The Lived Experience of Compound Carers in the Western Suburbs of Melbourne: A Qualitative Approach

AUTHOR(S)

Jessica M. Campbell

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by

Jessica M Campbell

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Submitted in fulfilment of the requirements for the degree of

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Abstract

Australia's population is ageing in response to increasing life expectancy and falling fertility rates. Informal carers play a significant role in alleviating the increasing pressure on the Australian healthcare system. In addition to the immediate and long-term economic impact of informal carers, their contribution has many other advantages for the person being cared for including delayed entry into residential care, improved quality of life, and better physical and mental health outcomes. Conversely, informal carers experience higher levels of emotional stress and physical strain, negative mental and physical health outcomes, and financial strain, when compared with non-carers. Compound carers are informal carers with pre-existing caring responsibilities for a family member or loved one, who subsequently becomes an informal carer for an additional person.

The aim of this study was to answer the following: What is the lived experience of compound carers residing in the Western Suburbs of Melbourne? Additionally, it sought to explore the lived experience of caring for an older person plus an additional person with significant illness/disability; capture a sample from diverse backgrounds; and explore compound carers' experience from an occupational perspective using the Pan Occupational Paradigm (POP). The POP is framework that aims to explain the relationship between occupations and health, and contains the domains *doing*, *being*, *becoming* and *belonging*. Participants were recruited by purposeful sampling through the Western Aged Care Assessment Service (ACAS), Melbourne, and via social media platforms. Participants were included in the study if they cared for two or more people with a disability and/or illness and resided in the Western Suburbs of Melbourne. Qualitative data were collected through focused, in-depth semi-structured interviews. Data analysis occurred through reflexive Thematic Analysis.

The themes and subthemes derived from the lived experiences of compound carers were contextualised under the domains of the POP. These included *doing compound care* which refers to the activities the compound carer undertakes as part of their occupation and contained subthemes: doing as a way of coping, systems create barriers, people create barriers and financial strain. *Being a compound carer,* which relates to how compound carers feel about their role and contained subthemes: satisfaction in the compound caring role, feelings of self-efficacy and the negative impact of compound caring. *Belonging as a compound carer* involves the importance of interpersonal relationships and included the subthemes: family conflict, less time for friendships and belonging as a way of coping. *Becoming a compound carer* refers to commencement of compound caring and how the compound carer evolves and included the subthemes: becoming an advocate and thinking about the future. This is the first known study to take an occupational perspective on the experience of compound carers. However further research with a larger sample that continues to capture diversity is needed.

Occupational therapists have a breadth of knowledge and skills that can be utilised in many ways when working with compound carers. Firstly, occupational therapists recognising the unique needs of these carers can provide an advocacy role to implement urgent formal supports allowing compound carers to engage in meaningful occupations. Occupational therapists can also address areas of occupational imbalance by encouraging compound carers to schedule time for sufficient rest, sleep, and self-care. Occupational therapists can assist compound carers with return-to-work interventions if productive occupations are meaningful to individual compound carers. Carer training provides a mode to improve feelings of self-efficacy and mastery which is known to mediate stress and depression in informal carers. It also provides an opportunity to assist with building advocacy skills to overcome systemic barriers compound carers face when accessing formal supports. Occupational therapists have the potential to significantly improve the quality of life and well-being of compound carers.

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I would also like to thank the Western Aged Care Assessment Service and Occupational Therapy Department at Western Health for allowing me to commence this project in 2016 and continuing to support recruitment over the COVID-19 pandemic. Specifically, I would like to thank my previous Supervisor, Jacinta Roberton, for encouraging me to turn what started as a clinical question, into a Masters. I would also like to acknowledge my current workplace, the Geelong Aged Care Assessment Service who have supported my study leave through the pandemic and periods of high waiting times for our service.

Lastly, I would like to acknowledge the contribution of my family and friends, as this would not have been completed without their support, which included hours of babysitting, hot meals, and words of encouragement. My biggest thanks must go to my husband, Gus for giving me the opportunity to finish this with two young and non-sleeping children, house renovations on the go and the commencement of new jobs. Thank you for the company on the many late nights and being a fantastic sounding board, I could not have done this without you.

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Glossary

Autism spectrum disorder (ASD): A developmental disorder that can affect the way people perceive and interact with the world around them.

Compound Carer: Informal carer of multiple people with significant illness and/or disability.

Informal Carer: Person completing unpaid caregiving activities to another person.

Intellectual and developmental disabilities (IDD): Impairments in mental and/or physical functioning occurring before adulthood (18 years of age).

My Aged Care (MAC): The Australian service system for older adults to access subsidised, formal care.

National Disability Insurance Scheme (NDIS): The Australian service system for children and adults (under 65 years) with a permanent and significant disability to access funding for therapy and community supports.

Pan Occupational Paradigm (POP): A theoretical framework that describes the relationship between occupation and health.

COVID-19 Thesis Impact Statement

This study occurred during the COVID-19 pandemic in one of the most impacted regions in Australia. The study was conducted in the state of Victoria, which experienced the most consecutive days of lockdown in Australia. Purposive recruitment through the Western Aged Care Assessment Service (ACAS) was negatively impacted due to changes in assessment practices, including changing assessment modes from face-to-face to telehealth or phone assessment. ACAS clients and clinicians were under significant and prolonged stress, which was a barrier to participation in additional activities such as research. The study sought to recruit six to eight compound carers, however ceased recruitment at five participants as the data collected was sufficient to address the aims of the study.

Chapter One: Introduction

National and international literature has long recognised the role carers play in reducing pressure on healthcare systems, by maintaining people who need care in an environment that facilitates and promotes independence, well-being, and quality of life (Australian Institute of Health and Welfare (AIHW), 2015). The complexity and challenges of being a carer, and the impact of caregiving on a person's physical and mental health is also well documented (Aggar et al., 2014; Butterworth et al., 2010; Temple et al., 2021). But what happens when a carer cares for more than one person? Is their experience different when caregiving is compounded? The student researcher became interested in better understanding the experience of 'compound' caring after observing the challenges faced by these carers in her practise as an occupational therapist. This study was therefore motivated by a desire to provide more relevant and effective support to an important group of carers, who have been the subject of little research to date.

In Australia the term *carer* is used to describe a person providing informal care and support to a loved one however, internationally the term is *caregiver*. As this study was completed in Australia, this thesis includes the term *carer*, although *caregiver* and *carer* can be used interchangeably. This thesis also uses the term *people being cared for* as per the terminology contained in s.7 of the *Carers Recognition Act 2012* (Vic). Children and adults being cared for have also been described in this thesis using identity first language. Identity first language includes terms such as autistic adult or intellectually disabled child and has been used to acknowledge "that disability is part of the person and is not a derogatory term" (Best et al., 2022, p. 127).

This study aimed to explore the lived experience of compound carers living in the Western Suburbs of Melbourne, Victoria, Australia. This chapter begins by contextualising the study in relation to the ageing population of Australia and national health care systems. Informal caring will be introduced, and the experiences of diverse carers reviewed to understand the social and cultural context of caring locally and globally. The definition of compound carers used in this study will be provided, and existing literature on compound caring introduced. The Pan Occupational Paradigm (POP) will be described and its choice as the guiding theoretical framework of the study justified. The chapter will then present the significance of the study, the researcher stance, research question and aims, and the impact of COVID-19 on its conduct. Finally, the chapter will conclude with an overview of the structure of this thesis.

Australia's Ageing Population

Australia’s population is ageing in the context of increasing life expectancy and falling fertility rates, (AIHW, 2021). According to the Australian Bureau of Statistics (ABS), the total numbers of older Australians (aged 65 years and over) rose from 14.3% in 2012 to 15.1 % in 2015 (ABS, 2016a). Furthermore, the proportion of older Australians is projected to represent 21-23% of the total population by 2066 (ABS, 2018), compared to just 2% in 2012 (ABS, 2013). In the Western Suburbs of Melbourne, Victoria, it is predicted the local population aged over 65 years will also experience significant growth, increasing by 55% to 292,000 people by 2031 (North-West Melbourne Primary Health Network [NWMPHN], 2018).

An ageing population will experience a higher rate of chronic conditions (such as dementia, osteoarthritis, diabetes) resulting in an increased need for support and services (Cullen, 2019). The services needed and their frequency will most probably vary over time, but may include financial support, medical, rehabilitation or psychological services or housing related assistance. The reliance on carers supporting older people will only increase as the Australian population ages, potentially placing significant pressure on the health care system (Cullen, 2019).

Australian Health Care System

In Australia, access to subsidised healthcare occurs via the Medicare scheme and includes access to medical services such as general practitioners, nurses, medical specialists, allied health professionals, public hospitals, and medications (Victorian Department of Health, 2018). There are two additional primary avenues to access formal supports and/or residential care depending on the age of the person. These are: the National Disability Insurance Scheme (NDIS, Australians under 65 years of age) and My Aged Care (MAC, over 65 years or over 50 years for Aboriginal and Torres Strait Islander people). Formal supports for the people being cared for may include in-home respite care, support with personal care and domestic tasks, and accessing the community. Formal supports are essential to ensuring carers can sustain caring roles and mediate the impact of caring on their health and well-being (Temple et al., 2021).

National Disability Insurance Scheme

The NDIS was implemented in 2013 and was the first change to disability service provision in Australia for nearly 30 years (Cortese et al., 2021). The National Disability Insurance Agency (NDIA) was established to implement the scheme, which aims to give control and choice to its participants when selecting services and community supports. To be eligible for the NDIS someone must be aged between 7 and 65 years and have a disability caused by a permanent impairment that substantially impacts function in at least one of the following areas: communication, socialising, learning, mobility, self-care, or self-management (NDIA, 2022).

People who meet the eligibility criteria are asked to complete and submit an Access Request Form with supporting evidence about their disability from health service providers. If accepted to the scheme, a plan for services for the following year is developed in a planning meeting with support available from Local Area Coordinators, early childhood partners, or NDIS planners if required. Once the plan is approved, participants have three ways to manage their plan and budget: self-manage, NDIA managed or plan managed (NDIA, 2021). A NDIS plan contains three sections: personal profile, goals (short, medium or long-term) and funded supports required to achieve goals (CareAbout, 2021). An example of a short-term goal could involve being able to independently access the community to complete further education. Supports funded to achieve these goals come under three sections: core supports (e.g., support workers to assist with tasks such as personal care or to build friendships in the community), capacity building supports (e.g., allied health therapies such as physiotherapy and occupational therapy), and capital supports (assistive technology, home modifications, and disability accommodation) (CareAbout, 2021).

My Aged Care

The Australian Government introduced a National Portal “My Aged Care” for older people to access community services and supports, in response to a report by the Productivity Commission (2011). The report identified the need for a single access point to the aged care system for older people to receive “information, assessment of needs and entitlement to care and support services, care coordination and carer referral services” (Productivity Commission (2011, p. 81). My Aged Care (MAC) was implemented to decrease barriers for older adults to access services, provide greater equity of assessment, and prevent the duplication or repetition of information required from assessors (Department of Social Services, 2014). Older people can self-refer or be referred by health professionals by phoning the MAC contact centre or completing an online form on the website. The needs, specificities, and complexities of the client, or older person, are then assessed. The two avenues for this assessment are the Regional Assessment Service (RAS) (to access basic supports via the Commonwealth Home Support Program) or the Aged Care Assessment Service (ACAS) if they need to be considered for other Commonwealth Funded Programs (such as Home Care Packages, Residential Respite or Residential Care).

The RAS and ACAS are both independent multidisciplinary teams that can include health professionals such as social workers, nurses, occupational therapists, and physiotherapists. Referrals are received through a variety of sources. Referral for RAS and ACAS assessments are received via the MAC portal. At the point of triage for either service, the needs and the complexity of the client's circumstances will determine which service is best placed to complete that initial assessment. The primary difference between the assessment teams lies in their roles. The role of the RAS is to setup services via the Commonwealth Home Support Service. These entry level services can include domestic and shopping assistance, delivered meals, and personal care. However, when a client requires flexible and more coordinated care that is beyond what the Commonwealth Home Support Service can provide, the assessment is completed by the ACAS team. ACAS undertake comprehensive assessments in collaboration with other health professionals such as a geriatrician. Services recommended following the ACAS assessment can include a Home Care Package, Residential Respite, or Permanent Residential care.

Home Care Packages were introduced shortly after the implementation of MAC and were intended to be more consumer directed than the previous packages available from the federal government. The results of the assessment completed by ACAS determine the level of Home Care Package based on the client's level of function (1= basic needs to 4 = high care needs). The client enters the national queue (waitlist) based on an additional assessment of priority (Medium or High) and is notified by mail when their package is ready for uptake. The client is then required to choose a package provider for their services as per the assigned budget.

The aim of the NDIS and MAC is to support people and their informal carers to remain in the community. However, both systems are known to be convoluted even for experienced professionals who engage with them on a regular basis. Compound carers often need to liaise with one (or both) systems to access services to allow them to sustain their carer role.

Informal Caring

As identified earlier, informal carers play a significant role in alleviating increasing pressure on the Australian healthcare system. An investigation by Deloitte Access Economics (2020) into the economic value of informal care estimated the replacement cost of their care to be $77.9 billion for the year 2020. Informal care can involve a variety of activities and can often occur outside of the carer’s home if they do not live with the people they care for. Informal caring activities can range from visiting weekly to assist a loved ones to complete grocery shopping or attend their doctor, to tasks that occur daily such as assisting with showering and dressing, medication management and functional mobility and transfers.

Regardless of the frequency and level of assistance provided, informal caring can often "be a sudden and unexpected challenge" (Coutinho et al., 2006, p. 48), and there are diverse reasons for taking on the role of informal carer. Data released by the ABS (2016a) showed the most common reason for assuming an informal caring role was familial responsibility (66.9%), followed by a sense of being the best person to care for their loved one (50.3%), and feelings of emotional obligation (44.2%). However, some informal carers have little choice about assuming the informal carer role, which can be a risk factor for negative impacts on carer health and well-being (Schulz et al., 2012).

Schulz et al. (2012) examined the predictors and consequences of perceived lack of choice for informal carers when assuming their role. Participants were included in the study if they were 50 years or older and were recruited through the United States National Alliance for Caregiving and the American Association of Retired Persons. Data were collected via 1000 structured telephone interviews using a random digit dial coupled with surname sample to ensure over-sampling of ethnic minorities such as the African American, Hispanic and Asian populations. Measures for the phone survey were developed and selected by a panel including specialist carer researchers, health researchers, and carer advisory groups. Overall, almost half (44%) the participants reported a perceived lack of choice about taking on their informal caregiving role. The results also demonstrated that lack of choice was a significant predictor of emotional stress, negative health impacts and physical strain (Schulz et al., 2012). Contrary to the authors initial hypothesis, a higher level of education was positively associated with a perceived lack of choice, which was attributed to these individuals perceiving caregiving tasks as a threat to their autonomy in contrast to carers with lower levels of education (who may have had fewer aspirations or realistic options).

The role of informal caring and its associated caregiving tasks has been shown to significantly impact the carer’s physical and mental health and the financial circumstances of both carers and their families. An Australian study focused on carer service utilisation (prior to the formation of NDIS and MAC) and the impact of caring on mental and physical health (Butterworth et al., 2010). The authors conducted a community survey of 2,222

Australian adults residing in Canberra, Australian Capital Territory and Queanbeyan, New South Wales to describe factors influencing their health, with mental health measured by the Goldberg Depression and Anxiety scales (Goldberg et al.,1988) and physical health measured using the 12 item Short-Form Survey (SF-12) (Ware et al., 2006). The results demonstrated older adults engaging in informal caregiving compared with non-carers had significantly worse mental and physical health, higher financial stress, experienced more family conflict, and received less informal support from their family and spouse (Butterworth et al., 2010). This research highlighted the importance of considering the social context where caring occurs and what supports are available for carers.

Aggar et al. (2014) explored the relationship between the use of services by carers and the carer experience in Metropolitan Sydney, Australia. Data were collected from a randomised controlled trial from 2008 to 2011 to examine the treatment of frailty in the community. Participants were older people (aged 70 years or older) who had recently been discharged from a metropolitan Sydney rehabilitation service. Participants were invited to give permission to contact their family caregivers and a total of 119 carers were recruited and completed a questionnaire. The questionnaire included the Caregiver Reaction Assessment, which comprises of five subscales exploring the impact of caring on carer's daily schedule, financial situation, health problems, family support, and self-esteem (Jacobi et al., 2003). Carers were also asked to identify what support services they used under the categories of domestic, personal, and respite care. The authors concluded that the carer role had the most negative impact on their engagement in usual activities because of a disrupted daily routine. The study showed that domestic assistance was the most common form of service accessed (57%), followed by personal care (39%) and respite care (7%). Interestingly, respite care was not accessed within the home and but only provided in a residential facility setting. Accessing residential respite was also limited by the financial strain experienced by carers.

Most recently, Temple et al. (2021) examined unmet support needs and well-being for carers of older Australians. Data was collected from the Survey of Disability, Ageing and Carers (SDAC) conducted by the ABS from June 2018 to March 2019. The survey included people with a disability and older Australians (65 years and over), and carers of people with long-term health conditions or disability. The sample included 1,955 informal carers, of whom 1,285 were caring for people 55 years and over. Data were collected using four well-being measures contained in the SDAC carer questionnaire (Temple et al., 2021) to assess the impact of caring on relationships with the people being cared for, financial circumstances, carer physical and emotional well-being, additional support needs, and overall satisfaction with the carer role. The authors estimated the association between unmet needs, the four well-being measures, and overall satisfaction using multivariable logistic regression models. The results showed that unmet needs were strongly associated with a doubling of carer dissatisfaction and a decrease in physical and emotional well-being (Temple et al., 2021). Unmet needs were also associated with an increase in carer dissatisfaction, and deterioration in physical health and well-being, finances, and the relationship between the carer and the person being cared for. Interestingly, the study identified distinctive unmet needs in different carer groups. The most frequent unmet needs for carers of people with dementia was respite, while it was financial support for culturally and linguistically diverse (CALD) carers, and emotional support for younger carers. Furthermore, despite the many formal supports available for Australian informal carers, 39% of participants continued to experience unmet needs (Temple et al., 2021).

Although the negative impact of caring on the health and well-being of the carer has been repeatedly reported in the literature, there is also evidence supporting the positive impacts of providing informal care. For example, a study by López et al. (2005) explored the experiences of carers of older adults. The authors employed a mixed method design to investigate factors associated with positive experiences of Spanish carers of dependent older relatives. A total of 111 carers completed semi-structured interviews and survey instruments including the Caregiver Burden Interview (Zarit et al., 1980), Rosenberg Self-Esteem Scale (Rosenberg, 1965), Social Support Questionnaire (Saranson et al., 1987), and the Brief-Coping and Orientation to Problems Experienced (COPE) Inventory (Carver, 1997). The findings demonstrated that engagement in paid employment was associated with reduced satisfaction in the caring role for informal carers. The authors suggested this could be explained by carers perceiving they underperformed in their role as a carer and their role as a worker (López et al., 2005). Importantly, the study identified a significant positive association between perceived satisfaction with the carer role and participation by carers in their own leisure activities, perceived choice upon becoming a carer, having a previous strong relationship with the person they are caring for, and not working outside the home.

A Study Set in Diversity

This study took place in the western suburbs of Melbourne, Victoria which includes the local government areas of Brimbank, Melton, Maribyrnong, Hobsons Bay, and Wyndham. Data released by the Victorian Department of Health (2018) showed that Melton and Wyndham combined are experiencing the fastest population growth in Victoria and one of the fastest in Australia. The areas of Brimbank, Maribyrnong, and Melton are also identified as socio-economically disadvantaged, as per their score on the Index of Relative Socio-economic Disadvantage (Victorian Department of Health, 2018). In the 2016 census, more than 40% of people in the Western Suburbs of Melbourne were born outside of Australia which was approximately 10% higher than the national figure (ABS, 2016b). Health literacy is a major issue in these communities due to the high levels of cultural diversity, refugee and asylum seeker new arrivals, and general social disadvantage (Victorian Department of Health, 2018). As per the 2016 census, almost one quarter of the local community had arrived in Australia since 2011, and listed India, Vietnam and China as the most common countries of birth outside of Australia (Victorian Department of Health, 2018). However, the proportion of older Europeans who arrived in Australia post World War II also remains high in the Western suburbs and includes people from Italy, Macedonia, Greece, Malta and Croatia (State Government of Victoria, 2018).

Benedetti et al. (2013) explored the experiences of Italian Australians caring for family members with dementia. The study used purposive criterion sampling to recruit carers who identified as Italian Australian and were the primary carer of an older person (over age of 65) with dementia. Participants were also required to have been in their caring role for at least six months and have sufficient English proficiency to understand and answer the questions contained in the interview without an interpreter. A total of nine participants were recruited: six through organisations such as aged care service providers and multicultural services, and another three via word of mouth. Data were collected from semi-structured interviews and the authors used an interpretative phenomenological approach to analyse data. The results highlighted that culture strongly impacted beliefs around obligation in taking on the care of family members for Italian Australians, influenced more specifically by Italian values and cultural identity (Benedetti et al., 2013). The overall view of the Italian Australian community also influenced expectations of how care is received as a person ages, which may result in feeling of guilt if carers subsequently relinquish care and place their loved ones in an aged care facility. Participants also acknowledged that watching their family member decline and experience changes in their personality and behaviour was emotional distressing. Participants who co-resided with the the person they cared for reported a negative impact on their ability to engage in a social life distinct from their carer role. Physical strain was commonly experienced due to caring for their loved one with dementia, along with poor sleep hygiene, and having little time to care for themselves (Benedetti et al., 2013).

