs/ or hospital costs/ or health expenditures/ or capital expenditures/ or economics, hospital/ or hospital charges/ or economics, medical/ or fees, medical/ or "fees and charges"/ or capitation fee/ or budgets/ or "rate setting and review"/ or health planning/ or health plan implementation/ or health resources/	263195
16	(budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ*).tw,kw.	525652
17	(value adj2 (money or monetary)).tw,kw.	1719
18	models, economic/ or models, econometric/	12106
19	or/14-18	686820
20	3 and 13 and 19	8002
21	Adolescent/ or Young adult/ or exp child/ or exp infant/ or (middle age/ not exp aged/)	4688119
22	(Editorial or letter or comment or news or review).pt.	3863928
23	(protocol* or systematic review or metaanalys* or meta-analys*).ti.	136872
24	20 not (21 or 22 or 23)	4493

CINAHL (EBSCOhost)

#	Query	Limiters/Expanders	Results

S1	(MH "Activities of Daily Living+") OR (MH "Occupational Therapy") OR (MH "Constraint-Induced Therapy") OR (MH "Hand Therapy") OR (MH "Home Occupational Therapy") OR (MH "Rehabilitation, Cognitive")	Search modes - Boolean/Phrase	48,649
S2	TI ((“occupational therap*” or "activities of daily living" or ADL or ADLs or IADL or IADLs or “self care” or selfcare or “daily living activit*” or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*)) OR AB ((“occupational therap*” or "activities of daily living" or ADL or ADLs or IADL or IADLs or “self care” or selfcare or “daily living activit*” or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*))	Search modes - Boolean/Phrase	235,920
S3	S1 OR S2	Search modes - Boolean/Phrase	268,217
S4	(MH "Dementia") OR (MH "AIDS Dementia Complex") OR (MH "Dementia, Presenile") OR (MH "Alzheimer's Disease") OR (MH "Creutzfeldt-Jakob Syndrome") OR (MH "Creutzfeldt-Jakob Disease, Variant") OR (MH "Dementia, Senile") OR (MH "Dementia, Vascular") OR (MH "Dementia, Multi-Infarct") OR (MH "Lewy Body Disease") OR (MH "Cognition Disorders") OR (MH "Delirium") OR (MH "Consciousness Disorders")	Search modes - Boolean/Phrase	52,142
S5	(MH "CADASIL")	Search modes - Boolean/Phrase	123
S6	(MH "Frontotemporal Lobar Degeneration") OR (MH "Frontotemporal Dementia") OR (MH "Pick Disease of the Brain")	Search modes - Boolean/Phrase	160
S7	(MH "Huntington's Disease") OR (MH "Parkinsonian Disorders") OR (MH "Parkinson Disease")	Search modes - Boolean/Phrase	9,224
S8	(MH "Delirium, Dementia, Amnestic, Cognitive Disorders")	Search modes - Boolean/Phrase	91
S9	(MH "Amyotrophic Lateral Sclerosis") OR (MH "Neurodegenerative Diseases")	Search modes - Boolean/Phrase	3,028
S10	(MH "Motor Skills Disorders")	Search modes - Boolean/Phrase	901
S11	(MH "Arthritis")	Search modes - Boolean/Phrase	5,685
S12	(MH "Frail Elderly")	Search modes - Boolean/Phrase	3,907
S13	(MH "Frailty Syndrome")	Search modes - Boolean/Phrase	261
S14	(MH "Accidental Falls")	Search modes - Boolean/Phrase	12,047
S15	(MH "Hip Fractures")	Search modes - Boolean/Phrase	4,582
S16	(MH "Multiple Sclerosis")	Search modes - Boolean/Phrase	10,166
S17	TI ((dementia or Alzheimer* or “progressive aphasia” or “progressive nonfluent aphasia” or “creutzfeldt-jakob” or cadasil or “frontotemporal lobar degeneration” or "pick disease*" or "pick’s disease*" or huntington* or “kluver-bucy” or “lewy bod*” or Parkinson* or delirious or delirium* or “Amyotrophic Lateral Sclerosis” or ALS or “multiple sclerosis” or “motor disorder*” or arthriti* or frail* or (fall* N2 prevent*) or (hip* N2 fracture*))) OR AB ((dementia or Alzheimer* or “progressive aphasia” or “progressive nonfluent aphasia” or “creutzfeldt-jakob” or cadasil or “frontotemporal lobar degeneration” or "pick disease*" or "pick’s disease*" or huntington* or “kluver-bucy” or “lewy bod*” or Parkinson* or delirious or delirium* or “Amyotrophic Lateral Sclerosis” or ALS or “multiple sclerosis” or “motor disorder*” or arthriti* or frail* or (fall* N2 prevent*) or (hip* N2 fracture*))) OR TI (((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) N2 (condition* or disease* or disorder* or declin* or impair*))) OR AB (((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) N2 (condition* or disease* or disorder* or declin* or impair*)))	Search modes - Boolean/Phrase	100,932
S18	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	Search modes - Boolean/Phrase	138,937
S19	(MH "Caregiver Burden") OR (MH "Caregivers") OR (MH "Caregiver Support") OR (MH "Caregiver Strain Index")	Search modes - Boolean/Phrase	23,907
S20	TI ((carer or carers or caregiv* or “care giv*”)) OR AB ((carer or carers or caregiv* or “care giv*”))	Search modes - Boolean/Phrase	33,896
S21	S19 OR S20	Search modes - Boolean/Phrase	42,519
S22	S18 OR S21	Search modes - Boolean/Phrase	171,763
S23	(MH "Economics") OR (MH "Costs and Cost Analysis") OR (MH "Cost Benefit Analysis") OR (MH "Cost Control") OR (MH "Cost Savings") OR	Search modes - Boolean/Phrase	98,648

	(MH "Case Mix") OR (MH "Health Care Costs") OR (MH "Health Facility Costs") OR (MH "Economic Aspects of Illness") OR (MH "Fees and Charges") OR (MH "Health Facility Charges") OR (MH "Rate Setting and Review") OR (MH "Capitation Fee") OR (MH "Fee for Service Plans") OR (MH "Economic Value of Life") OR (MH "Health and Welfare Planning") OR (MH "Resource Allocation") OR (MH "Health Resource Allocation") OR (MH "Budgets") OR (MH "Financial Management")		
S24	(MH "Taxes")	Search modes - Boolean/Phrase	4,497
S25	(MH "Medical Savings Accounts")	Search modes - Boolean/Phrase	199
S26	TI (budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ*) OR AB (budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ*)	Search modes - Boolean/Phrase	120,341
S27	TI ((value N2 (money or monetary))) OR AB ((value N2 (money or monetary)))	Search modes - Boolean/Phrase	521
S28	S23 OR S24 OR S25 OR S26 OR S27	Search modes - Boolean/Phrase	187,964
S29	S3 AND S18 AND S22 AND S28	Search modes - Boolean/Phrase	1,985
S30	(MH "Adolescence+") OR (MH "Child+")	Search modes - Boolean/Phrase	460,365
S31	S29 NOT S30	Search modes - Boolean/Phrase	1,874
S32	(MH "Middle Age") OR (MH "Young Adult")	Search modes - Boolean/Phrase	455,686
S33	(MH "Adult") OR (MH "Aged+")	Search modes - Boolean/Phrase	723,216
S34	S32 NOT S33	Search modes - Boolean/Phrase	91,757
S35	S31 NOT S34	Search modes - Boolean/Phrase	1,834
S36	PT (("brief item" OR "case study" OR commentary OR editorial OR interview OR Letter OR Protocol OR Review)) OR TI (protocol* or "systematic review" or metaanalys* or "meta-analys*")	Search modes - Boolean/Phrase	1,042,253
S37	S35 NOT S36	Search modes - Boolean/Phrase	1,503

PsycINFO 1806 to July Week 4 2016

#	Searches	Results
1	"activities of daily living"/ or self-care skills/	8612
2	occupational therapy/	5195
3	Cognitive Rehabilitation/	1977
4	(occupational therap* or "activities of daily living" or ADL or ADLs or IADL or IADLs or self care or selfcare or daily living activit* or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*).tw,id.	351357
5	or/1-4	354548
6	dementia/ or aids dementia complex/ or dementia with lewy bodies/ or presenile dementia/ or semantic dementia/ or senile dementia/ or vascular dementia/ or alzheimer's disease/ or cognitive impairment/ or corticobasal degeneration/ or creutzfeldt jakob syndrome/ or neurodegenerative diseases/ or neurofibrillary tangles/ or parkinson's disease/ or picks disease/ or senile plaques/	99209
7	huntingtons disease/	2656
8	kluver bucy syndrome/	52
9	exp DELIRIUM/	2706
10	Amyotrophic Lateral Sclerosis/	2799
11	nervous system disorders/ or neurodegenerative diseases/	18810
12	ARTHRITIS/	1920
13	falls/	2082
14	Injuries/ and Hips/	295
15	multiple sclerosis/	10190
16	(dementia or Alzheimer* or progressive aphasia or progressive nonfluent aphasia or creutzfeldt-jakob or cadasil or frontotemporal lobar degeneration or "pick disease*" or "pick’s disease*" or huntington* or kluver-bucy or lewy bod* or Parkinson* or delirious or delirium* or Amyotrophic Lateral Sclerosis or ALS or multiple sclerosis or motor disorder* or arthriti* or frail* or (fall* adj2 prevent*) or (hip* adj2 fracture*)).tw,id.	138830
17	((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) adj2 (condition* or disease* or disorder* or declin* or impair*)).tw,id.	81677
18	or/6-17	210074
19	caregivers/ or caregiver burden/ or elder care/	26857
20	(carer or carers or caregiv* or care giv*).tw,id.	50125
21	or/19-20	54570
22	economics/ or health care economics/ or budgets/ or "cost containment"/ or health care costs/ or human capital/ or money/ or resource allocation/ or "supply and demand"/	36434
23	professional fees/ or fee for service/ or "costs and cost analysis"/	14881
24	(budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ*).tw,id.	204885
25	(value adj2 (money or monetary)).tw,id.	785
26	or/22-25	215838
27	18 or 21	252168
28	5 and 26 and 27	2601
29	(childhood birth 12 yrs or adolescence 13 17 yrs or young adulthood 18 29 yrs or ((thirties 30 39 yrs or middle age 40 64 yrs) not aged 65 yrs older)).ag.	1015653
30	28 not 29	2076
31	(Column* or opinion* or comment* or reply or Editorial or Letter or review*).dt.	292463
32	30 not 31	1919
33	(protocol* or systematic review or metaanalys* or meta-analys*).ti.	22131
34	32 not 33	1852
35	limit 34 to all journals	1307

Econlit 1886 to August 2016

#	Searches	Results
1	(occupational therap* or "activities of daily living" or ADL or ADLs or IADL or IADLs or "self care" or selfcare or "daily living activit*" or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*).mp.	18236
2	(dementia or Alzheimer* or "progressive aphasia" or "progressive nonfluent aphasia").mp.	145
3	(creutzfeldt jakob or cadasil or frontotemporal lobar degeneration).mp.	5
4	(pick disease* or pick's disease* or huntington* or kluver bucy or lewy bod* or Parkinson* or delirious or delirium* or Amyotrophic Lateral Sclerosis or ALS or multiple sclerosis or motor disorder* or arthriti* or frail*).mp.	1583
5	((fall* adj2 prevent*) or (hip* adj2 fracture*) or ((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) adj2 (condition* or disease* or disorder* or declin* or impair*)) or carer or carers or caregiv* or "care giv*").mp.	1403
6	or/2-5	3052
7	(budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ* or (value adj2 (money or monetary))).mp.	1040998
8	1 and 6 and 7	95

ProQuest (Health & Medicine; Social Sciences databases)

