A Critical Exploration of the Systemic Complexities Impacting Rural Australian Spousal Caregivers in Later Life.

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This thesis is submitted in
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Thesis summary

As global population ageing continues at unprecedented rates, planning for the future care needs of older adults is a growing priority. Despite significant advances in health and medicine that facilitate healthier ageing and longevity, the majority of older adults will require some level of support in their later years. The preference to age in home environments relies heavily on the availability of spousal and other informal caregivers, with the vast majority of care both in Australia and around the world being provided by the partners, children, family, friends and neighbours of older adults (Productivity Commission, 2011). While research has previously demonstrated significant risks to co-resident spousal caregivers, there has been little consideration of the unique and often long standing nature of marital relationships as the context of care. Caregivers have also received little consideration in the extensive reform of Australia's aged care system within recent decades.

This thesis set out to explore how social, policy and practice systems interact with and impact on the provision of spousal care in later life. In order to analyse these multiple systems of care, a methodological framework based on systems theory was designed and implemented. Conceptually underpinned by critical social gerontology, this approach utilised multiple qualitative methods of critical discourse analysis, focus groups and in-depth interviews to analyse social policy, health care practitioners and spousal caregivers. This thesis empirically demonstrates challenges experienced by practitioners attempting to enact individualised policies within the context of familial social norms. This has important implications for the translation of policy into practice and highlights the need for greater critical reflection and supervision of direct care staff. Finally, this research contributes the first in-depth insight into the impact of wider sociocultural and systemic influences on the experience of providing care to a spouse in later life.

Statement of authorship

This thesis includes work by the author that has been published or accepted for publication as described in the text. Except where reference is made in the text of the thesis, this thesis contains no other material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the La Trobe University Faculty of Health Sciences Human Ethics Committee, reference number FHEC12/177.

This thesis includes four original papers published in peer-reviewed journals. Primary responsibility for the conducting of the research design, data collection and analysis, development and writing of the papers in this thesis were written by myself, the candidate, in co-authorship with my supervisors, Associate Professor Suzanne Hodgkin and Professor Jeni Warburton.

In addition to these publications comprising the body of this thesis, the findings of this thesis have been presented at conferences and other events. Details of these other forms of research dissemination are also listed below.

Belinda Cash

5 October 2018

List of papers written for and included in this thesis:

Cash, B., Hodgkin, S. and Warburton, J. (2013) Till death us do part? A critical analysis of obligation and choice for spousal caregivers. *Journal of Gerontological Social Work,* 56:8, 657-674

Cash, B., Hodgkin, S. and Warburton, J. (2016) Practitioners' perspectives on choice for older spousal caregivers in rural areas. *Australian Social Work.* Vol 69, p 283-296

Cash, B., Warburton, J. and Hodgkin, S. (2018) Expectations of care within marriage for older couples. *Australasian Journal on Ageing.* Accepted for publication on 27th August 2018, published online 3rd October 2018

Cash, B., Hodgkin, S. and Warburton, J. (2017) Using systems theory to design social work research. *Qualitative Social Work.* Accepted for publication 22nd November 2017, published online 25th December 2017

Associated publications and conference presentations

Cash, B. (2012) Obliged to Care? Social Policy and Informal Caregiving. Presented at the Australian Association of Gerontology National Conference. December 2012, Brisbane.

Cash, B. (2012) Many ways of knowing: Using multiple methods to explore caregiving. Presented at the Emerging Researchers in Ageing Conference. December 2012, Brisbane.

Cash, B. (2013) A focus on choice: Informal caregivers and rural healthcare practices. Presented at the Australian Association of Gerontology National Conference. November 2013, Sydney.

Cash, B. and Warburton, J. (2013) The changing arena of ageing: Using critical discourse methods to analyse current policy directions. Emerging Researchers in Ageing Conference Proceedings. Peer reviewed full paper, Sydney.

Cash, B. (2014) Obligation and Expectation: How policy and practice impact on choice for informal caregivers. Presented at the Australian Association of Gerontology National Conference. November 2014, Adelaide.

Cash, B. (2014) For Better, For Worse: The paradox of choice and spousal caregiving. Presented at the Social Work and Social Development Conference. July 2014, Melbourne.

Cash, B. (2014) Using multiple methods to contextualise ageing research. Presented at the Emerging Researchers in Ageing Conference. November 2014, Adelaide.

Cash, B. (2015) The paradox of choice and spousal caregiving: Lessons for policy and practice. Presented at the International Association of Gerontology and Geriatrics, October 2015, Chiang Mai, Thailand

Cash, B. (2015) Caregiving and marriage: A social exchange for better or worse? Table top presentation at the Australian Association of Gerontology National Conference. November 2015, Alice Springs

Cash, B.; Hayter, C.; Meyer, C. and Mihelcic, J. (2015) A critical consideration of choice, voice and decision making for policy makers, practitioners and older Australians. Symposium presented at the Australian Association of Gerontology National Conference. November 2015, Alice Springs.

Cash, B. (2016) Re-imagining social research: A transformative approach to understanding informal care. Presented at the Australian Association of Gerontology National Conference. November 2016, Canberra.

Cash, B. (2017) A critical understanding of family caregiving. Plenary presentation at the Dyuti Conference on Mental Health and Ageing, January 2017, Kerala, India

Cash, B. (2017) Beyond economics: The costs of reform for family caregivers. Invited Keynote at the South Australian Association of Gerontology Conference. June 2017, Adelaide.

CHAPTER 1: Introduction and overview

Introduction to the thesis

As the global population continues to age at unprecedented rates, planning for the future health and care needs of older adults has become a growing priority for governments and policy makers (Commonwealth of Australia, 2015a). In Australia, as observed in other developed countries, there are conflicting discourses and debates surrounding who should be responsible for the care of older adults and how this care should be provided. Perspectives of individualism, familialism, communitarianism and institutionalisation are all evident in deliberations about the roles and responsibilities of families, community services and governments in the funding and provision of support to older Australians. This thesis contributes to these crucial discussions of care, via a critical exploration of the systemic complexities impacting spousal caregiving in later life.

The care provided by spousal and other informal caregivers is assisted by the wider system of formal and informal services that support older adults in Australia. The Australian care system is comprised of a mixed economy of welfare, with formal aged care services being provided by a combination of government, not-for-profit and for-profit organisations (Meagher and Goodwin, 2015). These formal supports include both mainstream health and social services, as well as aged specific supports that range from community-based programs and in-home supports, through to high level residential care facilities (Australian Institute of Health and Welfare, 2015).

Essential to the overall success of this care system is the extensive contribution of informal caregivers, who continue to provide the vast majority of care and support to older adults in Australia (Australian Bureau of Statistics, 2012). Spousal caregiving represents an essential component of the system that supports Australia's ageing population, with almost 80% of all caregivers over 65 years providing care at home to their partner (Australian Bureau of Statistics, 2015). To quantify this contribution to aged care in Australia, more than 2.86 million informal caregivers provided an estimated 1.9 billion hours of unpaid care during 2015 (Deloitte Access Economics, 2015). In economic terms, the replacement costs of informal care by formal services is estimated to be $60.3 billion per annum (Deloitte Access Economics, 2015). These figures highlight both the social and economic importance of informal caregiving in responding to the care needs of an ageing population.

Of all informal care relationships, spousal caregivers provide the highest number of average hours per week caregiving than any other relationship type (Australian Bureau of Statistics, 2015). While this is likely to be somewhat resultant of the co-resident and interdependent nature of spousal relationships in later life (Racher, 2002), other factors contribute to the unique context of spousal care, particularly in rural areas. In Australia, a key contributor to informal care availability in rural areas is the long-term trend of older adults moving to rural areas and younger generations moving away from them (Baxter, Hayes & Gray, 2011; McDonald, 2016). Other geographic disadvantages, such as isolation, reduced access to specialised services and a reluctance to access formal supports all increase reliance on spousal care in rural locations (Davis & Bartlett, 2008; Winterton &

Warburton, 2011). In addition to these sociological drivers, spousal care is also impacted by the wider change occurring within health and aged care systems.

The contemporary aged care system in Australia has been described as a product of ad hoc reforms (Chomik & MacLennan, 2014). Emerging from early public health and welfare schemes, aged care has been heavily influenced by the changing political and social contexts that have impacted policy development over recent decades (Jeon & Kendig, 2016). The current era of aged care was driven by a major inquiry in 2011, which set out to examine the system's capacity to address the changing needs of a rapidly ageing population, as well as to overcome a number of challenges in the existing care system (Productivity Commission, 2011).

This landmark Productivity Commission review led to the Gillard Labor government unveiling a significant suite of reforms in 2012, known as the Living Longer, Living Better (LLLB) Aged Care Reform Package (Department of Health and Ageing, 2012a). These reforms set in motion a decade long series of transformations to aged care in Australia, central to which was a significant shift away from residential and provider controlled systems toward more community based and consumer-led approaches to care (Jeon & Kendig, 2016). Many of the recommendations made by the Productivity Commission were adopted in the LLLB reforms. The LLLB has also received bipartisan support, enabling the shift toward CDC to be strengthened by subsequent governments, including a growing emphasis on "user pays" payment structures. This provided greater scope for self-funding of higher levels of service and expanded capacity for means testing to

increase resident contributions (Deloitte Access Economics, 2016). These reforms are now entrenched in the *Aged Care (Living Longer Living Better) Act 2013* (Parliament of Australia, 2013). The introduction of a centralised online "gateway" to aged care services, known as *My Aged Care,* represents a further feature of reforms. This centralised system sought to overcome the challenges identified with access to and navigation of the care system (Commonwealth of Australia, 2015c).

This extensive overhaul of aged care has been accompanied by substantial variations in the profile of service providers, with changes in both the organisational mix and the modes of coordination (Meagher and Goodwin, 2015). These changes have resulted in part from increases in publicly funded social provisions, without a concurrent expansion of the public service sector. Government contracting of private agencies to deliver services has subsequently seen significant expansion of the for-profit care sector and an overall increase in the marketisation of the care system (Meagher and Goodwin, 2015).

A key example of the marketisation of care is reflected in the growing emphasis on individualised approaches to service delivery. Promoted as increasing choice for older adults, individualised care approaches seek to move away from agency-directed service provision toward options that enable greater consumer autonomy and control over care decisions. Within Australia, this shift has been particularly evident in the delivery of community care packages, which have been delivered under a consumer-directed care (CDC) model since July 2015 (Commonwealth of Australia, 2015c). This transition represents a significant shift

in the delivery of care, with packages no longer sitting with providers but with consumers. Early research has highlighted the complexity of enacting CDC policies within the established operational and cultural practices of organisations (Gill and Cameron, 2015; Prgomet, Douglas, Tariq, Georgiou, Armour & Westbrook, 2017). Market-based care presents further challenges in rural areas, where choices are constrained by the lack of aged care services outside of metropolitan and inner regional locations (Baldwin, Chenoweth and dela Rama, 2014).

This thesis sets out to critically examine the impact of these complex and changing systems of care on spousal caregivers in rural Australia. This first chapter introduces the reader to spousal caregiving in Australia, beginning with the researchers' standpoint and rationale for this thesis, then a brief discussion of the systemic context of this research. This is followed by an introduction to the aims of the study, as well as an outline to orient the reader to the thesis as a whole.

Researcher standpoint

My interest in spousal caregiving emerged from my professional background as a rural social worker in mental health and disability services. Direct practice in these fields regularly involved work with informal caregivers, most often family members such as parents and spouses. These familial care relationships were often complex, with caregivers frequently observed to experience significant stress and personal challenges relating to their care role.

It was also too often apparent in this practice context that policies rarely considered the geographic and social realities of the families and individuals living in regional and rural communities. The focus on rural caregivers within this thesis is dually influenced by these rural practice experiences, as well as by my own rural identity. The desire to contribute research that reflects the unique contextual richness of rural Australian communities is therefore both personal and professional.

This thesis is conducted within a multidimensional, complex and changing research context. In order to understand spousal care from a social work perspective, it felt necessary to look beyond micro level relationships to consider the broader societal influences and wider systems that provide the context for caregiving in rural Australia. As a social worker, I have long been influenced by the critical, systemic and social justice perspectives that underpin knowledge and practice in the social work profession. These professional influences have shaped my career long interest in understanding the impact of social systems on individual experience, at both theoretical and practical levels.

These critical and contextual perspectives align closely with the central tenets of critical social gerontology, which understands that ageing cannot be analysed in isolation from other societal forces around it (Estes, 2001). Within an environment of rapid reform in the Australian aged care sector, critical social gerontology provides a lens well suited to examining the impact of social, political and economic structures on older spousal caregivers. These perspectives and experiences influenced the understanding of, and approach to, this thesis. The

theoretical and conceptual foundations of this thesis are discussed in greater depth in Chapters Two and Three.

Rationale for this thesis

This thesis began in 2011, soon after the release of the Productivity Commission inquiry into the Australian aged care system. This inquiry marked a significant turning point for aged care in Australia, with recommendations seeking to transform the way that care for older adults was provided. This thesis has subsequently been completed during a time of rapid and extensive change within the Australian aged care sector.

One of the central recommendations in the Productivity Commission's (2011) report was the need to strengthen and improve systems of community based care for older adults. This recommendation reflected literature that consistently demonstrates older adults prefer to age in their own home and remain connected to their communities (Vreughdenhil, 2014; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). The preference to age at home is unsurprising, though perhaps not as simplistic as it may sound. Community based care for older adults relies heavily on the availability of spousal and other informal caregivers, with the vast majority of care both in Australia and around the world being provided by the partners, children, family, friends and neighbours of older adults (Productivity Commission, 2011).