Participants’ access to informal support varied, with four receiving family support but the remaining five (who were all daughters) not receiving any family support in their carer role. Despite feeling disappointed and hurt over this lack of support, these participants emphasised the need for negotiation and compromise to avoid family conflict when caring for their parents with dementia. One participant expressed a strong view that culturally it was solely her responsibility to provide care. However, the remaining eight participants could access some formal support and two accessed day respite. The carers who accessed day respite were surprised at how much the person they cared for enjoyed it and how it supported them to take a much-needed break (Benedetti et al., 2013). However, the participants also described frustrations in accessing formal support, which was influenced by language barriers for older carers, and beliefs that services would not be culturally appropriate. Financial strain was a strong theme in the results, with participants perceiving the available government assistance as insufficient to cover the cost of required services. The study demonstrated the caregiver burden can be influenced by cultural and familial obligations, financial strain, and the perceived lack of support (formal and informal) for Italian-Australian carers of family members with dementia (Benedetti et al., 2013).

Cosmini-Rose and Belperio (2015) examined family and caring practices among second generation Italian women residing in South Australia. Participants were recruited by snowball sampling and ethnography was employed to produce eleven case studies that described their experiences. The findings described how the assignment of caring responsibilities between siblings was influenced by personality, gender, and work commitments, the age of dependent children, proximity and transport. The primary carers within the family unit, that is the ones who provided most of the care, demonstrated a willingness to take charge, good organisational skills, and capability. Interestingly, half of the participants reported with each subsequent generation their behaviour was becoming 'less Italian' (Cosmini-Rose & Belperio, 2015). The participants that reported a superiority in their caregiving practices compared with those from non-Italian background felt this was evident in their level of commitment and amount of involvement with their parents. This study's findings are consistent with previous research about the impact of cultural values on feelings of obligation surrounding care for ageing parents (Benedetti et al., 2013). It also identified that "when a high level of care was required, second-generation women prioritised their caring duties towards their ageing parents, sometimes at the expense of their own health, work, and social lives" (Cosmini-Rose & Belperio, 2015, p.20).

Walker et al. (2019) investigated the experiences of older parental caregivers of intellectually disabled children from Greek and Italian cultural backgrounds in Australia. Parental carers refer to carers of an adult with a disability who also hold parental responsibility. Participants were first generation migrants born in either Italy or Greece and had an intellectually disabled child living in the community. As the researchers did not work with interpreters, and many of the parental carers had limited English proficiency, the inclusion criteria were extended to second generation sibling carers. A total of 19 family carers were recruited through purposive and snowball sampling techniques from Greek and Italian community organisations. The study utilized semi-structured interviews with an interviewing guide based on themes from existing literature including feelings of responsibility, thoughts for the future and plans for accommodating the future needs of their child with a disability. The data were analysed thematically.

Findings showed that informal caring for an intellectually disabled adult resulted in sacrifices at a personal and family level for the carers. There was also a physical and emotional toll on the carer, which became more challenging as the carer aged (Walker et al., 2019). One major stressor for the carers was uncertainty regarding their child's future, and while thinking about this issue took up a lot of time, they were often unable to translate this into concrete plans. The findings also highlighted the stress caused by trying to negotiate the system and difficulties commencing the process of moving their intellectually disabled child into residential care. A sense of responsibility and purpose strengthened the carers' intrinsic motivation while also acting as a coping strategy. Informal support from family was an additional coping strategy for these older carers. However, carers felt that it was not their other child's responsibility to take on the full-time carer role for their sibling and this contributed to the challenge of making future plans. The authors concluded second generation migrants were challenged by rigid cultural expectations of filial obligation and having to follow the wishes of their migrant parents, which was consistent with previous research by Cosmini-Rose and Belperio (2015).

Compound Carers

As defined by the Australian Institute of Health and Welfare (AIHW), informal carers "provide help, support or supervision to family members, friends or neighbours with a range of physical, mental and end-of-life health conditions, and disability" (2015, p. 61).

Compound carers are informal carers with pre-existing caring responsibilities for a family member or loved one, who subsequently become an informal carer for an additional person (Perkins, 2010). Data from a National Carer Survey of 8,500 Australians (Carers NSW, 2020) provided an estimate of the proportion of carers who met this criterion and revealed that 18.8 % of respondents cared for two people and 7.1 % for three or more people.

To our knowledge, there is no existing research exploring the lived experience of compound carers in Australia or in culturally diverse and socio-economically disadvantaged communities. The international studies on compound carers have been conducted in the disability sector specifically and have focused mostly of parental carers of autistic or intellectually disabled adults. These studies have also stated limitations around not being able to recruit carers which reflect socio-economic and cultural diversity. As previously presented, the experiences of compound carers are likely to be influenced by the social, cultural, and economic context of residing in the Western Region of Melbourne. Nevertheless, the existing research highlights the distinctive challenges this group of carers face. These challenges include higher levels of perceived burden and stress (Perkins, 2010; Lunsky et al., 2017; Lee et al., 2020; Marsack-Topolewski & Wang, 2022), decreased quality of life (Perkins & Haley, 2010; Marsack-Topolewski, 2020a, Wang et al., 2021), and worsening carer health and well-being (Lunsky et al., 2017).

Existing literature that has identified compound carers experiencing barriers to accessing formal supports (Perkins & Haley, 2010; Lunsky et al., 2017; Lee et al., 2020; Lee et al., 2022). Previous research into compound carers has also found that the additional stressors and challenges of compound caring led compound carers to more frequently or rapidly consider placing the primary person they cared for in residential care (Perkins & Hayley, 2010).

None of the existing research on compound caring has been conducted from an occupational perspective. Occupational therapists work with compound carers in a variety of settings across the continuum of care and throughout the disability and aged care sectors. Although there has been no extant literature from the occupational therapy field, research into the role occupational therapists play within family centred care and general carer education and training is more extensive. Warner and Stadnyk (2014) interviewed informal carers of older adults and surveyed occupational therapists in a rural setting in Canada to determine their perceptions of family-centred care. Family centred care was found to be provided in the form of education and training, and mostly involved with caregiving activities. The authors reported this reinforced the importance of occupational therapists understanding the carer context including their expectations and needs.

The role occupational therapists play when working with informal carers was further discussed by Bourke-Taylor (2016) in an editorial in the Australia Journal of Occupational Therapy. The author highlights that occupational therapists are experts on the occupation of caring, and how caring can impact the carer's ability to engage in work, maintain health and well-being and participate in society. However, they also acknowledged that caring is complex and unique to an individual, with episodic impacts on mental and physical health. This highlights the need for further research to ensure informal carers receive the most appropriate support.

The Pan Occupational Paradigm

This study has been conceptualised and developed from an occupational perspective to enhance the potential transferability of its findings to occupational therapy. Occupations are "all the things that people do, the relationships of what they do with who they are as human beings" (Wilcock, 1999, p. 10).

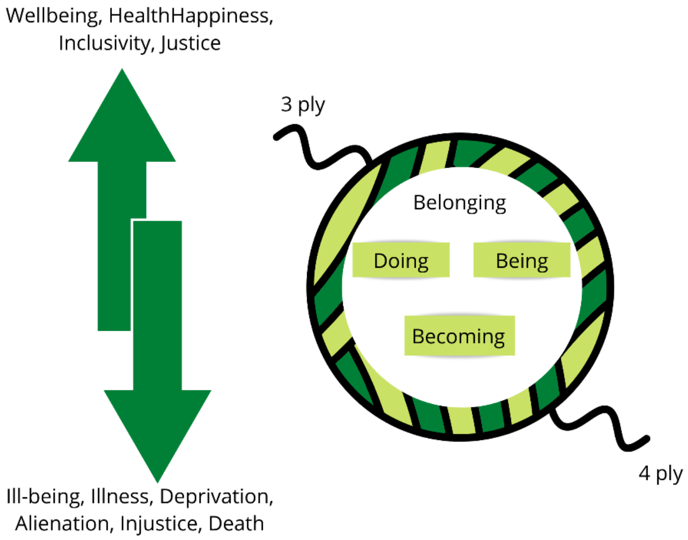
A core belief of occupational therapy is that health and well-being is directly influenced by the occupations (such as compound caring) that people engage in. The study's results were interpreted and contextualised under the occupational domains of *doing, being, becoming* and *belonging*, which were first proposed in Wilcock's Occupational Perceptive of Health (OPH) (Hitch et al., 2014a). The OPH sought to define these four concepts and explain how they contribute to the experience of occupational beings (Wilcock & Hocking, 2015). An occupational being is an identity which results from the interplay of the four dimensions of occupation – *doing, being, becoming* and *belonging* (Hitch et al., 2018). The term occupational being can refer to individuals, groups, or populations (Hitch et al., 2018). *Doing* is defined by the action aspects of occupations and is purposeful in nature, *being* relates to a person's essence and encapsulates how a person feels about what they do (Wilcock & Hocking, 2015). *Becoming* relates to personal growth and change, and aspirations for the future, and *belonging* refers to a person's need for interpersonal relationships and connectedness (Wilcock & Hocking, 2015).

Hitch et al. (2018) developed the Pan Occupational Paradigm (POP) in response to known barriers to the OPH's implementation by occupational therapists. The POP is shown in Figure 1.1 and acknowledges that all four occupational domains are in constant interplay, but they may be individually highlighted (or 'foregrounded') at times. For example: *becoming* may be foregrounded when working with compound carers to set goals for changing the amount of leisure time they have. The POP also contains an ill-being to well-being continuum which illustrates how interactions between the four domains influence occupational engagement by occupational beings, which in turns determines their outcomes along the continuum.

The final component of the POP is a nod to the profession's arts and crafts roots and relates to intertwined ply (threads) of yarns (Hitch et al., 2018). Occupational therapists engage in clinical practice using three ways of knowing (theoretical, evidentiary and practice), represented as a 3-ply yarn. Theoretical knowing refers to the therapist's knowledge of the association between occupation and health which is derived from various conceptual practice models (Hitch & Pepin, 2021), evidentiary knowledge refers to knowledge that has resulted from research in the occupational therapy field, and practise knowing is knowledge that has been gained from clinical experience, including reflective practise (Hitch et al., 2018). The fourth ply represents the fourth way of knowing which encompasses the lived experience of the occupational being. The green of the wool is also an acknowledgement of Wilcock's conceptualisation of sustainability as a key aspect of the occupational perspective (Wilcock & Hocking, 2015).

Figure 1.1

The Pan Occupational Paradigm



Note. Adapted from "The pan occupational paradigm: development and key concepts", by D. Hitch, G., Pepin and K. Stagnitti, 2018, *Scandinavian Journal of Occupational Therapy*, 25*(1),* 27-34, p.32.

The POP was chosen as the most appropriate theoretical framework for this study because it encapsulates the profession's values and beliefs in a paradigm (Hitch et al., 2018). The occupational domains of *doing, being, becoming* and *belonging* are at the core of the occupational therapy profession (Hitch et al., 2014a). The POP has a holistic approach to occupation, in contrast to the more reductionist practice models which focus on self-care, productivity and leisure. Instead, it represents what is important to the health and well-being of occupational beings, which can be enabled and enhanced via occupational therapy and occupational engagement (Hammel, 2017; Hitch & Pepin, 2021). The POP also acknowledges and encompasses that all the occupational dimensions are interdependent, and the paradigm is relevant to the lived experience for people from diverse backgrounds as this "complex, emergent paradigm enables multiple reinterpretations without the loss of its fundamental dimensions" (Hitch & Pepin, 2021, p. 21).

Significance of the Research

Currently, there is no known research with Australian compound carers. This means that knowledge about the lived experiences of compound carers is built on evidence from other parts of the world where healthcare systems and access to services are different and potentially influenced by other imperatives. In addition, existing evidence reveals an under-representation of carers from CALD and low socio-economic backgrounds (Green, 2013; Marsack-Topelewski, 2021; Marsack-Topolewski & Wang, 2022). This study was conducted in communities with some of the highest rates of diversity and disadvantage in Victoria, Australia, which was hoped would provide an opportunity to include a more diverse participant group.

The issue of compound caring will become ever more important as Australia's population continues to age, and the nation sees further demand on formal service systems and health care (AIHW, 2014). As previously presented, there may be more compound carers in the western suburbs of Melbourne than elsewhere in Australia because of the demographic distribution in this region. As a result, generating evidence that identifies and explains the impacts of compound caring on Australian carers in this community has the potential to generate a clearer, contextualised, and detailed understanding of the compound carer experience, and their contribution to both the people they care for and the broader Australian community. This is the first study to use the POP to frame and explain the experiences of carers, and this study therefore seeks to contribute to the literature on the paradigm's applicability to the field of occupational therapy. Occupations are activities that give meaning to the life of individuals, communities and society, and everyone has "an innate need and right to engage in meaningful occupations throughout their lives" (Taff et al., 2017, p.1). Occupational therapy is based on the philosophy that engagement in meaningful occupations is essential to achieve health and well-being (Taff et al., 2017). It is with this philosophy in mind, that occupational therapists can play a key role in identifying and addressing the occupational needs of compound carers across a variety of healthcare service settings. Occupational therapists can significantly influence the lived experience of compound carers in many ways, such as teaching skills to increase self-efficacy, arranging formal services, and advocating for the needs of this unique group of carers. This study will therefore aim to provide evidence upon which occupational therapists can more confidently base their practise.

Researcher Stance

The student researcher has 15 years of experience as an occupational therapist working with carers, including 10 years within the ACAS. In daily clinical practice and conversations with colleagues, she noted that many carers of the older adults being assessed were also caring for additional people. These carers of multiple people were initially thought by the student researcher to always experience their role negatively, although after further exposure to this group she realised this was not always the case. Some carers were master navigators of health systems and services and did not report significant strain or stress. However, others presented to ACAS at crisis point; seeking residential placement for their older loved one as they could no longer cope. Anecdotally, carers from CALD backgrounds sought services and engaged with ACAS later than other groups, which she assumed might be attributed to cultural expectations of the carer role or difficulties accessing services as mentioned in the literature. The student researcher engaged in this research to gain a deeper understanding of compound carers from an occupational perspective. The research was also in keeping with s.7 of the *Carers Recognition Act 2012* (Vic) which states that carers should "have his or her views and cultural identity taken into account, together with the views, cultural identity, needs and best interests of the person for whom he or she is a carer, in matters relating to the care relationship, including when decisions are made that impact on the carer and the care relationship" (p.6).

Although the student researcher no longer provides direct occupational therapy services through ACAS, she continues to assess and assist ACAS clients and their carers through an occupational lens in her new role. She therefore remains interested in the client's and carer's occupations, and the social and physical environments in which they are undertaken. The student researcher acknowledges that carer activities can be meaningful and satisfying, but they may also contribute to occupational deprivation. Occupational deprivation occurs when people are "unable to do what is necessary or meaningful in their lives due to external restrictions" (Whiteford, 2000, p.200). The student researcher acknowledges the negative impact that occupational deprivation can have on individual health and well-being and has witnessed this phenomenon in her clinical practice. Conversely, she understands the positive impact of occupational engagement, and therefore focuses on interventions of fostering this engagement as part of her daily clinical life.

The student researcher also acknowledges her own experience as a mother of young children and the impact this has on her ability to undertake enjoyable and meaningful occupations (such as self-care) for her own well-being. This personal experience, a deeply held occupational perspective on life and a sense of occupational justice led the student researcher to examine and learn from the compound caring lived experience during the study reported in this thesis.

Research Questions

The research question of this study was *What is the lived experience of compound carers residing in the Western Suburbs of Melbourne?* More specifically, this study also aimed to:

- Explore the lived experience of caring for an older person plus an additional person with significant illness/disability;
- Describe the experience of a diverse sample of compound carers and the impact of contextual factors; and

- Explore compound carers experience from an occupational perspective using the POP.

Thesis Structure

This thesis is comprised of six chapters. The current chapter has discussed background information including the context of the study and introduced the guiding theoretical framework. It then presented relevant background literature on carers, highlighted the significance of this study, and the research question and aims. Chapter two will present a critical appraisal of the current literature regarding compound carers and identify the gaps in the literature. Chapter three will describe the research methods, study design and theoretical framework in more detail. Chapter four will present the results from the data collected and chapter five will discuss these results in relation to the current literature and implications for practice. Additionally, chapter five will outline the strengths and limitations of the study and provide recommendations for future research. Finally, chapter six will conclude the thesis through providing a summary of the research.

Chapter Two: Literature Review

Chapter one introduced the study reported in this thesis. The context of Australia’s ageing population and Australia's healthcare and services systems were presented. Informal caring in Australia was discussed in terms of diversity, compound caring was defined, and an overview of the Pan Occupational Paradigm (POP) was provided. The chapter concluded with statements about the significance of the study, the stance of the researcher, the research question and aims, and an overview of the structure of the thesis.

This chapter will present a critical appraisal of literature relevant to the research question and aims. The search strategy and tools used to critically appraise this evidence will be detailed. The themes that emerged for the critical appraisal of the literature will be presented. These themes include perceived burden and stress; carer health, well-being, and quality of life; family distress and conflict; and use of formal supports. The chapter will conclude by identifying gaps in the literature and outlining the rationale for the study.

Search Strategy

An initial literature search was conducted using the following databases: CINAHL, Health Source: Nursing/Academic Edition and APA PsychArticles between January 2001 and December 2017. Search terms initially included “carer” OR “caregiv*” OR “caring” AND “additional” OR “multiple” AND “roles”. Subsequent searches used the following terms: “carer” OR “caregiv*” OR “caring” AND “compound” NOT “compound fracture” NOT “compound interest”; and “carer” OR “caregiv*” OR “caring AND “convergent”. Subsequent searches were completed with these databases and search terms to update and include literature from January 2018 to May 2022. A large date range was selected to locate older literature on the topic of interest as preliminary searches revealed minimal relevant results.

Inclusion Criteria

Evidence was included in this review if it was published between 2001 and 2022, peer reviewed, in the English language and included a sample of people who held multiple informal caregiving roles.

Exclusion Criteria

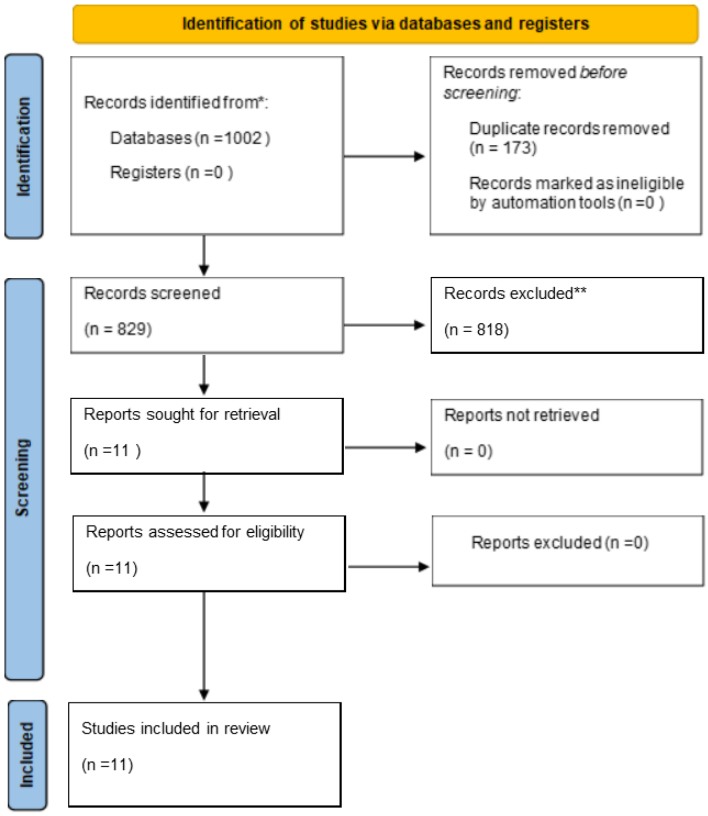
Articles that included formal or paid caregiving as the additional caring responsibility and literature that explored the multiple roles of carers as opposed to caring for multiple people were not included for critical appraisal.

Results

A total of 1002 articles were initially located. After 173 exact duplicates were removed, titles and abstracts were screened by the student researcher. A total of 11 articles met the inclusion criteria and were selected for full text review and critical appraisal. The review of the reference lists of these 11 articles did not identify further literature relevant for this review. The search strategy process is presented in Figure 2.1.

Figure 2.1

PRISMA template detailing search strategy



Note. Adapted from "The PRISMA 2020 statement: an updated guideline for reporting systematic reviews", by M. J., Page, J. E., McKenzie, P. M., Bossuyt, I., Boutron, T. C., Hoffmann, C. D., Mulrow, L., Shamseer, J. M., Tetzlaff, E. A., Akl, S. E., Brennan, R., Chou, J., Glanville, J. M., Grimshaw, A., Hróbjartsson, M. M., Lalu, T., Li, E. W., Loder, E., Mayo-Wilson, S., McDonald and D. Moher, 2021, *International Journal of Surgery, 88*, p.6.

Critical Appraisal

All articles included in the review were critically appraised by the student researcher to understand the rigour and methodological characteristics of the current evidence base about compound carers.

Quantitative Studies

Critical appraisal of the quantitative studies was facilitated by the MacMaster Critical Review Form specific to the study method (Law et al., 1998). These forms begin with reviewing the study purpose and background literature, before appraising the study design and its appropriateness to conduct the study (Law et al., 1998). These forms then move on to examining biases, the sample (size, sampling method), outcomes and outcome measures, intervention, results, and implications.

The National Health and Medical Research Council (NHMRC) Evidence Hierarchy (NHMRC, 2009) was used to assess the quality of the quantitative research based on the rigour of study designs and assigned them to one of six levels of evidence. Level I is the highest level of evidence and includes systematic reviews of Level II studies. Level IV denotes the lowest level of evidence, and includes case series, diagnostic yield, or cross-sectional study (NHMRC, 2009). Detailed information about the levels of evidence is presented in Table 2.1. The levels of evidence assigned to the quantitative studies included in this literature review can be found in Appendix A.