N=2956

all(("occupational therap*" OR "activities of daily living" OR ADL OR ADLs OR IADL OR IADLs OR "self care" OR selfcare OR "daily living activit*" OR rehabilitat* OR neurorehabilitat* OR telerehabilitat* OR intervention*) AND ((dementia OR Alzheimer* OR "progressive aphasia" OR "progressive nonfluent aphasia" OR "creutzfeldt-jakob" OR cadasil OR "frontotemporal lobar degeneration" OR "pick disease*" OR "pick’s disease*" OR huntington* OR "kluver-bucy" OR "lewy bod*" OR Parkinson* OR delirious OR delirium* OR "Amyotrophic Lateral Sclerosis" OR ALS OR "multiple sclerosis" OR "motor disorder*" OR arthriti* OR frail* OR (fall* NEAR/2 prevent*) OR (hip* NEAR/2 fracture*)) OR ((cogniti* OR neurocognitiv* OR neurodegenerat* OR degenerat* OR function*) NEAR/2 (condition* OR disease* OR disorder* OR declin* OR impair*)) OR (carer OR carers OR caregiv* OR "care giv*")) AND (budget* OR econom* OR costs OR costly OR costing OR price OR prices OR pricing OR expenditure* OR expense* OR financ* OR (value NEAR/2 (money OR monetary))))

Cochrane Central Register of Controlled Trials: Issue 8 of 12, August 2016

N=1700

(“occupational therap*” or "activities of daily living" or ADL or ADLs or IADL or IADLs or “self care” or selfcare or “daily living activit*” or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*) AND ((dementia or Alzheimer* or “progressive aphasia” or “progressive nonfluent aphasia” or “creutzfeldt-jakob” or cadasil or “frontotemporal lobar degeneration” or "pick disease*" or "pick’s disease*" or huntington* or “kluver-bucy” or “lewy bod*” or Parkinson* or delirious or delirium* or “Amyotrophic Lateral Sclerosis” or ALS or “multiple sclerosis” or “motor disorder*” or arthriti* or frail* or (fall* NEAR/2 prevent*) or (hip* NEAR/2 fracture*)) OR ((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) NEAR/2 (condition* or disease* or disorder* or declin* or impair*)) OR (carer or carers or caregiv* or “care giv*”)) AND (budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ* OR (value NEAR/2 (money or monetary)))

Health Technology Assessment Database: Issue 3 of 4, July 2016

N=6

(“occupational therap*” or "activities of daily living" or ADL or ADLs or IADL or IADLs or “self care” or selfcare or “daily living activit*” or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*) AND ((dementia or Alzheimer* or “progressive aphasia” or “progressive nonfluent aphasia” or “creutzfeldt-jakob” or cadasil or “frontotemporal lobar degeneration” or "pick disease*" or "pick’s disease*" or huntington* or “kluver-bucy” or “lewy bod*” or Parkinson* or delirious or delirium* or “Amyotrophic Lateral Sclerosis” or ALS or “multiple sclerosis” or “motor disorder*” or arthriti* or frail* or (fall* NEAR/2 prevent*) or (hip* NEAR/2 fracture*)) OR ((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) NEAR/2 (condition* or disease* or disorder* or declin* or impair*)) OR (carer or carers or caregiv* or “care giv*”)) AND (budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ* OR (value NEAR/2 (money or monetary)))

NHS Economic Evaluation Database: Issue 2 of 4, April 2015

N=71

(“occupational therap*” or "activities of daily living" or ADL or ADLs or IADL or IADLs or “self care” or selfcare or “daily living activit*” or rehabilitat* or neurorehabilitat* or telerehabilitat* or intervention*) AND ((dementia or Alzheimer* or “progressive aphasia” or “progressive nonfluent aphasia” or “creutzfeldt-jakob” or cadasil or “frontotemporal lobar degeneration” or "pick disease*" or "pick’s disease*" or huntington* or “kluver-bucy” or “lewy bod*” or Parkinson* or delirious or delirium* or “Amyotrophic Lateral Sclerosis” or ALS or “multiple sclerosis” or “motor disorder*” or arthriti* or frail* or (fall* NEAR/2 prevent*) or (hip* NEAR/2 fracture*)) OR ((cogniti* or neurocognitiv* or neurodegenerat* or degenerat* or function*) NEAR/2 (condition* or disease* or disorder* or declin* or impair*)) OR (carer or carers or caregiv* or “care giv*”)) AND (budget* or econom* or costs or costly or costing or price or prices or pricing or expenditure* or expense* or financ* OR (value NEAR/2 (money or monetary)))

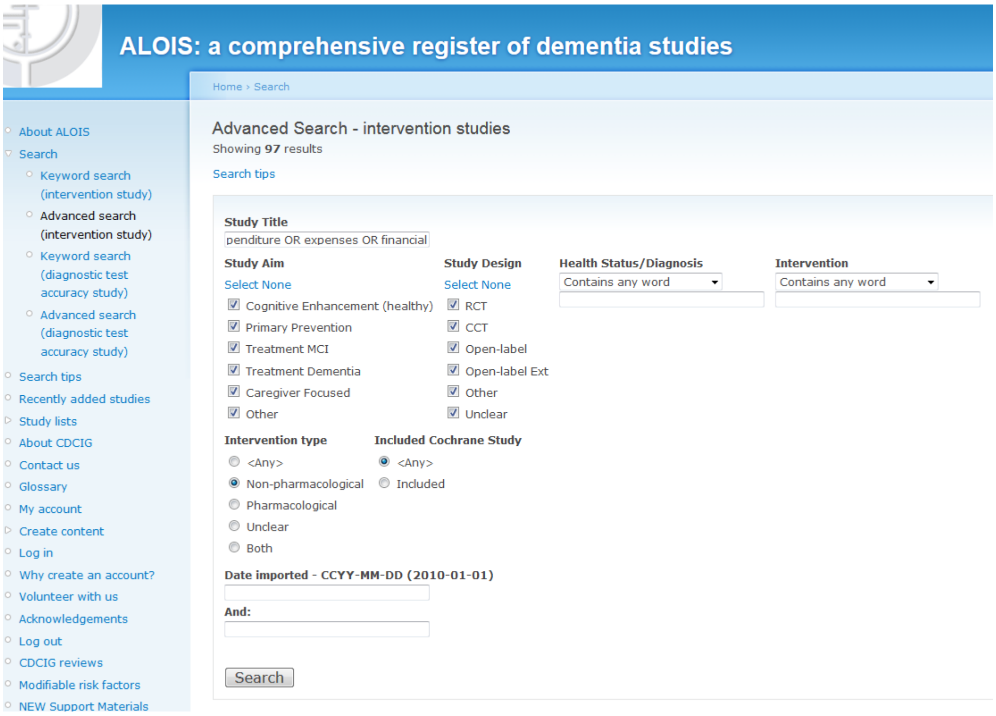
ALOIS database

Searched 27/9/16

N=97

Search strategy modified/simplified to work with the rudimentary interface. Search only required terms for costs/economics etc. Only limited number of terms allowed in search field, therefore I went with the most obvious.

Advanced search: budget OR economical OR costs OR costly OR costing OR price OR prices OR pricing OR expenditure OR expenses OR financial



ALOIS: a comprehensive register of dementia studies

Home › Search

- About ALOIS
- Search
  - Keyword search (intervention study)
  - Advanced search (intervention study)
  - Keyword search (diagnostic test accuracy study)
  - Advanced search (diagnostic test accuracy study)
- Search tips
- Recently added studies
- Study lists
- About CDCIG
- Contact us
- Glossary
- My account
- Create content
- Log in
- Why create an account?
- Volunteer with us
- Acknowledgements
- Log out
- CDCIG reviews
- Modifiable risk factors
- NEW Support Materials

Advanced Search - intervention studies

Showing **97** results

Search tips

Study Title
penditure OR expenses OR financial

Study Aim
Select None
☑ Cognitive Enhancement (healthy)
☑ Primary Prevention
☑ Treatment MCI
☑ Treatment Dementia
☑ Caregiver Focused
☑ Other

Study Design
Select None
☑ RCT
☑ CCT
☑ Open-label
☑ Open-label Ext
☑ Other
☑ Unclear

Health Status/Diagnosis
Contains any word

Intervention
Contains any word

Intervention type
○ <Any>
● Non-pharmacological
○ Pharmacological
○ Unclear
○ Both

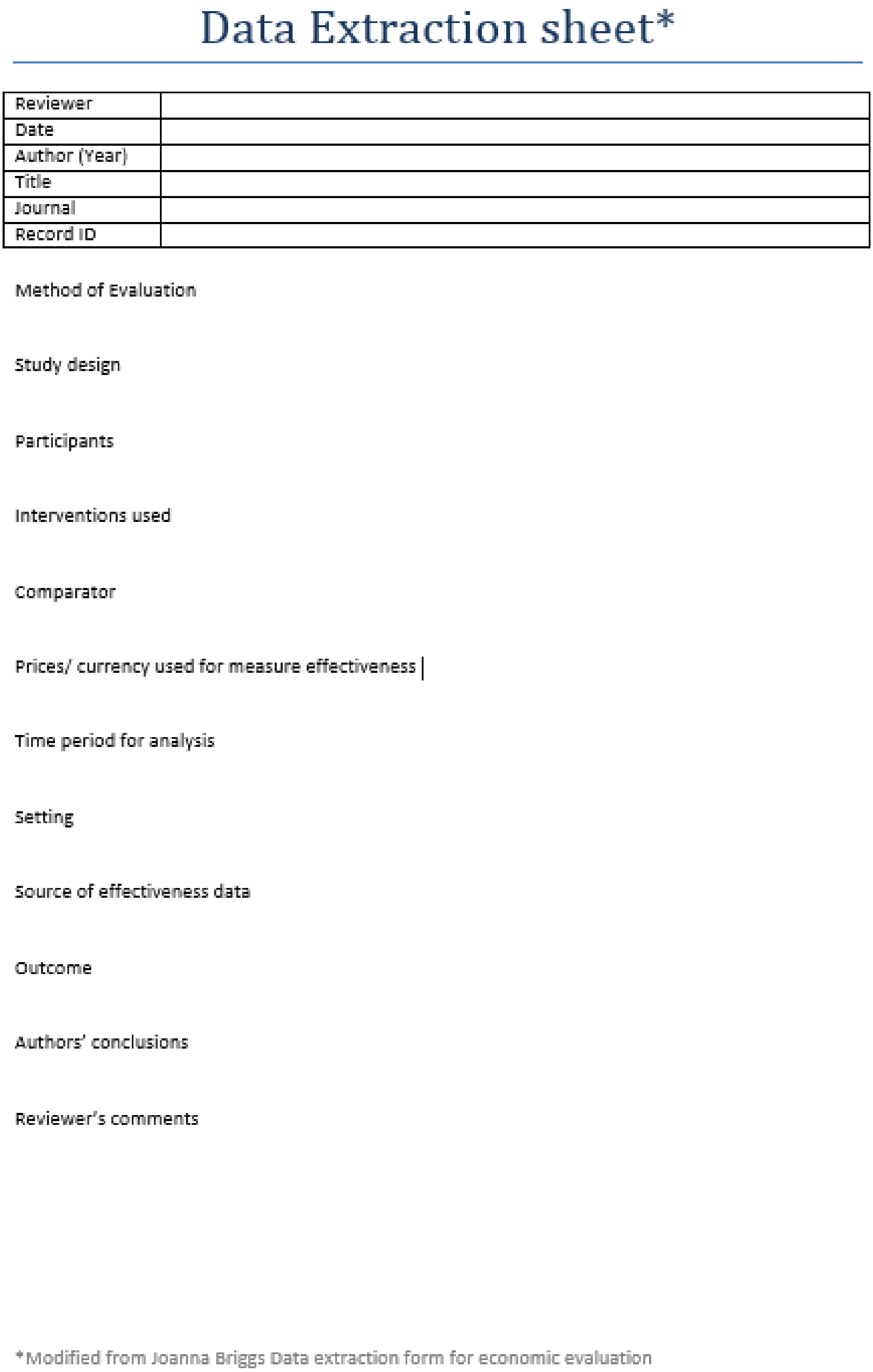
Included Cochrane Study
● <Any>
○ Included

Date imported - CCYY-MM-DD (2010-01-01)

And:

Search

APPENDIX D Systematic review; Data extraction sheet used



Data Extraction sheet*

Reviewer	
Date	
Author (Year)	
Title	
Journal	
Record ID	

Method of Evaluation

Study design

Participants

Interventions used

Comparator

Prices/ currency used for measure effectiveness

Time period for analysis

Setting

Source of effectiveness data

Outcome

Authors' conclusions

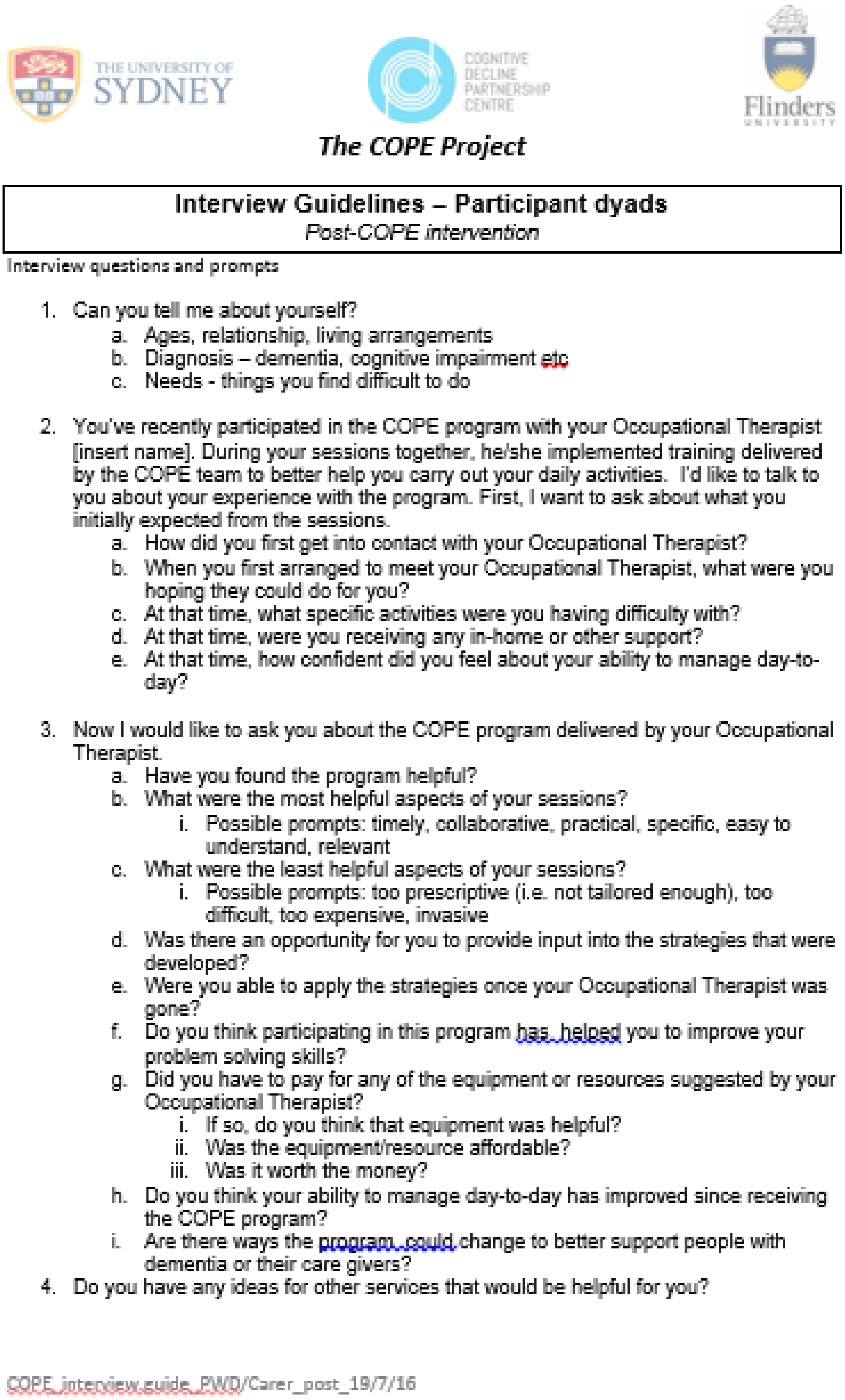
Reviewer's comments

*Modified from Joanna Briggs Data extraction form for economic evaluation

APPENDIX E Case note audit; data extraction tool

DATA COLLECTION FORM – CLINICAL AUDIT		
Site/service:		
Client gender:	M/F	
Client age:		
Client living situation:	Alone With spouse Other (specify)	
Severity of dementia as indicated by cognitive assessment tool score		
Duration of service		
Number of face-to-face consultations Number of phone calls to client/carer		
Assessments undertaken		
<u>Intervention approaches used</u> Environmental modification advice Prescription of assistive devices or equipment Education about dementia (for the person with dementia) Education about dementia (for the carer) Carer coping strategies Case management Placement/respite processes Aged Care Assessment applications Referral to other services Teaching compensatory strategies for basic ADLs Use of strategies to enhance memory Assisting clients choice and use of meaningful activities Rehabilitation for comorbidities (eg falls) Teaching compensatory strategies for instrumental ADLs Behavioural management approaches Functional mobility training Social activities Leisure activities Reminiscence therapy Driving cessation advice/transport options Psychosocial support (eg counselling) Cognitive retraining Validation therapy Reality orientation Teaching compensatory strategies for community activities Creative media (dance, drama, exercise/tai chi/yoga Other commonly used interventions Perceptual retraining Stress management/relaxation training Snoezelen		

APPENDIX F Participant experiences with the COPE program; interview guide



THE UNIVERSITY OF SYDNEY

COGNITIVE DECLINE PARTNERSHIP CENTRE

Flinders UNIVERSITY

The COPE Project

Interview Guidelines – Participant dyads

Post-COPE intervention

Interview questions and prompts

1. Can you tell me about yourself?
    a. Ages, relationship, living arrangements
    b. Diagnosis – dementia, cognitive impairment etc
    c. Needs - things you find difficult to do

2. You've recently participated in the COPE program with your Occupational Therapist [insert name]. During your sessions together, he/she implemented training delivered by the COPE team to better help you carry out your daily activities. I'd like to talk to you about your experience with the program. First, I want to ask about what you initially expected from the sessions.
    a. How did you first get into contact with your Occupational Therapist?
    b. When you first arranged to meet your Occupational Therapist, what were you hoping they could do for you?
    c. At that time, what specific activities were you having difficulty with?
    d. At that time, were you receiving any in-home or other support?
    e. At that time, how confident did you feel about your ability to manage day-to-day?

3. Now I would like to ask you about the COPE program delivered by your Occupational Therapist.
    a. Have you found the program helpful?
    b. What were the most helpful aspects of your sessions?
        i. Possible prompts: timely, collaborative, practical, specific, easy to understand, relevant
    c. What were the least helpful aspects of your sessions?
        i. Possible prompts: too prescriptive (i.e. not tailored enough), too difficult, too expensive, invasive
    d. Was there an opportunity for you to provide input into the strategies that were developed?
    e. Were you able to apply the strategies once your Occupational Therapist was gone?
    f. Do you think participating in this program has helped you to improve your problem solving skills?
    g. Did you have to pay for any of the equipment or resources suggested by your Occupational Therapist?
        i. If so, do you think that equipment was helpful?
        ii. Was the equipment/resource affordable?
        iii. Was it worth the money?
    h. Do you think your ability to manage day-to-day has improved since receiving the COPE program?
    i. Are there ways the program could change to better support people with dementia or their care givers?
4. Do you have any ideas for other services that would be helpful for you?

COPE_interview guide_PWD/Carer_post_19/7/16

APPENDIX G Chapter 7; Supplementary file

Implementing the COPE program in the Australian health context: A cost-benefit analysis

This file documents all variable inputs used for the analyses for the costs and benefits included in the study (and are described in Section 1 of this document). Section 2 includes completed base-case scenario results for the four perspectives (Market, Private, Efficiency, and Referent group) analysed.

The four analyses included market and/or non-market (shadow or efficient) prices. To re-iterate, market prices measure the benefits of all project outputs (and inputs) in actual monetary value, and a real exchange of currency occurs. Shadow prices are applied when there is no market price or a market price is not appropriate for the outcomes or impact of interest. It is common to apply shadow prices to reflect social costs and benefits in cost-benefit analyses (Campbell & Brown, 2015).

SECTION 1

Key operational variables

The program funding began in 2016, and implementation continued until 2019. A further five year projection (2020-2024) was completed to reflect the adoption of the program in standard care provision, and the costs and benefits are calculated from year 2019 onwards. We used three discount rates 2%, 5%, and 7% for all analyses.

The initial funding and costs attributable to training of therapist/ ongoing implementation are summarised in Table S7-1. During the implementation years, therapists and organisations did not have to pay for training, this was covered by the funding body (Cognitive Decline Partnership Centre; CDPC). Research costs were removed from ongoing projections and only costs attributable to therapist training and implementation were included as per Table S7-1.

Table S7-1 Initial funding and costs covered by funding agency

	2016	**2017**	**2018**	**2019**
Funding from CDPC	$ 51,161.00	$ 208,263.00	$ 221,610.00	$ 171,811.00
Attributable to training OTs / implementation		**$ 56,826.80**	**$ 56,826.80**	

The plan for program roll-out and basic design is outlined in Table S7-2.

- Three new occupational therapy training sessions per year is planned for future. The maximum number of therapists for each session is set at 20.
- The training is planned as two-day intensive (face to face) workshop.

- The cost for the program was averaged from current existing continuing professional development programs for occupational therapists (retrieved 24 February, 2019 from https://www.otaus.com.au/professional-development)
- Coaching session were planned at the discretion of the project team.

Table S7-2 Program basic design

COPE PROGRAM BASIC DESIGN	Unit
Number of trainng sessions (per year)	3
Number of participants per training session (target)	20
Number of days per training session (days)	2
Number of hours per training day (hours)	7
Number of hours preparation for training (hours)	7
Number of coaching sessions for an OT	3
Number of coaching calls planned a year	6
Price of COPE program for participant (training certification, 3	$ 900.00

Training and retaining of therapists

- Initially 38 occupational therapists (33 from public and 5 from private sectors) were trained over four training sessions in 2017 (two sessions in South Australia, and two in New South Wales) (Table S7-3)
- Of the 38 trained therapists, 26 delivered one or more programs by 2019. Table S7-4 illustrates drop off assumptions made for ongoing years.
- Tables S7-5 and Figure S7-1 summarise and illustrate the assumptions made for number of retained therapist for each year.

Table S7-3 Training plan for therapists

TRAINING OF THERAPISTS	Unit	Public	Private	% are private OTs
Number of training sessions (per year)	3			
Number of participants per training session	20			
Initial enrolment (COPE OTs as part of project, actual)	38	33	5	15%
Initial drop off (n therapists from COPE project, actual)	10	8	2	25%
Total number of new trained OTs a year (#sessions * #participants per session)	60			

Table S7-4 Drop off assumptions for retaining trained therapists

% drop off	year	2019	2020	2021	2022	2023	2024
0.32	**2019**	0.32	0.50	0.50	0.30	0.30	0.10
0.50	**2020**		0.32	0.50	0.50	0.30	0.30
0.50	**2021**			0.32	0.50	0.50	0.30
0.30	**2022**				0.32	0.50	0.50
0.30	**2023**					0.32	0.50
0.10	**2024**						0.32

Table S7-5 Number of trained and retained therapists

	year	trained new each year	total trained accumulative	retained new each year	retained					
					2019	2020	2021	2022	2023	2024
0	**2019**	38	38	26	26	13	7	5	4	4
1	**2020**	60	98	41		41	21	11	8	6
2	**2021**	60	158	41			41	21	11	8
3	**2022**	60	218	41				41	21	11
4	**2023**	60	278	41					41	21
5	**2024**	60	338	41						41
	Total				**26**	**54**	**69**	**78**	**85**	**91**

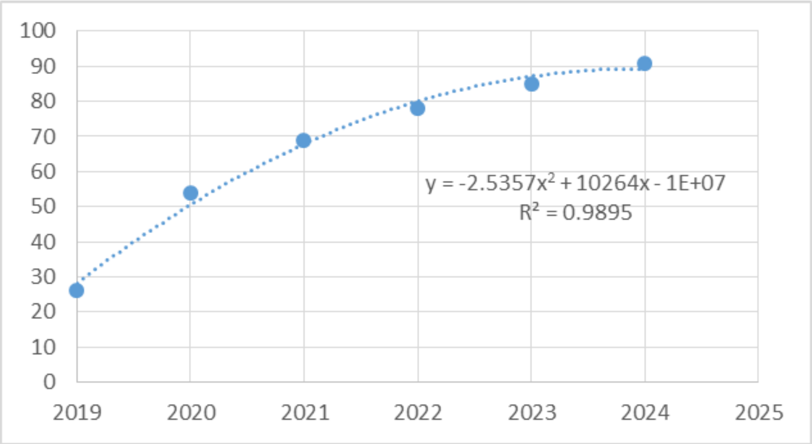


Figure S7-1 Trained and retained therapists curve

Nurse involvement

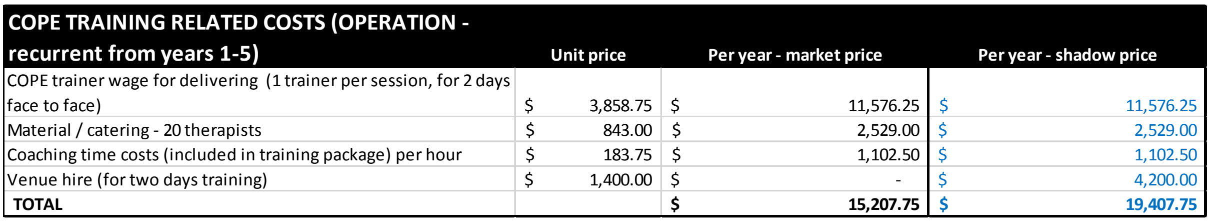
- Seventeen nurses were trained on the program during the project.
- No nurse training component is planned for long term implementation as care provision from nurses is considered standard and the program does not seek to change how this is delivered.