Spousal caregiving is an interpersonal activity between two individuals, yet it occurs within, and is impacted by, multiple facets of the social, political and practice aspects of the wider system of care. Social work recognises the importance of understanding and responding to people in their environment, with systems perspectives having long enabled issues of social and structural inequality to be examined at multiple levels (Connolly & Harms, 2013; Healy, 2005). In order to fully understand spousal caregiving in rural Australia, it was clear that this social phenomenon could not be analysed in isolation from these wider contextual factors.

A key contextual factor in this thesis is the rural location of the study, with ageing and caregiving in rural Australia presenting distinctive strengths and challenges. As with other cultural distinctions, however, these needs, strengths and challenges are seldom represented adequately in social policy and practice directives. Limited Australian research explores spousal care in rural areas, likewise the translation of contemporary policy and practice reforms in rural aged care is also scarce. These are important considerations and gaps considered in this thesis.

Policy analysts have noted that although the funding of formal aged care services in Australia presumes the existence of informal supports, the significant costs to individual caregivers are not adequately considered in contemporary policy (Chomik & MacLennan, 2014). This oversight remains apparent in recent reforms, despite acknowledgment of the overwhelming evidence demonstrating significant risks and adverse effects on caregivers' physical, psychological and financial wellbeing that arise from the stressful nature of informal care (Butterworth,

Pymont, Rodgers, Windsor & Anstey, 2009; Butler, Turner, Kaye, Ruffin & Downey, 2005; Hirst, 2005; Lavela and Ather, 2010).

Also largely absent has been consideration to how increasingly consumer focused systems of care would impact on spousal and other informal caregivers, who have been largely overlooked in reforms focused on the individualisation of care (Larkin & Mitchell, 2015; Moran, Arksey, Glendinning, Jones, Netten & Rabiee, 2012). The recent suite of reforms in Australia are similar to those introduced in other places such as the United Kingdom (UK), where policies promoting self-directed support and individualised budgets have been the focus of aged care for more than a decade (Department of Health, 2005). The UK has subsequently had a much greater critical engagement in the tensions between informal caregivers and individualised support systems. British authors such as Susan Pickard (2010), Hilary Arksey and Caroline Glendinning (2007) were early contributors to highlight the significant conceptual mismatch between individualist approaches to care and the rights and needs of informal caregivers. These concerns have also been explored by Australian sociologist Michael Fine (2012), who critically examines the challenges of meaningfully translating concepts of individualisation into care and the impact of these changes on caregivers.

In Australia, however, these contributions serve largely to emphasise the dearth of research that empirically or critically considers spousal caregiving in the context of individualised aged care reform. Although discussed at a conceptual level, there remains an absence of research that considers this important intersection of informal and formal care domains. This observation is not new,

with authors such as Dow and McDonald pointing out in 2003 that although the social work profession is well placed to contribute critical and theoretically informed research to the understanding of caregiving, this is largely not evident or explicit in caregiving research. Other authors such as Asquith (2009) and Aberdeen and Bye (2011) have also discussed the absence more broadly of critical social gerontology in Australia, highlighting the need for research that engages in the nexus between social processes, political structures and wider demographic shifts. This absence is particularly evident in the lack of critical and empirical research that examines the impacts of recent reforms on informal caregivers.

This thesis set out to critically examine spousal care in this complex and changing system of care in contemporary Australia. As aged care systems continue to transition toward greater individualisation and market-based choice, the examination of how social, political and economic structures impact on older adults' opportunities and experiences of ageing becomes increasingly important. This research is therefore underpinned by a critical social gerontology approach (Estes, 2001), which enabled consideration of both the individual and structural aspects of ageing and caregiving within the rural Australian context. This critical approach provided a conceptual framework to analyse and understand how macro social and policy changes filter down to impact the individual experience of spousal care in Australia. This critical exploration of care seeks to question and challenge dominant perspectives that assume the availability and willingness of care. It does so by examining the structural and socially located nature of spousal care and by seeking to give voice to caregivers.

In the absence of research that critically considers spousal care within its socio-political context, this thesis makes a much needed critical and systemic contribution to knowledge about spousal caregiving in Australia. This chapter will now briefly discuss the systems of aged care that present the research context for this thesis.

The research context

In order to understand the experience of spousal caregiving in the Australian context, it is necessary to consider in more detail the broader contextual systems in which informal care is located. The complex social and structural environment of spousal care means that caregivers are impacted by both social and demographic changes, as well as the changing environments of policy and practice. As economic and social systems around the world respond to the challenges of providing care to a growing and rapidly ageing population, the context of spousal care has become increasingly complex.

Ecological systems theories enable spousal care to be conceptualised as a series of interrelated systems (Healy, 2005). This comprises the micro aspects of the individual caregiver's immediate home and social environment; the meso practice environment and the macro values, policies and legislation that all impact upon informal care.

Systems theory also recognises the importance of considering wider societal influences on these macro, meso and micro systems (Healy, 2005). This is

particularly crucial for research utilising a critical social gerontology perspective, which is concerned with structural and social level influences on the experience of ageing. The following presents a brief discussion of the sociocultural, macro, meso and micro systems of care that provide the research context for this thesis.

The sociocultural context of care

Spousal caregiving is influenced by social norms and values, cultural and religious perspectives, and other shared ideologies, which are recognised as providing a social blueprint of sorts to the expectations and parameters of social life (Harms, 2010). Although many of these facets remain stable over prolonged periods, these systems do change over time.

A key societal shift impacting informal care in contemporary Australia is the changing construct of *family*. Traditional notions of the nuclear family are being progressively challenged in contemporary society, with greater diversity in family structures and a lessening of normative role prescription becoming increasingly evident (de Vaus, 2012). While assumptions about what constitutes a typical Australian family has shifted, *family* remains an institution strongly associated with expectations of informal care (Bell & Rutherford, 2013). These wider social norms are reflected in recent surveys that identify family responsibility and emotional obligation amongst the most common responses given by informal caregivers as their reasons for providing care to a family member (Australian Bureau of Statistics, 2015).

It appears these ingrained societal expectations may also be shifting somewhat, with research highlighting factors such as greater participation in the workforce by women and older adults, smaller family sizes and rising childlessness, single resident households and changing social perspectives about familial care obligations resulting in fewer informal caregivers and a reduced propensity to care (Deloitte Access Economics, 2015; Department of Health and Ageing, 2012a; Guberman, Lavoie, Blein, & Olazabal, 2012). Recent generations of older Australians also express the desire to remain independent and in control of their own care needs. This often includes a preference not to accept or expect care from their adult children, as well as social changes that see families more often comprised of fewer children who do not necessarily live in geographic proximity to ageing parents (Quine & Carter, 2006). This is particularly evident in rural areas, where heightened expectations of informal care have been associated with reduced availability of formal supports; fear of stigma; and social connections with service providers (Winterton & Warburton, 2011).

Familial constructs of caregiving are also impacted by cultural considerations, which can play a significant role in how older adults and family caregivers perceive and enact informal care within the family. The cultural blueprint of Australia is complex and multidimensional, beginning more than 50,000 years ago with the Aboriginal and Torres Strait Islander people who first inhabited Australia. Despite this long and rich cultural foundation, contemporary Australian culture has been more heavily influenced by British traditions that were introduced during the colonisation of Australia after 1788. These cultural foundations continue to broaden and change as immigration and population

changes enrich Australia's recognition as a multicultural society (Australian Bureau of Statistics, 2017).

This rich diversity means that spousal care in Australia is constructed within a range of contexts and cultural heterogeneity cannot be assumed. The Australian care system, however, tends to reflect growing individualism within aged care policy directions; ideals that can contrast sharply with cultural values of collectivism and respect for older adults evident in other cultures. This is particularly evident in Aboriginal Australian culture, which places great value on the importance of kinship and respect for the integral role of Elders within families and communities (Warburton & Chambers, 2007). In contrast, Western societies have been associated with pervasive issues of ageism and the devaluing of older adults as burdensome (Hughes & Heycox, 2010). These present important considerations for understanding how ageing and care are constructed within Australia.

A final note on sociocultural context is to draw attention to the concept of rural culture as it relates to ageing and care. Rural Australians are often characterised as being independent, stoic and self-reliant (Beard, Tomaska, Earnest, Summerhayes and Morgan, 2009), with rural communities demonstrating richer social capital, well-established social networks and greater community connectedness potentially providing greater support for older adults and their caregivers (Davis & Bartlett, 2008; Horton et al., 2010). These constructs of rurality are similar to those posited by Keating, Swindle and Fletcher (2011) in Canada, who reflected on the incongruence of rural seniors reporting higher

satisfaction with health than their urban counterparts, despite experiencing considerable health disadvantages. A stoic attitude toward health problems and a strong belief in the availability of social networks if required were identified as factors that helped to explain this incongruence in older rural adults (Keating, Swindle & Fletcher, 2011). This sense of resilience, however, has also been associated with possible disadvantages, such as rural people perceiving less need to visit medical professionals and having hindered development of social networks (Winterton and Warburton, 2011). As with other cultural distinctions, these unique needs, strengths and challenges of rural Australia, however, are seldom represented adequately in social policy and practice directives.

The macro context of care

Ageing and aged care have become increasingly important within Australian society during recent decades. This importance has grown in part due to growing concerns about the adequacy of care and support systems for the steadily growing number of older adults in the population (Jeon & Kendig, 2016). Demographic data highlights that while population ageing came into policy prominence in the 1980s, fertility and mortality rates have actually been falling in Australia for the past 150 years (McDonald, 2016). The demographic shifts of population ageing will also contribute to a decrease in proportionate numbers of working aged adults in the population, reducing both the number of people in the paid care workforce as well as the number of tax payers contributing to health and welfare expenditure (Commonwealth of Australia, 2015a). Other macro demographic shifts impacting the care workforce include the increasing diversity in family structures and growth in geographic mobility. These factors in particular are

contributing to reduced availability of informal caregivers at the very time when demand for care is increasing (Deloitte Access Economics, 2015; Hokenstad & Roberts, 2011; Hugo, 2007).

Patterns of geographic mobility have particularly important implications for the provision of aged care services to older Australians in rural areas. Australia is a geographically large country that has one of the lowest population densities per square kilometre in the world, with around one third of the total population residing outside of major urban centres (Australian Institute of Health and Welfare, 2016). The old age dependency ratio is increasing in rural and regional areas, impacted by both the migration of retired adults to these areas as well as the out migration of young people for education and employment (Baxter, Hayes, & Gray, 2011). These long-term trends of inter-generational relocation, as well as the preference of migrants to settle in cities, has contributed significantly to the variation of population ageing between regions (McDonald, 2016).

Ageing is also closely linked to other social determinants, with the outcomes experienced in later life reflecting the accumulation of economic and social advantage or disadvantage throughout the life course (Kendig, 2016). Older Australians are living longer and healthier lives, with many living independently with little or no support (Australian Institute of Health and Welfare, 2017). Despite these positive indicators, there remain both pockets of disadvantage within the Australian population for whom later life is more complex, coupled with the reality that with longevity also comes much greater risk for chronic health

conditions, disabilities and limitations in activities of daily living (Australian Institute of Health and Welfare, 2016).

As the overall prevalence of age related health concerns increase, care has become a significant global issue over recent decades. The increasing demands on government to provide support to older adults has subsequently resulted in extensive economic and political reform. As with other countries within the Organisation for Economic Co-operation and Development (OECD), Australian policy solutions have favoured options to support older adults to "age-in-place". This approach dually addresses the preferences of older adults themselves to remain in their home as they age, while simultaneously reducing the economic costs of residential care in favour of less expensive home-based supports (Chomik & MacLennan, 2014). These macro approaches are also supported by a broader health promotion focus on healthy ageing, with a greater emphasis on prevention and early intervention that encourages older adults to require less supports and ultimately to remain longer in the community (Chomik & MacLennan, 2014).

Unlike many other countries within the OECD, where social security benefits are tied to past earnings and are financed by employers and employees, Australia has a flat-rate payment system that is financed solely from taxation revenue (Australian Institute of Health and Welfare, 2015). Similar to countries such as Ireland, Austria and France, Australia has adopted a means-tested aged care system, which determines benefits based on an individual's level of income and wealth (Chomik & MacLennan, 2014). The supply of care places is also controlled by the government via gatekeeping mechanisms such as the single entry point of

the My Aged Care website, Aged Care Assessment Teams and regulated price structures. Economists such as Chomik & MacLennan (2014) identify that while this tight grip on the aged care system is unsurprising in light of the fiscal exposure that comes from being the primary funder of these services, this approach to rationing aged care resources via waiting lists can mean that those who are in most need may miss out.   These concerns are reflected in recent data, which reveals that despite increases in funding to home care packages, more than 108, 400 people remained on the national queue at close of the last quarter (Department of Health, 2018b). These figures represent an increase of 3.7 per cent in people waiting for support since the previous quarter, with older adults now waiting a minimum of three months for level one packages and more than twelve months for high level packages (Department of Health, 2018b).

Responses to population ageing have been evident in Australian government policies for more than three decades. The most significant early reforms to aged care began under the Hawke government in the mid-1980s. These reforms sought to reduce government spending by increasing self-reliance in later life and increasing privatisation of care systems (Cullen, 2003). Early stages of this reform saw the introduction of home and community care supports, designed to encourage aged care away from residential models and into the community (Hughes & Heycox, 2010). Further reforms such as compulsory superannuation schemes and extending the age of eligibility for pensions through later life labour participation have been increasingly evident for some time, aiming to reduce reliance on the aged pension as the primarily source of income for older Australians (Chomik & Piggott, 2012).