Table 2.1

Quantitative Evidence Hierarchy

Intervention	Level of Evidence
Systematic reviews of level II studies.	I
Randomised controlled trials.	II
Pseudorandomised controlled trial.	III-1
A comparative study with concurrent controls • Non-randomised experimental trial. • Cohort study. • Case-control study.	III-2

• Interrupted time series with a control group.	
A comparative study without concurrent controls	III-3
• Historical cohort studies.	
• Two or more single-arm studies.	
• Interrupted time series without a parallel control group.	
Case-series with either post-test or pre-test/post-test outcomes.	IV

Note. Adapted from *NHMRC levels of evidence and grades for recommendations for developers of guidelines* (NHMRC, 2009)

Qualitative Studies

The Critical Review Form tool for qualitative studies by McMaster University (Letts et al., 2007) was used to critique the qualitative studies included in this literature review. The tool first reviews the study purpose, background literature and appropriateness of the study design. It then appraises the methods, sampling, data collection and analysis before moving onto rigour and overall conclusions.

The Rosalind Franklin-Qualitative Research Appraisal Instrument (RF-QRA) (Henderson & Rheault, 2004) was then applied to allocate a level of evidence to these studies based on their trustworthiness, or the degree of confidence in the quality of a study. Trustworthiness is an important aspect of the rigour of qualitative studies (Liamputtong, 2017) and the RF-QRA appraises this in relation to the concepts of credibility; transferability; dependability; and confirmability. Studies are assigned to one of five levels of evidence in consideration of the researcher(s) ability to uphold the aspects of trustworthiness in their study. Level I is the highest level of evidence, indicating that all components of trustworthiness have been upheld and there were no relevant issues identified with the study. Conversely, Level V is the lowest level of evidence, indicating that all aspects of trustworthiness had been compromised (Henderson & Rheault, 2004). Table 2.2 presents detailed information for each level of evidence. The levels of evidence for the included qualitative studies can be found in Appendix B.

Table 2.2

Qualitative Evidence Hierarchy

Level	Description
1	No relevant issues identified.
2	Problems in one trustworthiness element.
3	Problems in two trustworthiness elements.
4	Problems in three trustworthiness elements.
5	Problems in all trustworthiness elements.

Note. Adapted from *Appraising and incorporating qualitative research in evidence-based practice (Henderson & Rheault, 2004)*

The studies included in the critical appraisal that utilised a mixed methods study design (i.e., contained both quantitative and qualitative approaches) were appraised using both the quantitative and qualitative tools mentioned above and their level of evidence is also included in both Appendix A and B.

Themes within Existing Literature

Four themes were identified based on common aims and/or findings in the literature. The themes included: Perceived Burden and Stress; Carer Health, Well-being, and Quality of Life; Family Distress and Conflict and Use of Formal Support.

Perceived Burden and Stress

This theme includes the existing research in this field which commonly reports compound carers experience elevated levels of perceived burden and stress. The theme contains six articles: four quantitative studies, two qualitative and two mixed method studies.

Perkins (2010) was the first to explore the experiences of compound carers. These carers were already lifelong carers for adult children with a disability, which was “compounded” by additional caring duties for their older parent or other family members, leading to the first use of the term “compound” carers. Perkins (2010) undertook a single case study of a 60-year-old American woman, with two adult sons, one who is intellectually disabled and has Down’s Syndrome. Data were collected using a series of in-depth interviews that were thematically analysed. Identified themes included a reduced support network, the need to prioritise competing demands, and decreased stress resiliency. In addition, each subsequent episode of compound caring became more difficult, physically challenging, emotionally draining, and resulted in further losses of the emotional and practical support she drew on to care for her son with Down’s Syndrome. In addition, compound caring tasks occurring outside the carer’s home such as completing housework, shopping for groceries, and providing respite for other family members, were particularly burdensome. Increased burden was linked to needing to manage competing demands between different care environments and to provide care in an unfamiliar setting (Perkins, 2010). Despite the inherent limitations of single case studies, the study was able to capture the experience of multiple episodes of caregiving over time. The author also acknowledged that the study was exploratory in nature and there was a need for future research into the experiences of compound carers. Furthermore, and as mentioned earlier, this was the first time that compound caring activities were identified in the literature.

Lunsky et al. (2017) compared the experiences of 199 Canadian parents of intellectually and developmentally disabled adolescents and adults (16 years and older) who had compound caring responsibilities (n=98) to those with singular caring responsibilities (n=101). The carer groups were compared regarding perceived burden, personal mastery such as problem-solving the needs of the people they cared for, and family distress. Participants completed a postal questionnaire and other standardised measures by telephone. The postal questionnaire included a question rating the impact of the additional caring activities on the carer's ability to care for the person with IDD on a 5-point Likert scale (1=*no impact* to 5= *severe impact*). The postal questionnaire also included the Brief Family Distress Scale (BFDS; Weiss & Lunsky, 2011) that measured family distress. Perceived burden and mastery were measured using the burden and mastery subscales from the Revised Carer Appraisal Scale (Lawton et al., 2000) which were completed by telephone. Survey results showed 36% of compound carers felt the addition of another person to care for had a serious to severe impact on their ability to care for their child with disability. The study also found significantly higher levels of burden, lower perceived mastery, and higher levels of distress for compound carers in comparison to singular carers. A lack of information on the people being cared for, and the broader family context limited the generalisability of the results, although this study provided interesting insights on compound caring.

The relationship between carer burden and Basic and Instrumental Activities of Daily Living (BADL, IADL) of compound and non-compound carers was explored by Marsack-Topolewski (2021), using a non-experimental correlational research design. Participants were recruited purposefully in the United States via disability organisations and professional contacts, and through snowball sampling. Participants were included in the study if they were caring for at least one autistic adult child, were able to comprehend English, were at least 50 years of age, and had the internet to complete an online survey. The total sample included 320 parents of autistic adults and included 35% compound and 65% non-compound carers. The researcher created a demographic data survey to collect personal information about the parent and their child with ASD. Carer burden was measured using the Carer Burden Inventory (CBI) and included time dependence, and developmental, emotional, and financial burden (Novak & Guest, 1989). Carer burden was also assessed using the Carer Reaction Assessment (CRA) (Given et al., 1992). Activities of Daily Living (ADL) were measured on a 4-point scale (1=*able to perform independently* to 4= *requires total assistance*). Six tasks related to BADL including personal hygiene/grooming, eating, and dressing, and five tasks related to IADL including community participation and cooking simple meals.

The results demonstrated that BADLs were significantly associated with perceived carer burden for both compound and non-compound carers. Compound carers experienced higher perceived burden than non-compound carers however, non-compound carers had statistically significantly higher levels of financial burden. Compound carers had lower scores on both BADLs and IADLs, indicating their child was more independent compared with non-compound carers (Novak & Guest, 1989). These findings suggest that less financial burden is associated with increased independence in ADLs. The study included a homogeneous sample mostly consisting of well educated, Caucasian women with higher-than-average annual incomes. The study also recruited participants from disability support agencies followed by snowball sampling and may therefore not have captured carers who were not receiving such informal or formal support.

More recently, Marsack-Topolewski and Wang (2022) re-analysed data from the previously mentioned study by Marsack-Topolewski (2021) to compare compound carers and non-compound carers of adults with ASD on specific dimensions of carer burden including time dependence, and developmental, emotional, and financial burden. Recruitment occurred as per the previously mentioned study (Marsack-Topolewski, 2021), and included the 320 parents of an adult child with ASD. Carer burden was measured using the CBI and the CRA. Carers were categorised into three groups: compound 1 carers (caring for autistic child with ASD and another person being cared for; n=78), compound 2 carers (caring for one autistic adult child and dependent child; n=45) and non-compound carers (caring for one adult child with ASD; n=197).

No statistically significant differences were found between the three carer groups for demographics apart from the compound 2 carer group being younger. Compound 1 and non-compound carers were found to have statistically significantly lower levels of time dependence burden than compound 2 carers. The authors thought this may be because their normally developing children were able to assist with caregiving occupations therefore lessening the time burden overall. Regarding developmental burden, non-compound carers' social lives were more affected by caregiving when compared to compound 2 carers. The authors attributed this to compound 2 carers being able to leave their child with ASD in the care of their other typically developing child. The authors had anticipated that compound 1 carers would experience greater burden than the other carer groups. However, this was not demonstrated in the results, which is consistent with previous research that demonstrated compound caring does not always have a negative impact (Green, 2013; Marsack-Topolewski, 2020a).

Other studies by Lee et al. (2020) and Green (2013) identified both positive and negative aspects of compound caring, with the former going some way to mitigating the burden posed by the latter. Green (2013) explored the experiences of compound carers, calling them "convergent" carers, via qualitative analysis of narratives from eight mothers residing in the United States who were simultaneously caring for their child with a disability and an older parent. The participants were recruited through paediatric clinics and the researcher's own personal contacts as she too had a child with disability. The results were consistent with the findings of Perkins (2010), in that compound carers described losing a previously important source of personal support as their older parent needed care, because their parent had previously provided additional social and emotional support for their child with a disability. The compound carers faced additional challenges as the time and energy resources used for one person being cared for reduced the resources available for the other, placing further strain on already depleted financial, social and support resources. However, compared to Perkins (2010), the study also identified some positive aspects of compound caring and found the skills involved in parenting children with disabilities (such as advocacy and navigating medical or social service systems) could be useful in eldercare. Although the study completed in-depth qualitative analysis it contained a small sample of eight participants therefore results could not be generalised to other carers. The study was also limited like Marsack-Topolewski (2021) in that the sample of participants were also largely homogeneous with a lack of diversity a cultural background and income, and the carers recruited were likely to be benefiting from social support.

Lee et al. (2020) compared the experiences of 152 compound (n=86) and non-compound (n=94) carers of a sibling with IDD with the aim of identifying positive and negative impacts of compound caring. Participants were included in the study if they had at least one sibling with IDD and were at least 18 years of age. Participants were recruited through various sibling support groups and other disability support organisations across the United States. Data were collected from an online questionnaire that included both open and closed questions and demographic specific questions. Sibling relationship was measured using the Positive Affect Index (Bengston & Black, 1973). Level of advocacy was measured using questions based on a previous study by Burke et al. (2015) using a 6-point

Likert scale (1=*not at all to* 6=*extremely*). To capture their level of future planning, participants were asked to answer yes or no to eleven questions used in a previous study by Heller and Caldwell (2006), and to comment on their participation in disability training. To determine sibling support needs, participants were given examples of different support needs and were asked to rate them on how much they felt they were needed on a Likert scale (0=*not at all to* 4=*a lot*).

Significant differences in demographics between the three groups were identified with compound carers and their siblings with IDD being older. Compound carers were also more likely to be married and have greater household incomes compared to non-carers and single carers. This difference was believed to be due to individuals who could afford formal care being more likely to take on the compound carer role. The relationship between the five dependent variables was then explored: sibling relationship, level of advocacy, level of future planning, participation in disability training and sibling support needs. The results showed that single and compound carers were statistically more likely to engage in advocacy activities. Compound carers were found to experience more positive aspects of caregiving such as greater understanding, affection and closeness, compared with the two other groups. Compound carers also most frequently described systemic barriers to accessing support, such as difficulty navigating service systems, and more frequently reported they struggled to balance life with caregiving due to “the difficult and overwhelming nature of fulfilling multiple caregiving roles” (Lee et al., 2020, p.8). As with other studies (Green, 2013; Marsack-Topolewski & Wang, 2022), the sample lacked diversity and is therefore difficult to generalise to the wider population. The study also used measures without established psychometric data so validity and reliability could not be confirmed.

Carer Health, Well-being, and Quality of Life

This theme includes existing literature that reports the negative impacts of compound caring on carer health, well-being and quality of life and includes three studies: two quantitative and one mixed methods.

Perkins and Haley (2010) compared the experiences of American compound carers and non-compound carer and examined the association of caring with quality of life. Participants were recruited using convenience sampling through parent support groups, therapy and employment agencies, list-serves and various websites, and through snowball sampling. Ninety-one older carers of intellectually disabled adult (34 compound carers, 57 non-compound carers) participated in the study. This mixed methods study combined semi-structured interviews and a survey. Demographic data were collected using a variety of measures including the Maladaptive Behavior subscale of the Scales of Independent Behavior-Revised (Bruininks et al., 1996), and the functional independence of the person being cared for was measured using Activities of Daily Living (Katz, Ford, & Moskowitz, 1963) and IADL scales (Lawton & Brody, 1969). The survey measured physical and psychological impacts on carers with the Medical Outcomes Study-Short Form (Ware & Sherbourne, 1992), Center for Epidemiological Studies-Depression Scale (Radloff, 1977), and the Life Satisfaction Index-Z (Wood, Wylie, & Schaefer, 1969). Quantitative data were analysed using independent sample t tests and Pearson’s Chi square analyses. The interview contained questions to identify compound carers or determine if any carers anticipated becoming a compound carer in the future. Participants were asked to identify the level of difficulty they had with eight potential problems such as a lack of support from others and an inability to do things they enjoy on a Likert scale (1=*not a problem to* 5=*a very serious problem*). Participants were also asked to rate their level of desire to place their intellectually disabled child in a residential care setting based on a scale developed by Morycz (1985) with scores from 1 to 6 (1=*I have considered residential placement* to 6=*I have made actual steps towards placement*). Participants were also asked to contribute any additional insights about their experience.

There were no significant differences between the participant groups' life satisfaction, depressive symptomatology, and physical and mental health (Perkins & Haley, 2010). Compound carers however were significantly more likely to consider placing their intellectually disabled child in residential care. The authors interpreted this as an indication that caring for a spouse or elder with chronic health conditions prompted them to think about future planning if they were to become ill (Perkins & Haley, 2010). Potential sample biases were identified by the authors, such as the parent-to-parent referral process which may have captured carers who already have established support networks.

Marsack-Topolewski (2020a) was the first author to examine quality of life of parental carers of adults with ASD who were caring for additional loved ones. Potential participants were initially recruited through disability and autism support agencies/organisations across the United States of America. Snowball sampling was also used to increase the number of participants. The study included parents over the age of 50 who cared for at least one adult autistic child (18 years of over). Three hundred and twenty parents, including 112 compound carers and 208 non compound carers, participated in the study. Participants were mostly female with above average family incomes and higher levels of education (Bachelor or Graduate degrees). Data were collected via an online survey which consisted of a demographic survey created by the researcher, the Enhancing Recovery in Coronary Health Disease (ENRICHD) Social Support Inventory (Mitchell et al., 2003), three subscales from the Carer Burden Inventory (Novak & Guest, 1989), one subscale from the Carer Reaction Assessment (Given et al., 1992), one domain from the World Health Organization [WHO] Quality of Life-BREF (WHO, 1996), and access to formal and informal support was determined by questions developed by the researcher.

The results revealed compound carers were significantly more likely to have trouble concentrating, however they were less likely to experience negative feelings. The authors hypothesised that the difficulty concentrating was due to needing to split their attention between the two people being cared for, which was consistent with previous findings from Perkins (2010). However, compound carers experienced fewer negative feelings than their non-compound counterparts. This was interpreted as indicating compound caring duties were all encompassing leaving limited time to think about negative feelings or that compound carers were more accepting of their role. The remaining four domains of quality of life: enjoys life; life is meaningful; accepts bodily appearance, and satisfied with self, and overall quality of life did not demonstrate statistically significant differences between the two groups. Similarly, to Perkins and Hayley (2010), the study identified issues with the heterogeneity of the participants which may have resulted from recruitment through support groups and various organisations.

Wang et al. (2021) examined differences between personal health and quality of life in ageing families, specifically comparing compound (n=48) and non-compound (n=64) carers. Cross-sectional data were collected via an online survey of 112 carers over the age of 50 years. Quality of life of the carer was measured by one question from the brief version of the WHO Quality of Life scale (BREFQOL; Skevington et al., 2004) with participants asked to rate how satisfied they are with their health on a 5-point Likert scale (5=*very satisfied* to 1=*very dissatisfied*). Quality of life of the family was measured using the general version of the Family Quality of Life (FQOL) Survey (Brown et al., 2006). The FQOL rates the participant’s top three domains by the family’s perceived importance, opportunities, initiative, attainment, stability, and satisfaction using a 5-point Likert scale. Opportunity was measured on a Likert item by participants rating availability of opportunities (5=*great many opportunities* to 1=*hardly any opportunities*). Initiative was measured by participants rating how much effort family members take to improve the health of the family (5=*a great deal of effort* to 1=*hardly any effort*). Attainment was measured by participants rating the degree by which the family is in good health (5=*a great deal* to 1=*hardly at all*). Stability was measured by asking participants their perception of their families’ health in the near future (5= *greatly improve* to 1=*greatly decline*). Satisfaction was rated by participants in relation to how satisfied they were in relation to their family’s health (5=*very satisfied* to 1=*very dissatisfied*).

Compound carers reported significantly lower perceived personal health, and perceived attainment and satisfaction in health compared to non-compound carers on the BREFQOL. Multivariate analysis showed compound caregiving was significantly related to family health but not personal health, with being older and not employed also significantly related to poorer personal health. The authors reported that carers who were not working reported poorer physical health, which was consistent with previous research examining the health and well-being of older carers in Australia (O’Loughlin et al., 2017). However, this study and many other studies (Green, 2013; Lee et al., 2020; Marsack-Topolewski & Wang, 2022) failed to capture carers with minimal or no engagement with services, those overwhelmed by the caring role and those from low economic status who may not have been able to access the web-based survey.

These results differ from an earlier study by Perkins and Haley (2010) who found no significant differences between the life satisfaction, depressive symptomatology, and physical and mental health of compound and non-compound carers. Their study compared the experiences of compound carers (n=34) and non-compound carers (n=57) in 91 older American carers of adult children with disabilities. This mixed methods study combined semi-structured interviews and a survey. The survey included the following measures: the Medical Outcomes Study-Short Form (Ware & Sherbourne, 1992), Center for Epidemiological Studies-Depression Scale (Radloff, 1977), and the Life Satisfaction Index-Z (Wood, Wylie, & Schaefer, 1969). Quantitative data were analysed using independent sample t tests and Pearson's Chi square analyses. There were no significant differences between compound and non-compound carers in characteristics such as education, age, and household income but there were more non-compound carers (68%) in the sample. All compound carers were Caucasian compared to 86% of the non-compound carers. The most common health issue for the secondary person being care for was Alzheimer's disease (20.58%). Again, potential sample biases were identified by the authors, such employing snowball sampling which may have captured carers who already have established support networks.

Family Distress and Conflict

Family distress and conflict were not the primary focus of any of the articles included in the review but were a secondary finding in one quantitative study and one mixed methods study.

Lunsky et al. (2017) investigated family distress in their study of compound and non-compound carers and found significantly higher levels of family distress in compound carers compared with non-compound carers. Family distress was also significantly higher when a child required medical support needs or had a dual diagnosis including a psychiatric disorder (Lunsky et al., 2017). Lee et al. (2020) identified family conflicts as a theme in the qualitative data they collected, which indicated non-carers and single carers experienced more frequent family conflicts compared to compound carers. These conflicts were specifically related to limited communication about future planning for their siblings with disability, and the importance of compound sibling carers was emphasised as an under-recognised issue.

Use of Formal Supports

This theme focuses on the lack of formal support accessed by compound carers and the potential impact compound caring has on healthcare systems. The theme includes two studies: one qualitative and one mixed methods.

Perkins and Haley (2010) explored the impact of managing multiple caring roles by rating compound carers' experience of eight problems such as insufficient support from others and difficulty prioritising competing demands on a 5-point Likert scale (1=*not a problem* to 5=*a very serious problem*). The Likert scale was developed by the researcher and based on findings from an earlier study by Perkins (2010) and a Cronbach's alpha of 0.86 indicated good internal consistency. The results demonstrated insufficient time to do things that the compound carer enjoyed as the most common issue followed closely by a lack of support from others. The potential consequences of lack of adequate clinical support were also highlighted by Lunsky et al. (2017), who found that insufficient support meant parents may be unable to continue their caring roles, leading to premature placement of one or both people being cared for in residential care facilities.

Lee at al. (2020) identified systemic barriers, lack of information and a lack of formal supports as key factors contributing to a more challenging experience of compound caring. Compound carers reported issues with systemic barriers most frequently, however all three groups (sibling carers of one intellectually and developmentally disabled adult, sibling compound carers, and non-carers) reported difficulties accessing information about available services. A third of all carers experienced a lack of support, with compound carers identifying a particular need for respite care.

There is also some evidence that compound carers use formal and other supports differently to other groups of carers. Marsack-Topolewski (2020b) for example, reported compound carers to be more likely to use formal psychiatric and occupational therapy services while social work was underutilised by both groups of carers. Regarding informal support, compound carers were more likely to request assistance from others regarding finances and information. The authors assumed that compound carers accessed more formal support because their situation required greater needs for those supports and because they experienced greater difficulty managing dual caregiving duties. The authors also hypothesised that the complexity and lengthy processes to obtain formal financial support led compound carers to opt for more informal financial support.

Finally, a recent literature review (Lee, et al., 2022) explored the existing literature on compound carers to define their characteristics, identify issues with previous research, and provide recommendations for future studies, policy, and clinical practice. The authors defined compound carers as people providing informal care to an adult family member with a disability (including Down’s Syndrome; ASD; IDD) and another family member. In many of the included studies, compound carers were caring for an adult with IDD and in some studies healthy dependent children were also considered an additional person being cared for. Lee et al. (2022) reinforced that future research should address other care relationships, include further information about the people being cared for, and the extent and duration for which care has occurred. The authors also highlight that as compound caring can occur multiple times over a lifespan, longitudinal research is required to capture the fluidity of compound caring (Lee, et al., 2022).