Costs

The costs related to initial investment was derived from the actual expenditure data of the project. These costs were: trainer related salary, travel and accommodation, partner related travel, training materials and printing, catering and other material provided at training. Table S7-6 provides estimated costs for ongoing training and coaching of occupational therapists (from 2020 to 2024). For all items, except venue hire, market and efficient prices were equal. This was because we assumed that occupational therapy is a ‘competitive market’ and their salaries reflect the values of their marginal productivity. We also perceived that the catering was priced competitively. In this project, the training venue was provided by the hosting university free of charge, therefore, the market price was set at zero. However, if a venue hire was required for the training, an exchange of payment would have occurred, which was reflected as shadow (efficient) price in Table S7-6.

- Coaching time based on Level 2 casual academic rate at the hosting university, A$183.75 (AUD) per hour (retrieved 24 February 2019, from https://www.flinders.edu.au/hr-files/documents/Salary%20Rates/Casual_Acad_Gen_08072017_V1.pdf).
- Catering costs derived from hosting university's catering company.
- Venue hire based on the rate at the hosting university.

Table S7-6 Therapist training related costs for COPE team



COPE TRAINING RELATED COSTS (OPERATION - recurrent from years 1-5)	Unit price	Per year - market price	Per year - shadow price
COPE trainer wage for delivering (1 trainer per session, for 2 days face to face)	$ 3,858.75	$ 11,576.25	$ 11,576.25
Material / catering - 20 therapists	$ 843.00	$ 2,529.00	$ 2,529.00
Coaching time costs (included in training package) per hour	$ 183.75	$ 1,102.50	$ 1,102.50
Venue hire (for two days training)	$ 1,400.00	$ -	$ 4,200.00
TOTAL		**$ 15,207.75**	**$ 19,407.75**

Table S7-7 includes costs related to training of occupational therapists for participating organisations. We used data (including salaries) from partner organisations on therapist and/or nurse involvement time. Therapist time to attend program specific training was recorded and each completed service records of time spent with participant dyads. The records included detail about average total minutes spent delivering a session (including travel, one-on-one, documentation and follow up time), resources provided, and consultation related charges to the dyad (if applicable). We estimated the number of therapists available for training (National Health Workforce Dataset, 2018) and used audit findings from Rahja, Comans, et al. (2018a) to inform changes in therapist intervention delivery.

The market and shadow price was only equal for the cost of therapist training program. This was because the cost of the program reflects the value of the program in the market. As already mentioned, the cost was derived from true costs of other professional development and training programs aimed at occupational therapists (retrieved 24 February, 2019 from https://www.otaus.com.au/professional-development). However, shadow prices were applied to therapist training and coaching time, as well as management engagement. In this project, the market price for these is zero, as the therapists (and management) remain employed with the organisation and receive a salary while being involved in training or set up. A shadow price was used to reflect the opportunity cost of missed time 'at work place' due to commitments to the COPE program. The costs were drawn from actual data reported by the participating organisations on therapist and management salary and are reflected as shadow prices in Table S7-7.

Table S7-7 Organisation specific therapist training costs

ORGANISATIONS THAT HAVE OT TRAINED WITH COPE PROGRAM		Government organisation		Private organisation		Weighted average price per OT (by % private)	
Staff related expenditure (per OT)	**Unit**	**Unit price**	**Per OT - government**	**Unit price**	**Per OT - private**	**Market price**	**Shadow price**
Attending COPE training sessions (per OT, 2 full days, in hours)	14	$ 56.25	$ 787.50	$ 153.00	$ 2,142.00	$ -	$ 992.73
Attending COPE coaching and mentoring sessions (per OT, in hours)	3	$ 56.25	$ 168.75	$ 153.00	$ 459.00	$ -	$ 212.73
Price of COPE program for participant (training certification, 3 coaching sessions)	1 package	$ 900.00	$ 900.00	$ 900.00	$ 900.00	$ 900.00	$ 900.00
Management involved/ set up costs (hours - set by COPE team)	4	$ 81.00	$ 324.00	$ 81.00	$ 324.00	$ -	$ 324.00
TOTAL, per one staff receiving COPE training			**$ 2,180.25**		**$ 3,825.00**	**$ 900.00**	**$ 2,429.45**

- A training session consists of two days (14 hours) of COPE specific training. For the purpose of the program, some therapists also attended a one day training module on Allen’s Cognitive Level Screen (Allen, 1985), a standardised test used by occupational therapist to determine a level of person’s cognitive function related to day to day activities. These attendances were calculated in training related costs for implementation phase (2017-2019).
    - The Allen’s training module is not planned for future roll-out as it is independent of the program and is not required for successful completion.
- Whilst occupational therapists acquire a new skill following training, an assumption is made that this does not warrant an increase in industry award rate (salary).
- Actual data were used for number of therapists and / or nurses trained, including coaching calls these therapists attended, costs of training time and subsequent missed therapist hours in the office (opportunity cost) (Table S7-7).

Table S7-8 summarises the basic components for the program delivery by a therapist, including a nurse component. These numbers were drawn from actual data (averages, minimum and maximum attendance calculated).

- An assumption is made that a therapist delivers COPE to an average of five participant dyads per year. This number was calculated as visiting one dyad (with up to 10 sessions) once a week during the year.
    - A sensitivity analysis included an assumption that therapist delivers COPE to an average of 3 dyads per year (a minimum requirement for COPE certification) and 10 dyads per year (2 dyads once a week during a one year period).
- An average number of sessions per dyad was 7.
    - A sensitivity analysis was completed for a total of 10 sessions and a minimum of 3 sessions (the lowest number of sessions delivered as part of the project)
- Average total minutes spent delivering a session (includes travel, one-on-one, documentation and follow up) was 169 minutes.
- Due to the large variance in time spent per session with clients, we modelled a minimum and maximum time spent per session by subtracting and adding (respectively) 30% to the total average time per dyad (including travel and documentation). We also calculated the

average one-on-one time (only) spent delivering session (which was 85 minutes), as well as estimated that research related time consisted of 30 minutes during the first session (to complete consent and pre study questionnaires), and 15 minutes during final session (to complete post questionnaire). These variances were explored in the sensitivity analyses.

- Therapist and nurse salaries were averaged from reports from participating organisations.
- An average charge (income received for organisation) per session based on actual charges reported in study was A$181.30 per session (range A$102.73 – A$259.88). These variances were included in sensitivity analysis.
- Approximately 5% of the participants had nursing component recorded as part of the program.
- The average number of nurse visits per program for these participants was four; some COPE nurses attended all sessions with COPE therapists. However, the intended program prescription for nurse component is up to two sessions. The program calculations were based on one visit and is counted for 5% of the participants.
- Caregiver companion guide was provided as part of the program. An assumption is made that each participant will buy this companion on own. The cost is A$30 as per bookdepositry charges (accessed February, 2019 https://www.bookdepository.com/A-Caregiver-s-Guide-to-Dementia/9781933822907)

Table S7-8 Delivery of the COPE program (per therapist)

DELIVERY OF COPE INTERVENTION TO CLIENTS (ANNUAL) Per OT (including nursing hours)	Average	Minimum	Maximum
Number of clients per OT (per year average, min=3, max=10)	5	3	10
Number of sessions per client (average, min=3, max=10)	7	3	10
Total time spent delivering a session (in minutes, including travel, 1:1, documentation, follow up)	169	118	219
Total time spent delivering a session in minutes (includes: travel, 1:1, documentation, follow up) – without project documentation	157		
Total time spent delivering a session in minutes (includes: 1:1 time only)	85		
OT wage per hour (weighted average of public and private)	$ 70.91	$ 56.25	$ 153.00
Nurse wage per hour	$ 68.76		
Standard number of sessions per COPE package	10	1	10
Number of nursing sessions per COPE package	1	0	2
Client fee per session (average, $)	$ 181.30	$ 102.73	$ 259.88
COPE caregiver guide book	$ 30.00		

Therapist and participant participation

Table S7-9 summarises the predicted total number of dyads (person with dementia and their caregiver) who will receive the program per year for the adoption period (2020-2024); counted as estimated number of therapists trained (Table S7-5) and average number of participants per therapist a year (Table S7-8). The Table (S7-9) also includes estimates of expected revenue from sessions delivered for an organisation that is calculated as:

$$\begin{gathered}\mathit{Total\ revenue} = \\ \mathit{Total\ clients}\ \ *\ \mathit{Maximum\ number\ of\ sessions}\ *\ \mathit{Average\ client\ fee}\end{gathered}$$

Total time spent delivering the program (including occupational therapist and nurse sessions) is also estimated in Table S7-9. Finally, the estimated total cost for delivering the program per client is calculated as:

$$\begin{gathered}\mathit{Total\ delivery\ cost} = \\ \mathit{Therapist\ wage} * \mathit{Total\ therapist\ time\ (hrs)} + \mathit{Nurse\ wage} * \mathit{Total\ nurse\ time\ (hrs)}\end{gathered}$$

Table S7-9 Predicted total number of people with dementia who will receive the program, including costs

TOTAL - CLIENTS RECEIVING COPE PROGRAM	Year 0 (2019)	Year 1 (2020)	Year 2 (2021)	Year 3 (2022)	Year 4 (2023)	Year 5 (2024)
Total number of clients (dementia dyads /person with dementia), per year		270	345	390	425	455
Total revenue from COPE sessions delivered (what clients pay per COPE package, 10 sessions)		**$ 489,521**	**$ 625,500**	**$ 707,087**	**$ 770,543**	**$ 824,934**
Time spent delivering COPE program to clients (in hours, per year)		5,457	6,972	7,882	8,589	9,195
Time for nursing sessions		546	697	788	859	920
Time for OT sessions		4,911	6,275	7,093	7,730	8,276
Total cost to deliver COPE to client ($, per year) = hour spent * hourly wage (split 20% nursing sessions)		**$ 385,747**	**$ 492,899**	**$ 557,191**	**$ 607,195**	**$ 650,056**

Benefits

The benefits for the COPE project team were related to the revenue from training of therapists. The main benefits for organisations and therapists delivering the program were from participants paying for accessing the program.

The anticipated benefits for the participants were related to health service use and caregiver wellbeing, including quality of life. The participants completed the revised version (-Lite) of the Resources Use in Dementia questionnaire (Wimo et al., 2010; Wimo & Winblad, 2003). Actual data from 84 participants were used to calculate the benefits. Paired mean pre- and post-program differences for health service use are calculated as per reports from each participant dyad. SPSS statistical software package (IBM Corporation, 2013) was used to aid the calculations.

We also expected overall benefits for health and aged care systems. Table S7-10 includes detail about the changes in healthcare use and care provision as per reports from the returned questionnaires. For all items except for healthcare services accessed at home, market and efficient prices varied. For the home care services accessed at home it was assumed that consumers (who access services through home care packages in the community) pay for these services, and full exchange in currency occurs (as reflected in Table S7-10).