In 2002-03, the Australian federal treasury released its first Intergenerational Report, which highlighted the importance of population ageing to both social and economic policy and identified the need for further significant reform (Commonwealth of Australia, 2002). Subsequent governments built on this momentum by commissioning a comprehensive inquiry into the Australian aged care system, with the Productivity Commission contracted to provide an economic analysis of the social and cultural issues surrounding population ageing. As highlighted earlier in this chapter, this momentous review led to the 2012 Living Longer, Living Better Aged Care Reform Package (LLLB), which set out to transform aged care in Australia (Chomik & MacLennan, 2014; Department of Health and Ageing, 2012a).

This new era of aged care in Australia has a number of central themes. Community based and consumer-led approaches to care have been forefront to recent reforms (Jeon & Kendig, 2016), with expansion of community care packages designed to keep older adults living longer in their own homes (Department of Health and Ageing, 2012a). This has been accompanied by the reinforcement of free market principles, which are designed to create consumer-led markets within the aged care sector. This has resulted in government contracting of private agencies to deliver services, leading to a significant expansion of the for-profit care sector and an overall increase in the marketisation of the Australian care system (Meagher and Goodwin, 2015).

The marketisation of care in Australia is an overt policy approach, promoted by government as creating an aged care system that is "more consumer-driven, market-based and less regulated" (Department of Health, 2016). It is crucial here, however, to consider the potential impacts of these neoliberal economic principles within health policy. It has been noted that health policy-makers tend to favour dominant medical paradigms over the social determinants of health, with neoliberal approaches in this context contributing to the reinforcement of health inequalities (Lynch, 2017). The impact of recent policy changes on existing structural inequities remains an important area for further examination. This exploration is especially important for spousal and other informal caregivers, who have been frequently identified in research as being particularly vulnerable to negative health and social outcomes because of their provision of care (Bittman, Hill & Thomson, 2007; Lima, Allen, Goldscheider & Intrator, 2008).

This process of reform also raises a number of important considerations for the provision of care supports to older Australians in rural areas. The context of rural health is geographically, sociologically and demographically different to metropolitan settings, meaning the health challenges faced by rural Australians are also significantly different (Paliadelis, Parmenter, Parker, Giles, & Higgins, 2012). Models of health and aged care developed for metropolitan areas often fail to translate well into rural settings, largely because of the tendency to make assumptions about the availability of an appropriately skilled workforce, of consumers and providers living in reasonable proximity to services and that adequate social infrastructure exists to support health services (Department of Health and Ageing, 2012b).

These assumptions are problematic for rural service providers, with the outsourcing of service provision and competitive tendering processes often not allowing for any perceived inefficiencies in allocation of time and resources (Bay, 2012). This can be difficult for service providers needing to justify the delivery of services in areas with low population density, limited infrastructure and the significantly higher costs associated with rural and remote health care delivery (Department of Health and Ageing, 2012b). Extensive literature highlights major structural constraints to accessing affordable and available health and social services across rural Australia (Bourke, Humphreys, Wakerman, & Taylor, 2012; Edwards, Gray, Baxter, & Hunter, 2009; Horton, Hanna, & Kelly, 2010; Paliadelis et al., 2012). A key factor that repeatedly emerges in this literature is the challenge of physical distance impacting access to health and aged care, where services may be too geographically distant to be helpful (Bourke et al., 2012; Butler et al., 2005; Russell et al., 2013). This becomes increasingly important in the event of mobility or transport issues, which can be compounded by the high travel costs associated with geographic distance.

A further challenge of neoliberal policy reform in rural locations stems from the reality of choice-oriented sentiments in the context of limited available services. Although this limitation is acknowledged within policy documents, there remains a significant gap between rhetoric and reality for older Australians in rural areas. An analysis of aged care trends in Australia by Baldwin, Chenoweth and dela Rama (2014) demonstrated the limited for-profit sector in rural areas. This analysis showed that unlike metropolitan areas, where aged care is dominated by growing

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numbers and sizes of for-profit services, the capacity and choice of services in rural areas is limited. Supports in remote areas in particular remain primarily operated by the government due to the lack of market for aged care services outside of metropolitan and inner regional locations (Baldwin, Chenoweth and dela Rama, 2014). These trends highlight the problematic nature of market-based care systems for the third of older Australians who live outside of metropolitan areas. The absence of choice in rural contexts is simply a reality of this economically driven care system. The implementation of these reforms, as well as a broad overview of the aged care service system will now be discussed.

The meso context of care

As highlighted above, the provision of care to older adults in Australia is provided via a mixed economy of welfare. This involves a complex and interwoven system of informal, government, not-for-profit and for-profit organisations (Meagher and Goodwin, 2015). The range of available aged care services reflects the differing needs of the older population, from community-based programs and in-home supports, through to high level residential care facilities. In addition to aged care services, mainstream health and social support services also contribute significantly to the wellbeing of older adults in Australia. More than two thirds of all adults over 65 years of age utilise these mainstream supports rather than aged care services (Australian Institute of Health and Welfare, 2015). Within Australia these include Commonwealth funded medical and pharmaceutical support schemes, public housing and rent assistance, acute health care and income supports such as the aged pension, disability payments and carer allowances.

A key criticism that emerged in the Productivity Commission Inquiry into Aged Care was that the existing system was both complex and difficult to navigate (Productivity Commission, 2011). In attempting to overcome this challenge, all information and access points to services for aged care consumers, caregivers and service providers was centralised via the *My Aged Care* website. This service acts as a single entry point to all aged care services, offering service finder tools, fee estimators and centralised client records (Department of Health, 2018a).

While overcoming many of the previous issues of a fragmented and difficult to navigate system, research has revealed that many older adults and their families continue to report feeling confused, uncertain and ill-informed about the availability of services, their eligibility and the costs involved (Belardi, 2017). Researchers in this study highlighted a widespread need for greater one-on-one support to better understand and make decisions about which services would best suit their needs (Belardi, 2017).

Aged care services are currently provided to older adults through three central programs:

- Commonwealth Home Support Programme (CHSP), which provides entry-level support services (such as transport, assistance with food preparation and meals, and personal care) to assist older adults to remain independent and in their homes and communities for longer.
- The Home Care Packages Program, which offers packages of services at four levels of care to enable people to live at home for as long as possible, with care

needs (including clinical services) increasing incrementally for each level of care.

- Residential aged care, which provides a range of care options and accommodation on a permanent or respite basis for older adults who are unable to continue living independently in their own homes.

Source: (Australian Institute of Health and Welfare, 2017)

In addition to care packages and supports for older care recipients, the government also recognises the work of informal caregivers via the provision of income supplements, respite services and other instrumental and emotional supports to assist caregivers in their role (Commonwealth of Australia, 2015b). Other caregiver supports can include workforce strategies such as family leave and flexible work hours, though as with other available supports, this requires caregivers to be both aware of the services and eligible to access them. Other challenges for informal caregivers include the inadequacy and inconsistency of carer payments (Maker & Bowman, 2012) and the need for greater availability of adequate, affordable and flexible respite services (O'Connell, Hawkins, Ostaszkiewicz, & Millar, 2012).

A further feature of recent reforms was the aim to increase consumer directed care (CDC) within the aged care system. Following a pilot in 2010-11 within Home and Community Care (HACC) services (Department of Health, 2016), it was announced in April 2012 that CDC would be implemented as part of all new home care packages from August 2013 and all existing packages from July 2015 (Department of Health, 2016). Despite these changes, the home care system continues to be

plagued by limited availability of support packages; a challenge exacerbated by the absence of a central waiting list and lack of clarity around prioritisation processes for care recipients (Low, Fletcher, Gresham, & Brodaty, 2015). These unmet care needs are associated with adverse outcomes for both the care recipient and their informal caregiver (Low et al., 2015).

At the time of writing this thesis, all aged care packages in Australia are now provided under the CDC model following the transition periods between 2103 and 2015. Early studies show that the implementation of CDC has been more difficult than expected, with significant need for effective change management processes and leadership to support these transitions (Gill & Cameron, 2015; Laragy & Allen, 2015; Prgomet, Douglas, Tariq, Georgiou, Armour & Westbrook, 2017). The lack of evidence-based guidelines to support the implementation of CDC, as well as the superimposition of CDC principles onto existing traditional service providers, are particularly inhibiting successful implementation of the approach in practice (Gill & Cameron, 2015). It was also noted by Gill and Cameron (2015) that front-line staff, care recipients and informal caregivers all indicated little difference between CDC and traditional care packages.

The roll out of consumer directed reforms also presents a distinct set of issues for older adults in rural and remote areas of Australia. Many older adults residing in a rural area already experience health disadvantages when compared to their urban counterparts, resulting from a lack of available, adequate, affordable and accessible health and social services (Bourke, Humphreys, Wakerman & Taylor, 2012; Davis & Bartlett, 2008; Edwards et al., 2009). The introduction of market-

based care approaches adds complexity to this situation due to the limited capacity and choice of services in rural areas (Baldwin, Chenoweth and dela Rama, 2014). The inadequacy of formal support services increases reliance on informal caregivers, however the anticipated shortage of informal caregivers is likely to be more evident in rural areas, as younger generations relocate to cities for education and employment opportunities (Edwards et al., 2009; McDonald, 2016). These issues will be compounded by fewer people of working age to provide care to older people and a shortage of residential care facilities (Winterton & Warburton, 2011). These are important contextual considerations for spousal caregivers in rural Australia and for this thesis.

The micro context of care

Embedded within this complex environment of social, demographic, and political change are the 2.86 million informal caregivers who provide care in homes and communities across Australia. The provision of family based care to support older adults has long been established as a central function of families over many generations. Research exploring the formation of care networks has highlighted that care relationships are usually familial in nature, due to the prior shared exchanges within these relationship types (Bell & Rutherford, 2013). These exchanges and interactions forge a type of social insurance, creating expectations of reciprocity in the event of future adversity and need for support (Bell & Rutherford, 2013). These concepts of socialisation into care roles and familial solidarity will be explored further in Chapter Two.

The socially situated nature of marriage creates a particularly distinctive context for caregiving, with wider social and cultural expectations of marriage also increasing anticipation of care by spouses (Arksey & Glendinning, 2007; Bruhn & Rebach, 2014; Egdell, 2013; Ray, 2006). From a sociological perspective, marital relationships involve the exchange of social and emotional supports in such a way that forges inextricably linked lives and demonstrate an interdependence that extends beyond the usual caregiver-care recipient dyad (Bruhn & Rebach, 2014; Lima, Allen, Goldscheider, & Intrator, 2008; Racher, 2002). Obligations to provide spousal care are also evident after remarriage, though interpersonal complexities that can emerge from the reconfiguring of families has been highlighted as an additional source of stress in some cases (Sherman & Boss, 2007).

It is perhaps then unsurprising that research exploring this relationship dyad as the context of care has highlighted spousal caregivers are frequently motivated to provide care because of feelings of obligation, reciprocity and a commitment to fulfil their marital vows (Boeije & Van Doorne-Huiskes, 2003; Braun et al., 2009; Davies, 2011; Ray, 2006). For older couples, changing support needs often result in a shifting of roles, as they navigate the provision of assistance to one another (Racher, 2002; Singh, Hussain, Khan, Irwin, & Foskey, 2015). This commencement of care often reflects both the long standing patterns of reciprocity and interdependence that characterise marital relationships, as well as wider societal obligations and expectations of spouses to provide care (Calasanti & King, 2007; Ray, 2006).

Spousal caregivers, however, are as unique and diverse as the older adults to whom they provide care. Expectations and assumptions to provide care often fail to consider the complex foundation of interpersonal relationships and family dynamics. As highlighted earlier, there is an extensive and concerning body of knowledge that emphasises the risks and adverse outcomes associated with the provision of informal care, and particularly co-resident care. The nature of formal services that supplement informal care for older adults provide some degree of support to caregivers, though the challenges and shortfalls of these systems have also been briefly considered above. As population ageing continues to dually see increasing numbers of older adults remaining at home into later life, as well as the changing nature of policy and service contexts attempting to respond to the fiscal concerns associated with this demographic shift, it becomes increasingly important to consider the impact of these changes on spousal caregivers.

It is therefore critical that spousal caregiving is explored within these systemic complexities; to examine how social, cultural, policy and practice systems interact with, and impact on, spousal care in Australia. Conceptually underpinned by critical social gerontology (Estes, 2001), this research utilises a systemic design framework that utilises a multiple methods approach to systematically analyse the social and structural complexities surrounding spousal care in Australia. This thesis therefore presents a timely and important new contribution to understanding spousal care in the Australian context.

Aims of the thesis

This thesis set out to explore spousal caregiving, by analysing the interactions between systems of care at policy (macro), practice (meso) and individual (micro) levels. Conceptually underpinned by a critical social gerontology perspective, this approach considers the complexity and context of the phenomenon being investigated. As such, it was a central aim of this research to ensure that it reflected both the sociocultural context of family based care, as well as the wider systemic influences of changing social policy and health care practices. In order to explore the systems of care surrounding spousal caregivers within this study, three key systems were identified for analysis: policy documents, the service and practice environment, and individuals providing spousal care. These particular aspects of the care system were chosen to provide multiple perspectives of spousal caregiving.

This aim informed the development of the research question guiding this thesis:
How do social, cultural, policy and practice systems interact with, and impact on, spousal care in the rural context?

The breadth of this overarching question led to the development of four sub research questions that reflect the multiple stages of this project:

1. How is choice portrayed in contemporary social policy with regard to informal caregiving?

2. How do practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities?

3. How do expectations of informal care impact spousal caregivers in later life?

4. What are the implications of this knowledge for future policy and practice?

Thesis overview

This research was designed to enable a contextualised and systemic exploration of the impact social, policy and practice systems have on spousal caregivers. The distinct stages of the project were developed in order to capture each component of the caregiving system, yet designed so that each stage informed the next and ultimately had the ability to be integrated to create a more holistic understanding of the issue being studied.