The authors recommended further research to identify which other variables should be examined with previous compound caring research being limited to the carer's mental and physical health, and family well-being and distress. The authors reflected on previous research conducted in the field of gerontology which stated that the addition of multiple carer roles depleted the carer's social network. This suggests compound carers have no or little time for themselves (Lee et al., 2022, p.71) and emphasises the importance of understanding the impact of compound caring on social support. Lee et al. (2022) proposed that prevalent financial strain and difficulties with workforce engagement identified in the literature (Parish et al., 2004; Thyen et al., 1999) can lead to increased disadvantage and hardships and suggested further research on these specific aspects of compound caring. The authors also wish to include caregiving appraisal such as feelings of satisfaction and self-efficacy as an outcome for further examination and facilitate further exploration of positive role experiences for compound carers. Lee et al. (2022) suggests mediators and moderators in compound caregiving research also need to be reviewed including "race, gender, income, parent mental health, parenting stress, problem-solving strategies, coping style and social support" (p.72).

Regarding policy and clinical practice, Lee et al. (2022) suggest compound carers should be given priority access with flexible delivery to address their evolving and ever-changing needs. The authors also suggest the provision of financial support for compound carers as previous research has demonstrated that the hours engaged in care exceed a typical working week which is likely to reduce the ability of compound carers to engage in paid employment. Lastly, they propose synchronised respite care as currently respite hours are attached to the person being cared for and not the carer. For compound carers, this means respite may be available for one person but not the other, and therefore the caring activities never stop. This article provides a synthesis of the known literature related to compound carers however the search strategy for the literature review was not included in the article and there is nil evidence that the studies were critically appraised. The article was also written by an author of many of the articles included in the review.

Gaps in Literature and Rationale for This Study

The existing international literature on compound caring included six quantitative (Lunsky et al., 2017; Marsack-Topolewski, 2020a; Marsack-Topolewski, 2020b; Marsack-Topolewski, 2021; Wang et al., 2021; Marsack-Topolewski & Wang, 2022), two mixed methods (Perkins & Hayley, 2010; Lee at al., 2019) and two qualitative study designs (Perkins, 2010; Green, 2013). All quantitative designs were assessed as being Level III-2 as per the NHRC Quantitative Evidence Hierarchy (2009) as they were cohort studies. The mixed methods studies were also assigned a Level of Evidence of Level III-2 and a Level 1 regarding their qualitative component with no issues identified for trustworthiness as per the Qualitative Hierarchy of Evidence (Henderson & Rheault, 2004). The remaining two qualitative studies were also assessed as Level 1 as no issues with trustworthiness were recognised. However, there have been relatively few qualitative explorations of the lived experience of compound carers to date. Qualitative research (specifically phenomenology) aims to gain a deep understanding of the lived experience of participants, in this case compound carers, as it describes and interprets human behaviour and the meaning we assign to our experience (Liamputtong, 2013).

For the purposes of this study and as mentioned earlier, compound caring is defined as caring for two or more people with significant illness or disability. However, the definition, terminology, and description of compound caring is not currently consistent in the literature for example Green (2013) uses the term convergent carers. Some studies defined compound caring as caring for a child with a disability and another typically developing child (Lunsky et al., 2017; Marsack-Topolewski & Wang, 2022) while in other studies, compound carers are those who care for two people with significant illness and or disability (Perkins, 2010; Green, 2013; Perkins & Hayley, 2010; Marsack-Topolewski, 2020a; Marsack-Topolewski, 2020b; Marsack-Topolewski, 2021; Lee et al., 2020; Wang et al., 2021; Marsack-Topolewski & Wang, 2022). Most participants in existing compound caring literature were already lifelong carers of a child with a disability (Perkins, 2010; Green, 2013; Perkins & Hayley, 2010; Lunsky et al., 2017; Marsack-Topolewski, 2020a; Marsack-Topolewski, 2020b; Marsack-Topolewski, 2021; Marsack-Topolewski & Wang, 2022). However, compound carers of adult children with disabilities may have already acquired skills from prolonged experience that allow for self-efficacy and proficiency when commencing an additional caring role. The study in this thesis focused on the aged care service sector in Australia, so all participants were caring for at least one older person (over the aged of 65 years). This provides a different perspective on compound caring by exploring a relationship which has received limited attention.

All the previous research on compound carers was conducted in North America where population demographics might not reflect the current and predicted situation in Australia and where the healthcare and service systems are very different. This study can contribute some evidence to understanding the experiences of compound carers unique to the Australian context. Participants in the previous studies were homogeneous and lacked socio-economic and cultural diversity and were predominantly well-educated (Perkins & Hayley, 2010; Green, 2013; Marsack-Topolewski, 2020a; Marsack-Topolewski, 2020b; Marsack-Topolewski, 2021; Marsack-Topolewski & Wang, 2022). To address this imbalance in participant representation, this study was based in a diverse environment and sought to include participants that were socially, culturally, and economically diverse. This study's geographical location enabled the recruitment of participants who have been underrepresented in compound carer research until now. In addition, previous studies (Perkins & Hayley, 2010; Green, 2013; Lunsky et al., 2017; Marsack-Topolewski, 2020a; Marsack-Topolewski, 2020b; Marsack-Topolewski, 2021; Wang et al., 2021; Marsack-Topolewski & Wang, 2022) employed purposive and snowball sampling through a variety of formal support groups and disability organisations, assuming that participants may have been receiving some form of formal and/or informal support which may have failed to capture the experience of compound carers who are isolated. While participants in this study were also recruited via a formal support service, the recruitment was also expanded to the public via social media which may have reached a broader population of carers.

Finally, there is no existing literature on compound caring from the field of occupational therapy. The articles included in the literature have predominantly been situated in the fields of sociology, social work, intellectual/developmental disabilities, and psychology. Although the themes found in the existing literature can be related to some of the domains of the POP e.g., perceived burden and stress (*being*); carer health, well-being, and quality of life (*being*); family distress and conflict (*belonging)* and use of formal supports (*doing*), the focus has not centred on the core belief that health and well-being is influenced by engagement in meaningful occupations. The concept of *becoming* has also not specifically been examined. Therefore, this study adopted an occupational perspective on the health and well-being of compound carers, contributing a new view of compound caring. The Pan Occupational Paradigm (POP) was used to contextualise the findings and ensure this study was embedded in theoretical understandings of the relationship between occupation and health. Therefore, the methodological choices made for this study supported an in-depth understanding of the lived experience of Australian compound carers and targeted carer-person being cared for relationships which have not previously been subjected to investigation.

Conclusion

This chapter has presented a critical appraisal of the current literature related to compound carers. The search strategy and tools used to critically appraise this evidence was presented. The themes derived from the existing literature were discussed and included: perceived burden and stress; carer health, well-being, and quality of life; family distress and conflict; and the use of formal supports. The chapter concluded by identifying gaps in the literature and the rationale for the current study. Chapter three will now describe the research methods, study design and theoretical paradigm used to frame the research.

Chapter Three: Methods

Chapter two critically appraised the literature related to the experiences of compound carers. The chapter included a comprehensive description of the search strategy and critical appraisal tools used to understand the current evidence base. Four major themes in the existing literature were identified; perceived burden and stress; carer health, well-being, and quality of life; family distress and conflict, and the use of formal supports. The chapter concluded with an overview of the gaps in the literature and the rationale for this study. Key to this rationale was the lack of published research about Australian compound carers, under-representation of compound carers from culturally and socio-economically diverse backgrounds in current research, limited presence of qualitative research and in-depth exploration of the lived experiences of compound carers, and an absence of research from an occupational perspective.

This chapter will describe the methodology of this study. The research questions will be re-stated, and a detailed description of the research design provided. The procedures implemented to conduct this study, including recruitment and sampling, participants, and instruments will also be described. Data collection and analysis processes will then be outlined, along with the strategies implemented to ensure trustworthiness. This chapter will conclude with an overview of the theoretical model; the Pan Occupational Paradigm (POP), which framed the overall study.

Study Aims and Research Questions

The study sought to answer the following research question: What is the lived experience of compound carers residing in the Western Suburbs of Melbourne?

More specifically, this study aimed to:

- Explore the lived experience of caring for an older person plus an additional person with significant illness/disability.
- Capture a sample of compound carers from diverse backgrounds.
- Explore compound carers experience from an occupational perspective using the POP.

Research Design

A qualitative research design was chosen for this study as it focuses on how people construct meaning and make sense of their lived experience and their life world (Merriam & Tisdell, 2015). The main objective of qualitative research is to identify and understand these meanings (based on the researcher's interpretation) and to practise reflexivity throughout this process. Furthermore, qualitative research aims to gain an in-depth understanding of people's lived experiences through the collection of rich, phenomenological data (Austin & Sutton, 2014). In qualitative studies, emphasis is placed on exploring how different phenomena are perceived and interpreted, often using homogeneous samples with desired characteristics or a shared experience (Fawcett, 2015). Qualitative approaches are considered the preferred method to answer research questions that examine the "'how', 'what' or 'why' of a phenomenon, rather than 'how many' or 'how much'" (Green & Thorogood, 2014, p.5). Therefore, a qualitative approach was the preferred research design for this study because it does not aim to test a hypothesis, but to construct a description from the perspective of people with relevant lived experience which acknowledges that reality is perceived subjectively (Green & Thorogood, 2014).

The methodology below has been reported in reference to the Consolidated Criteria for Reporting Qualitative (COREQ) research to ensure an appropriate level of methodological documentation was achieved (Tong et al., 2007). The COREQ is a checklist that promotes in-depth reporting of qualitative studies such as interviews and focus groups (Tong et al., 2007). It includes items such as aspects of the study design, the research team, methods, findings, qualitative analysis, and the researcher's interpreted meanings (Tong et al., 2007). Reporting the methodology in accordance with these guidelines ensured the student researcher documented the study in a way that enables readers to assess the strength and rigour of the methodology (Tong et al., 2007).

Phenomenology

Phenomenology is both a type of qualitative research and a philosophy associated with twentieth-century philosopher, Edmund Husserl (Merriam & Tisdell, 2015). Husserl developed phenomenology to study the human conscious experience in a way that other commonly employed scientific methods could not (Lala & Kinsella, 2011).

Phenomenology seeks to build understanding by describing and interpreting human behaviour and the meaning individuals assign to their experiences (Liamputtong, 2013). The source material required for phenomenological studies are rich, detailed, and subjective accounts of participants' experiences. Phenomenology is also a way of thinking, questioning, and writing for a researcher (Wright-St Clair, 2014). It aims to get as close as possible to understanding a phenomenon, its meaning and not purely just how it appears or how it seems to be (Wright-St Clair, 2014). A phenomenological approach was selected as the best way to gain a better understanding of the meaning of compound caring from the perspective of people with diverse backgrounds, ages, gender, and relationships with the persons they care for.

Phenomenology in Occupational Therapy

Phenomenology is an appropriate method to study humans as occupational beings because it aims to "uncover the essence of what occupations means" (Reed et al., 2011, p.

307). Reed et al. (2011) also emphasised that occupational therapists can never understand the meaning of occupation through direct observation only and need to understand meaning in its entirety as it is experienced by an individual. Lala and Kinsella (2011) also assert the importance of phenomenology in the study of human occupation due to its focus on two main questions: What is our interaction with the world? and What is our world made up of? Phenomenology attempts to answer these questions by applying the concepts of intentionality and lifeworld. Intentionality assumes our thoughts, experiences and occupations are always consciously aimed at something. This leads to the notion of lifeworld which explains that human interaction with the world is experienced via the meanings people consciously derive from the objects within it (Crotty, 1998).

Furthermore, phenomenology can uncover information about an individual's experiences with occupational engagement within their social, cultural, and political contexts (Lala & Kinsella, 2011). A phenomenological approach is also appropriate to the chosen theoretical framework and its occupational domains of *doing, being, becoming* and *belonging*. Phenomenology foregrounds a person's sense of *being*, with the researcher investigating the interrelationship between *being* and *doing* by explaining "how people as occupational beings plan, think and feel about what they do" (Wilcock & Hocking, 2015). Phenomenological enquiry is also fitting for the study of a person's *becoming* by investigating how people experience and achieve personal growth, as well as individual's sense of *belonging* by seeking to understand a person's connectedness and the importance they place on relationships. An integrated understanding of these domains enabled the student researcher to describe compound carers as occupational beings, and how their caring role impacted on their health and well-being, or ill health and ill being.

Theoretical Framework

The Pan Occupational Paradigm (POP) as shown earlier in Figure 1, was the theoretical framework chosen for this study. As mentioned in Chapter One, this paradigm further developed the original concepts of *doing*, *being*, *becoming* and *belonging* which were first presented in Wilcock's Occupational Perceptive of Health (OPH) (Hitch et al. 2014a). The OPH was developed to "discuss the meaning given to occupation in relation to health" (Wilcock & Hocking, 2015, p. 134). The occupational perspective presented by the OPH also expresses an occupational science and social justice worldview; for a person or group of people to achieve well-being all needs must be met for physical, mental and social capacities to be developed, maintained and balanced (Wilcock & Hocking, 2015).

Initially, the OPH only included the three domains of *doing, being* and *becoming*, with the final domain *belonging* added subsequently (Wilcock & Hocking, 2015). The OPH presented *doing* as the key concept that constantly interplays with the other three dimensions *being, becoming* and *belonging*.

In the OPH, *doing* was defined as the "action" component of occupations which can be influenced by personal wants and needs, and external factors such as cultural and socioeconomic environments (Wilcock & Hocking, 2015). *Being* referred to the quiet parts of occupations such as time for thought and reflection. *Belonging* encompassed people *belonging* to familial, social, and cultural groups, and the influence of these interrelationships on occupations. Lastly, *becoming* referred to the importance humans place on goals and aspirations, and relates to personal growth and change. Furthermore, the OPH approached ill-health and well-being from a public health perspective and was deeply rooted in the views of the World Health Organization around health promotion (Hitch et al., 2018). This perspective asserts that illness is caused by unmet needs and capacities, or when the environments in which occupation occur are exploited or disrespected (Hitch et al., 2018).

Hitch et al. (2014b) sought to clarify the definitions of the four OPH domains and examine their interplay with each other. As a result, the POP was developed to address the barriers identified by occupational therapists to the use of the OPH as a paradigm for practice, education, and research (Hitch et al., 2018). Unlike the OPH, the POP acknowledges that all four domains constantly interact with each other, that there is no key or predominant domain, and any of them may be highlighted (or 'foregrounded') at times. For example, *becoming* is foregrounded during the process of goal setting but continues to be influenced by the other three dimensions. *Belonging* is depicted in the background of the three other dimensions in the model diagram as an acknowledgement that it provides the social, environmental, and temporal context for the experience and meaning of occupations. However, it's interdependence with the other three domains is just as constant as the others.

The POP also includes a continuum ranging from ill-being to well-being which explains the relationship between occupational engagement by an occupational being (in this case, compound carers) and their well-being and health. These outcomes are emergent, in that they arise from the complex relationships between the main domains rather than being an additional domain in themselves (Hitch & Pepin, 2021). For example, there is a significant interaction from the dimensions of *doing* and *belonging* for compound carers when enjoying time out with friends. This occurs as caring tasks are delegated to formal or other informal supports to support their engagement in their own *belonging* to social and friendship groups. The three-ply yarn represents the three ways of knowing (theoretical, evidentiary and practice). The occupational therapist works with their clients in each of the occupational domains to foster engagement with meaningful occupations. When the occupational therapist concludes their work with the client, they have gained a fourth way of knowing from the lived experience of the client as an occupational being. This fourth way of knowing then informs and strengthens their future practice in partnership with their theoretical, evidentiary and practice knowledge.

The POP was chosen as the best theoretical framework to understand and conceptualise the experience of compound carers, due to its focus on understanding the meanings and motivations behind occupations and roles. The multidimensional nature of the paradigm also allowed for exploration of both the positive and negative aspects of compound caring and helps to conceptualise the role as its changes over time (and the occupational being moves up and down the continuum in response). The equal weighting given to all four dimensions of occupation also enables analysis of asynchronous engagement and experiences with each domain e.g., the compound carer might feel comfortable with the current *doing* of carer activities, but not their sense of *becoming* into the future. The conceptual practice models commonly used in occupational therapy focus on occupational engagement and performance in the context of ill-health and/or disability, which did not directly apply to the study's research questions and aims. Table 3.1 provides definitions of the four domains of the POP as developed by Hitch et al. (2014a) and examples of their relevance to the role of compound caring from the existing literature.

Table 3.1

Definitions of Doing, Being, Becoming, Belonging and relationship with compound caring

Definition as per POP	Compound caring within POP

Doing	• Doing involves engagement in uniquely meaningful occupations. • Doing does not have to be purposeful, contribute to one's health or organised. • Doing involves being active but can be either overt (i.e., visible, and physical) or implied (cognitive and emotional).	• Tasks and activities undertaken by the carer. • Engagement or participation in occupations in the environmental and social context they occur.
Being	• Being is a person's essence of self as both a human and occupational being. • Being is a result of the conscious experience and can involve creativity and life roles. • Being relates to personal choice and agency.	• Compound carer feelings about what they do and the value they assign to their caring role. • Compound carer's view about their capacity and abilities • Objective measures or observations of compound carer capacities and abilities
Becoming	• Relates to ongoing personal growth, development and evolution that occurs throughout the lifespan. • Becoming encompasses and is driven by goals and aspirations for the future.	• Compound carer's evolution in their role. • How compound caring tasks influence the compound perceptions of the future.
Belonging	• Importance people place on interpersonal relationships, and relationships with places,	• Compound caring's impact on relationships (with people, culture, time etc).

	cultures, communities, and times. • Reciprocity, mutuality, and sharing are the main components of belonging. • Belonging relates to the context and setting in which occupations are undertaken.	• The impact relationships have on compound caring.

Ethics

An application to the Western Health Low-Risk Ethics Panel was approved in July 2019 [HREC/19/WH/53277] and then sent to Deakin University for ratification before commencing data collection. A later amendment was submitted and approved in November 2019 to broaden the recruitment strategy to include social media, due to difficulties with recruitment in the COVID-19 pandemic. Ethics approval documentation can be found in Appendix C.

Procedure

Recruitment

Recruitment was completed using purposeful sampling, which involves selecting potential participants based on a particular shared experience or characteristic (Gilbert & Stoneman, 2016) and who can offer a rich experience of the phenomenon being explored (Palinkas et al., 2015). Specifically, criterion-i sampling, as presented by Palinkas et al. (2015) was applied, with the student researcher identifying and selecting all cases that met a "predetermined criterion of importance" (p.17). In this study, the criterion of importance was the shared experience of compound caring, so participants who were engaged in this role were purposefully sought.

The inclusion criteria for in the study required participants: to care for two or more people with a disability and/or illness; reside in the Local Government Areas (LGAs) of Brimbank, Melton, Hobsons Bay, Maribyrnong, or Wyndham; and be able to read and write in English, Arabic or Vietnamese. The first criterion aligns to the definition of compound carer used in this study, while the second ensure participants resided in the culturally diverse and socio-economically disadvantaged communities selected to address known gaps in the current literature. The final criterion reflected the language resources available to the research team and was intended to ensure participation by as broad a range of compound carers as possible.

Two methods were used to identify potential participants. The first one was through the Western Aged Care Assessment Service (ACAS), Victoria, Australia and the second was via social media platform Twitter

The Western ACAS completes comprehensive assessments of people aged 65 years and older living in the Western Region of Melbourne who have complex health needs. The role of ACAS is to assess the health and service needs of these older adults, send referrals to appropriate services and supports, and complete approvals for Commonwealth Funded Programs such as Home Care Packages, Residential Respite and Permanent Residential Care. ACAS agreed to support recruitment for this study and during their assessments, Western ACAS clinicians were asked to find out if primary carers of their clients also provided care to another person. These primary carers caring for another person were provided with a project summary and a copy of the Participant Information and Consent Form (PICF) by the ACAS clinician (refer to Appendix D). If the potential participant indicated an interest in taking part, the ACAS clinician obtained verbal consent for the carer to be contacted by a member of the research team to further discuss the study and passed on their contact details to the researchers. This contact was made by a member of the research team who was not a member of Western ACAS (DH, GP) to limit the risk of perceived coercion. If the carer agreed to participate in the study, they were asked to return their signed consent form via post or email. Once the signed consent for was received, the student researcher contacted them by phone to arrange a time, place, and mode for the interview.

Participants were also recruited via the social media platform of Twitter to reach compound carers, people being cared for, and people working with compound carers in the Western Suburbs of Melbourne more broadly. The social media summary was posted via the Deakin University Occupational Therapy Twitter account and included a summary of the project and the contact details of a member of the research team (GP). The social media summary was then retweeted by Nursing, Social Work and Occupational Therapy academics, and Western Health. People who wished to participate in the study were invited to contact this member of the research team, who determined if they met the inclusion criteria. Once the participants' eligibility was established, they were sent a copy of the PICF and were asked to return their signed consent form. As per the process for participants recruited via ACAS, once the signed consent for was received, the student researcher contacted them by phone to arrange a time, place, and mode for the interview. The social media invitation can be found in Appendix E.

A total of six participants were recruited from Western ACAS clinicians and one participant through social media. Once consent forms were returned, the student researcher contacted the participants to arrange a convenient date and time for the interview. Interviews were offered at the carers' home, the home of the person being cared for, all three of the hospitals within Western Health, and/or via phone. Access to on-call interpreters was available to provide accredited translation, interpreting, and transcription but were not required as all participants could read and write in English.