The Government funded Medicare scheme guarantees free public hospital care and also funds a range of other services, including primary care; most Australians access this scheme. Therefore, the market price was set to ‘zero’ for items related to hospitalisation and long term care (Table S7-10). However, as these stays still cost money for the Government, shadow prices were applied based on the retrieved, publicly available, data (for example from: Independent Hospital Pricing Authority, 2018) as is itemised below. Additionally, the market prices for healthcare services accessed in the community reflected in Table S7-10 include an 80% ‘benefit’ that is covered by the Australian Medicare as per the Extended Medicare Safety Net (EMSN) benefit (Department of Health Australia, 2017). However, as also stated earlier, a shadow price applied in the Table (S7-10) does not include this ‘benefit’, as there is still full cost that needs to be paid for the service by the Government. These costs were drawn from the publicly available ‘Medicare Benefits Schedule Book’ (Department of Health Australia, 2017a).

Lastly, it was perceived that informal caregivers do not receive a salary/remuneration for the care they provide; the market price value therefore was set at ‘zero’. However, if a caregiver received payment for providing care for the person with dementia, and exchange of payment occurred, a shadow price was applied to reflect the value of this care (see below for more detail). Similarly, the market value for caregiver ‘time away from paid employment’ was set as ‘zero’. This was because it was assumed that a caregiver would not miss salary for the time taken away from their employment; employment terms in Australia include paid leave that a caregiver is entitled to.

However, a shadow price to this item was applied in order to reflect the opportunity cost of ‘lost productivity’ at workplace (Table S7-10).

The value for the items described in Table S7-10 were drawn as follows:

- Changes in overnight hospital and long term care needs.
    - Care at hospital emergency room, (for less than 24 hours) as the national average cost for emergency department presentation: A$584 per presentation (Independent Hospital Pricing Authority, 2018).
    - An ambulance call-out fee varies per state, this was costed as A$976, as the participant was from South Australia (accessed 20th April 2018 through http://www.saambulance.com.au/ProductsServices/Ambulancefees.aspx.
    - Nights spent in hospital ward as the national average per admitted person acute separation A$2179 (Independent Hospital Pricing Authority, 2018).
    - Nights spent in accommodation other than home (e.g. Respite or long term care) was costed as 85% of the single person rate of the basic age pension equating to A$50.16 per day (accessed 20th April 2018, through https://www.myagedcare.gov.au/costs/aged-care-homes-costs-explained/aged-care-home-basic-daily-fee).
- Changes in services accessed at home, that is, health professional visits to a person’s home (for example through home care packages).
    - Costed based on online search of known home care package providers, such as https://achgroup.org.au/wp/wp-content/uploads/2017/02/ACH-Group-Home-Care-Price-List-March-2017.pdf (accessed 20th April 2018).
    - Food delivery costed based on assumption that people get two meals a day with A$10 per meal = A$140 per week. Prices derived from www.nswmealsonwheels.org.au/About/About-Us/What-our-meals-cost (accessed 20th April 2018).
- Healthcare services used in the community; counted as 80% of costs covered by Medicare as per the Extended Medicare Safety Net (EMSN) benefit (Department of Health Australia, 2017a).
- Changes in time spent caregiving (in activities of daily living (ADLs), instrumental activities of daily living (IADLs), and ‘supervising’ the person with dementia).
    - Caregiver time spent assisting in ADLs, IADLs and / or supervising was costed as the average wage of home care worker A$22.27 per hour (accessed 20th April 2018, through www.payscale.com/research/AU/Job=Home_Care_Worker/Hourly_Rate).
- Caregiver time spent away from paid employment was costed as the median weekly pay in Australia in 2017, valued at A$1019 per week (Australian Bureau of Statistics, 2018b).

- Change in quality of life (QoL) utility score for caregiver was assumed to be minimal (0.01) for Willingness to Pay Threshold of A$60,000 for Quality Adjusted Life Year (QALY) gained (Shiroiwa et al., 2010). The estimated 0.01 improvement in a person's health state is less than the minimum important change if using QoL instruments, such as the EQ-5D, used to measure change in health utility (Coretti et al., 2014). The minimal change in score (0.01) was used as a baseline in order to ensure that the outcome was not 'overvalued' in the included analysis (i.e. the change in QoL was not expected to be too high).

Table S7-10 Changes in healthcare use and care provision

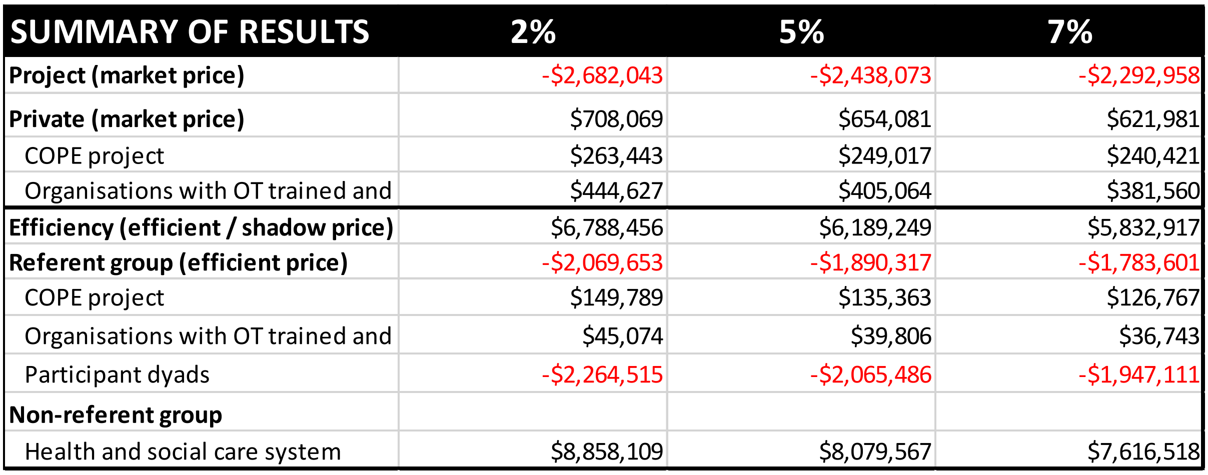
CHANGES IN HEALTHCARE USE AND CARE PROVISION	Changes	MARKET PRICES		SHADOW PRICES	
Person with Dementia (+ is cost; - is benefit)	**(unit)**	**Unit price**	**Total**	**Unit price**	**Total**
Hospital and long term care (health system and aged care -)					
Hospital night visists	-2.23	$ -	$ -	$ 2,179.00	-$ 4,859.17
ED presentations	-0.10	$ -	$ -	$ 584.00	-$ 58.40
Ambulance	0.01	$ -	$ -	$ 976.00	$ 9.76
Respite or long term care (nights)	-0.73	$ -	$ -	$ 50.16	-$ 36.62
TOTAL			**$ -**		**-$ 4,944.43**
Services accessed at home (Out of pocket - client)					
District NURSE	-0.41	$ 90.00	-$ 37.14	$ 90.00	-$ 37.14
Personal care	1.60	$ 50.00	$ 80.22	$ 50.00	$ 80.22
FOOD delivery	0.03	$ 140.00	$ 4.20	$ 140.00	$ 4.20
Day care / respite	1.09	$ 50.00	$ 54.53	$ 50.00	$ 54.53
TRANSPORT	0.23	$ 50.00	$ 11.50	$ 50.00	$ 11.50
Allied health assistance	0.22	$ 90.00	$ 19.51	$ 90.00	$ 19.51
HOME care assistance (eg. Cooking or cleaning)	-0.36	$ 50.00	-$ 17.84	$ 50.00	-$ 17.84
CASE management	0.01	$ 60.00	$ 0.71	$ 60.00	$ 0.71
GP home visits	-0.01	$ 57.05	-$ 0.68	$ 57.05	-$ 0.68
Group type therapy	0.17	$ 10.00	$ 1.67	$ 10.00	$ 1.67
TOTAL			**$ 116.69**		**$ 116.69**
Healthcare services used in the community (Medicare - health system)		80%			
Change in visits to GP	0.10	$ 11.41	$ 1.14	$ 57.05	$ 5.71
Change in visits to Geriatricians	-0.01	$ 76.50	-$ 0.77	$ 382.51	-$ 3.83
Change in visits to Neurologist	-0.07	$ 54.05	-$ 3.78	$ 270.27	-$ 18.92
Change in visits to PSYCHIATRIST	-0.06	$ 73.26	-$ 4.40	$ 366.32	-$ 21.98
Physiotherapist	0.10	$ 38.98	$ 3.90	$ 194.91	$ 19.49
Occupational therapist	0.16	$ 38.98	$ 6.24	$ 194.91	$ 31.19
social worker	-0.16	$ 38.98	-$ 6.24	$ 194.91	-$ 31.19
psychology	0.00	$ 38.98	$ -	$ 194.91	$ -
Other allied health	-0.23	$ 38.98	-$ 8.97	$ 194.91	-$ 44.83
Change in visits to SPECIALIST	0.02	$ 27.35	$ 0.55	$ 136.75	$ 2.74
Change in visits to PATHO	0.04	$ 1.08	$ 0.04	$ 5.40	$ 0.22
Change in visits to RADIO	-0.03	$ 18.89	-$ 0.57	$ 94.45	-$ 2.83
TOTAL			**-$ 12.85**		**-$ 64.24**
Carer (+ is cost; - is benefit)					
Change in minutes spent helping person with dementia: iADL	480.85	$ -	$ -	$ 0.37	$ 178.48
Change in minutes spent helping person with dementia: ALD	-388.37	$ -	$ -	$ 0.37	-$ 144.15
Change in minutes spent supervising person with dementia	-212.23	$ -	$ -	$ 0.37	-$ 78.77
Time away from paid empoyment (FT) (hours)	-0.10	$ -	$ -	$ 25.48	-$ 19.40
Time away from paid empoyment (PT) (hours)	0.14	$ -	$ -	$ 25.48	$ 14.55
TOTAL			**$ -**		**-$ 49.30**

SECTION 2

Results

Table S7-11 summarises the base case results for each analysis (Market, Private, Efficiency, Referent group). Tables S7-12, S7-13, S7-14, S7-15 provide breakdown of the results for each analysis.

Table S7-11 Summary of results



SUMMARY OF RESULTS	2%	5%	7%
Project (market price)	-$2,682,043	-$2,438,073	-$2,292,958
Private (market price)	$708,069	$654,081	$621,981
COPE project	$263,443	$249,017	$240,421
Organisations with OT trained and	$444,627	$405,064	$381,560
Efficiency (efficient / shadow price)	$6,788,456	$6,189,249	$5,832,917
Referent group (efficient price)	-$2,069,653	-$1,890,317	-$1,783,601
COPE project	$149,789	$135,363	$126,767
Organisations with OT trained and	$45,074	$39,806	$36,743
Participant dyads	-$2,264,515	-$2,065,486	-$1,947,111
Non-referent group			
Health and social care system	$8,858,109	$8,079,567	$7,616,518