This research was also designed to enable stages of the project to be disseminated to relevant audiences via targeted publications of findings. As such, this thesis is presented as a thesis containing publications. The thesis contains eight chapters in total, with the bulk of work in four chapters (4-7) being comprised of published material.

Due to the nature of journal articles being published as standalone manuscripts, there may be some unavoidable repetition in this thesis with regard to the contextual and methodological concepts discussed in these published works. As each publication contains its own list of references, the reference list to this thesis contains only the citations pertaining to unpublished content within chapters. In accordance with the copyright requirements of publishers, the manuscripts

presented within this thesis are accepted versions rather than the final version copy edited by the respective publishers.

The following provides a brief overview of the structure and content of this thesis to orient the reader to the document as a whole. This thesis began with a brief introduction to the context surrounding spousal caregivers in contemporary rural Australia. This introduction sets the scene to the complex social and political context in which this thesis is located. This chapter has also presented an overview of the research aims and a short overview of the contributions made to knowledge through the achievement of these objectives.

The second chapter of this thesis introduces the theoretical concepts that underpin this research project. As a critical social worker, this thesis is heavily influenced by social gerontology and systems theories. This second chapter provides contextual understanding to the reader of these key influences that inform the subsequent chapters.

In the third chapter, the overarching methodological considerations of this thesis are presented. As a thesis by publication, each respective findings chapter further discusses the methods utilised at each stage of the project. Chapter Three provides an introduction to the unique critical and systemic design of this thesis.

Chapter Four of this thesis presents stage one of the findings, which consider research question one: *How is choice portrayed in contemporary social policy with regard to informal caregiving?* This question was explored by way of a critical discourse analysis of contemporary Australian social policy. The findings of this

critical analysis are presented in an article published in the *Journal of Gerontological Social Work*.

The fifth chapter presents stage two of the findings, which consider research question two: *How do practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities?* In order to explore this question, a series of focus groups were conducted with health and aged care practitioners in rural North East Victoria. The participants in these focus groups represented health and aged care practitioners across a range of professional disciplines and roles. The findings of these discussions are presented by way of an article published in *Australian Social Work*.

The sixth chapter presents stage three of the findings, which consider research question three: *How do expectations of informal care impact spousal caregivers in later life?* In order to provide the reader with a contextual understanding of the caregivers who participated in this research, brief vignettes of the caregivers interviewed are provided as Appendix Seven. These stories highlight the diversity of individual, social and relationship factors experienced by older adults providing care to their partner. The findings of these interviews are presented by way of an article published in the *Australasian Journal on Ageing* and reports on a series of interviews undertaken with older spousal caregivers.

Chapter Seven presents a reflection on the innovative theoretical and methodological approach taken in this thesis. This discussion considers the rationale and

implementation of the critical and systems based research design. This is presented by way of an article published in *Qualitative Social Work*.

The final chapter presents the integration of the three key stages of this project and considers the overall research question of this thesis: *How do social, cultural, policy and practice systems interact with and impact on spousal care in the rural context?* This final chapter also considers the fourth and final research question of this thesis: *What are the implications of this knowledge for future policy and practice?*

Summary of chapter

This chapter has provided a brief introduction to the aims and significance of this research project. It has also provided an overview of the content and structure of the overall thesis. The following chapter will introduce the theoretical concepts central to the development and implementation of this research.

CHAPTER 2: Theoretical and conceptual foundations

Introduction

This chapter presents an overview of the key theoretical and conceptual foundations that inform and influence this thesis. These frameworks provide an important scaffolding to this thesis, as they underpin how spousal care is understood and constructed within contemporary familial and social contexts.

As identified in Chapter One, spousal caregiving occurs within a complicated network of both formal and informal care systems. These care systems have been impacted over recent generations by changing social and demographic factors, which have concurrently increased the need for care and decreased the availability of informal caregivers. The structural changes in health and aged care systems over recent decades have also seen shifts in the ways that care is both constructed and provided (Fine, 2012). The question of how care will be provided for a rapidly ageing population has subsequently dominated policy in the ageing arena over several decades. There are conflicting debates about who is responsible for the funding and provision of care to older adults, central to which is the role of family in the provision of care.

Although recent policy directions have been heavily influenced by concerns about the sustainability of aged care, sociological paradigms of familialism and individualism have contributed extensively to both historical and contemporary systems of care for older adults. Familialism has long been a central tenet of both marriage and caregiving, though these assumptions are increasingly challenged

by growing individualism within society (Davey & Takagi, 2013). These discourses are dually evident across the various layers of the care system at individual, practice and policy levels and therefore underpin key aspects of this thesis.

In order to understand these discourses within their socio-political context, it was necessary to identify a conceptual framework with the capacity to explore the relationship between these macro ideological discourses of care and the experience of practitioners and caregivers at micro levels. This research therefore adopted a critical approach, which provided a conceptual framework to analyse and understand how macro social and policy changes filter down to impact the individual experience of spousal care in Australia. This critical perspective will be introduced after first discussing key concepts that underpin how family caregiving is understood within this thesis.

The social construction of care

Caregiving is commonly identified as a central function of the family, an expectation reflected in the longstanding patterns of informal caregiving within social structures across the world. Classical theories of the family primarily emerged from economic and sociological origins, so are most often associated with promoting reproduction and the provision of social and economic support. Perhaps most recognised amongst this work is that of United States (US) sociologists Talcott Parsons (1902–1979) and Robert Bales (1916–2004), who presented a functionalist perspective on the sociology of the family. Parsons and

Bales (1955) posited that the nuclear family was the most economically sound family structure in the context of modernisation. Central to their arguments was the premise that the primary functions of family are socialisation and personality stabilisation. Parents were therefore responsible for ensuring children were adequately socialised to roles within the family and wider society to ensure their effective functioning as social agents (Parsons & Bales, 1955).

These classical theories are founded on assumptions of a family structure comprising a female housewife and male breadwinner; assumptions that are becoming increasingly less applicable since Parsons and Bales propositions were published. Within traditional family structures, the unpaid care of children and older family members was primarily viewed as an unpaid domestic duty of women, or "women's work" (Fine, 2007; 2012). As such, care was a largely untheorised domain until more recent times. Occurring in the privacy of homes, care was only deemed a public consideration when related to formal or institutional style aged care supports, which emerged alongside the welfare system (Fine, 2012).

The rise of feminism in the 1960s and 70s began to bring more public awareness and discussions to the forefront about the unequal distribution of care work. Prominent feminists such as Janet Finch and Dulcie Groves (1982) challenged the systemic reliance on women as unpaid informal caregivers. These debates also drew attention to the alternatives of low paid formal care, also most commonly provided by women, as not being a satisfactory substitute to informal care (Finch and Groves, 1979; 1982). Even in the early 1980s, they concluded that "the notion

of community care depends so fundamentally upon women's unpaid domestic labour that it is a challenge to envisage viable community care policies which could operate without it" (Finch and Groves, 1982, p 433). These early critiques of the gendered nature of care provided important impetus for the shifts seen in contemporary society, where social and structural inequalities in the gendered nature of care work are now more open to analysis and critique.

More recently, welfare commentators such as Gosta Esping-Andersen (2009) have explored in great depth the complexity inherent in the transformation of women's roles in society. A central implication of this role revolution has been on social phenomenon such as caregiving (Esping-Andersen, 2009). Philosopher Tove Pettersen (2012) also highlights how proposals that set out to resolve inequities in the social division of care work tend to transfer burden and responsibility from one group of women to another. She further identifies that the promotion of altruism in care work requires far greater expectations on the forsaking of self-interests for the good of others than other professions, prioritising the care recipient over the care giver (Pettersen, 2012). This disadvantage in the social division of care work impacts the financial security, health, independence and quality of later life for women (Durey, 2009). Feminist gerontologists Bozalek & Hooyman (2012), point out that the overrepresentation of women from low socioeconomic backgrounds in both informal and formal care sectors contributes to a growing divide between those who can afford to pay for care provided by some of the poorest in society.

As family structures become increasingly diverse and female workforce participation continues to grow, the historical social and economic dependency created by marriage is disrupted (White, 2013). These changes are reflected in more recent theories of the family, which increasingly demonstrate critical social constructionist views that recognise the complexity of gender in contemporary family roles and social interactions (Murry, Mayberry, & Berkel, 2013). This growing diversity of family forms was discussed by Hodgkin (2014), who explored how opportunities such as female workforce participation have enabled an expansion of women's identities beyond traditional family roles of wife and mother. Hodgkin's (2014) work is one example of contemporary family research demonstrating the changing roles of women within society that are beginning to challenge traditional assumptions of care.

Despite these theoretical advances, however, historical assumptions of family roles remain evident in the division of labour and the gendering of care (Calasanti, 2010; Esping-Andersen, 2009; Fine, 2007; Meagher, 2007; Murry et al., 2013). Disproportionate numbers of women continue to comprise both the informal and formal care workforce, contributing to the significant socioeconomic disadvantage experienced by women across the lifespan. Some theorists suggest that there is a lessening of the normative discourses surrounding gender in later life, with gendered roles become more malleable with age (Silver, 2003). This is perhaps reflected in the shifting of gendered roles relating to spousal care, where the gender disparity is less evident and where men are most likely to contribute to informal care (Australian Bureau of Statistics, 2015; Glauber, 2016). A recent Survey of Disability, Ageing and Carers report demonstrated that care of a partner

represents the most significant contribution by men to informal care in Australia, with almost equal numbers of men and women over 75 years providing care to a partner (Australian Bureau of Statistics, 2016; de Vaus, 2004). This is somewhat explained by qualitative explorations of gender and care, such as interviews with spousal caregivers conducted in the US by Calasanti and King (2007). This, and other studies, have found that although normative roles of women as caregivers are embedded across the life course, marital intimacy creates an interdependence where care and commitment are normative for both men and women (Allen, Goldscheider, & Ciambrone, 1999; Calasanti & King, 2007). Rather than focus on the gendered nature of care, this thesis instead explores how structural and systemic factors impact care within marriage for both men and women.

Familialism and care

Regardless of significant changes in family structures, the notion of familialism prevails in Australian culture and certainly in debates around the provision of care to older family members. Familialism is seen as essentially prioritising the needs of the family, which evokes emotional constructs of family connectedness and intergenerational transfer (Costello, 2009). Although degrees of familialism are impacted by interpersonal, cultural and socioeconomic factors (Davey & Takagi, 2013), family roles are often characterised by a range of obligations, responsibilities and expectations (Bruhn & Rebach, 2014; Ter Meulen & Wright, 2012). These characteristics are widely accepted as normative social and cultural expectations of behaviour within marriage and families (Arksey & Glendinning, 2007; Costello, 2009; Egdell, 2013; Ray, 2006).

Caregiving is strongly associated with familialism, with care often perceived as being altruistic in nature and the demonstration of a relational concern for the wellbeing of others (England, 2005; Fine, 2012). This relational concept is explored in sociological theories of solidarity, which consider the mutual obligations that individuals may perceive toward one another (Ter Meulen & Wright, 2012). In his renowned thesis on the social division of labour, French sociologist Emile Durkheim (1858-1917) explored social relationships in modern society. It was in this work that Durkheim first discussed changes in familial solidarity. He identified pre-modern societies as demonstrators of uniform beliefs and values based on spontaneous and unquestioned social cooperation; or as he termed it, mechanical solidarity (Durkheim, 1984). Durkheim considered that a consequence of modernisation was replacement of the collective conscious of traditional societies, with increased emphasis on individual values. He posited that this more organic form of solidarity demonstrated more functional and complementary interdependence between individuals cooperating for both their own and society's best interests (Durkheim, 1984). This more modern form of solidarity reflects the interdependence that arises on others to provide specific tasks within society. Within health and social policy, solidarity tends to refer to the obligation to contribute to supporting and protecting the interests of those who are vulnerable or need care in society (Ter Meulen & Wright, 2012).

In the many decades that have followed Durkheim's observations of solidarity in modern societies, sociologists such as Vern Bengtson (2001) have built on these theories of solidarity. Bengtson's work on normative expectations of

intergenerational and filial obligations to care has prompted a new wave of research exploring solidarity within contemporary social contexts (see for example Hodgkin, 2014; Silverstein, Conroy, & Gans, 2012; Ter Meulen & Wright, 2012; Timonen, Conlon, Scharf, & Carney, 2013). This research by Bengtson and others on intergenerational care highlights that solidarity theories remain relevant in modern families and societies. Although changing family relationships are reducing the social and economic interdependence proposed by classical theories of family, the affective nature of family relationships continues to create a context where willingness and obligation to offer care and support remain central. Theories of solidarity therefore recognise that individual actions should not be considered in isolation, as socially structured processes influence the obligations that exist in wider society (Ter Meulen & Wright, 2012). Ethicists such as Ruud Ter Meulen and Katharine Wright (2012) highlight that perceptions of informal care as a personal decision and voluntary action overlook the strong moral duty and emotional involvement that exists between family members. These emotional and moral aspects make it difficult for family members to consider the option of not providing support, particularly for those in spousal relationships.

Silverstein and colleagues (2012) also highlight that while there are not formal sanctions enforcing the provision of informal care, children and families are socialised to familialistic values that create internalised norms of appropriate behaviour. They describe this aspect of solidarity as moral capital, where investments by parents and altruism in children helps to "resolve the paradox of how self-interest and selflessness can co-exist within families" (Silverstein et al.,

2012, p. 1259). This is arguably also evident within marital relationships, where partners invest in, and are socialised to, fulfil a prescribed set of expectations and values attributed to marriage. In a review of studies exploring the experience of spouses caring for a partner with dementia, LoboPrabhu, Molinari, Arlinghaus, Barr, and Lomax (2005) highlighted marital exchanges and commitment to family solidarity as key themes in the literature. Commitment to care in marriage is implied both implicitly in the nature of the relationship, as well as explicitly by way of vows. The pressures to care, however, extend beyond moral expectations, with studies of spousal caregiving highlighting the intimately connected nature of spouses physical, social and financial situations (Lima et al, 2002).