Participants

Historically the concept of data saturation has guided sample size estimates in qualitative research. Data saturation refers to “the point at which no new information, codes or themes are yielded from the data” (Braun & Clarke, 2021b, p.202). However, the study employed reflexive Thematic Analysis (TA), which assumes coding can never be finite as codes can “evolve, expand, contract, be renamed, split apart into several codes, collapsed together with other codes, and even abandoned” (Braun & Clarke, 2021b, p. 207). As a sample size range was required to assess the feasibility of the study, the student researcher referred to the model of “information power” as proposed by Malterud et al. (2016). This model explains that by increasing the information power in the sample, the sample size can be lowered. Items that increase information power include narrowing the study aim, increasing the specificity of the sample, collecting quality dialogue, and choosing an appropriate analysis strategy (Malterud at al., 2016). Exploration of compound carer experiences is a broad topic; however, the specificity of this sample (i.e., compound carers in the Western Suburbs of Melbourne) narrows the focus and increases the information power. The quality of dialogue during data collection was supported by the student researcher’s previous clinical experience, as she has acquired excellent communication and interviewing skills through her career and has considerable experience working with the target population. The analysis strategy also supported information power by iteratively returning to the complete data set as each interview was completed and monitoring when or if new themes appeared that required further data for confirmation. As per Braun and Clarke’s (2021) guidance, the student researcher, in conjunction with her supervisory team decided when recruitment could cease based on the quality of the data collected and subsequent themes derived. Considering all this, the researcher estimated a sample of six to eight would be sufficient, which also aligns with Creswell (2013) recommendation for phenomenological studies.

A total of seven compound carers consented to be contacted to find out more about the study. However, two withdrew secondary to time constraints, moving interstate and stress in their caring role. Recruitment occurred during the COVID-19 pandemic, during which recurrent lockdowns significantly impacted the Western ACAS. The assessments of older adults were also limited to completion by telephone to reduce the risk of infection, which may have prevented the identification of further participants as clinicians do not always explicitly ask carers if they have other caregiving responsibilities. Further information is often gathered in the client’s home at the time of assessment and/or through the development of a greater rapport with the carers. The shift to telephone assessment therefore reduced the opportunity for further information gathering, which may have identified more potential participants.

Data collection

Qualitative data were collected through focused, in-depth semi-structured interviews of approximately 60 minutes in length. These interviews generated rich and detailed accounts of the participants' lived experiences of compound caregiving. As stated by Liamputtong (2013), in-depth interviews are an appropriate data collection method for qualitative research and phenomenological analysis. Semi-structured interviews were specifically chosen as they allow free flowing, natural conversation with the student researcher providing gentle prompts and guidance using the previously prepared interview guide. This process also allowed for participation in an environment where the participants felt safe to tell their story and express their thoughts and feelings without fear of judgement (Smith & Nizza, 2022).

The interviewing guide was developed especially for this study as no existing tool directly addressed the research aim. The interview guide was designed to include questions aligning with the four occupational dimensions of the POP; *doing*, *being*, *becoming* and *belonging*. The interview guide was reviewed by members of the Western Health Allied Health Quality and Research Committee, other researchers within Western Health and members of the Western Aged Care Assessment Service, who provided feedback and suggested minor amendments prior to commencement of data collection. Examples of the questions included in the interview guide are shown in Table 3.2. The full interview guide can also be found in Appendix F. At the commencement of each interview, demographic data were also collected, including the compound carers' age, cultural background, local government area and relationship to the people they care for.

Table 3.2

Example interview questions as per the POP framework

POP	Example interview questions
Doing	Could you give me a brief history of when you first started caring for two people till now? Are there things you miss doing because you are too busy caring for your loved ones?
Being	How would you describe yourself as a person? How do you usually handle stressful situations?
Becoming	What do you see as your role in your family? Do you feel a responsibility to your family and/or the people you care for to continue in your caring roles?
Belonging	Do you think about the future much?

Are there things that you thought you might have been doing in this stage of your life that you cannot do because of your caring roles?

Data collection commenced in 2019 and ended in early 2022 following a period of intermission in the student researchers' candidature. Each interview lasted between 43 and 66 minutes, depending on the amount of information the participant wished to disclose. Given the high prevalence of COVID-19 in the Western Suburbs of Melbourne and recurrent lockdown restrictions, all interviews conducted between 2020 and 2022 were offered and completed via phone, however all interviews completed prior the pandemic were also conducted via phone as per the participants preference. The interviews were audio-recorded for verbatim transcription, which was completed by online transcription service "REV" or computer-based software "Descript," with any errors corrected by the student researcher prior to commencing data analysis. The researcher documented field notes in a journal post each interview, including personal reflections and considerations for future interviews. Personal information that might identify participants were removed and names were changed to pseudonyms to ensure confidentiality.

Data Analysis

Reflexive Thematic Analysis (TA) was applied to analyse the data collected in this study. Reflexive TA was chosen over other methods as it aligns with the aims of this study and allows the researcher to understand "how personal experiences are located within wider socio-cultural contexts" (Braun & Clarke, 2021a, p. 42). Reflexive TA aims to establish themes of shared meaning, as opposed to describing individual experiences, and this allows for the researcher to identify recommendations for clinical practice (Braun & Clarke, 2021a).

Reflexive TA promotes engagement with knowledge generation through critical reflection and necessitates an ability to read the data actively and analytically. In addition, reflexive TA requires an awareness of the researcher's cultural background and how it may influence their assumptions (Braun & Clarke, 2021b). Reflexive TA does not see the researcher's subjectivity as a barrier to quality analysis or a source of bias. Subjectivity is harnessed to produce insightful, rich, and complex analysis that is contextually bound. Therefore, this type of data analysis acknowledges that the researcher's experience will inevitably influence analysis and interpretation.

In this study, analysis and interpretation of the data was influenced by the student researcher's 15 years of clinical experience with other compound carers and her observations of the difficulties they experience in accessing aged care systems and supports. The student researcher was aware of their own assumptions, that when a compound carer was experiencing occupational deprivation, it would lead to a negative caring experience and poor physical and/or mental health, and this could have potentially prevented her from seeing positive outcomes of compound caring. Acknowledgement of this preconception throughout the data collection and analysis process was important and with this knowledge the student researcher ensured that when participant accounts challenged her assumptions, she sought to understand the participant's perspective and explored the space between them and her understanding. This is in line with Smith and Osbourne (2015) who state researchers must acknowledge and limit the impact of their own biases and recognise that each participant is the expert in their respective field. Reflexivity was also supported by regular supervision sessions with GP and DH, which included iterative and rich discussion of the evolving interpretation of the data.

Data were analysed using the six steps for reflexive TA identified by Braun and Clarke (2022). Step one involves *familiarisation* with the data set. Transcripts were re-read several times to ensure a real understanding of the data and deep engagement with its contents, and thoughts and reflections were documented in a journal. Step two involves *coding the data* by extracting significant and meaningful statements and providing them with labels in the form of codes. These codes describe the researcher's interpreted meaning of the text and comprised of short phrases (e.g., "becoming better at asking for help" or "lack of choice in carer role"). Coding contributed to the reflexive TA approach by promoting sustained immersion in the data and repeated engagement with the transcript to identify and refine both codes and themes (Braun & Clarke, 2021b).

Step three is the identification of initial *themes* and involves placing codes into tables and organising them into groups that share main ideas or concepts. Step four involves *further development of the themes and subthemes* by reviewing them with the original data and ensuring they reflect the most crucial meanings that relate to the research question (e.g., "systems create barriers" or "ways of coping").

Step five requires further *refining, defining,* and *naming* of themes and is the last "fine tuning" on the analysis (Braun & Clarke, 2022). It involves ensuring each theme has a significant core or essence, and selecting both concise but resonant names for each theme and subtheme (e.g. "doing as a way of coping" or "becoming an advocate"). While open coding was utilised in steps three and four, *a priori* themes based on the domains of occupation contained in the POP were applied to refine the themes in step five. These *a priori* themes were identified to ground the analysis within an occupational perspective. Although the student researcher was aware this was not purely inductive as per reflexive TA, Braun & Clarke (2022) acknowledge that findings are always underpinned by theoretical assumptions. The *a priori* themes included: *Doing* compound care; *Being* a compound carer; *Belonging* as a compound carer; and *Becoming* a compound carer, and were examined at length with other members of the research team to ensure they were reflective of the previously developed subthemes.

The final step consisted of *writing* up of the results and occurred throughout the analysis as early as step three, with the student researcher taking note of initial meaningful concepts. The student researcher also wrote down reflections and impressions through both the data collection and analysis phases in the form of reflexive journals. These journals assisted the writing process with initial concepts then refined and grounded with significant participant quotes.

Trustworthiness

Trustworthiness is the way in which the quality of qualitative research is measured and relates to the ability of the researcher to draw the correct conclusions regarding the meaning of the phenomenon (Liamputtong, 2017). Lincoln and Guba (1985) presented the most widely adopted criteria for the development of trustworthiness in qualitative research which is based on the four concepts: Credibility, Dependability, Confirmability and Transferability.

Credibility. Credibility refers to how well the researcher presents the participant's ideas and views (Cope, 2014). Credibility was supported in this study by the student researcher reflexively documenting thought processes when drawing conclusions from participant statements. The researcher also ensured credibility by practising reflexivity and recognising the influence of her experience and assumptions on the data analysis (Henderson & Rheault, 2004). Reflexivity refers to critical reflection on the role of the researcher, including their research practice and process, and awareness of the potential impact of pre-existing perspectives or assumptions on the analysis (Braun & Clarke, 2022). Reflexivity was implemented using a field journal documenting the student researcher's thought processes and reflections throughout the research process (Henderson & Rheault, 2004). These reflections were then presented to the other members of the research team and used as a resource to discuss potential biases and influences on data analysis.

Transferability. Transferability is the ability of the results to be applied to other situations and groups of people (Cope, 2014). In the context of this study, an individual's experience of compound caring is unique and therefore generalisability was not an appropriate aim for the results. However, generalisability, as discussed by Polit and Beck (2010) can be enhanced by the student researcher thinking conceptually and reflexively, having strong immersion with the data and "intensive within-case and across-case analysis" (p. 1456). The student researcher engaged with the data over an extended period as data collection was delayed by the COVID-19 pandemic. She also read and re-read the transcripts prior to analysis and engaged in iterative within and cross case analysis with the support of her supervisors.

Dependability. Dependability refers to the consistency of the results, and whether the findings would be still true if data collection occurred at another time. The student researcher demonstrated dependability by providing an in-depth description of the research procedures to ensure they were logical, able to be traced, and had been clearly documented (Tobin & Begley, 2004). Dependability was further enhanced by other members of the research team assisting with data analysis and independently coding the data (Henderson & Rheault, 2004). Given the research occurred during the COVID-19 pandemic and in one of the most impacted areas of Australia, dependability over time may be difficult to maintain given the new and ever-changing Australian health, aged and disability sectors as the nation continues to adjust to the “post-COVID world”.

Confirmability. Confirmability refers to the student researcher demonstrating that the analysis represents the participant’s point of view that has emerged directly from the data and is not that of the student researcher (Cope, 2014). Confirmability is demonstrated by grounding the thematic analysis with verbatim quotes from the participants and ensures the accuracy of student researcher’s interpreted meaning. Confirmability was also achieved by the implementation of triangulation across all areas of the study including the research question/aims, methodology and data analysis, and ensures for a “richer or multi-faceted account of the phenomena under study” (Braun & Clarke, 2022, p.279).

Conclusion

This chapter described the methodology of the study and outlined the research aims and questions. The chapter then provided a detailed description of the research design including recruitment and sampling, participants, and instruments. The data collection and analysis processes were defined, and an overview was given of the chosen theoretical model for this study, the POP, which was used to frame the analysis. The chapter concluded with the strategies that were implemented to ensure trustworthiness.

The next chapter will present the results of this study, including an outline of the themes and description of the study participants. The findings will be presented in detail and related to the research question and sub questions. The findings will then be contextualised in reference to the POP.

Chapter Four: Results

Introduction

Chapter three presented the methodological approach underpinning this thesis. More specifically, it described and justified the research design and presented the Pan Occupational Paradigm (POP) which is a theoretical model developed from the domains of the Occupational Perspective of Health (OPH). The procedure was detailed including recruitment, participants, and data collection tools and strategies, as well as the data analysis process using reflexive thematic analysis (TA). It concluded by presenting how the research aimed to ensure trustworthiness.

This chapter will present the results of this study, beginning with a description of the study participants. Then, themes and subthemes will be described in detail and supported by quotes from the participants. The themes and sub-themes are:

- *Doing* compound care (*doing* as a way of coping, systems create barriers, people create barriers and financial strain).
- *Being* a compound carer (satisfaction in compound caring role, feelings of self-efficacy and negative impact of compound caring).
- *Belonging* as a compound carer (family conflict, less time for friendships and belonging as a way of coping).
- *Becoming* a compound carer (*becoming* an advocate and thinking about the future).

Study Participants

Five compound carers residing in the western suburbs of Melbourne recruited via purposive sampling participated in this study. The five participants included three women and two men aged between 25 and 79 years. Amongst those, two compound carers spoke

Italian and English with at least one person they cared for, and a third carer was an Indian migrant who spoke English. All the other participants used English as their primary language and were born in Australia. Participants resided in the Local Government Areas of Brimbank (n=2), Wyndham (n=2), and Melton (n=1). Four of the compound carers cared for two people and one cared for three people. One of the compound carers also previously cared for a parent who was now deceased and had therefore experienced multiple episodes of compound caring in her life. Table 4.1 presents further information about the compound carers and the persons they cared for.

Table 4.1

The relationship between carer and the person being cared for.

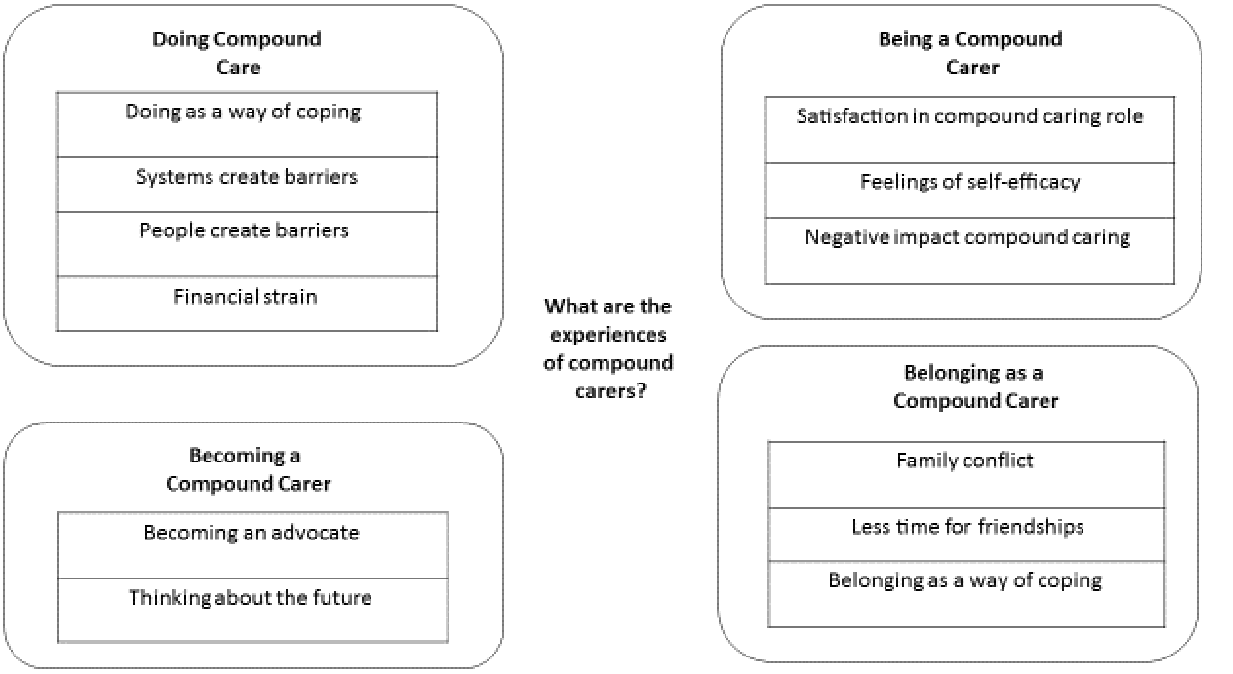
Compound carer	Person being cared for 1	Person being cared for 2	Person being cared for 3
Morgan	Son	Mother	N/A
Rory	Son	Wife	N/A
Sam	Daughter	Son	Father
Charlie	Mother	Grandmother	N/A
Andy	Husband	Mother	N/A

Findings

Figure 4.1 displays each *a priori* theme and subthemes which related to the four dimensions of occupation in the POP. While these themes and subthemes are presented in a categorical format, there is significant overlap and interdependence between them and the boundaries between them are not firm. For example, the theme of '*doing* compound care' has many close links with other domains and includes concepts which exist in the spaces between them (such as *doing* as part of *belonging* to a family). *Becoming* is depicted last as it was the least prevalent theme in the findings. However, *belonging* is usually the final domain of the POP as per its origins in the OPH which list the order as *doing*, *being*, *becoming* and *belonging* (DB3) with *belonging* being a contextual element.

Figure 4.1

A priori derived themes and subthemes



Doing Compound Care

Doing compound care is more than just performing the activities required to support multiple people. The *doing* of compound carers encompasses why they undertake these activities as part of their occupation, how they feel about those activities, and the influence of social and physical environments. As described by the POP, some occupations undertaken by compound carers can drive them towards a state of ill health. Others may steer the compound carer towards a state of well-being derived from the satisfaction and happiness they gain from their role. The occupations that compound carers are not able to do (or deprived of) because of their carer role could also have a negative, positive or both positive and negative impact. There were four sub-themes identified regarding *doing* compound care; doing as a way of coping; systems create barriers; people create barriers; and financial stress.

Doing as a Way of Coping.

Doing enabled coping for many of the compound carers. Morgan felt that she needed to keep *doing* her compound caring activities, without thinking too much about how it made her feel; “I've handled so much in my life that I just move forward, I do what I have to do and try not to have all the emotions”. Sam also used *doing* as a way of coping and prioritised her compound caring occupations over giving herself time to reflect on how she felt; “You just do it. You suck it up and you get on with it and if you need to fall apart, you do that later”.

Morgan and Sam also valued their ability to undertake other life roles such as study and paid work, which gave them a sense of meaning and satisfaction, and allowed them to continue compound caring. The meaning and importance of paid employment outside of compound caring for Morgan was evident when she was forced to decide whether to quit or return to work after a period of unpaid leave; “this is part of me doing something for myself, so I started working again”. Sam also undertook full-time study as something she did for herself and acknowledged that study was linked to her sense of identity and *being*; “I had to because I felt like I didn't exist”.

Andy had multiple coping strategies including allowing time for self-care, which has been made possible by the implementation of formal supports. Andy’s engagement with genealogy also provided a break from her compound caring role; “I like being on the computer and I go into another world. I get into my genealogy world for an hour and then I feel refreshed”. Andy also enjoyed gardening, although she used that time to plan her compound caring occupations and so her leisure was still subsumed by her caring role; “I like to get out there and get some air. And often I can think clearly, think things through". For Sam, her self-care was allowing time to be still and clear her mind rather than engage in active occupations; "if I do have time, I just want to sit and vegetate and try not to think about anything".

In contrast, Rory and Morgan were unable to undertake self-care at times due to being overwhelmed by their compound caring activities, and a lack of formal and informal support. Morgan described how her compound caring prevented her from engaging in her usual leisure activities; "I used to take my dog out, I couldn't walk her anymore". Rory had enjoyed swimming as a leisure activity since childhood; "I used to go to the lakes swimming and exercise... for about three to four hours a day, every day" until he began compound caring. Rory now has no time alone in his compound caring role; "I can't leave her even for two minutes because she straight away looks around where I am." Even with some formal support, he doubted whether he would ever be able to return to swimming; "I don't think I'll ever be able to do it because, with her, she's not comfortable if I'm not around." For all compound carers, the importance of engaging in self-care as a way of coping was important, and leisure remained an important category of occupation whether their compound caring role prevented or enabled their occupational engagement.

Systems Create Barriers.

The degree of formal support received varied significantly across the compound carers and included formal services through the Commonwealth Home Support Program (CHSP), Home Care Packages (HCP), Permanent Residential Care, and the National Disability Insurance Scheme (NDIS). As alluded to in the previous subtheme, formal support was crucial to allowing compound carers time for self-care. However, accessing this support was problematic for four compound carers. Barriers to accessing formal support were perceived to be systemic, in that compound carers wanted and needed support but navigating the service systems was extremely difficult.

For the people being cared for, formal support was accessed through the MAC portal. Andy reported that after four years of requesting help for her husband, when he was finally offered an appointment with ACAS, he was hospitalised due to a relapse in his condition and therefore the appointment was cancelled. On his return home, Andy attempted to rebook the assessment only to find her husband had been made “deceased” in the system; “when I rang up a month later, they said… I'm sorry, we can't do a package for your husband, he's dead". Morgan also found accessing formal support through MAC considerably increased her carer burden; “the amount of meetings and talking to people and saying the same story” and “just to organise very basic services for my mum… it was six hours, six meetings with different people”. Similarly, Charlie missed out on receiving formal support in his caring role through Carers Victoria as he misunderstood the system. He feared if he received support through Carers Victoria it would negatively impact his ability to obtain a HCP for his grandmother. When Carers Victoria called and offered support, he told them; “I'm all good… I didn't want it to negatively reflect any possible thing we could get from My Aged Care”.

For Rory and Sam, the formal support readily available was inadequate and did not meet their needs or the needs of the people they cared for. Rory accessed fortnightly cleaning as formal support for his wife, but this service did not complete the tasks as frequently as he required; “every fortnight, I have to wait for cleaning”. Sam reported dissatisfaction with the aged care providers for her father and their ability to engage in meaningful conversation and occupations; “... they tend to be pretty rubbish at actually talking to him and engaging with him”. Rory also reported he wanted assistance with gardening which is not often available through the entry level CHSP; “I can't go into the garden now because she comes behind me and then, of course, she might fall”. He reflected that this basic support would significantly improve his life; “I could relax a little bit more. At the same time, things would be fulfilled too".