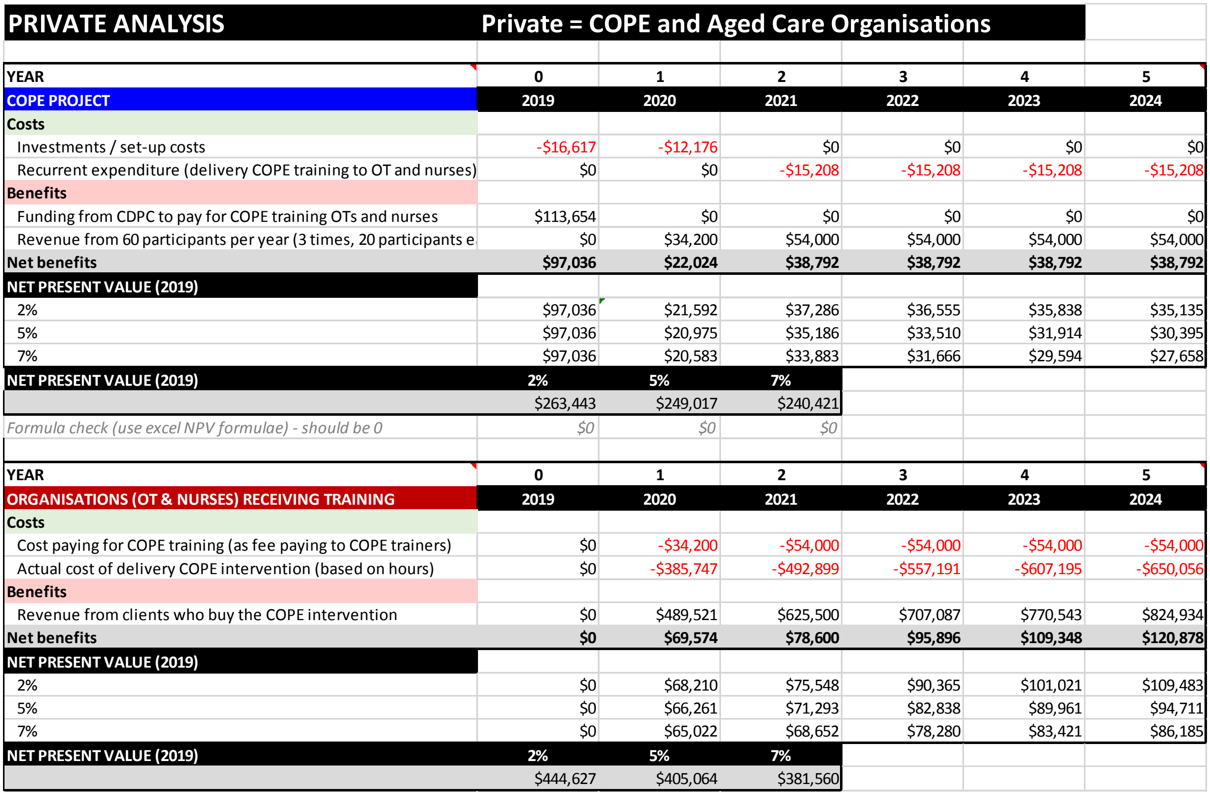
Table S7-12 Market (or Project) analysis

PROJECT ANALYSIS (market price)

YEAR	0	1	2	3	4	5
	2019	2020	2021	2022	2023	2024
COSTS						
COST - COPE PROJECT						
Investments / set-up costs	-$16,617	-$12,176				
Recurrent expenditure (delivery COPE training to OT and nurses)			-$15,208	-$15,208	-$15,208	-$15,208
TOTAL	**-$16,617**	**-$12,176**	**-$15,208**	**-$15,208**	**-$15,208**	**-$15,208**
COST - ORGANISATION (OT & NURSES) RECEIVING TRAINING						
TOTAL	**$0**	**-$34,200**	**-$54,000**	**-$54,000**	**-$54,000**	**-$54,000**
COST - OT DELIVERING THE INTERVENTION TO CLIENTS						
Actual cost of delivery COPE intervention (based on hours)	$0	-$385,747	-$492,899	-$557,191	-$607,195	-$650,056
TOTAL	**$0**	**-$385,747**	**-$492,899**	**-$557,191**	**-$607,195**	**-$650,056**
COST - CLIENTS PAYING FOR COPE INTERVENTION (DEMENTIA DYADS)						
Fee that clients pay for a COPE intervention (per COPE package)		-$489,521	-$625,500	-$707,087	-$770,543	-$824,934
TOTAL	**$0**	**-$489,521**	**-$625,500**	**-$707,087**	**-$770,543**	**-$824,934**
TOTAL COST	**-$16,617**	**-$921,645**	**-$1,187,607**	**-$1,333,485**	**-$1,446,946**	**-$1,544,198**
BENEFITS						
REVENUE - COPE PROJECT - TRAINING OT						
Funding from CDPC to pay for COPE training OTs and nurses	$113,654					
Revenue from 60 participants per year (3 times, 20 participants each, $90	$0	$34,200	$54,000	$54,000	$54,000	$54,000
TOTAL	**$113,654**	**$34,200**	**$54,000**	**$54,000**	**$54,000**	**$54,000**
REVENUE - ORGANISATION (OT & NURSES) RECEIVING COPE TRAINING						
Revenue from clients who buy the COPE intervention		$489,521	$625,500	$707,087	$770,543	$824,934
TOTAL	**$0**	**$489,521**	**$625,500**	**$707,087**	**$770,543**	**$824,934**
BENEFIT - PERSON WITH DEMENTIA (CLIENT)						
Changes in services accessed at home (out of pocket payment)		-$31,505	-$40,257	-$45,508	-$49,592	-$53,092
TOTAL	**$0**	**-$31,505**	**-$40,257**	**-$45,508**	**-$49,592**	**-$53,092**
BENEFIT - HEALTH AND SOCIAL CARE SYSTEMS						
Change in hospital and long term care spending (health system and aged care)		$0	$0	$0	$0	$0
Change in healthcare services used in the community (Medicare - health system)		$3,469	$4,432	$5,011	$5,460	$5,846
TOTAL	**$0**	**$3,469**	**$4,432**	**$5,011**	**$5,460**	**$5,846**
TOTAL BENEFIT	**$113,654**	**$495,685**	**$643,675**	**$720,590**	**$780,412**	**$831,688**
NET BENEFIT	**$97,036**	**-$425,960**	**-$543,931**	**-$612,895**	**-$666,534**	**-$712,510**
NET BENEFIT PRESENT VALUES (2019)						
2%	$97,036	-$417,607	-$522,810	-$577,545	-$615,774	-$645,342
5%	$97,036	-$405,676	-$493,362	-$529,442	-$548,359	-$558,270
7%	$97,036	-$398,093	-$475,091	-$500,305	-$508,496	-$508,010

NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**
	-$2,682,043	-$2,438,073	-$2,292,958

Table S7-13 Private analysis



PRIVATE ANALYSIS — **Private = COPE and Aged Care Organisations**

YEAR	0	1	2	3	4	5
COPE PROJECT	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Costs						
Investments / set-up costs	-$16,617	-$12,176	$0	$0	$0	$0
Recurrent expenditure (delivery COPE training to OT and nurses)	$0	$0	-$15,208	-$15,208	-$15,208	-$15,208
Benefits						
Funding from CDPC to pay for COPE training OTs and nurses	$113,654	$0	$0	$0	$0	$0
Revenue from 60 participants per year (3 times, 20 participants e	$0	$34,200	$54,000	$54,000	$54,000	$54,000
Net benefits	**$97,036**	**$22,024**	**$38,792**	**$38,792**	**$38,792**	**$38,792**
NET PRESENT VALUE (2019)						
2%	$97,036	$21,592	$37,286	$36,555	$35,838	$35,135
5%	$97,036	$20,975	$35,186	$33,510	$31,914	$30,395
7%	$97,036	$20,583	$33,883	$31,666	$29,594	$27,658

NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**
	$263,443	$249,017	$240,421
Formula check (use excel NPV formulae) - should be 0	*$0*	*$0*	*$0*

YEAR	0	1	2	3	4	5
ORGANISATIONS (OT & NURSES) RECEIVING TRAINING	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Costs						
Cost paying for COPE training (as fee paying to COPE trainers)	$0	-$34,200	-$54,000	-$54,000	-$54,000	-$54,000
Actual cost of delivery COPE intervention (based on hours)	$0	-$385,747	-$492,899	-$557,191	-$607,195	-$650,056
Benefits						
Revenue from clients who buy the COPE intervention	$0	$489,521	$625,500	$707,087	$770,543	$824,934
Net benefits	**$0**	**$69,574**	**$78,600**	**$95,896**	**$109,348**	**$120,878**
NET PRESENT VALUE (2019)						
2%	$0	$68,210	$75,548	$90,365	$101,021	$109,483
5%	$0	$66,261	$71,293	$82,838	$89,961	$94,711
7%	$0	$65,022	$68,652	$78,280	$83,421	$86,185

NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**
	$444,627	$405,064	$381,560

Table S7-14 Efficiency analysis

EFFICIENCY ANALYSIS (shadow price)	Actual transactions and opportunity costs					
YEAR	0	1	2	3	4	5
	2019	2020	2021	2022	2023	2024
COSTS						
COST - COPE PROJECT						
Investments / set-up costs	-$16,617	-$12,176				
Recurrent expenditure (delivery COPE training to OT and nurses)			-$15,208	-$15,208	-$15,208	-$15,208
TOTAL	**-$16,617**	**-$12,176**	**-$15,208**	**-$15,208**	**-$15,208**	**-$15,208**
COST - ORGANISATION (OT & NURSES) RECEIVING TRAINING						
OT time spending on COPE training (op. cost of time, in hours)		-$37,724	-$59,564	-$59,564	-$59,564	-$59,564
OT time spending on COPE coaching and mentoring (op. cost of time, in hours)		-$8,084	-$12,764	-$12,764	-$12,764	-$12,764
Management time involved / set up (op. cost of time, in hours)		-$12,312	-$19,440	-$19,440	-$19,440	-$19,440
Cost paying for COPE training (as fee paying to COPE trainers)		-$34,200	-$54,000	-$54,000	-$54,000	-$54,000
TOTAL	**$0**	**-$92,319**	**-$145,767**	**-$145,767**	**-$145,767**	**-$145,767**
COST - OT DELIVERING THE INTERVENTION TO CLIENTS						
Actual cost of delivery COPE intervention (based on hours)	$0	-$385,747	-$492,899	-$557,191	-$607,195	-$650,056
TOTAL	**$0**	**-$385,747**	**-$492,899**	**-$557,191**	**-$607,195**	**-$650,056**
COST - CLIENTS PAYING FOR COPE INTERVENTION (DEMENTIA DYADS)						
Fee that clients pay for a COPE intervention (per COPE package)		-$489,521	-$625,500	-$707,087	-$770,543	-$824,934
TOTAL	**$0**	**-$489,521**	**-$625,500**	**-$707,087**	**-$770,543**	**-$824,934**
TOTAL COST	**-$16,617**	**-$979,764**	**-$1,279,374**	**-$1,425,252**	**-$1,538,713**	**-$1,635,965**
BENEFITS						
REVENUE - COPE PROJECT - TRAINING OT						
Funding from CDPC to pay for COPE training OTs and nurses		$34,200	$54,000			
Revenue from 60 participants per year (3 times, 20 participants each, $900 per participant)				$54,000	$54,000	$54,000
TOTAL	**$0**	**$34,200**	**$54,000**	**$54,000**	**$54,000**	**$54,000**
REVENUE - ORGANISATION (OT & NURSES) RECEIVING COPE TRAINING						
Revenue from clients who buy the COPE intervention		$489,521	$625,500	$707,087	$770,543	$824,934
TOTAL	**$0**	**$489,521**	**$625,500**	**$707,087**	**$770,543**	**$824,934**
BENEFITS - CARER (CLIENT) - note that they did not pay - receive any mone						
Time spent caregiving		$12,001	$15,334	$17,334	$18,890	$20,223
Less time spent away from paid employment		$1,310	$1,673	$1,892	$2,061	$2,207
Improved quality of life		$162,000	$207,000	$234,000	$255,000	$273,000
TOTAL	**$0**	**$175,310**	**$224,008**	**$253,226**	**$275,951**	**$295,430**
BENEFIT - PERSON WITH DEMENTIA (CLIENT)						
Changes in services accessed at home (out of pocket payment)		-$31,505	-$40,257	-$45,508	-$49,592	-$53,092
TOTAL	**$0**	**-$31,505**	**-$40,257**	**-$45,508**	**-$49,592**	**-$53,092**
BENEFIT - HEALTH AND SOCIAL CARE SYSTEMS						
Change in hospital and long term care spending (health system and aged care)		$1,334,995	$1,705,827	$1,928,326	$2,101,381	$2,249,714
Change in healthcare services used in the community (Medicare - health system)		$17,344	$22,162	$25,053	$27,301	$29,229
TOTAL	**$0**	**$1,352,340**	**$1,727,990**	**$1,953,380**	**$2,128,683**	**$2,278,943**
TOTAL BENEFIT	**$0**	**$2,019,866**	**$2,591,240**	**$2,922,184**	**$3,179,586**	**$3,400,215**
NET BENEFIT	**-$16,617**	**$1,040,102**	**$1,311,866**	**$1,496,932**	**$1,640,873**	**$1,764,250**
NET BENEFIT PRESENT VALUES (2019)						
2%	-$16,617	$1,019,708	$1,260,925	$1,410,593	$1,515,913	$1,597,936
5%	-$16,617	$990,573	$1,189,901	$1,293,106	$1,349,950	$1,382,336
7%	-$16,617	$972,058	$1,145,834	$1,221,943	$1,251,814	$1,257,886