Contemporary constructions of care

The eminent voice on care in contemporary Australia is sociologist Michael Fine, whose work has contributed much thoughtful debate to this changing context of care. Fine's extensive work explores the social division of both informal and formal care in contemporary climates of social and economic change (see for example; Fine, 2007, 2012). Fine's work emphasises the importance of understanding the relational and interdependent nature of caregiving, where care is not seen as one-way and instead reflects the reciprocity and mutuality of relationships (Rummery and Fine, 2012; Fine & Glendinning, 2005).

Fine's more recent work has analysed the individualisation of care. He cautions the need to distinguish individualised care from the concept of market-based individualism, which manifests in choice oriented neoliberal economic theory

(Fine. 2012). This is an important consideration in the contemporary climate of aged care and caregiving within Australia, and particularly to this thesis. As discussed in Chapter One, recent decades have seen significant neoliberal economic influence in Australian aged care reform. The desire for older adults to have greater autonomy and control over later life is at times conflated with the market-based choices available within contemporary aged care systems.

Individualism captures the shifts of modernisation toward individuals being accountable as social beings in their own right; concerned with personal fulfilment, self-actualisation and emancipation from traditional predefined social groups (Fine, 2012; Pickard, 2010; Ter Meulen & Wright, 2012). These broad societal shifts embracing individual ideals have been attributed to the changing expectations of older generations of Australians such as the baby boomers, who are observed to increasingly seek independence and control in later life decisions (Quine & Carter, 2006). These macro societal shifts are also becoming increasingly apparent in Australian policy directions and other aspects of ageing and care. The individualisation of care, however, is a complex, incomplete and ongoing social revolution (Fine, 2012).

Individualisation more broadly was a central concept in Durkheim's work on solidarity, in which he argued the rising of individualism was a necessary function in modern societies and a prerequisite in the complex social division of labour (Durkheim, 1984). These early observations considered the impacts of individualism on family structures and familial solidarity, though it is also of interest in this thesis to consider the theoretical implications of growing

individualisation on the provision of family based informal care. As highlighted by Fine:

> *"Individualised care promises much, but the concept is applied to a wide range of phenomena, often in ways that conceal rather than reveal the character of the transactions involved. In particular, I argue, it is important to distinguish individualised care finance arrangements from real attainments in the practice of care. For individualisation to become meaningful it must be developed as a condition of recognition that is equally applicable to those who provide and those who depend on care" (Fine, 2012, p 2).*

In his work with Kirstein Rummery, they argue that in order for those who give and those who receive care to achieve self-determination and social participation, then care must encompass an element of choice and be framed within a discourse of citizenship rather than markets (Rummery & Fine, 2012). They emphasise that this involves dual attention to the needs of both care givers and care recipients; with being able to choose whether or not and how to provide care labour being regarded equally with care receiver's choices regarding service providers and types of support accepted (Rummery & Fine, 2012). It is acknowledged here that care recipients can experience limited opportunities for meaningful involvement in decisions around care. The overt focus on individualised and consumer-directed care in contemporary contexts, however, actively seeks to address this lack of voice for recipients of care. This thesis, therefore, focuses instead on capturing the voices and experiences of caregivers, who have received little consideration throughout the transition toward individualised care.

The distinction is now made between these theoretical constructions of care, and the practice of individualised care within contemporary policy and practice

environments. Shifts toward individualised care have been increasingly evident within Australian policy over recent years, and represent a significant move away from conventional and often restrictive agency-directed aged care options to encourage greater choice and autonomy for service users. Throughout this thesis, individualised care is used to refer not only to the newly released consumer directed care programs, but to the wider ethos and approaches that promote individual responsibility for ageing and control over later life care. Although there has been limited consideration of this within Australia, the UK has engaged in several crucial discussions around the problematic nature of choice, personalisation and individualised budget systems on caregivers (Arksey & Glendinning, 2007; Larkin & Mitchell, 2015; Moran, Arksey, Glendinning, Jones, Netten & Rabiee, 2012). This body of work draws attention to the serious inequalities that can emerge in the implementation of individualised choice within social and familial contexts (Larkin & Mitchell, 2015) and highlights similarities to the Australian context, where policies to support caregivers have tended to evolve along separate lines from policies for service users (Moran et al., 2012).

Choice and consumer-led care are portrayed as offering greater satisfaction, self-determination and control (Markus & Schwartz, 2010). Within the aged care context, this suggests greater control over one's own ageing and the promise of independence and autonomy in later life. Choice is promoted as improving psychological and physical conditions, assisting people to feel more in control of their own future and providing a mechanism to increase life satisfaction and health status (Botti & Iyengar, 2006). As highlighted above, however, choice within the context of health and aged care is more often indicative of market-based

consumer choice. This type of choice is characteristic of the growing neoliberal emphasis on individualism (Pease, 2009) and is based on principles of rational choice theory. This thesis is particularly concerned with the impact of these shifts on spousal caregivers.

Economist Gary Becker, whose Nobel award winning work on rational choice analyses of human capital and family behaviour, argued that economics largely fail to consider guilt, obligation, affection and interpersonal factors that impact family commitments (Becker, 1992). This renowned work highlighted a number of key elements of choice within social policy that continue to resonate today. These include observations that while economic approaches draw on theories of individual choice, this micro level theory is concerned with macro level implications rather than with individuals (Becker, 1992). He further detailed how rational choice makes many assumptions about laws, norms, traditions, opportunities and market equilibrium (Becker, 1992), concerns echoed in recent years as individualist choice principles are increasingly applied within health and aged care contexts (Arksey & Glendinning, 2007; Fine, 2012; Markus & Schwartz, 2010; Pickard, 2010).   On the surface, discourses of individual autonomy are constructed as providing opportunities to increase personal responsibility for managing and financing your own care. Existing discussions in this space have pointed out that these notions of individual autonomy often extend to increasing responsibility to remain healthy, active, connected and able to prevent or at least delay the need for support in later life (Asquith, 2009; Hastings & Rogowski, 2014).

The importance of understanding and considering individualisation within this thesis is therefore twofold. Firstly, the individualisation of care as discussed by Fine (2012) provides a critical and central foundation to understanding the contemporary construction of care theory. The changing social contexts at present see the dual discourses of emerging individualisation of care coexisting with an established and ongoing promotion and reliance on familialism and expectations of unpaid care by spouses and other family members. The impacts of these constructions of care will be explored throughout this research. Secondly, the significant neoliberal influence of market-based choice in social policy and subsequently practice with older adults represents the socio-political context of ageing and caregiving in Australia. These individualistic policy reforms are predicted to continue in the foreseeable future, so understanding the impact of these manifestations of individualised care is also explored within this thesis.

Critical perspectives in social gerontology

The theoretical perspectives outlined above provided useful frameworks within this thesis to understand the sociological construction of spousal care. This brief overview, however, also highlights the multidimensional and complex nature of this research context. Proponents to ethics of care approaches such as Joan Tronto (1993) have drawn attention to the historical constructions of care as "the work of slaves, servants and women" (Tronto, 1993, p 21). Some authors have gone so far as to describe unpaid familial care as the "most exploitative" form of care (Morris, 1997). The impacts of informal care on its providers are well

documented, highlighting the central importance of considering structures of power and inequality in attempts to understand care.

Contemporary academics and commentators have also raised concerns about the disadvantage that can result from focusing on individual responsibility in older age as the individualisation of aged care systems becomes more pronounced (Asquith, 2009). This is of particular concern to spousal caregivers, who have been largely overlooked in reforms focused on individualised care (Larkin & Mitchell, 2015; Moran et al., 2012). This thesis set out to critically examine both the individual and structural perspectives of spousal care in contemporary Australia. In order to do this, it was important to consider how wider theoretical perspectives enabled both the critical and social elements of this gerontology topic to be understood in this complex and changing system of care.

The field of gerontology is comprised of many disciplines interested in the multi-faceted nature of human ageing (Aberdeen & Bye, 2011; Hughes & Heycox, 2010). Although broadly drawing on biological, psychological, social and political theories, gerontology in Australia has been dominated since its early inception by biomedical and health focused perspectives (Aberdeen & Bye, 2011). The influence of critical perspectives in social gerontology did not emerge until the 1970's, at a similar time to other feminist and radical ideas becoming more prominent in social work (Hughes & Heycox, 2010). These critical perspectives began to challenge assumptions of homogeneity in later life by drawing attention to the impact of social, political and economic structures on older adults' opportunities and experiences of ageing.

Critical gerontology emerged most strongly in the United Kingdom and the United States, where early political economy theories sought to challenge dominant perspectives of the time that reduced and individualised problems in older age. The work of American sociologist Carroll Estes (1978) and British sociologists such as Peter Townsend (1981) and Chris Phillipson (1982) contributed much to the development of political economy theories in gerontology. These early theorists are credited with providing an approach that sought to overcome the inadequacies of individual disciplinary approaches by combining the ideas of sociology, gerontology, economics and political science.

The critical gerontology movement, however, has progressed very differently in Australia. In their historical analysis of gerontology in Australia, Lucinda Aberdeen and Lee-Anne Bye (2011) explored the evolution from early biomedical gerontology societies in the 1960s to contemporary perspectives. Their analysis illustrates the emergence of social gerontology in research and education in the 1980s, with a more critical consideration of policy becoming apparent in the 1990s (Aberdeen & Bye, 2011). Texts by authors such as Borowski, Encel, and Ozanne (1997) and Kendig and McCallum (1990) began to demonstrate this broadening of perspectives in gerontology; though Aberdeen and Bye (2011) conclude that the critical movement in Australia has never fully emerged. This view echoes that of other Australian sociologists, such as Nicole Asquith, who has also discussed the lack of critical perspectives in social research (Asquith, 2009).

It remains unclear why critical gerontology has been less prominent in Australia than in the United Kingdom or the United States. This lack of critical engagement in Australian gerontology has created a concerning void in social research and policy analysis. It is a central principle of Estes (2001) work in critical gerontology that ageing cannot be analysed in isolation from other societal forces and phenomena, as the experience of ageing is directly related to the society in which it is situated. While much has changed within society and social policy in the decades since critical and political economy theories first emerged in gerontology, the implications of these structures on older adults continues to resonate in contemporary contexts.

As discussed in Chapter One, successive Australian governments have continued to compel aged care systems toward greater individualisation and market-based choice. These policy shifts are inherently fraught with opportunities for serious, structural inequities for particular subgroups of older adults. It is well known that economic, social and health determinants can significantly impact the experience of ageing for older Australians (Australian Institute of Health and Welfare, 2015). Life course factors such as education, employment, disability and access to resources can significantly impact the ability for older adults to engage in the choices and options of free markets. These are important considerations for this thesis, which focuses on the experiences of spousal caregiving in rural areas. The decision to draw on critical social gerontology as the theoretical framework underpinning this thesis therefore presented the most appropriate lens for understanding and analysing care within these complex contemporary contexts.

Summary of chapter

This chapter has briefly introduced the key theoretical concepts that underpin this thesis. Further details of how these theories and concepts have informed and been drawn on are discussed and applied throughout the thesis and included publications as appropriate. The following chapter will explore how critical and sociological theories informed the methodological decisions in this thesis.

CHAPTER 3: Methodology

Introduction

The current chapter presents the conceptual and methodological considerations that informed the design of this thesis. As highlighted in Chapter Two, a central consideration of this thesis was to create research founded on principles of critical social gerontology. This critical approach is reflected in the methodology of this thesis through the influence of the transformative paradigm. Key principles of this critical paradigm and its influence on this thesis will be introduced in this chapter.

In addition to these critical foundations, this thesis set out to analyse and understand the interaction between systems of care and the practice of caregiving discourse at individual and practice levels. Preliminary exploration identified very few social work researchers utilising similar critical or systemic approaches in their research design (see Appendix One). This chapter will present the design framework developed for this thesis.

A transformative approach to social work research

As stated in Chapter One, this thesis set out to explore the experience of older spousal caregivers in contemporary rural Australia. It became evident early in the development of this project that the micro level interaction of informal care between couples was located within, and impacted by, a range of complex contextual factors. A key contextual factor was the significant reform occurring within aged care, as outlined in Chapter One.

This context of rapid and ongoing reform within the aged care sector presents a somewhat moving social policy target for social workers and other professionals within gerontology. It remains both necessary and important, however, for social gerontologists to engage in ongoing critical reflection of the impact changing social and political contexts can have on vulnerable groups within society.

While broadly encompassing a critical social gerontology approach, this thesis draws specifically on theoretical principles of the transformative paradigm. The transformative paradigm is most often attributed to the work of Donna Mertens, who presents an approach that encompasses research theories and methods that prioritise social justice and human rights (Mertens, 2010). The ontological assumptions of the transformative paradigm recognise constructivist views of reality, though Mertens extends this by positing there is one reality about which there are multiple opinions (Mertens, 2010).

This key ontological assumption reflects the conceptual underpinnings of this thesis, which recognises that the multiple perspectives of stakeholders within the care system are key to understanding the social construction of spousal care. This is reflected within this thesis in methodological decisions to capture diverse voices and perspectives, including those from marginalised groups themselves (Mertens, 2013).

Mertens (2013) further highlights the importance of considering the consequences of accepting one version of reality over another. This is particularly imperative in a research context where unequal power relations create

complexity and tension between informal caregivers and their social environment. A key principle of the transformative paradigm adopted within this research was to consider not only how individuals are impacted by the changes in aged care policy, but also to analyse how power structures and discourses can perpetuate social inequalities (Allan, 2009; Mertens, 2010).