The highest level of formal support in the aged care system is through a HCP. When his Aged Care Assessment was completed, Andy’s husband was identified as a High Priority for a package, reinforcing that she was at the point of crisis and her compound caring role was unsustainable. However, when the package was offered, there were further delays with commencing services; “... it took a long while to set up... a lot of teething problems and they don't help you set it up, they hinder you”. When Morgan’s mother was offered a HCP, she anticipated the time burden to set it up would be too great to be accommodated within her compound caring role; “… the shopping around, I didn't even try that.” The perception that she had to self-manage her mother’s package also influenced her decision not to access the package and instead pursue residential aged care; “I'd never heard of a case manager, no one ever told me that, that I could've gotten a case manager”.

Accessing support through the NDIS was also convoluted and difficult for some of the compound carers. Charlie reported significant stress and strain when supporting his mother to gain access to the NDIS; “my mother had sent all the relevant information to the NDIS individual… NDIS sent an email back to us saying, I need a more in-depth explanation… my mother's doctor, mentioned that it's an incurable disease”. Charlie faced further barriers when they needed a specialist to confirm his mother’s disability but was given less than a month to provide supporting evidence; “basically asked for the same information that the doctor had already sent. So we’ve decided to call the Lymphoedema clinic at [a local] hospital”. Language and jargon differences between the aged care and disability systems prevented Morgan from receiving an entire year of funding for her child. Despite already receiving respite via the local council, Morgan was not approved for NDIS “respite” as it was not a term their system used; “They don't give you money for respite and it was all a learning curve”.

People Create Barriers.

Apart from hindrances posed by formal systems of care, compound carers and the people they care for may also put-up barriers to accessing and implementing support. Rory declined a trial of in-home respite, despite his role as a compound carer being 24 hours a day, as he did not believe his wife would accept the support; “I don't think she will sort of be comfortable because, even with my son, she keeps asking, when is dad coming, when is dad coming”. Rory also declined in-home respite services for his wife as he worried it would alert her to the severity of her illness and result in further decline; “… she's asked me on many occasions, why are you talking and telling these people about respite… am I that bad?”.

Andy’s mother had a long history of declining services, however had recently commenced support through a Transition Care Program after a hospital admission. However, her mother’s perceptions of in-home help continued to be a barrier to accessing this support; “… she won't shower full stop... and when the carer arrives to clean, she … makes them just sit there for the time… and then she says to me, my place is dirty... you need to clean it up”. Morgan’s mother also declined to access formal support, which influenced the eventual decision to access residential aged care for her. She had attempted to organise day respite in the form of a social outing, but her mother declined; "I don't want to do that, I'm not social”.

Financial Strain.

The financial impact of providing informal care was identified as a factor influencing *doing* by three compound carers. Morgan highlighted the impact her compound caring role had on her ability to engage in paid employment, which had been a source of enjoyment and satisfaction for her, as well as a needed source of income. When asked directly if her inability to work for a period took a financial toll on her family, she answered confidently and reported this contributed to resentment towards her siblings; “Definitely, so I'll look at my brother and sister and they can work as much as they want”. Charlie was unable to continue at university as he was required to work to fix things around the home; “I was at university and I had to stop that because the house was sinking, and I had to get a job to help pay for it”. He subsequently also had to cease paid employment due to the demands of his compound caring role and still contributed substantially to the household expenses and personal expenses of his grandmother; “I’m paying for all her medication. And the food and everything on Centrelink support”.

The path to diagnosis and NDIS access was also a significant financial strain on Sam’s family. Initially, Sam did not pursue formal diagnosis for her children as she knew it would not lead to formal support; “they don't get any help, so spending a whole bucket load of money is not going to be helpful”. She later felt compelled to pay for a formal assessment in response to problems her son was having at school; “only because the school was putting pressure, or the teacher was putting pressure on me”. Later, Sam noticed her eldest child was having similar difficulties, and sought a diagnostic assessment but described receiving no help throughout this process; “We got no help. We got no help financially. We got no help from the school system... All of the assessments and everything are very expensive”. This financial toll on the family has led Sam to also miss out on *belonging* as a way of coping as her husband is unable to assist in the caring tasks due to providing financially for the family; “he doesn't tend to do a lot of the running around… He works full-time and he works overtime”.

Being a Compound Carer

This theme described the relationship between the role of compound carer and their personal identity. This relationship is influenced by the compound carers’ individual lived experience and the meaning they derive from their role. There are three sub-themes related to *being* a compound carer: satisfaction with compound caring role; feelings of self-efficacy; and the negative impact of compound caring.

Satisfaction with Compound Caring Role.

This subtheme represents how the compound carers feel and make sense of their role, and how they obtain satisfaction from enabling the people they care for to maintain some independence. Rory is aware of how hard his wife worked to maintain their home in earlier years and he remembers this when reflecting on his new role of homemaker; “So that's why I take it on myself, and I say, you did your work, now let me do my work”. He also valued allowing his spouse to continue engaging in the basic household tasks she enjoys and drew greater satisfaction from his carer role by supporting her dignity in this way; “It gives her a boost that she's not completely helpless, but she's still doing work”. Andy is aware that her husband’s personal care occupations would take less time if she assisted but she gains satisfaction from helping him maintain as much independence as possible; “...it doesn't matter how long my days are, the concern is that [Name] is still getting something out of his life”. Andy identifies a sense of motivation and satisfaction in her caring role of her husband; “It's the job I want to do. So, it's not something I find a real grind to do. It's something I want to do”.

Feelings of Self-efficacy.

In some accounts, compound carers who brought pre-existing skills and capacities to a new compound carer role described its impact on their feelings of self-efficacy. Their prior experience included work in related health and disability fields. Morgan believed she was the right candidate for the additional caring role of her mother due to her own skills and experience working in a hospital; “I'm very strong emotionally and I'm able to converse with doctors and health professionals. I work in the health field”. Sam also brought her skills from previous work to parenting and caring for her children with disabilities; “I've got a background in youth work, and I've worked a lot with kids with special needs”. Sam took pride in coping with daily life and study despite the demands of her multiple caring roles; “It probably just proves that I'm capable of coping with everything”. Andy also reflected on her experience as a medical practice manager when dealing with medical professionals when her husband became unwell; “I ran the practice... And that sort of stood me in good stead because when [Name] got sick, I didn't have this fear of talking to doctors because I used to socialise with them”.

Negative Impact of Compound Caring.

This subtheme highlighted how compound caring occupations may lead to experiences of ill-health and ill well-being across multiple aspects of health, how compound caring can have an impact on other roles for carers, and how choice around commencing the compound caring role influenced their experience. Rory felt his sedentary lifestyle as a compound carer and inability to participate in his usual exercise had negatively impacted his health; “I was just sitting a little bit too much. I have this back problem in the lower back and that sort of like agitated it”. The impact of compound caring also extended beyond his physical health; “… very stressful. I want to just go in the open area and scream… as loud as I can". Charlie reported difficulties with his breathing impacting his sleep but not being able to receive appropriate medical care; “I haven't been able to make specialist appointments just because I can't find the time”. For him, the effect of his compound caring on his mental health was also significant; “I'm kind of losing my mind here… I have a spotty memory…just forgetting so many things”. He did not perceive any positive aspects to *being* a compound carer; “people would say, look on the bright side and I got experience caring and all that stuff, but that's definitely an environment I really would rather not continue to be in or for anyone else”.

For Morgan the biggest impact of her compound caring role was a dissatisfaction with her abilities to undertake her other roles within her greater family unit. She described how the time burden involved with negotiating services for her mother meant that;

> *I was actually neglecting my family. They got a really thin serve of me for months… I just think that caring for two people, we can't do either of them properly... I haven't done any home therapy with him. No, no homework. My other son's out of control, he's gotten addicted to Fortnite (video game) because I just don't have time to spend with him.*

Whether the carer had a choice around talking on the care of an additional person also influenced their role satisfaction. Charlie had no choice in taking on additional caring for his grandmother and suddenly found himself needing to manage her medical needs without guidance; “… when COVID hit… my Aunty stopped coming over, so she didn't call me and say, here is what she supposed to take every day... And so I had to call the doctor, ask what she's taking”. Sam did not overtly identify a lack in choice in taking on additional caring for her father but believed her siblings; “… would never have done it”. Morgan had a similar experience in that her brother and sister could not deal with their mother's difficult personality; “I don't know why I just kept on going back and I knew that she needed help and I'd just take whatever it was but my brother and sister didn't and they kept away from her”.

Belonging as a Compound Carer

Belonging as a compound carer focuses on the relationships compound carers have with the people they care for, how their compound caring role affects their interpersonal relationships more broadly, and how coping was achieved through a feeling of connectedness with the loved ones they cared for. There were three sub-themes identified: family conflict; less time for friendships; and *belonging* as a way of coping.

Family Conflict.

Conflict between the compound carers and their larger family unit was a challenging reality for three compound carers which made their role even more difficult at times. Charlie’s aunty relinquished care for his grandmother suddenly and he felt forced to take on the additional caring role. Despite these circumstances, he reports ongoing difficulties with communication and coordination of his grandmother’s care when dealing with his aunty and extended family. When his grandmother became confused and stopped eating, Charlie tried to discuss accessing residential care with the family, but his aunty resisted; “… she's saying elder abuse and saying I want money and the house”. He also had difficulty arranging support through MAC as his aunty remained listed as his grandmother’s representative on this system as well as on all her utility accounts. Charlie is aware of the process to arrange Power of Attorney, but he does not want to pursue this; “… the extended family… they already probably see me as a low person trying to scam my grandmother out of money”.

Morgan described a new feeling of resentment towards her siblings when she took on the additional caring role of her mother; “And I started disliking my brother and sister and not contacting them and just taking it all on-board myself". Although she later acknowledged feeling that her mother may have manipulated the situation and contributed to this conflict when she would complain to her about their lack of contact; "They never see me, they never call me… I realise now that was a manipulation". This led to her being cut off from *belonging* with her siblings as a way of coping with her compound caring role.

Sam had also experienced conflict with her siblings when she previously cared for her mother. She felt they did not understand that their mother's dementia meant her accounts of events were often inaccurate and including when she was cast in a negative light. This negatively impacted Sam's relationships with her siblings and lead to the loss of potential informal support; "I didn't have a lot of support from them because they were taking what she was saying at face value".

Less Time for Friendships.

All compound carers reported disruption to their previous participation in social activities and *belonging* outside of their compound carer roles. Rory no longer attempted to go out socially as he always needed to leave early when he attended gatherings; "I can't because my obligation is to my wife. So, if she has to go home, I better not come then". Charlie lost the social engagement he enjoyed at university when he needed to leave and fulfill the financial needs of his family; "I made plenty of friends at university and we went out every week... It was good fun". Charlie's *doing* aspect of his *belonging* is now mostly limited to online exchanges and when asked whether face-to-face interactions were an option he responded, "not really, except for maybe 11 o'clock at night".

Sam also reported having less ability to catch up with friends due to her compound carer role; "… when weeks are really, really heavy with appointments... I don't tend to do anything much. And the more stressed I am, the more I shut down". Andy also described a cessation of social activities, however, acknowledged this won’t be forever as she will relinquish care in the future when the people, she cares for pass away. She was therefore more pragmatic and again engaged in *doing* as a way of coping when thinking about it as a temporary disruption; “I used to love getting out and *doing* things with some friends, just have an afternoon out or something. That's all had to stop, but that's not permanently stopped”.

Belonging as a Way of Coping.

This subtheme describes the importance compound carers placed on their interpersonal relationships and includes feelings of reciprocity and mutuality and relates to the context and setting in which occupations are undertaken. For some compound carers, *belonging* experienced within their familial and cultural environments was a vital source of strength and support. Andy’s *belonging* related to the strong bond she shared with her husband which contributed to a more positive compound caring experience. She holds the knowledge that her husband would care for her; “... if the shoe was on the other foot, he would do it for me”. Morgan found strength from shared experience with her husband; “My husband also comes from a carer's background... his mum was a quadriplegic, so both of us... I don't know, he's given me strength, we both try to be... we're pretty resilient the two of us”. She also felt she could emulate the example provided by her own mother; “my mum was extremely strong, so I'm the strong one for my mum”. Outside of the family, Rory’s *belonging* to his faith gave him the ability to shift his thinking through his spirituality; “I lost my freedom... freedom can always be regained, if not in this world, then the next world”.

When formal services were absent or limited, informal supports were crucial to allowing compound carers to maintain their role and provided contrasting experiences to the previous subtheme of family conflict. Sam received informal support and respite for her father from her extended family;

> *… my aunty and my uncle live nearby and they come and have a coffee with dad once a week… I get all the coffees and I'll talk with them for a little bit and then I'll kind of wander off in the house.*

Sam also received emotional and informational support from her friend who also has caring experience "One of my friends has got kids with ASD (Autism Spectrum Disorder) as well… And that has been extremely useful". For Andy, her aunt provides emotional support when they speak regularly on the phone; "... talk it out and then she puts her six pence in it and then we're both happy". Her daughter has a background in healthcare and is also a source of emotional and information support as "a great sound board… always there when I need her, doesn't matter when". Morgan identified incidences of strengthened relationships and reconnection with her siblings as a result of her compound caring and now can engage them in the carer of their mother; "So we've started talking and they've realised what I was going through and yeah, we speak every day now and we organise things and we help each other."

Becoming a Compound Carer

This sub-theme described how the participants evolved in their compound caring roles, and how their perceptions, abilities and capacities as compound carers have shifted over time. There are two sub-themes related to *becoming* a compound carer: b*ecoming* an advocate and thinking about the future.

Becoming an Advocate.

Many of the compound carers described coming to a point where they felt they needed to become advocates for the people they care for, usually when negotiating systemic barriers or when dealing with family conflict. Morgan reported advocating for herself when discussing her mother's offer of a HCP with her brother; "... you want to take her out... and undo all the work I did to put her in the nursing home, you go ahead and do it, I don't have time to make the meetings". Charlie placed some appropriate limits on his family when his grandmother was unwell to put their conflict aside and focus on her care; "I contacted my Aunty and I said, you know, for the benefit of your mother and my grandmother, let's just put aside our differences and, and see if we can get her into a home".

Andy actively advocated for support every time her husband was admitted to hospital, but it wasn't until she "really stood up for herself" that a referral for supports through MAC was completed; "You've got to learn how to jump up and down… Unfortunately… nobody wanted to know. And unfortunately for carers, in the world there is not a lot of help available, unless you know exactly how to get it". Sam employed her pre-existing organisation and advocacy skills when she took on the role of managing her child's NDIS package; "I'm self-funded so I can play... with how I use that... It gives me control". Sam also hoped that when her father signed up his Level 2 HCP it would allow for her to advocate more effectively for the care he receives; "I get to be really bossy with them and tell them what I need them to do".

Thinking About the Future.

Thinking about the future is an important aspect of *becoming*, however planning goals and aspirations requires time and energy. Findings showed some compound carers felt they didn't have time or didn't want or need to think of the future. As stated by Andy; "the future takes care of itself". There are strong links to *doing* as a way of coping and this aspect of their experience can result in compromised *becoming*. Sam reported she was not able to think about the future at all; “I would say no. I'm too busy coping”. When discussing potential plans for the people she cares for when she commences placement for her studies, she stated, “I don't know. We'll just have to cope.” Andy’s compound caring role meant she needed to focus on the present, but this was a shift in how she previously engaged in planning her life;

> *I used to be very organized. I'd know a long way ahead what I was doing six months down the track... my house now, it's from minute to minute because it's just as the situation arises, I deal with it.*

Charlie‘s *becoming* was significantly impaired by his compound caring occupations. However, when discussing a potential return to the workforce, he agreed this was a personal goal; “… absolutely. I haven't worked since 2018… just so much I could have done… here with regards to money. We need a new fence; we need new walls”. His desire to be in the workforce was further demonstrated previously when he thought he was placing his grandmother in residential care and sought employment straight away “… applied for a job at a warehouse and I got the job immediately”.

Morgan, in contrast, acknowledged the importance of *becoming*; “I think that the future, you manipulate it and you make it to what you want. So, if you do nothing, the future becomes what you don't want, you don't have control of it”. After placing her mother in an aged care facility, she had the time and space to focus on the future for herself and her family and had discussed moving interstate with her husband; “ever since I was married, we've wanted to move away... we've got a job where we can work from home, and I said to him, you know how we wanted to move to Queensland”. Her experience of relinquishing care for her mother therefore emphasised the negative impact her compound caring role was having on her own *becoming*.

Conclusion

This chapter has presented the lived experience of compound caring in detail and their relationship to the domains of the POP. The lived experience of a diverse sample was described and included compound carers with a range of ages, both genders, and from culturally diverse backgrounds. The findings contained the strong theme of *doing* as a compound carer. It presented barriers compound carers face to accessing support and how *doing* compound caring tasks can also be a way of coping. The results also illustrated the theme of *being* a compound carer and identify factors that can influence negative and positive feelings in their compound carer role. *Belonging* as a compound carer was also discussed and presented compound carers experiences with family and friendships and *belonging* as another method of coping. Lastly, *becoming* as a compound carer was the least prevalent theme and suggested compound caring itself may prevent *becoming* in some instances.

The next chapter will further discuss the findings from an occupational perspective and relate them to the known existing literature about the experience of compound carers and carers of older adults. It will present the limitations of the study and discuss the implications of the study for both future policy making and research.

Chapter Five: Discussion and Conclusion

Introduction

The previous chapter presented findings from the semi-structured interviews conducted with five compound carers residing in the western suburbs of Melbourne. Findings were organised and presented in line with the domains of the Pan Occupational Paradigm (POP), which was used to frame this study from an occupational perspective. The findings showed that compound caring experiences are variable and unique, however there are some common factors, such as individual feelings of self-efficacy and difficulty engaging in leisure activities. The findings described the lived experience of compound caring from an occupational perspective and highlighted how this role can result in occupational deprivation by posing barriers to usual avenues of occupational engagement and well-being support for carers. The findings also detailed the challenges faced by compound carers in accessing formal and informal support for the people they care for, along with aspects of the role that were experienced as positive and satisfying.

This chapter will contextualise the new knowledge arising from the findings of this study in the context of the existing evidence base and occupational therapy practice. The discussion will also draw upon the established concepts of occupational deprivation, occupational imbalance, carer burnout and occupational exclusion. The implications of the study findings will also be discussed with reference to policy, education and further research. The strengths and limitations of this study will be identified and recommendations for future change and development made. Finally, the thesis will be summarised in the conclusion.

Compound Caring and the POP

The findings of this study emphasise the interdependence of the four domains of the POP. For example, participants described how the choice or obligation to become a compound carer was influenced by the *doing* of compound caring activities and *being* a compound carer whilst trying to *belong* to a family unit or group of friends. As a result, *becoming* a compound carer evolved and was shaped by *doing*, *being* and *belonging* leading in turn to further adjustments and modifications to their *doing, being and belonging*. It is not possible to understand the occupational *being* of compound carers without taking all four domains into account, as their constant interactions clearly influence where the participants are on the health and ill-health continuum at any moment in time.

Emergent properties of the compound caring role from the POP have been identified and will be discussed further in this chapter. The emergent properties include occupational deprivation as defined by Whiteford (2000) "as a state in which a person or group of people are unable to do what is necessary and meaningful in their lives due to external restrictions" (p.200). Occupational imbalance will also be discussed and "occurs when there is an incompatibility or mismatch between occupational requirements and time, talent or skill; when there is occupational overload or scarcity" (Wilcock & Hocking, 2015, p.315). Table 5.1 provides a summary of the overall findings and clinical implications as discussed in this chapter.

Table 5.1

Summary of Findings and Recommendations for Practice

	Findings	Recommendations for Practice
Doing	Doing as a way of coping could lead to carer burnout.	Promotion of occupational balance such as time for restorative occupations.
	Systemic barriers to accessing formal supports threatens occupational deprivation.	Link compound carers with support and advocacy networks
	Engagement in productive occupations were impacted by the flexibility of work environments.	Facilitate return to work programs for compound carers and set-up formal supports for people they care for.
	Financial strain can be experienced by compound carers.	Promote engagement in the workforce and address systemic barriers to formal support.
Being	Feelings about being a compound caring were influenced by the ability to maintain independence of the person being cared for.	Focus interventions to increase occupational engagement of compound carers loved ones.
	Feelings of self-efficacy were impacted by previous employment in health and disability sectors.	Carer training should focus on building compound carers' skills and confidence.
	Negative feelings toward compound caring can impact emotional and mental health.	Addressing the cause of negative feelings e.g., fostering choice and agency,

		and belonging as a way of coping.
	- Younger carers can experience worse psychosocial outcomes when compound caring activities are at a high frequency.	- Addressing occupational exclusion in social activities and promoting engagement in paid employment.
Belonging	- Belonging can be a mode of coping for compound carer and compound carers are at risk of being deprived of belonging or at risk of “occupational exclusion”.	- Ensuring compound carers have formal supports in place to allow time for belonging and/or setting up flexibility around environments to engage such as online.
	- Family conflict can be experienced because of compound caring.	- Further research into the relationship of compound caring family conflict is needed.
	- Cultural belonging and filial expectations can be the source of family conflict.	- Allowing opportunities for mediation across the continuum of care and a variety of settings.
	- Spiritual or religious belonging can be a mode of coping.	- Occupational therapists need to provide increased awareness and consider spiritual and religious factors.
Becoming	- Perceived choice surrounding becoming a compound carer impacted overall experiences.	- Provide a sense of control, volition, and autonomy via engagement in interventions and decision making with compound carers.

	• Becoming an advocate for the people they cared was required for compound carers to overcome systemic barriers.	• Assist with learning advocacy skills if identified as a goal in carer training.
	• Compounds carers can be deprived of becoming due occupational overload in their multiple caregiving roles	• Implement strategies to improve occupational imbalance.

Doing Compound Care

The findings of this study highlight the need for compound carers to have opportunities to continue engagement in their own occupations. These occupations which were personally meaningful to them as individuals, were a strategy to maintain their health and well-being, and sustained their longer-term engagement in the compound carer role. However, there are considerable systemic barriers for compound carers to overcome when seeking support for their occupational participation. This includes the onerous demands of formal service and support systems and negative financial impacts which further reduced their opportunities.