NET PRESENT VALUE (2019)	2%	5%	7%
	$6,788,456	$6,189,249	$5,832,917

Table S7-15 Referent group analysis

REFERENT ANALYSIS

YEAR	0	1	2	3	4	5
	2019	2020	2021	2022	2023	2024
Efficiency net benefits	-$16,617	$1,040,102	$1,311,866	$1,496,932	$1,640,873	$1,764,250

YEAR	0	1	2	3	4	5
COPE PROJECT	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Costs						
Investments / set-up costs	-$16,617	-$12,176	$0	$0	$0	$0
Recurrent expenditure (delivery COPE training to OT and nurses)	$0	$0	-$15,208	-$15,208	-$15,208	-$15,208
Benefits						
Funding from CDPC to pay for COPE training OTs and nurses	$0	$34,200	$54,000	$0	$0	$0
Revenue from 60 participants per year (3 times, 20 participants each	$0	$0	$0	$54,000	$54,000	$54,000
Net benefits	**-$16,617**	**$22,024**	**$38,792**	**$38,792**	**$38,792**	**$38,792**
NET PRESENT VALUE (2019)						
2%	-$16,617	$21,592	$37,286	$36,555	$35,838	$35,135
5%	-$16,617	$20,975	$35,186	$33,510	$31,914	$30,395
7%	-$16,617	$20,583	$33,883	$31,666	$29,594	$27,658
TOTAL NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**			
	$149,789	$135,363	$126,767			

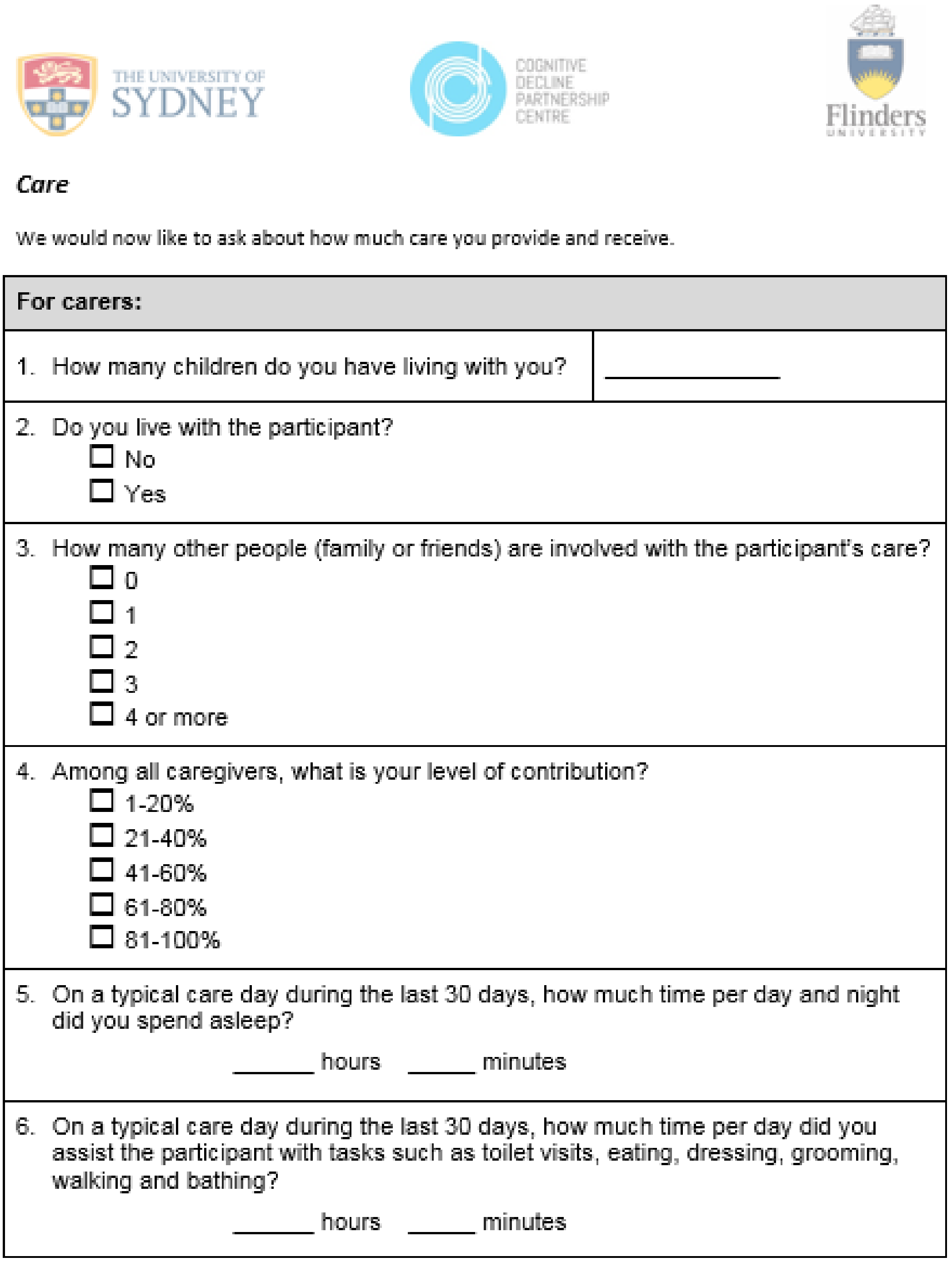
YEAR	0	1	2	3	4	5
COST - ORGANISATION (OT & NURSES) RECEIVING TRAINING	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Costs						
OT time spending on COPE training (op. cost of time, in hours)	$0	-$37,724	-$59,564	-$59,564	-$59,564	-$59,564
OT time spending on COPE coaching and mentoring (op. cost of time	$0	-$8,084	-$12,764	-$12,764	-$12,764	-$12,764
Management time involved / set up (op. cost of time, in hours)	$0	-$12,312	-$19,440	-$19,440	-$19,440	-$19,440
Cost paying for COPE training (as fee paying to COPE trainers)	$0	-$34,200	-$54,000	-$54,000	-$54,000	-$54,000
Actual cost of delivery COPE intervention (based on hours)	$0	-$385,747	-$492,899	-$557,191	-$607,195	-$650,056
Benefits						
Revenue from clients who buy the COPE intervention	$0	$489,521	$625,500	$707,087	$770,543	$824,934
Net benefits	**$0**	**$11,455**	**-$13,167**	**$4,129**	**$17,581**	**$29,111**
NET PRESENT VALUE (2019)						
2%	$0	$11,230	-$12,656	$3,890	$16,242	$26,367
5%	$0	$10,909	-$11,943	$3,566	$14,464	$22,809
7%	$0	$10,705	-$11,501	$3,370	$13,412	$20,756
TOTAL NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**			
	$45,074	$39,806	$36,743			

YEAR	0	1	2	3	4	5
DEMENTIA DYADS - PERSON WITH DEMENTIA AND CARERS	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Costs						
Fee that clients pay for a COPE intervention (per COPE package)	$0	-$489,521	-$625,500	-$707,087	-$770,543	-$824,934
Benefits - people with dementia						
Changes in services accessed at home (out of pocket payment)	$0	-$31,505	-$40,257	-$45,508	-$49,592	-$53,092
Benefits - carers						
Time spent caregiving	$0	$12,001	$15,334	$17,334	$18,890	$20,223
Less time spent away from paid employment	$0	$1,310	$1,673	$1,892	$2,061	$2,207
Improved quality of life	$0	$162,000	$207,000	$234,000	$255,000	$273,000
Net benefits	**$0**	**-$345,716**	**-$441,749**	**-$499,368**	**-$544,183**	**-$582,596**
NET PRESENT VALUE (2019)						
2%	$0	-$338,938	-$424,595	-$470,566	-$502,741	-$527,675
5%	$0	-$329,254	-$400,679	-$431,373	-$447,701	-$456,479
7%	$0	-$323,100	-$385,841	-$407,633	-$415,155	-$415,383
TOTAL NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**			
	-$2,264,515	-$2,065,486	-$1,947,111			

NON-REFERENT GROUP

YEAR	0	1	2	3	4	5
HEALTH AND SOCIAL CARE SYSTEM	**2019**	**2020**	**2021**	**2022**	**2023**	**2024**
Change in hospital and long term care spending (health system and	$0	$1,334,995	$1,705,827	$1,928,326	$2,101,381	$2,249,714
Change in healthcare services used in the community (Medicare - h	$0	$17,344	$22,162	$25,053	$27,301	$29,229
Net benefits	**$0**	**$1,352,340**	**$1,727,990**	**$1,953,380**	**$2,128,683**	**$2,278,943**
NET PRESENT VALUE (2019)						
2%	$0	$1,325,823	$1,660,890	$1,840,713	$1,966,574	$2,064,109
5%	$0	$1,287,943	$1,567,337	$1,687,403	$1,751,273	$1,785,611
7%	$0	$1,263,869	$1,509,293	$1,594,540	$1,623,962	$1,624,855
TOTAL NET PRESENT VALUE (2019)	**2%**	**5%**	**7%**			
	$8,858,109	$8,079,567	$7,616,518			

APPENDIX H Resource Use in Dementia (-Lite) questionnaire used



THE UNIVERSITY OF SYDNEY

COGNITIVE DECLINE PARTNERSHIP CENTRE

Flinders UNIVERSITY

Care

We would now like to ask about how much care you provide and receive.

For carers:

1. How many children do you have living with you? ______________

2. Do you live with the participant?
   - ☐ No
   - ☐ Yes

3. How many other people (family or friends) are involved with the participant's care?
   - ☐ 0
   - ☐ 1
   - ☐ 2
   - ☐ 3
   - ☐ 4 or more

4. Among all caregivers, what is your level of contribution?
   - ☐ 1-20%
   - ☐ 21-40%
   - ☐ 41-60%
   - ☐ 61-80%
   - ☐ 81-100%

5. On a typical care day during the last 30 days, how much time per day and night did you spend asleep?

   _______ hours _____ minutes

6. On a typical care day during the last 30 days, how much time per day did you assist the participant with tasks such as toilet visits, eating, dressing, grooming, walking and bathing?

   _______ hours _____ minutes

7. During the last 30 days, how many days did you spend providing these services to the participant?

_____ days

8. On a typical care day during the last 30 days, how much time per day did you assist the participant with tasks such as shopping, food preparation, housekeeping, laundry, transportation, taking medication and managing financial matters?

______ hours _____ minutes

9. During the last 30 days, how many days did you spend providing these services to the patient?

_____ days

10. On a typical care day during the last 30 days, how much time per day did you spend supervising (that is, preventing dangerous events) the participant ?