Within this thesis, it is argued that the overt reliance by government and families on unpaid care at the policy and practice level socially obliges caregivers to provide unpaid support. Although theoretically presented with the same options and choices as other older Australians, the nature of marital and caregiving relationships can constrain their ability to enact these. This thesis draws on these critical transformative foundations in order to understand how macro policy filters down to impact practice with, and the individual experiences of, caregivers in a changing social and policy environment. This underlying philosophy conceptually underpinned and informed the development, analysis and presentation of this thesis.

The research design

The design of this research was subsequently constructed upon these critical foundations. It is a central tenet of the transformative paradigm that methodological decisions are made with conscious awareness of the contextual and historical factors impacting the research, and particularly how these relate to inequity (Mertens, 2012). This was a key consideration in setting out to explore a topic such as spousal caregiving, which is situated amidst many historical and

contextual complexities, as highlighted in Chapters One and Two of this thesis. The decision to pursue a qualitative approach was therefore informed by the opportunity to capture the nuances and complexity of spousal caregiving beyond what would have been possible with deductive approaches to research (Patton, 2002).

The multidimensional nature of this topic guided the decision to address the research problem from a range of positions and views, in order to capture multiple perspectives within the care system. The use of multiple methods also contributes to theoretical and methodological rigor, by overcoming the potential bias of single method approaches and enabled the depiction of diverse voices and perspectives in a way that reflects trustworthy understandings (Mertens, 2013; Patton, 2002). Multiple qualitative methodologies were therefore particularly suited to examining the depth and complexity of individuals within their social systems (Morrow, 2005) and better equipped to give due consideration to the depth of perceptions and understandings that participants attached to spousal care (Denzin & Lincoln, 2011).

Figure 1 presents a visual representation of the research design developed for and utilised in this thesis. This figure demonstrates how this thesis is conceptually located within wider social contexts and guided by principles of the social work profession. The figure also demonstrates how epistemological and methodological frameworks informed each stage of the research design. The components of this framework will now be discussed.
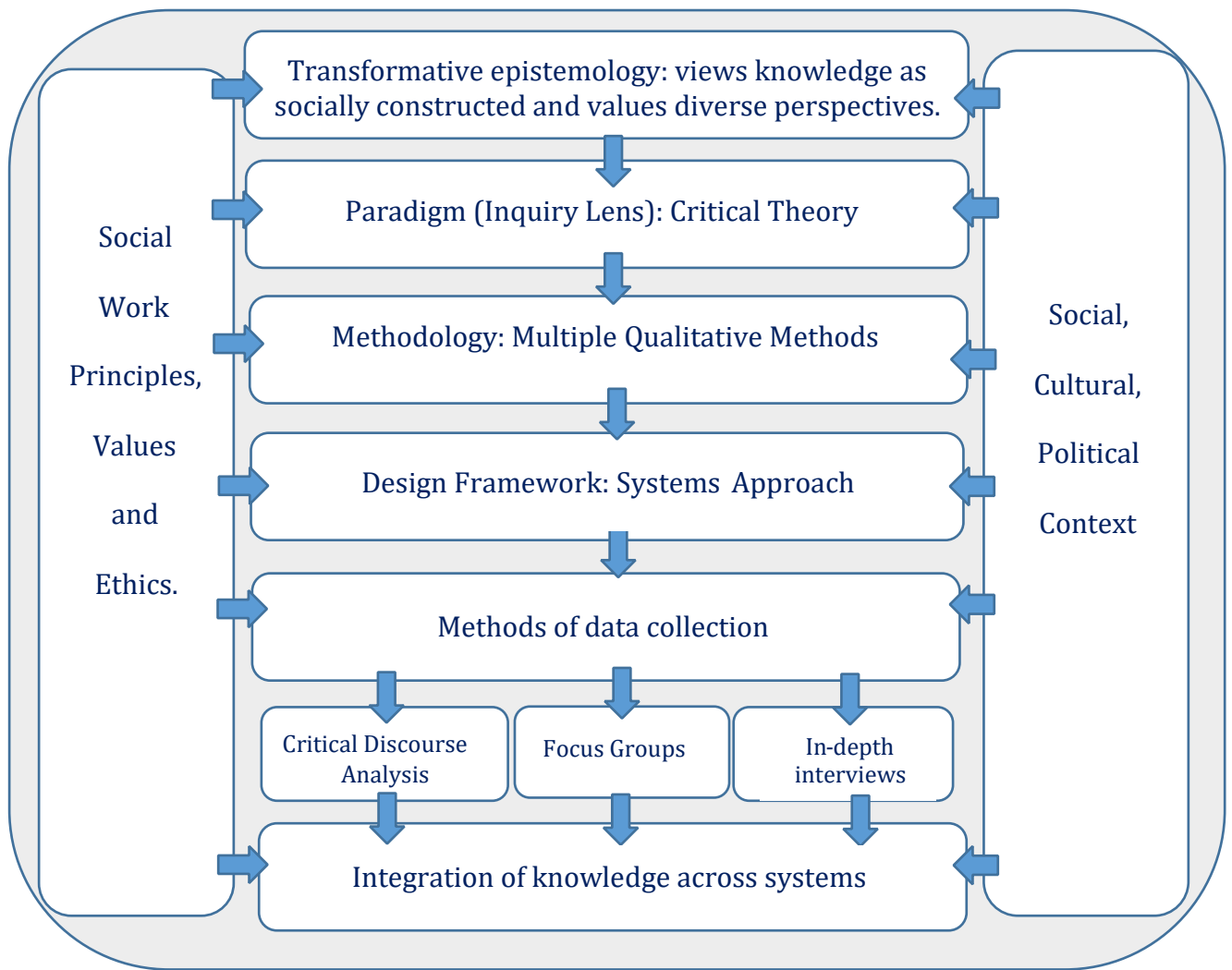
Figure 1: Research design framework

A systems based research framework

The aims of this thesis broadly aligned with multiple qualitative methodologies, though the design framework was less immediately evident. Some appeal lay in the critical examination of constructivist grounded theory approaches, yet this thesis did not set out to develop theory. Likewise, understanding the lived experience of spousal caregivers led toward a phenomenological design, yet this did not adequately capture the systemic influences that were apparent in this

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social phenomenon. Considerable deliberation occurred around the use of case study designs, which are used to evaluate and examine complex social phenomena from multiple perspectives (Stake, 2005), yet there was a struggle to align with the evaluative purposes of this approach. This dilemma highlighted the inclination as a social worker toward an ecosystems approach to understanding the individual caregiver within their environment, rather than focusing on any one aspect of this interconnected system. Much as it felt impossible to understand and unravel the complexity of the issue without understanding all of the parts, it was also important that the findings too reflected the interactional nature of these systems as being more than simply understanding the sum of the parts.

Systems theories have long been influential in social work practice, and it is arguably a perspective that distinguishes social work from other human service professions (Germain & Gitterman, 1996; Healy, 2005). This is evident in the social work profession often being differentiated by its focus on understanding and responding to people in their wider environment (Connolly & Harms, 2013; Healy, 2005). This contextually focused perspective reflects a central principle of systems theories, which is to understand the influence of direct and indirect social contexts on individual experiences (Harms, 2010). The influence of systems theory led to the development of a practice model that considers an individual within their wider environment at micro (home and family), meso (institutional and practice) and macro (policy) levels. This contextual framework aligned well with the critical aims of this thesis, which sought to examine the impact of wider systems on spousal caregivers, from the understanding that no one system can be interpreted without understanding those around it.

Although central to many assessment techniques within social work practice, it is less clear how systems approaches inform social work research. Preliminary exploration identified very few social work researchers utilising similar critical or systemic approaches in their research design. In order to explore this methodological hypothesis more clearly, a systematic review was conducted with the intention of locating examples of studies that utilised systems approaches in the design of research. In order to capture a representative snapshot of social work research, the systematic review included all articles published during the past ten years in two key academic social work journals, Australian Social Work and Qualitative Social Work. These two journals were identified as providing the most comprehensive examples of research designs relevant to the Australian care context. This review is presented in Appendix One and discussed further in Chapter Seven.

The findings of this review suggest that despite the strong association between social work and systems theories in practice, the systems perspective remains underutilised in social work research. Despite this lack of methodological guidance, systems theories continued to present the most appropriate framework to focus on the complexity of spousal care at both individual and structural levels (Campbell & Fouche, 2013). The decision was ultimately made to situate this research within an ecosystems framework, enabling the issues and challenges facing spousal caregivers to be explored from a systemic vantage. Choices and decisions available to informal caregivers are recognised as being situated within families and communities (Arksey & Glendinning, 2007; Egdell, 2013), so valuing

the interconnected nature of social systems was key to understanding how macro level consumer directed and individualised choice based approaches can impact decisions and experiences of informal care at the individual and family level.

Research methods

Qualitative methodologies seek to explore social problems in a holistic way, which was well suited to the intentions of this thesis. The transformative approach supports the use of mixed and multiple methods as a mechanism for capturing the complexity of the phenomenon being studied (Mertens, 2013). This guided the decision to use multiple qualitative approaches in this research design, in order to collect and analyse data across the diverse systems of policy, practice and individual caregiving.

In order to understand spousal care, an assessment of the social and cultural constructions of ageing and caregiving within the Australian context was undertaken as the primary task. These contextual considerations provided the foundation for understanding each of the systems being explored within the study. This preparatory stage was therefore key to ensuring that the collection and analysis of data, as well as the interpretation of findings, occurred within its wider sociocultural and political environment. Although complicated by the multiple cultures of country, family, religion and other groups to which individuals belong (Harms, 2010), these contextual considerations provide the social framework for ageing and caregiving within Australia.

These overarching contextual factors influence other aspects of the social systems at macro, meso and micro levels. In order to explore the phenomenon of choice for spousal caregivers within this critical and systemic qualitative research design, three key systems were identified: social policy relating to health and aged care; community based practice with older couples; and individuals providing spousal care. Methods of data collection and analysis were then selected to best represent the critical focus of the project. As such, the decision to use critical discourse analysis, focus groups and in-depth interviews were determined as the most appropriate methods to address the research questions. The rationale and application of these individual methods are discussed in the respective findings chapters and associated published papers as outlined below.

Chapter Four – Critical discourse analysis of social policy

Social policy relating to health and aged care was analysed using critical discourse analysis. This method sought to understand the discourses of choice for spousal caregivers in contemporary social policy.

Chapter Five – Focus groups with practitioners

Seven focus groups, comprising a total of 42 participants, were conducted with health and aged care practitioners involved in work with community based practice with older couples. These focus group discussions sought to understand the translation of policy directives and organisational guidelines around choice into direct practice with spousal caregivers.

Health practitioners were recruited from seven health services in the identified region. These services were either the sole health service within a rural locality (n = 4), or a regionally based organisation providing acute or outreach services to these rural locations (n = 3). Initial contact was made with each health service and a key contact within each service invited all staff who met the inclusion criteria to participate. Criteria included being a healthcare practitioner, working in a rural or outer regional area providing services to a rural population, and being engaged in work with older community residing couples.

Chapter Six – In-depth interviews with spousal caregivers

Ten in-depth interviews were conducted with individuals over the age of 65 years who were providing or had recently provided spousal care in their home. These interviews sought to understand the lived experience of choice within the social context of long term marriage.

Participants were recruited via non-probability self-selection sampling, where individuals responded to written advertisements displayed in health care centres and caregiver support groups. Inclusion criteria comprised being either male or female; aged over 65 years; live in regional North East Victoria, Australia, and be or have recently been a co-resident caregiver to a spouse or partner.

Chapter Seven – The systematic approach to research design

This chapter reflects on the implementation and integration of this systems based research framework and demonstrated how the findings were drawn together in a systemic way.

Ethical considerations

Engaging with stakeholders from potentially vulnerable groups is a paramount consideration of transformative research. The exploration of practitioners and spousal caregivers' experiences in this research raised a number of important ethical considerations.

A primary concern in conducting research with human populations is ensuring all potential participants are fully aware of the proposed research so that they can make an informed decision about participation. Each individual who expressed interest in participating in this research was provided with an information statement in plain English (see Appendices Four and Six). These statements provided information outlining details of the research, the information being sought, how this was to occur and how information would be recorded, transcribed and used. The information contained in these statements was verbally reiterated at the beginning of each focus group and interview, at which time participants signed consent forms (see Appendices Four and Six). All participants were advised of the voluntary nature of participation and of the option to withdraw or have their contributions withdrawn at any stage during the research process.

Although no harm to participants was anticipated, there is always potential risk to the emotional wellbeing of participants when conducting research with individuals and groups. This was a particular concern for interviews with spousal caregivers, due to the personal nature of care potentially triggering an emotional

reaction in participants. Questions were therefore developed with sensitivity to participants' emotional wellbeing in mind (see Appendices Five and Seven for interview guides). This risk was also somewhat mediated by the interviews being conducted face to face by a qualified and experienced social worker with extensive interviewing and direct practice experience in mental health care. Precautions were also taken to ensure adequate conclusion to each interview, with each participant provided with the contact details of support and counselling supports should they wish to access these services following participation in the research.

Interviews with caregivers were conducted individually to ensure the greatest possible comfort, privacy and confidentiality for caregivers to share their story. The nature of focus groups in small rural communities however raised considerations about the issue of confidentiality of conversations occurring in the presence of colleagues. This issue was discussed at the beginning of each focus group, with participants requested to respect the confidence of conversations occurring during the research, including not discussing the names or views presented by fellow participants outside of the session. The anonymity of participants was further protected during this research via the use of pseudonyms and removal of identifying information prior to analysis and dissemination of results.