One of the methods of coping identified by compound carers was *doing* as a way of coping. In some instances, compound carers felt they needed to just keep *doing* their compound carer tasks to cope and “falling apart” would have to come later. While some of the compound carers in this study perceived this focus on continuous *doing* as a coping strategy, it may inadvertently worsen their health and well-being in the longer term. The risk associated with this continual *doing* includes compound carers reducing time for restorative practises (such as sleep and rest), which has been highlighted by occupational therapists working with women in the sandwich generation who also need to balance multiple caring and competing demands (Evans et al., 2017). These risks also place compound carers at higher risk of carer burnout; a concept which has been explored by Gérain and Zech (2019). Their theoretical framework of carer burnout includes determinants, mediators, specific outcomes and general outcomes, and the authors noted that carer burnout was like the burnout experienced by people under prolonged stress at work. In addition, the specific outcomes of carer burnout include emotional exhaustion, and depersonalisation and detachment with the person being cared for (Gérain & Zech, 2019).

A notable barrier to engaging in meaningful occupation for study participants was a lack of sufficient flexibility to match the demands of their carer role. Engagement in paid employment or education was only possible for some participants due to accommodations in their workplace environment e.g., changed work hours, taking unpaid leave, online learning. A report by the Australian Human Rights Commission (Australian Human Rights Commission, 2013) confirmed the negative impact of informal caring on participation in paid employment and emphasised that female carers had the lowest rates of employment across their lifespan. Furthermore, most carers of older people are women (Cullen, 2019). The findings of this study showed that inflexible work environments for compound carers do not support their needs and deprive them of the opportunity to apply existing skills and abilities, and offset the financial burden associated with caring. These findings are similar to those of Wang et al. (2021) who found that carers who were not working reported significantly poorer physical health.

Conversely, compound carers who were engaged in study or paid employment as a meaningful occupation reported this enabled their sense of *being* and identity. This is consistent with a previous longitudinal study in the United States that identified carers who undertook at least one other productive role (e.g., paid work, volunteering) reported significantly higher perceived personal health (Rozario et al. 2004). An Australia study by O'Loughlin et al. (2017) also found working carers to report higher perceived health and higher socio-economic status, which further reinforces the potentially protective role of productive occupations on a carer's health and well-being. Productive occupations are not the only form of *doing* that enabled the health and well-being of compound carers in this study. Participants who had sufficient support, either formal or informal, to engage in self-care and leisure activities reported gaining some respite or rejuvenation which supported them to return to the *doing* of compound caring. Previous research has identified the most problematic issue for compound carers was not having time for oneself to engage in meaningful activities (Perkins & Hayley, 2010). Further, the impact of caring on the ability to engage in leisure activities has been highlighted by a phenomenological study by Steber et al. (2017). The study found carers perceived a shift in their leisure participation due to their caregiving role with a reduction in social outings and a loss of control on how they spend their time. This current study provides further evidence of the importance of self-care and leisure activities to compound carer health and well-being, and the risks of occupational deprivation if engagement is not supported. While engaging in personally meaningful occupation has the potential to improve compound carer health and well-being, the contribution of systematic barriers to occupational deprivation (and therefore ill-health and degreased well-being) was a strong theme in the findings. Aged care and disability service systems both presented ongoing barriers for the participants, and similar barriers have also been consistently identified in existing literature. The study completed by Lee et al. (2020) comparing compound, single and non-carer siblings of Intellectually and Developmentally Disabled (IDD) adults found that compound carers most frequently experienced systemic barriers. A mixed methods study into aged care service use by Australian informal carers identified that the process of accessing support increased the administrative burden of the carer and did not necessarily improve their stress (Heath et al., 2018). As was the case in the current study, barriers to accessing formal support were administrative rather than interpersonal, as when a participant was distressingly told her husband had been (mistakenly) designated as “dead” in the system. These issues were not limited to accessing complex care, with one participant describing the difficult experience of multiple meetings and repeating her story to set up basic services. The sheer number of administrative tasks required in her compound caring role overwhelmed her opportunities to engage in any personally meaningful occupations and led to the decision to pursue aged care placement for her mother.

The financial impact of compound caring was identified as an issue by half of the compound carers in this study. Aside from the reduced opportunities to participate in paid employment mentioned previously, financial strain was further increased by the costs of formal assessments required to access funding through services like the NDIS. A longitudinal study conducted by Tooth and Mishra (2014) with young and middle-aged female carers reinforces that sustained caring roles have the most negative cumulative socioeconomic impact on carers. Compound carers may not be able to afford the formal supports they need on their reduced income or may not have the time to apply for freely available supports via the government. This is particularly serious in regions of Australia like the western suburbs of Melbourne where a high proportion of the population is already socially and economically disadvantaged. This sets up a vicious cycle where the role of compound carer is itself the main barrier to gaining the support needed to remain in the role long term, and carer burnout becomes inevitable. The impact of the cumulative cycle of being unable to access the support they need was highlighted in an Australian qualitative study of suicidal ideation and resilience for informal carers of people with dementia (O'Dwyer et al., 2013). The length of time a person has been a compound carer should therefore be an important consideration for those working with this group, as the risks of negative outcomes for health and well-being are likely to increase over time.

Being a Compound Carer

Being a compound carer encompasses how the carer feels about their role, its contribution to their identity and sense of self as an occupational being, and perceptions of choice and agency. Participants in this study also experienced positive feelings of reciprocity from their caregiving activities and gained satisfaction from returning the care their loved one had one provided to them. Others valued the opportunity to employ their existing skills and abilities. However, the compound caring role also had negative impacts on the carers existing health issues and was perceived as contributing to the development of new problems.

The positive aspects of *being* a compound carer included *being* there for their loved one to support their independence. In the study by Lee et al. (2020) sibling compound carers were found to experience more positive aspects of caregiving including greater understanding, affection, and closeness. In this study, the way that participants felt about *being* compound carers was influenced by several factors, particularly opportunities to support the people they care for to engage in valued occupations which maintained their independence and quality of life. Occupational therapists often focus on increasing the function of the people being cared for, and these findings indicate these interventions may also contribute to improved mental health for compound carers.

Feelings of self-efficacy were increased by participants' previous experience of working in the health and disability sector and were a factor in compound carers deciding they were best suited for the role within their larger family unit. Research into feelings of self-efficacy for carers of loved ones at end of life identified that self-efficacy was significantly correlated with stress, in that those with higher feelings of self-efficacy had lower levels of perceived stress (Hampton & Newcomb, 2018). Previous research has also demonstrated that feelings of self-efficacy can mediate depressive symptoms in informal carers (Tang et al. 2015) and burnout (Gérain & Zech, 2019). While previous literature has highlighted the cumulative negative impact of compound caring episodes (Perkin, 2010), past experiences of caring may also better prepare them for performing the role effectively. Green (2013) also identified that skills acquired through parenting a child with a disability including advocacy and navigating medical or social service systems were useful when they took on the additional role of caring for an older loved one.

The negative aspects related to *being* a compound carer on the health and well-being of participants were also described in this study and included impacts on psychological and physical health. Sedentary compound caring activities impacted carer physical health for one participant in this study and another participant did not have time to follow up on their own serious health issues. A meta-analysis by Vitaliano et al. (2003) examining the impact of informal caregiving on physical health revealed strong relationships between caregiving and physical health indicators. Carers were found to have higher levels of stress hormones and lower levels of antibody responses than non-carers which could be attributed to the physiological impact of psychological distress.

In the current study, participants who reported negative feelings towards their compound caring role, also perceived a more negative impact on their emotional and mental health. Two of the participants highlighted the mental load of scheduling appointments and other supports for the people they cared for and the impact on their cognitive abilities. This is consistent with Marsack-Topolewski (2020a) and Perkins (2010) who also found that compound carers had greater difficulty with concentration. The authors attributed difficulty concentrating was due to needing to split their attention between the needs of two people and at times across two different environments.

The youngest participant (25 years old) described the significant impact his compound caring took on his emotional well-being, and that concurs with findings from previous literature specific to the needs of young carers. A longitudinal study into the impact of informal care on young people (aged 10-25 years) in the United Kingdom revealed they suffer significantly worse mental health compared with their non-carer counterparts (Brimblecombe et al., 2020). Furthermore, a study of the association between young carers and mental health found the impact on their well-being is ‘dose dependent’; that is, young carers who are exposed to a greater frequency of carer activities have worse psychosocial outcomes (King, et al., 2021).

Belonging as a Compound Carer

Connections with loved ones, family members and friendship groups were an important coping strategy for the compound carers in this study. However, the compound carers were often deprived of opportunities to cope via *belonging* due to the very nature of their role. In some cases, family conflict around care arrangements or decisions also contributed to compound carers being unable to use this strategy.

Belonging was a medium for coping for some of the participants and was highlighted in the findings of Alpert and Womble (2015) who investigated coping strategies of carers of older family members. Carers in their study reported the carer role had resulted in them being able to “reconnect with family members through the redefinition of relationships and roles” (Alpert & Womble, 2015, p. 719) which again highlights the interplay between the domains of occupation in the carers’ experience. Previous research with informal carers has demonstrated that social support (*belonging*) is significantly associated with satisfaction in occupational balance (Röschel et al., 2022).

All the participants reported a disruption to their ability to engage in social activities and *belonging* outside of their compound carer roles. For the younger carer participant, the new role of compound caring was so burdensome that his social engagement was now limited to online exchanges. *Doing* compound caring activities led directly to deprivation in *belonging* in some cases, as participants could not prioritise their friendships or withdrew to manage a feeling of being overwhelmed. The term “occupational exclusion” has been proposed by Hitch et al. (2014a) to describe the emergent property of *being* deprived of *belonging*. Conversely, occupational inclusion via *belonging* can support health, happiness, and well-being. Many carer support forums and groups are now accessible online and have been shown to reduce caregiver stress and improve well-being (Hu et al., 2015). The societal shift to greater online occupational engagement in the COVID-19 era also provides opportunities for compound carers to engage in other activities (i.e., self-care, leisure) and sustaining participation while limited to the home environment.

Many of the compound carers in this study experienced some degree of family conflict, but this issue has not been the primary focus of research in this field to date. This conflict was at times a barrier to arranging formal care for the people being cared for and had a negative impact on the ability of carers to receive informal support via their *belonging*. Participants reported experiencing feelings of resentment towards their siblings as they felt they had less choice on taking on the compound caring role due siblings’ lack of ability or willingness. These findings were also identified in a previous qualitative study by Tatangelo et al. (2018) exploring the experience of adult child carers of people with dementia with a main theme identified relating to family expectations and lack of choice on taking on the caring role. Participants in this study also faced distressing hostility and doubts from their family members about their performance of their caregiving activities. Similarly, a review by Pesiah et al. (2006) of guardianship and administration applications in New South Wales found family conflict often arose from accusations or perceptions of inadequate care.

Acknowledging differences in opinion between family members while clearly putting the needs of their loved one first seemed like a successful strategy for one participant. Open and clear communication where emotions can be named, and the identification of support required also seemed to lead to better sense of *belonging* to a family unit for the compound carers. The dynamic nature in the way the compound carers interacted within their family displays the interplay between *belonging* and *becoming*.

As per the study's aims, three out of the five participants were from culturally and linguistically diverse (CALD) backgrounds, and all from socio-economically disadvantaged communities. Interestingly, the two compound carers who belonged to Italian families both reported family conflict. This finding was personally important to the student researcher who identified as *belonging* to an Italian family herself and therefore reflexivity in interpretation of the results was conducted carefully in conjunction with the other members of the research team. Family conflict arose for one participant due to differences in feelings of moral obligation to be her mother’s carer compared with her siblings. These differences could be accounted for by changing beliefs around cultural obligations for the care of parents including that which has been identified in second generation Italian women (Cosmini-Rose & Belpero, 2015; Walker et al., 2020). This compound carer also reported stigma and judgements from her extended family around ceasing her compound caring role and placing her mother in an aged care facility. This again was consistent with previous research by Benedetti et al. (2013) with the general views of the Italian-Australian community influencing the expectations of filial care on the person being cared for and resulting in feelings of guilt if children subsequently relinquish and place their parent in residential care.

The study also included a compound carer who belonged to an Indian family. This compound carer's dedication to his wife and his children is consistent with previous research about caring in Indian culture where family carers are known to provide "remarkable quantity as well as quality of assistance" to their loved ones (Kalia et al., 2021, p. 7). As per the findings of Kalia et al, (2021) the compound carer in this study described a lack of *belonging*, specifically regarding friendships and informal support, however, he did not report an overall negative experience. This could be attributed to the role of his Christian faith to make sense of his role and put into perspective that his current occupational deprivation will be regained in the next life. Other previous research has also highlighted religion as a way of coping for informal carers of older and dependent relatives (López et al., 2005). In a concept analysis by Jones at al. (2016) occupational therapists were encouraged to practise reflection relating to their own personal values, attitudes and beliefs surrounding spirituality, and be mindful of others' values, beliefs, and experiences of *belonging.*

Becoming a Compound Carer

For some participants *becoming* a compound carer was a conscious decision, but for others there was no choice. Some participants also described how the process of *becoming* included opportunities to become an advocate, but overall, the compound carers perceived their *becoming* as individual occupational beings was inhibited by this role.

Varying levels of choice about assuming the compound carer role were described by the participants in this study. The factors influencing this choice have been explored in previous literature. A literature review completed by Arksey and Glendinning (2007) identified factors which strongly aligned with the *belonging* and *being* of carers. These factors included the unique relationship of the carer–person being cared for dyad, with experiences of caring often influenced by a "history of reciprocity, closeness, obligation and respect for the other person's preferences" (Arksey & Glendinning, 2007, p. 172). The influence of perceived choice about commencing the compound caring role was evident in the current study, with those who held spousal caregiving responsibilities reporting a more positive experience overall. Conversely, carers who perceived a lack of choice or control about *being* a carer were found to be at significant risk of emotional stress and physical strain in a qualitative study with 1397 informal carers in the United States (Schulz et al., 2012). For participants in this study, perceptions of lack of choice were influenced by the circumstances (i.e., whether a previous carer suddenly withdrew) or the unavailability of feasible alternative carers within the broader family unit.

The findings from this study described an evolution of the compound carer roles over time. Their individual experiences of *being* a compound carer and *doing* compound caring activities increased their awareness of the health care systems, services, and programs such as MAC and NDIS. The complexity of those services and programs not meeting the needs of carers or the people they care for, and the negative impact of unnecessary delays and errors, resulted in some participants *becoming* an advocate as part of their compound carer role. In common with a study into the use of aged care services by informal carers, compound carers did not want this aspect of their role to be taken away however reinforced the need to be better informed when making decisions for their loved ones (Heath et al., 2018).

Many of the compound carers in this study, particularly those who had little informal and formal support, were deprived of opportunities to become as an individual. The cause of this deprivation is closely related to findings from other occupational domains including not having enough time, not wanting, or needing to think of the future, and adopting the “don’t think just do” approach. One compound carer who placed her mother in residential care, saw a shift in her perception of the future toward prioritising her own well-being and the needs of her husband and children. The only way this participant could enact her personal *becoming* was to vastly reduce her compound carer role.

The importance on *becoming* for individual health and well-being has been known in occupational therapy for some time. Fidler and Fidler (1978) characterised *becoming* as the “ability to adapt, to cope with the problems of everyday living, and to fulfil age-specific life roles” (p.306) that “requires a rich reservoir of experiences gathered from direct engagement” (p. 306). Compound carers can be deprived of *becoming* through the development of occupational imbalance, which can be defined as disparity between occupational environments and time, leading to occupational overload and insufficiency (Wilcock & Hocking, 2015).

The findings of this study have presented the experiences of compound carers, the interrelationships between the domains of the POP and the factors that influenced the emergent properties of occupational imbalance, occupational deprivation, occupational engagement, and occupational exclusion. The study has uncovered unique occupational insights and many different potential options for occupational therapists to improve the lived experiences of compound carers in the future.

Limitations of Study

The recruitment phase of this study became difficult due to the COVID-19 pandemic, and it's associated restrictions and lockdowns while being completed in one of the most impacted areas in Victoria, Australia. As a result, the sample size was less than originally planned, however the decision to cease recruitment was made in-situ and based on the richness and complexity in the collected data, and the sufficient diversity found in the sample which addressed the research aims (Braun & Clarke, 2021b). The sample included both male and female carers, from a wide range of age groups and with varying relationships between the carers and carer recipients (e.g., spouse, child, and parent). It also included carers who spoke languages other than English at home, capturing a culturally diverse sample as per the study's aims. However, as per the third inclusion criteria of capturing those who also speak Vietnamese or Arabic, the social media summary should have been disseminated in these languages and therefore remains a limitation of the research.

Only two of the participants were older adults (65+) years which could support previous findings that the willingness of carers to participate in research decreases as a person gets older (Malm et al., 2021). The older carers did report an impact on their physical health which was consistent with previous research however further participants in this age cohort could have led to themes emerging around this issue. Findings could not be related to participants' level of socio-economic disadvantage as household income data was not collected, and therefore researchers could only state participants' self-report of financial strain.

The semi-structured interviews were all completed via phone as the study occurred during the COVID-19 pandemic with periods of lockdown restrictions, and the participants also chose phone interviews as it was easier to schedule time with their competing demands. Compared with face-to-face interviews, phone interviews may have had an impact on data collection as they can be limited by preventing the researcher from observing non-verbal cues, may result in a reduction of rapport building and impact the interpretation of responses (Novick, 2008). As the study contained a small sample size and data were gathered via a qualitative phenomenological approach, the results are not able to be generalised to a larger population of compound carers however this was not the aim of the exploratory study (Holloway & Galvin, 2016). The study also took an occupational perspective on the experiences of compound carers and thus may have not uncovered some insights specific to other fields such as sociology or psychology.

Clinical Implications

The occupation of compound caring can have a significant impact on the health and well-being of compound carers. This impact is influenced by the compound carers current state of occupational engagement, occupational balance, occupational deprivation, and occupational exclusion, all of which contributed to their position on the well-being continuum as an occupational being. As defined by the World Health Federation of Occupational Therapists, occupational therapists can address the impact of the compound caring role on health and well-being by promoting an “ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement” (2010, p.4).

Systemic barriers to accessing formal supports were found in the aged care and disability sectors in this study, despite both having undergone significant reform in the past decade. This study reinforced the administrative burden experienced by compound carers who often need to negotiate both systems simultaneously. It is therefore important for the occupational therapists working with compound carers to think about what additional formal supports can be accessed and provide information on local avenues for support and advocacy. These include Access and Support Workers, Aged Care Specialist Officers, NDIS Local Area Coordinators and Early Childhood Partners. The profession could also take on a wider advocacy role by participating in further system reforms at both the local and national level.

The most important avenue to ensuring compound carers receive the most appropriate support is to understand and value their experience, and what they as individuals place importance on in their daily lives. As demonstrated by this study, there cannot be a one size fits all approach to meeting the needs of these carers. However, a significant theme in the findings is that when compound carers have adequate support (informal or formal) it allows them to undertake meaningful occupations outside of their caring role and have a more positive experience. Occupational therapists should therefore aim identify the unique needs of these carers and implement urgent supports. Occupational therapists can work to address areas of occupational imbalance by aiding compound carers to implement strategies such as scheduling time for sufficient rest, sleep and self-care, and the technological age presents new and exciting ways to facilitate this with phone applications and online scheduling tools.

The importance of engaging in paid employment has been presented by the present study and existing literature. Therefore, occupational therapists working with compound carers need to enable the implementation of formal supports for caregiving activities, to support the freeing up of time and energy for productive occupations, if these are meaningful occupations for compound carers. Occupational therapists can also work with compound carers around goal setting and return to work plans that support in their transition back into the workforce.

Feelings of self-efficacy and mastery has also been shown to impact the health and well-being of carers therefore occupational therapists focus on building compound carers' skills and confidence when taking on caregiving tasks and thus relieving stress. As per the findings of this study, compound carers often needed to become advocates to overcome systemic barriers and access appropriate support and care for the people they care for. This reinforces the role occupational therapists could play in carer education (particularly for carers with no prior experience). Assessing carer skills, highlighting pre-existing knowledge they can apply to their carer activities, and increasing carer confidence can significantly improve the overall compound caring experience.

The study highlights that religion and spirituality can be a coping mechanism for some compound carers although the Canadian Model of Occupational Performance and Engagement (Polatajko et al, 2007) is the only occupational therapy practice model to explicitly include spirituality as a domain. Other practice models, however, include considerations of these factors in their environmental domains and can also guide clinical practice.

Lastly, occupational therapists should always engage compound carers in the discussions surrounding interventions and planning for their loved ones, as identified in this study and previous literature, many do not choose to become compound carers so providing a sense of control, increased volition and autonomy is essential to improving their lived experience.

Further Research and Policy

Further research into the experience and needs of compound carers is urgently needed. The current study was able to examine a small sample of five compound carers, therefore a study with a larger number of participants which reflects the diversity of the Australian community would be beneficial to providing evidence-based care and support. Further information regarding how to better assist carers and compound carers navigating the complex service systems of My Aged Care (MAC) and the National Disability Insurance Scheme (NDIS) should also be considered when completing service reform. Further involvement of carers in the review, design and implementation of services pertaining to the compound caring role is essential to ensuring we are meeting these needs and is their legal right as per the s.9 of the *Carers Recognition Act 2012* (Vic).

Family conflict was identified as a contributing factor to the compound caring experience and as highlighted in previous research minimal support is available to mediate families through these challenges (Pesiah et al., 2006). In practise, family meetings aimed at addressing family conflict often occur as a one off either to plan discharge from the inpatient setting or to arrange community supports. However, little is available in the community to mitigate ongoing issues of family conflict and the impact it has on providing safe and appropriate care. Therefore, research into the family conflict experienced by informal (and compound) carers is needed along with the development of targeted supports and strategies to reduce the potentially detrimental impact of this experience on carers and the people they care for.