______ hours _____ minutes

11. During the last 30 days, how many days did you spend providing these services to the patient?

_____ days

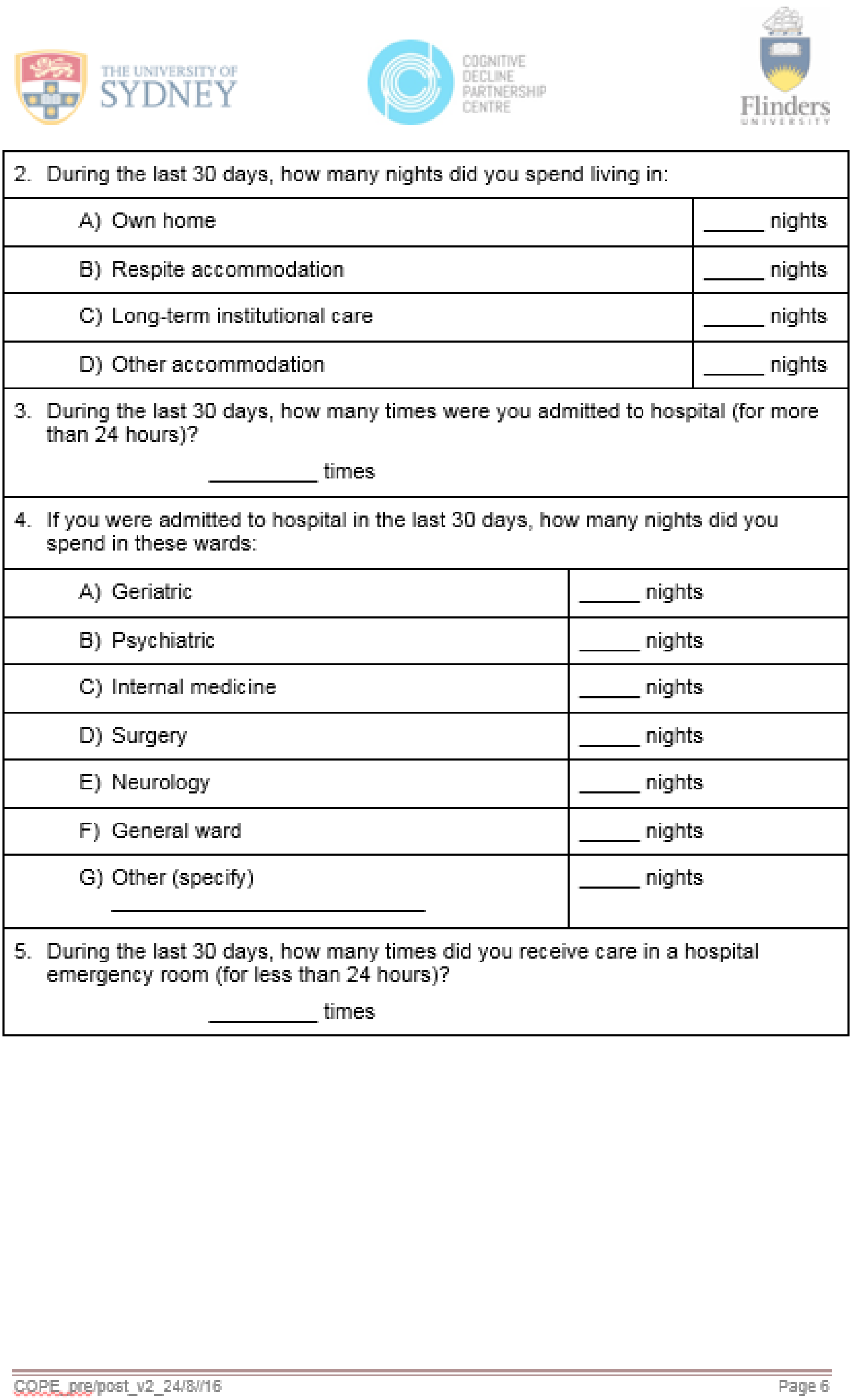
12. During the last 30 days, have you worked for pay?
☐ No
☐ Yes

13. During the last 30 days, please specify the number of times that your caregiver responsibilities affected your work:

13a. Missed a whole day of work	______ times	☐ None
13b. Missed part of a day of work	______ times	☐ None

For the participant:

1. Who do you live with? (choose all that apply)
☐ Alone
☐ Spouse
☐ Sibling
☐ Child
☐ Other



2. During the last 30 days, how many nights did you spend living in:

A) Own home	______ nights
B) Respite accommodation	______ nights
C) Long-term institutional care	______ nights
D) Other accommodation	______ nights

3. During the last 30 days, how many times were you admitted to hospital (for more than 24 hours)?

__________ times

4. If you were admitted to hospital in the last 30 days, how many nights did you spend in these wards:

A) Geriatric	______ nights
B) Psychiatric	______ nights
C) Internal medicine	______ nights
D) Surgery	______ nights
E) Neurology	______ nights
F) General ward	______ nights
G) Other (specify) ______________________________	______ nights

5. During the last 30 days, how many times did you receive care in a hospital emergency room (for less than 24 hours)?

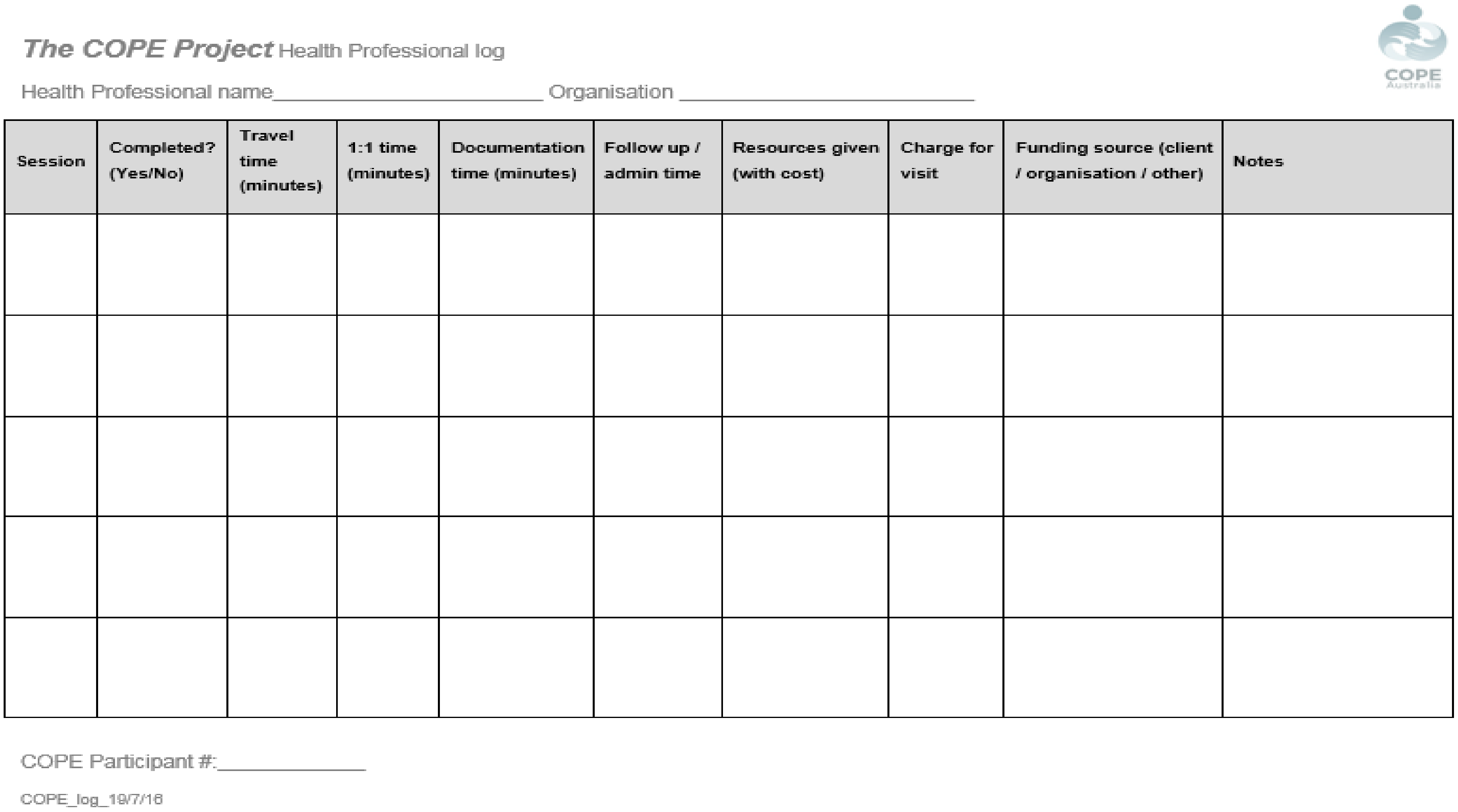
__________ times

6. During the last 30 days, how many times did you visit…	
A) General practitioner (GP)	_____ times
B) Geriatrician	_____ times
C) Neurologist	_____ times
D) Psychiatrist	_____ times
E) Physiotherapist	_____ times
F) Occupational Therapist	_____ times
G) Social worker	_____ times
H) Psychology	_____ times
I) Other (specify)___________________________	_____ times

7. During the last 30 days, how many times have you been visited by…

	# visits	# hours per visit
A) District nurse	_____ visits	______ hours per visit
B) Home aid / orderly	_____ visits	______ hours per visit
C) Food delivery	_____ visits	N/A
D) Day care	_____ visits	______ hours per visit
E) Transportation (care related)	_____ visits	N/A
F) Other (specify) ________________________________	_____ visits	______ hours per visit

APPENDIX I Therapist time use logs



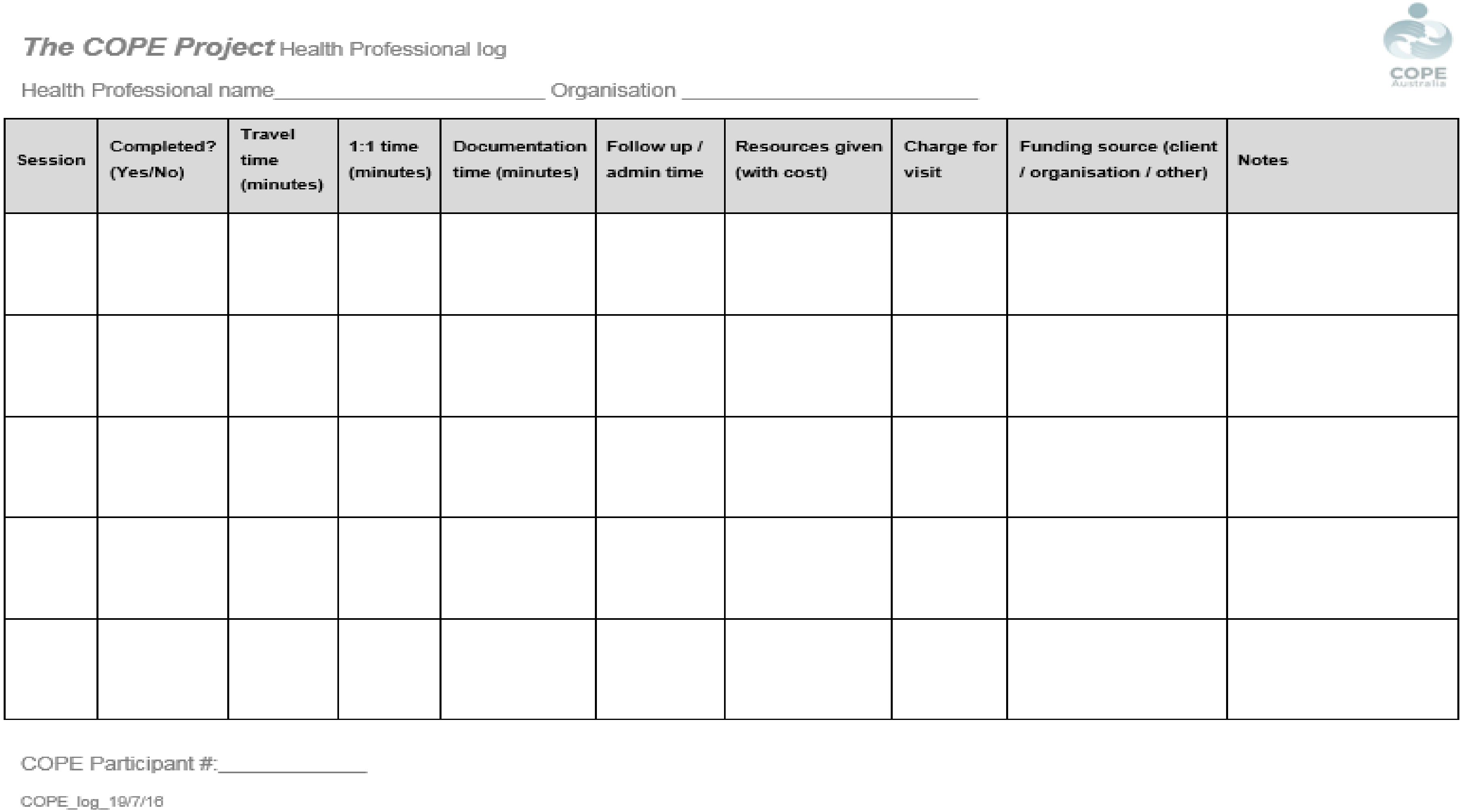
The COPE Project Health Professional log

Health Professional name________________________ Organisation __________________________

Session	Completed? (Yes/No)	Travel time (minutes)	1:1 time (minutes)	Documentation time (minutes)	Follow up / admin time	Resources given (with cost)	Charge for visit	Funding source (client / organisation / other)	Notes

COPE Participant #:_____________

COPE_log_19/7/16



The COPE Project Health Professional log

Health Professional name______________________ Organisation ________________________

Session	Completed? (Yes/No)	Travel time (minutes)	1:1 time (minutes)	Documentation time (minutes)	Follow up / admin time	Resources given (with cost)	Charge for visit	Funding source (client / organisation / other)	Notes

COPE Participant #:_____________

COPE_log_19/7/16