Ethics approval for all research procedures undertaken in this thesis was sought and obtained by the La Trobe University Faculty of Health Sciences Human Ethics Committee (FHEC12/177; see Appendix Two).

Summary of chapter

This chapter has discussed the methodological rationale and design decisions that underpin this thesis. As a thesis by publication, as well as a multiple methods project, each of the papers comprising the findings chapters contain a discussion of the respective methods utilised within each stage of data collection and analysis. Chapter Seven of this thesis also contains a published manuscript that further reflects on the development and implementation of this systems based research design.

CHAPTER 4: Stage one findings – A critical analysis of social policy

Introduction

This chapter presents the findings from the first stage of the research. In particular, it focuses on the first research question of this thesis: *How is choice portrayed in contemporary social policy with regard to informal caregiving?*

As discussed in Chapter One, the health and aged care sectors in Australia are undergoing a period of significant reform. Understanding these macro policy contexts was therefore an important foundation for this thesis. The strong influence of social policy on funding for both individuals and formal services, as well as practice directions more broadly, established this as a central and early priority for this thesis.

There are many theoretical and methodological approaches for conducting policy analysis, informed by a range of disciplines including economics, law, health, welfare, sociology and psychology (Carlson, 2011). Although many of these diverse approaches can be applied to the analysis of social policy, it was a central consideration that the chosen method would reflect the critical aims of this thesis.

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Author	%	Contribution
Belinda Cash	60	Critical discourse analysis of policy documents Completion of first draft of article Reviewed and responded to track changes and feedback from co-authors on each version of manuscript Prepared and submitted article to journal
Suzanne Hodgkin	20	Regular peer discussion of data analysis Provided critical review and feedback on manuscript
Jeni Warburton	20	Regular peer discussion of data analysis Provided critical review and feedback on manuscript

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Till Death Us Do Part? A Critical Analysis of Obligation and Choice for Spousal Caregivers

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Till Death Us Do Part? A Critical Analysis of Obligation and Choice for Spousal Caregivers

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Abstract: Research demonstrates a significant number of carers identify obligation or lack of other alternatives as the reasons they undertake informal care. By utilising critical discourse analysis, this research explores choice for informal caregivers in contemporary Australian social policy. Analysis demonstrates increasing shifts in policy toward choice in consumer directed care, a feature absent for those who provide care. Familial care is a central pillar of Australian social policy, as it is in many liberal and conservative welfare regimes. Analysis reveals that these core social policies are fundamentally incongruent, with significant implications for individuals and social work practice.

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Introduction

Global population ageing has prompted both national governments and international economic organisations to explore the policy implications of this significant demographic shift (Bessant, Emslie, & Watts, 2011). Across the world, governments are struggling to develop social policies in line with a growing proportion of older people and the broad challenges this offers. Countries such as Australia who generally fall under the liberal welfare regime, as determined by Esping-Andersen (1996), have responded by strengthening their neoliberal policies of individualism and privatisation. These measures reflect trends within wider global economic and social policy, which aims to reduce the role of governments in the delivery of social welfare, by promoting individual responsibility and facilitating private alternatives to public support (Bittman, Hill, & Thomson, 2007; Hughes & Heycox, 2010; Spies-Butcher & Stebbing, 2011). These policy approaches are having a significant impact on classes of citizens,

including older caregivers. In liberal and conservative welfare regimes, unlike social democratic regimes such as Sweden and the Netherlands, the state adopts little responsibility for caregiving, leaving the task to families and volunteers (Pfau-Effinger, Flaquer, & Jensen, 2009; Warburton & Jeppsson Grassman, 2011).

In the case of Australia, the federal government has responded to fiscal uncertainties created by rapid population ageing by encouraging older Australians to be more self-reliant. This approach is embodied in two primary policy approaches. Firstly, financial independence is encouraged through increasing age of eligibility for pensions, encouraging later retirement via tax offsets and forcing compulsory superannuation (Chomik & Piggott, 2012). Secondly, the government has moved, in line with other countries worldwide, to the promotion of healthy and active ageing strategies (Hughes & Heycox, 2010). Despite this, ageing is often accompanied by an increased need for care and assistance, with principles of familialism and traditional caregiving roles also evident in social policy. With increasing shifts toward community based care, the vast majority of this in-home support continues to be provided by partners, family, friends and other informal supports (Esping-Andersen, 2009). Many health care policies are formed on the familial premise that spouses, family and friends will continue to provide the majority of care to older persons in need (Sims-Gould & Martin-Matthews, 2008).

In this context, it is therefore not surprising that research demonstrates a significant number of informal carers identify obligation or lack of other choices as the reason they undertake caregiving roles (Australian Bureau of Statistics, 2008; Burridge, Winch, & Clavarino, 2007; Kuscu, Dural, Yasa, Kiziltoprak, & Onen, 2009). Although the personal risks of caregiving are well documented, there is very little research exploring the issues around choice to provide informal care. Despite recent shifts in social and health policy toward consumer directed care and individual choice, these ideas remain largely absent from policies aimed at family caregivers, which continue to emphasise traditional family roles and caregiving obligations (Pickard, 2010).

Data provided by Access Economics Australia (2010) estimated that if the informal care currently provided by unpaid family and friends was replaced by formal care arrangements, the cost would be in excess of $40 billion per annum, without considering anticipated increases of older persons and their subsequent needs in coming years. The significant economic and social costs of aged care thus make informal caregiving a topic of considerable relevance within the Australian policy environment (Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2009).

Although here focused on Australian social policy, these issues are not exclusive to the Australian context, with the increasing influence of neoliberalism on social welfare policy being observed globally (Marston, 2002). This paper presents a critical analysis of the discourses around choice for informal caregivers, as examined in three key Australian social policy initiatives. Language concerning choice, family responsibility and obligation is analysed with regard to the implications for future policy direction, caregivers and the social work profession.

Literature Review

The term 'care' is complex; referring not only to an emotional concern for others or the practice of tending to another's needs, but also to an intricate social relationship (Rummery & Fine, 2012). While care was historically viewed as a private familial concern, undertaken by women out of love or duty, it is now more often regarded as a social complexity, and therefore a topic of consideration for policy makers and governments.

In many countries, the most notable shift in policy direction has been the influence of neoliberal ideology and discourse over the past thirty years, which serves to ease public spending by reinforcing individualism and personal responsibility (Esping-Andersen, 2009; Hughes & Heycox, 2010). Within Australia, this neoliberal influence co-exists with socially conservative and communitarian values (Hughes & Heycox, 2010). In keeping with these trends, developing countries have observed a shift in resources from institutional care toward in-home and community based support. As with other examples of deinstitutionalisation, there is little doubt that these shifts are based on the expectation that partners and families will provide most of this 'rebalanced' care in the community, reinforcing conservative values that emphasise the family and traditional caregiving roles (Hughes & Heycox, 2010).

While the emphasis on community based care can enable people to remain longer in their homes and connected to their community, the underlying motivation from government is ultimately focused on alleviating public finances. Further, it is important to consider that for many older persons, the ability to age at home is dependent on the availability of a co-resident partner or other informal caregiver. This reliance on informal caregivers, alongside an ageing population, will significantly increase the need for informal carers in the future, yet demographic predictions suggest that at this time of increased need there will be less informal carers available (Productivity Commission, 2011). Significant sociological changes are also contributing to the expected lack of informal carers in the future, placing increased expectation to care on ageing spouses, who are largely overlooked in discussions of informal care. These shifts suggest that government policies which rely heavily on the family to provide support and care for older people may be inappropriate for the future (Bittman et al., 2007).

An extensive body of literature has demonstrated that being a caregiver significantly increases the risks to the physical, psychological and social health and wellbeing of caregivers (Butterworth et al., 2009; Hartke, King, Heinemann, & Semik, 2006; Pinquart & Sörensen, 2003), particularly for co-resident carers, such as those in spousal relationships (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Hirst, 2005). Spouses are thought to be particularly susceptible to depression as a consequence of providing the most extensive range of care to their partner (Butler et al., 2005) with the sense of obligation and family responsibility to take on a caring role (Australian Bureau of Statistics, 2008).

The impact of factors such as age and relationship with the care receiver may also place older spousal caregivers at particular risk of strain from caregiving, with spouses "likely to demonstrate a more intense commitment to the caregiving role but also to suffer lack of support and isolation prompted by the incapacitation of a life partner" (Hartke et al., 2006, p. 151). Of the 2.5 million informal caregivers in Australia, 42 per cent of these provide assistance to a spouse, increasing to 83 per cent for carers over 65 years of age (Australian Bureau of Statistics, 2008; Butterworth et al., 2009). So while their own age and health concerns become increasingly complex, older spouses are in situations of providing at home care for their ageing partner. Research has confirmed that providing care within your own household is around four times more intensive as providing care to someone living outside of your home, with spousal care being the most intensive type of care relationship for both men and women, close only to mothers caring for a child with disabilities (Hirst, 2005). It is also suggested that dependency on familial care may actually weaken the bonds of kinship, meaning familialistic welfare solutions can very easily become counter-productive in terms of the very same goals they pursue (Esping-Andersen, 2009).

Despite the overt dependence of the aged care system on informal carers, research to date has been limited in developing an understanding of the underlying choices, or lack of, in providing informal care. This is particularly the case with spousal care. Of the studies located, the Australian Bureau of Statistics survey of Australian carers found emotional obligation was identified by 35% of carers as the reason they took on the role, and a further 25% stated it was due to no other choice being available (Australian Bureau of Statistics, 2008). This lack of choice is a recurring theme in caregiving literature, with several studies identifying marital or family obligation as a common motivating factor behind carers choosing in-home care (Burridge et al., 2007; Duner, 2010; Kuscu et al., 2009). Burridge et al (2007) also suggests that individuals who accept the caregiving role may feel ambivalent, reluctant, or lacking opportunity to weigh up whether they actually want to commence or continue to provide care, particularly as additional responsibilities are added.

From a sociological perspective, this highlights the competing discourses of individualism and familialism. As Durkheim originally identified, individualism is a functional need within the complexity of our social systems, and is concerned with personal fulfilment and self-actualisation (Durkheim, 1893, cited in Roulstone & Morgan, 2009). This is evidenced in social policies emphasising choice and individual control over personal decisions, in contrast with the traditional roles and responsibilities of family and society (Pickard, 2010). This illustrates incongruence in social policy relating to older Australians and informal caregivers. There is an assumption that spouses will care for partners as they age, with this viewed as essentially altruistic in nature, contrasting sharply with individualisation or the emergence of a preoccupation with self (Fine, 2012). Yet for individualisation to become meaningful it must be equally applicable to both those who depend on care and those who provide it (Fine, 2012).

Within research, policy and practice, the perception continues that a spousal relationship is associated with caregiver availability (Allen, Goldscheider, & Ciambrone, 1999; Egdell, 2012), with spousal care often assumed of marital commitment and as an expression of loyalty and reciprocity in the relationship (Boeije, Duijnstee, & Grypdonck, 2003; Burridge et al., 2007). It is not a simple consideration of obligation or duty to care, as caregiver decisions are socially situated within families and wider social and cultural expectations (Egdell, 2012). While many partners and family members readily take on and enjoy the role of caregiver, this cannot be assumed of all who find themselves in this situation. A sense of moral or social responsibility provides the cultural context for many Australian families, increasing the likelihood that people may not readily disclose a reluctance to care, as this goes against social norms and their desire to provide socially desirable responses (Burridge et al., 2007).

The dependence of the aged care system on informal carers can place heavy expectations on older spouses, which is an important ethical consideration for both policy makers and health care professionals involved in decision making around care needs for older people. It is important to ask questions that will consider how best to provide social supports that strengthen families "so that they can fulfil their commitments under reasonable and non-coercive conditions" (Hirschfield & Wikler, 2003, p. 58).

It has become clear that while we have much evidence about the increasing need for informal caregivers, there is an absence of knowledge about the underlying assumptions within policy that see spouses commence and continue providing in home care out of obligation or a lack of choice. This seems remiss considering existing knowledge of the personal risks associated with caregiving, and in light of the focus on individual choice for health and aged care consumers. It is thus important to explore Australian caregiver policy in order to understand better some of the assumptions underlying it. This paper adopts a critical discourse analysis approach to contemporary policy debates in an Australian reform environment, with the specific intention of understanding discourses of choice for older spousal caregivers and enabling more profound understandings of this critical social issue.

Methodology

Use of critical discourse analysis within a social constructionist epistemology enables an analysis of dominant discourses and meanings of choice for caregivers, bringing a critical edge to the research and opening up alternate possibilities for action and policy intervention (Marston, 2002). Here we draw on the approach of Fairclough and van Dijk in order to understand inequities in discourses surrounding choice for spousal caregivers. This method also facilitates an analysis of hegemony as it relates to informal caregivers, by understanding how power can be exercised through the use of language and texts to promote specific ideological agendas (Fairclough, 1995).

While discourse analysis has long been used within linguistic studies to explore the function and structure of language (McCloskey, 2008), critical discourse analysis (CDA) moves beyond the linguistic level to study the impact of language on social phenomena (Van Dijk, 1993; Wodak & Meyer, 2009). Thus, by analysing language use within its social and political context, it strengthens its operational utility and addresses flaws in prior social research using linguistic technique (Fairclough, 2010; Marston, 2004). The critical nature of this method makes it a very useful approach for social work researchers, who aim to promote clear principles of equality and social justice in both policy and practice, particularly amongst vulnerable populations (Thompson, 2009).

As one of the founders of CDA, Fairclough (2010) provides a systematic framework to consider the connection between text and social practice, offering a three dimensional approach to analysis. In addition to micro level textual analysis to examine its content, structure and meaning, this framework also incorporates broader sociocultural and practice dimensions which seek to explain the relationship between discursive practices (the production and interpretation of the text) and social context (Fairclough, 1995, 2003, 2010; Marston, 2004; McCloskey, 2008). The selection of Fairclough's model within this study was based on the explicit focus on context, which was crucial to understanding the systemic social environment of caregiving.