Another important theme from the study related to engagement in paid employment and the impact of workplace exclusion on the health and well-being of carers is well documented (Rozario et al. 2004; O'Loughlin et al., 2017). Despite this issue being acknowledged in a report by the Australian Human Rights Commission (2013), the participants in this study still struggled to obtain and sustain the work they wanted due to inflexible workplaces. This remained evident despite the widespread shift to working from home arrangements with data collection occurring during the COVID-19 pandemic. Therefore, future policy needs to address ways to promote engagement in employment and other productive occupations to maintain the well-being of compound carers and reduce the financial burden of compound caring on individuals and families. This action could potentially be modelled on the programs and incentives currently available to other equity groups, such as people with disability and Indigenous Australians.

This study was the first time the POP was used to contextualise the experience of carers, and the paradigm was found to provide a useful framework for a deep understanding of negative and positive experiences, and outcomes from an occupational perspective. As per the POP, this study has further strengthened the three-ply yarn by combining the student researcher’s practise knowledge, the findings evidentiary knowledge and known theory. The challenge moving forward is for occupational therapists to take this three-ply yarn and add the fourth ply as they engage with compound carers in their practise and through the POP to deepen their understanding of them as occupational beings.

Conclusion

This chapter has presented the findings in the current study in relation to the POP. Findings consistent with existing literature into the experience of informal carers and compound carers included the negative impacts of caring on physical and psychological health and quality of life, and issues arising from family conflict. The mediating factors of engaging in meaningful occupations such as paid employment and feelings of self-efficacy were also presented. Unique findings from the study included the impact of compound caring on *becoming* and *doing* as a way of coping. The chapter then presented the limitations of the study, clinical implications and recommendations for future research and policy. The next chapter will conclude the thesis.

Chapter Six: Conclusion

This study was the first to delve into the lived experience of compound carers in a specific region of Melbourne, Australia. It answered the research question *What is the lived experience of compound carers residing in the western suburbs of Melbourne?* by detailing the experiences of caring for an older person plus an additional person with significant illness/disability. The sample included diverse compound carers and compound caring was explored from an occupational perspective using the POP.

The lived experience of compound carers is unique as is the case for all human and occupational beings. Most findings are specific to this study and contributed new knowledge and understanding of the lived experience of compound carers. While there were five participants, they lived in local areas of Melbourne, Victoria that represent some of the most culturally diverse, lowest socio-economic, and growing population groups in Australia. Some findings support existing international evidence on compound carers and can contribute to enhancing supports, practices, and engagement with compound carers.

This study is the first-time occupational therapy has contributed to the knowledge of the lived experience of compound carers and provides us with a new way of understanding the impact of compound caring as an occupation on the health and well-being of compound carers. The Pan Occupational Paradigm was chosen to contextualise the findings as it contains the four key domains at the heart of occupational therapy practice; *doing, being, belonging* and *becoming*, and allows for a complex and multidimensional exploration and understanding of compound carers as occupational beings.

Doing as a way of coping was a strong theme in the findings however did not necessarily contribute to improved health and well-being for compound carers due to the emergent properties of occupational deprivation in *doing, being* and *becoming*, and occupational exclusion in *belonging*. Family conflict was an unfortunately prevalent theme that impacted compound carers *belonging* within their family contexts and subsequently placed a barrier to informal supports, contributing to negative feelings of *being* a compound carer and *doing* other meaningful tasks. *Doing* compound caring was often found to prevent *becoming*, however those who reported development and evolution described *becoming* an advocate.

Occupational therapists have a unique perspective that is based on the premise that engagement in meaningful occupations is essential to promoting health and well-being. Occupational therapists are now invited to take the new and confirmed knowledge of the lived experience of compared caring from this study and implement changes in the way they see, treat, work, and engage with compound carers in their clinical practice.

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Appendix A

Level of Evidence of Included Quantitative Studies

Study	Intervention	Level of Evidence
Lee et al. (2020)	A comparative study with concurrent controls: cohort study.	III-2
Lunsky et al. (2017)	A comparative study with concurrent controls: cohort study.	III-2
Marsack-Topolewski (2020a)	A comparative study with concurrent controls: cohort study.	III-2
Marsack-Topolewski (2020b)	A comparative study with concurrent controls: cohort study.	III-2
Marsack-Topolewski (2021)	A comparative study with concurrent controls: cohort study.	III-2
Marsack-Topolewski and Wang (2022)	A comparative study with concurrent controls: cohort study.	III-2
Perkins and Haley (2010)	A comparative study with concurrent controls: cohort study.	III-2

Wang et al. (2021)	A comparative study with concurrent controls: cohort study.	III-2

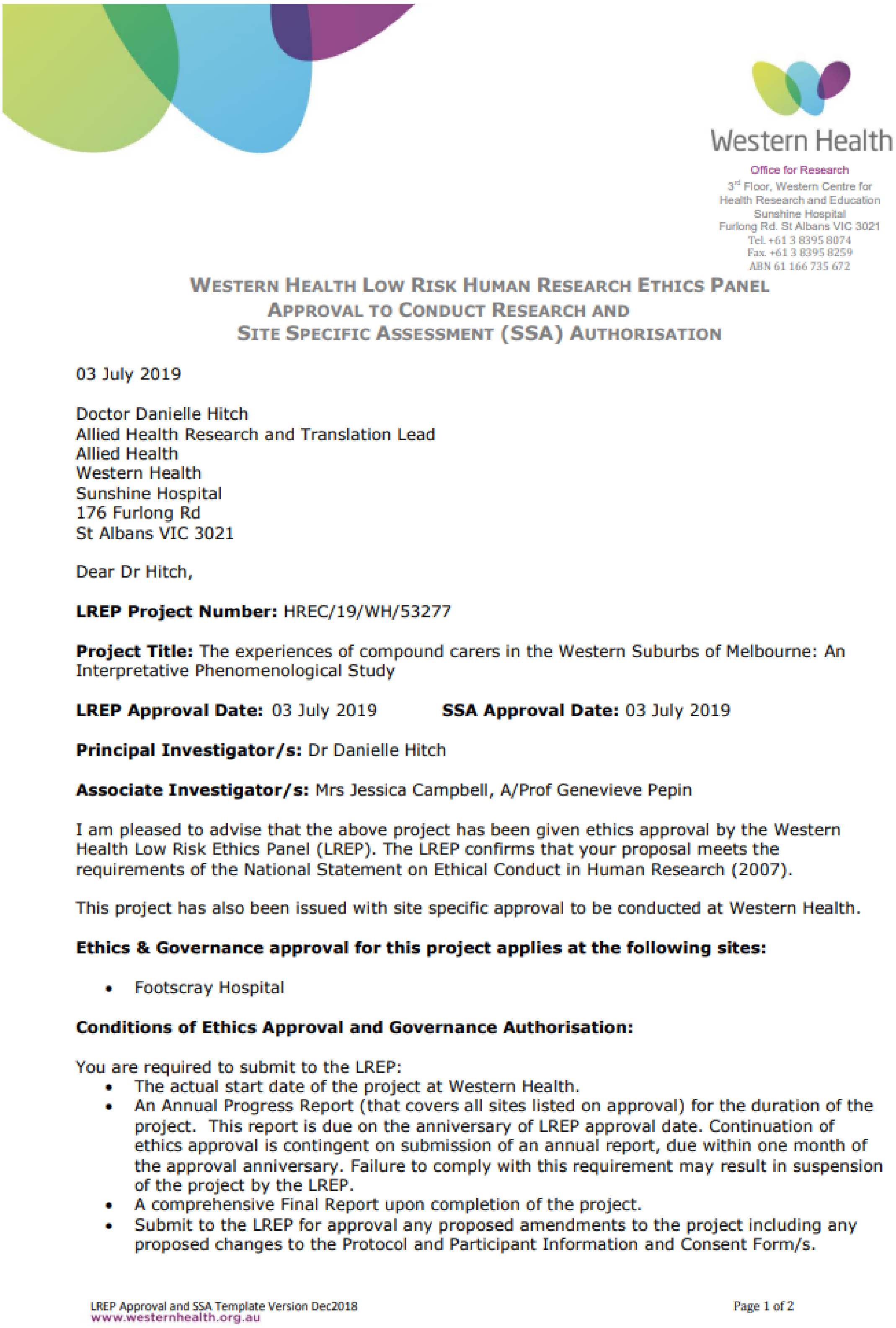
Appendix B

Levels of Qualitative Evidence

Study	Description	Level
Green (2013)	No relevant issues identified.	1
Perkins (2010)	No relevant issues identified.	1
Lee et al. (2020)	No relevant issues identified.	1
Perkins and Hayley (2010)	No relevant issues identified.	1

Appendix C

Ethics Approval



Western Health
Office for Research
3rd Floor, Western Centre for
Health Research and Education
Sunshine Hospital
Furlong Rd. St Albans VIC 3021
Tel. +61 3 8395 8074
Fax. +61 3 8395 8259
ABN 61 166 735 672

WESTERN HEALTH LOW RISK HUMAN RESEARCH ETHICS PANEL APPROVAL TO CONDUCT RESEARCH AND SITE SPECIFIC ASSESSMENT (SSA) AUTHORISATION

03 July 2019

Doctor Danielle Hitch
Allied Health Research and Translation Lead
Allied Health
Western Health
Sunshine Hospital
176 Furlong Rd
St Albans VIC 3021

Dear Dr Hitch,

LREP Project Number: HREC/19/WH/53277

Project Title: The experiences of compound carers in the Western Suburbs of Melbourne: An Interpretative Phenomenological Study

LREP Approval Date: 03 July 2019 **SSA Approval Date:** 03 July 2019

Principal Investigator/s: Dr Danielle Hitch

Associate Investigator/s: Mrs Jessica Campbell, A/Prof Genevieve Pepin

I am pleased to advise that the above project has been given ethics approval by the Western Health Low Risk Ethics Panel (LREP). The LREP confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007).

This project has also been issued with site specific approval to be conducted at Western Health.

Ethics & Governance approval for this project applies at the following sites:

- Footscray Hospital

Conditions of Ethics Approval and Governance Authorisation:

You are required to submit to the LREP:

- The actual start date of the project at Western Health.
- An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of LREP approval date. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the LREP.
- A comprehensive Final Report upon completion of the project.
- Submit to the LREP for approval any proposed amendments to the project including any proposed changes to the Protocol and Participant Information and Consent Form/s.

- Notify the LREP of any adverse events that have a material impact on the conduct of the research.
- Notify the LREP of your inability to continue as Principal Investigator.
- Notify the LREP of the failure to commence the study within 12 months of the LREP approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the LREP of any matters which may impact the conduct of the project.

Approved/Noted Documents:

Document	Version	Date
Human Research Ethics Application (HREA) Form; HREC/53277/WH-2019-176500	2	03 June 2019
Victorian Specific Module (VSM)		18 April 2019
Western Health LREP Site Specific Form		24 April 2019
Statement of Approval – Western Aged Care Assessment Service		31 May 2019
Protocol	2	03 June 2019
Participant Information and Consent Form	2	27 May 2019
Master Re-Identifier Tool	1	24 April 2019
Data Collection Tool	1	24 April 2019
Research Collaboration Agreement between Western Health and Deakin University		02 July 2019
PowerPoint Presentation – ACAS In-service presentation	1	18 April 2019
Masters Confirmation Seminar Report – Jessica Campbell	1	18 April 2019
Response to Peer Review of Candidature Recommendations	1	18 April 2019
Curriculum Vitae & WH Researcher Code of Conduct (2012) • Danielle Hitch • Jessica Campbell		01 November 2018 22 November 2018 23 February 2018
ICH Good Clinical Practice • Danielle Hitch		05 November 2019

The Office for Research may conduct an audit of the project at any time.

The Office for Research Western Health wishes you and your colleagues every success in your research.

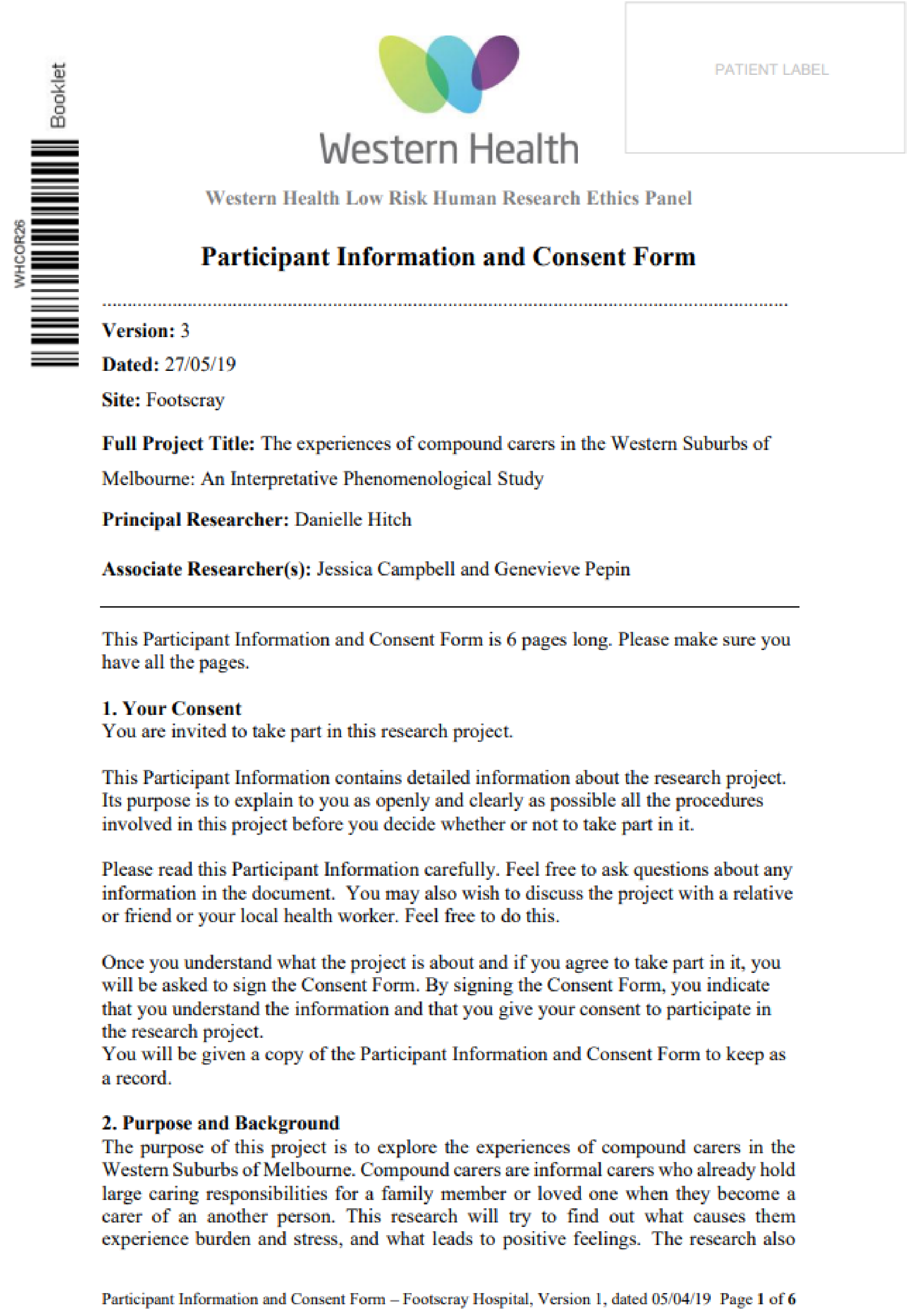
Yours sincerely,

Signature Redacted by Library

Meera Senthuren
Ethics & Governance Administration Officer
On behalf of the Western Health Low Risk Ethics Panel
Western Health Office for Research
Email: ethics@wh.org.au

Appendix D

Patient Information and Consent Form



WHCOR26 Booklet

PATIENT LABEL

Western Health

Western Health Low Risk Human Research Ethics Panel

Participant Information and Consent Form

Version: 3

Dated: 27/05/19

Site: Footscray

Full Project Title: The experiences of compound carers in the Western Suburbs of Melbourne: An Interpretative Phenomenological Study

Principal Researcher: Danielle Hitch

Associate Researcher(s): Jessica Campbell and Genevieve Pepin

This Participant Information and Consent Form is 6 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to explore the experiences of compound carers in the Western Suburbs of Melbourne. Compound carers are informal carers who already hold large caring responsibilities for a family member or loved one when they become a carer of an another person. This research will try to find out what causes them experience burden and stress, and what leads to positive feelings. The research also aims to find out if compound carers have time to do things that are important to them such as leisure activities or paid work. It also aims to find out whether compound carers have difficulty accessing services, and if services and supports meet their needs. A total of ***6-8*** people will participate in this project.

Informal carers "provide help, support or supervision to family members, friends or neighbours with a range of physical, mental and end-of-life health conditions, and disability" (AIHW, 2015, p. 61). Informal carers are important as they can keep people living at home longer and give them a better quality of life. Informal carers also help take the pressure off aged care services which we expect to get busier as Australia's population is getting older. In the researcher's experience in working for the Aged Care Assessment Service, caring for one person alone has an impact on the well-being of carers, but the impact is often greater when caring for two people. This is the first time that compound carers have been investigated in Australia.

You are invited to participate in this research project because you can share your unique experience of what it is like to care for more than one person.

The results of this research may be used to help researcher, Jessica Campbell to obtain a Masters of Applied Science degree through Deakin University.

3. Procedures

Participation in this project will involve

- Completion of an interview of approximately 60 minutes which will be offered via telephone or at a place that suits you such as your home, the home of the elderly person you care for, or your local hospital (Footscray, Sunshine or Williamstown)
- Interviews will only commence once you have read through this information regarding the study and signed the attached written consent form

4. Possible Benefits

Possible benefits include compound carers experiences being understood by the greater community; this includes health professionals and service providers, and may result in them being more able to the needs of compound carers. Although, we cannot guarantee or promise that you will receive any benefits from this project.

5. Possible Risks

You may experience discomfort or psychological distress from discussing personal feelings and experiences of being a carer. You are able to cease the interview at any time. The researcher will advise you of methods to access formal counselling, including through Carers Victoria (PH: 1800 242 636) or by completing a Mental Health Care Plan with your General Practitioner.

6. Alternatives to Participation

You do not have to participate in this research project to receive any care that you or the people you care for require.

7. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. Electronic data will be stored for 5 years on a password protected file and hard copies in a locked filing cabinet at Deakin University. Electronic copies will be permanently deleted and hard copies shredded at the end of the 5-year period.

If you give us your permission by signing the Consent Form, we plan to share and discuss the results with health professionals, services providers and agencies who provide assistance to carers, and publish the results in academic journals.

As this research is aimed at increasing our knowledge of your experiences as carer, the results will be shared with the greater community including health workers through presentations at conferences and written articles in journals. In any publication, information will be provided in such a way that you cannot be identified. Information collected from you will be assigned a pseudonym in the form of a unisex name.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws you have the right to access the information collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please contact one of the researchers named below if you would like to access your information.

8. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

9. Results of Project

If you would like to receive a summary of the results at the completion on the project, you can provide your mailing or email address at the time of your interview.

10. Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact the principal researcher or the associate researcher. The researchers responsible for this project are Jessica Campbell (M: 0434 247 895) and Danielle Hitch (M: 0468 574 735)

12. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

Position:	Manager, Western Health Office for Research
Telephone:	(03) 8395 8073
Email:	ethics@wh.org.au

(You will need to tell the Manager the name of one of the researchers given in section 11 above.)

13. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Western Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

14. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Western Health Low Risk Human Research Ethics Panel.

15. Reimbursement for your costs

You will not be paid for your participation in this project.

Western Health

16. Consent Form

Site: Footscray
Project title: The experiences of compound carers in the Western Suburbs of Melbourne: An Interpretative Phenomenological Study

I have read, or have had read to me in my first language and I understand the Participant Information.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed) ……………………………………………………

Signature………………………………… Date

Name of Witness to Participant's Signature (printed) …………………………………

Signature………………………………… Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed) ……………………………………………………

Signature………………………………… Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.

Western Health

REVOCATION OF CONSENT FORM

Revocation of Consent Form

Full Project Title: The experiences of compound carers in the Western Suburbs of Melbourne: An Interpretative Phenomenological Study

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with ***WESTERN HEALTH***.

Participant's Name (printed) ……………………………………………………

Signature………………………………… Date

Appendix E

Social Media Summary

"Deakin and Western Health are leading a study into the unique experiences of carers of multiple people in the Western Suburbs of Melbourne. Do you work with carers? Or are you caring for multiple people? We want to hear from you! Contact Genevieve Pepin at genevieve.pepin@deakin.org.au”

Appendix F

Interview Guide

Doing:

Could you give me a brief history of when you first started caring for two people till now?

Could you describe what it is like to care for more than two people? Prompt: What does a typical week involve? Do you work in paid employment? Do you have other family responsibilities outside of your caring roles e.g., looking after children, household chores?

Are there things you miss doing because you are too busy caring for your loved ones?

Being:

How would you describe yourself as a person?

How do you think other people see you?

Has the way you view yourself changed since you started caring for two people? Prompt: In a positive or negative way

How do you usually handle stressful situations?

How does caring for two people make you feel? Prompt: physically, emotionally and mentally, positive/negative feelings

Belonging:

What does family mean in your culture?

What do you see as your role in your family?

Do you feel a responsibility to your family and /or the people you care for to continue in your caring roles?

Do you feel guilt impacts your decision to continue your caring roles?

Is it yourself or other people in your family who decides whether you take on or continue caring roles?

Do you get any support from others? Prompt: Family, friends and care workers

Is it acceptable in your culture to accept help from others?

What would make life easier for you? Prompt: Any services, supports

Becoming:

Do you think about the future much?

Did your thoughts about the future change when you started caring for two people?

Are there things that you thought you might have been doing in this stage of your life that you cannot do because of your caring role?