CDA is a highly interpretive process that acknowledges multiple interpretations can arise from the data (Fairclough, 2003). The findings that do emerge need to be rigorously supported by the data, with the reliability and validity of findings relying on the strength and logic of the researcher's argument. In light of this, the present analysis commenced with a comprehensive exploration of key documents underpinning Australian social policy in relation to informal caregiving. As Australia is currently undergoing major reforms in aged care policy and this reform agenda is driven by the Commonwealth government, it is logical to explore key contemporary documents emanating from this source.

In order to produce comprehensive and rigorous findings in relation to this topic, three documents were selected for analysis. These comprised, first, the National Carer Strategy, the key policy document relating to carers produced in 2011; the Productivity Commission Report into Aged Care, Caring for Older Australians (2011), which was a major commissioned report aimed at a radical overhaul of the Australian aged care system; and the reform document that followed emanating from the responsible Commonwealth Department of Health and Ageing (2012), Living Longer, Living Better, which presents a blueprint for contemporary aged care policy. These documents together provide a picture of the contemporary Australian aged care environment and ageing policy discourse. Together they represent Australian government attempts to radically reform the aged care arena, driven by the pressures of population ageing and the related need for more care, including an acknowledgement of the decline in the numbers and availability of informal carers (Hughes, 2011; Productivity Commission, 2011).

All documents were then read through carefully in order to determine relevant sections for analysis. Criteria for inclusion involved all sections which discussed key terms determined as; choice, spousal, informal caregiver, carer, willingness to care, obligation and responsibility. These sections were coded using NVivo to distinguish identified sections into key themes to allow deeper analysis of each area of discourse. At this level of textual analysis, specific focus was given to *assumptions*, *presuppositions*, *absence* and *language*. It was also conducted with consideration of hegemony, through the analysis of discursive strategies which can maintain social inequality and power imbalance (Van Dijk, 1993). This concept is particularly relevant to the study of vulnerable groups such as informal caregivers, where there is a general acceptance of dominance by broader health and care systems dependent on their cooperation and contribution.

Key themes were then reviewed within and between documents to draw findings together in a congruent way. Applying Fairclough's model to policy analysis involves moving between description, interpretation and explanation, to make visible connections between properties of texts and social processes (Marston, 2004). Documents were revisited throughout to check for exceptions to ensure a balanced representation of discourse. The first author undertook the analysis, with reliability determined by iterative discussion and cross checking by the other two authors.

Discussion of Findings

This analysis explores assumptions within government policy which impact on the availability of choice to provide informal care. Several key discourses emerged reflecting the assumptions and expectations of older spouses as discussed below.

The Aged Care system depends on the availability of informal carers

All three documents analysed clearly identify the dependence of the aged care system on informal carers, highlighting that there is often no alternative for them but to provide care. Within the National Carer Strategy, this is apparent in the emotive modality, which repeatedly refers to the 'enormous', 'critical' and 'invaluable' social and economic contributions of carers to the Australian community. The emotion laden choice of words places burden on caregivers, even more explicitly with statements such as "most carers provide care out of love and believing they can provide a better quality of life for their family member or friend than anyone else. In many cases carers provide care because the demand for formal care services far exceeds supply and there is no alternative" (Commonwealth of Australia, 2011, p. 17). This disclaimer precedes a negative comment, with the placement of an emotive statement prior to acknowledging the lack of choice to care seemingly placed to offset the reality of there being no alternative for informal carers. In stating that "most people provide care out of love" there is a connotation that those who do not provide care do not love their

family member, or that perhaps love should be the primary motivation for providing care. This creates an emotive moral discourse for carers, of those who care out of love versus those who do not. In a systematic review of reluctance to care, Burridge et al. (2007) argued that this powerful discourse can reduce the likelihood of carers and family members disclosing an unwillingness to care, as this may be seen to not fit within socially desirable responses. In order for older persons to remain at home there is usually the need for informal support, so statements which establish love as the primary reason for caregiving fail to acknowledge the complexity and underlying expectations of informal caregivers.

Within the other documents, it is overtly stated that "their role is not only fundamental to those they care for, but for the functioning of the aged care system overall" (Productivity Commission, 2011, p. 325), and that "community care often relies on the availability of an informal carer" (Department of Health and Ageing, 2012, p. 16). The repetition of words such as 'depends', 'relies' and 'fundamental to' conveys the reliance on informal carers to the functioning of the overall care system. Data has demonstrated that government funded services such as low and high care residential and community based supports provided by nursing and allied health care staff, could not replace the informal care currently provided by unpaid family and friends, with this estimated to cost in excess of $40 billion per annum (Access Economics, 2010). The repetitive message about the dependence on caregivers seemingly justifies the system being developed on the significant assumption that informal supports have historically and will continue to provide this care. This lack of choice for informal caregivers, identified in these key documents, serves to highlight a broader social and economic dependence in the Australian health care system on a model of supported familialism.

Support for caregivers is to enable them to continue providing care

The system's dependence on informal carers is accompanied by a need to preserve this valuable social and economic resource, which is evident in all three documents. While it is acknowledged that "being a carer can involve significant personal costs, including poorer physical and mental health and increased social isolation" (Department of Health and Ageing, 2012, p. 16), it is of interest to explore further the language around providing support to caregivers.

The Productivity Commission identifies the reason for supporting carers as "a reduction in family caring would add significantly to the cost of formal care services" (2011, p. 327) and "without support and assistance, carers can burn out which can then mean greater reliance on more formal forms of care" (Productivity Commission, 2011, p. 91). This language reflects its neoliberal influence, suggesting the primary reason to support carers is to reduce pressure on publicly funded services, implying the wellbeing of carers is only of value if it reduces financial burdens on the government. This is further evident in statements such as "the desirability of supporting carers, however, depends on trading off the costs and benefits of doing so, including the benefits and costs for older people requiring

care and the carers and taxpayers" (Productivity Commission, 2011, p. 328) and "weighing up the costs and benefits suggests a role for governments in supporting informal carers" (Productivity Commission, 2011, p. 329). While there is a clear acknowledgement of the serious risks to carers, the decision to support informal caregivers appears to have been weighed up in a cost-benefit analysis.

The provision of support to carers is also portrayed as being to encourage continuation of their caregiving role, as "support services are not intended to decrease the caring load but provide mechanisms by which carers can provide better quality care and continue to be willing to maintain a caring role" (Productivity Commission, 2011, p. 335). Supports promised in the Aged Care Reform Package are targeted at supporting carers to continue to provide informal care, because it is 'critical' and 'invaluable' to the system working. This language again reflects that the function of supporting carers is to reduce financial burden on governments and the formal aged care system. Stating this in such an overt fashion draws attention to the justification as being common sense, rather than considering that social and financial exploitation of individuals occurs despite significant personal risks, or that carers are not the ones afforded the decision to care. An economic rationale to provide support suggests the personal risks to caregivers is acceptable.

This would seem appropriate under the assumption that all caregivers want to be providing informal care, however recent research demonstrates a significant percentage identify having had no alternate choice but to provide care (Australian Bureau of Statistics, 2008). Essentially then the Australian mixed welfare system is financially reliant upon informal carers, performing with limited choice, a challenging and personally risky role.

There is a greater expectation of choice and independence for older persons

The adoption of neoliberal policy is reflected in both the Productivity Commission and aged care reform reports, with clear acknowledgement of societal shifts and increased expectations of individual choice and consumer driven care. This is portrayed as being what the new system needs to enable older Australians to maintain independence, retain control and exercise choice. Of the 23 references to choice in the Living Longer, Living Better reform, 12 of these relate to residential care choices and a further four acknowledge barriers and challenges to choice in the existing system. There are at least six references to plans to increase consumer choice for the care recipient, yet only one reference to caregivers in relation to choice. Interestingly, within this solitary reference the reader is advised that during extensive consultations, carers indicated they wanted more choice; although plans to explore or enable this are notably absent from discussion.

While it is stated that "older Australians generally want to remain independent and in control of how and where they live; to stay connected and relevant to their

families and communities; and be able to exercise some measure of choice over their care" (Productivity Commission, 2011, p. XXIII), this raises the question of what this might mean for carers if a person insists on staying at home. A real absence is noted in the lack of consideration given to the implications of increased choice for older persons on their co-resident spouse or other family members.

In contrast the National Carer Strategy does not focus on choice, with this word only present in its vision statement. Instead there are 12 references in the document to caring responsibility, and an emphasis on the need for recognition and acknowledgement of carers, promoting familial responsibility. This lexical choice of language (van Dijk, 2001) demonstrates the underlying position within the strategy of caregiving as a duty rather than something which can be chosen. The strategy commences with the Ministers Foreword stating that "some carers shoulder their responsibilities alone; some share their responsibilities with others" (Commonwealth of Australia, 2011, p. 5) and goes on to make statements such as "ensuring Australia's carers have the support they need to balance their caring responsibilities with participation in economic, social and community life" and that "carers and families need adequate and timely breaks from their additional responsibilities to attend to their own needs" (Commonwealth of Australia, 2011, p. 33). These statements reflect the reliance upon informal care, despite key social commentators and academics in the field warning that conventional models of caregiving cannot be sustained due to changing family structures and a diminished focus on traditional family roles and obligations (Pickard, 2010). This significantly impacts discourses of informal caregiving, with this changing landscape resulting in caregiving no longer being regarded as a solely private and familial concern, with care now being acknowledged as a social problem (Fine, 2007).

When analysing the language of choice across these documents, it is evident that expectations of choice for older care recipients are supported and encouraged, yet for caregivers there remains little choice around whether to provide at home care, or what types of care you wish to provide. With a plan to "explore innovative and flexible models of respite delivery that will enable care recipients to have greater choice and control in how respite services are delivered to them" (Department of Health and Ageing, 2012, p. 37), it is clear that even when proposing services supposedly for carers, the choice is still firmly located with the care recipient. While this is fitting with the provision of consumer directed care, it overlooks the availability of choice for carers, assuming carers agree with the choices of the older person. Emphasis on increasing choice via consumer directed care appears to further reduce the availability of choice for caregivers.

Choice is about access and control

When considering the word choice, there are a number of notable differences across the documents. While the National Carer Strategy steers away from use of the word choice, both the Productivity Commission and Aged Care Reform documents use the word freely throughout. Choice in these documents is used to

indicate the ability to select from a range of offered services and supports. Within the Productivity Commission report, choice is defined as "care recipients being able to choose between services that are differentiated to some degree" (2011, p. 55) and is frequently framed as being to "enable older people to retain some control over their lives" (Productivity Commission, 2011, p. 160). The Aged Care Reform continues focus on developing a system that provides more choice, with choice often used alongside both "access" and "control".

There is also a clear focus on choice being about selection of services rather than about the choice to provide care or not. This highlights the presupposition that caregivers will be available, with this availability an unquestioned assumption. The choice to care or not is absent from all three documents analysed, presumably an omission that for the average reader would simply result in its absence not being noted and therefore not scrutinised.

Spouses are willing to provide informal care

In the Productivity report the following statement is made: "The number of frail aged couples who may wish to remain together in care is yet another dimension of the type of demand that is likely to grow in the future. Increasing longevity, the narrowing gap in life expectancy between the sexes, and the likelihood that some older people will require residential care simply because their frail partner or spouse is no longer able to appropriately care for them, are likely to place additional demands on residential care for more flexible accommodation arrangements for couples" (Productivity Commission, 2011, p. 54). This comment demonstrates a presupposition, where the implicit meaning is in the unstated assumption that this type of support is only required if a spouse is no longer able to provide care at home. When we consider that older caregivers themselves have increasing frailty and complex health needs, it is clear that greater focus needs to be provided to supporting couples as a unit, not only in light of one being "no longer able to care". This assumption of care fails to take into account the complexity of the care relationship, particularly given the advancing age of spousal caregivers.

This assumption of spousal care is also evident in plans to offset future predictions of less informal caregivers, with "an increasing number of partners are living longer, which could increase the availability of informal carers" (Productivity Commission, 2011, p. 57). Research suggests obligation or lack of other choices underlies the reason for many who provide informal care (Australian Bureau of Statistics, 2008). Despite this body of research existing in the public domain, there is little acknowledgement of this in the Productivity Commission report and none at all in the subsequent reform package. In fact, the Living Longer, Living Better reform makes no specific mention of spousal caregivers at all, other than with reference to partners impacting on income and asset testing. While the Carers Strategy does acknowledge that for many carers there is no other alternative, it makes no attempt to discuss this further. The Productivity Commission Report makes a few mentions of "willingness to care" (2011, p. 57), which implies choice,

though again this does not progress beyond acknowledgement. Phrases such as "no other alternative" and "willingness to care" demonstrate euphemisms to "no choice" and "unwilling to care".

This certainly demonstrates the assumption within the policy arena that all caregivers wish to take on and carry out their roles, which conflicts with recent Australian data to the contrary (Australian Bureau of Statistics, 2008). These dominant ideas have created a discourse where there is often no question around the availability or willingness of a partner to provide care, as this can be assumed as an expression of marital commitment and loyalty (Burridge et al., 2007).

Conclusion and Implications

The discourse of caregiving has evolved and changed over time. This analysis focuses on the way these discourses are constructed and employed in political rhetoric and social policy. Social welfare commentators such as Esping-Andersen (2009) have highlighted that any analysis of population ageing should avoid exclusive focus on immediate issues, such as need for care beds and economic constraints. Instead it is necessary to look beyond these issues to consider the broader profound impacts on social and economic structures. Critical discourse analysis provided a unique opportunity to contribute to discussion on these broader social considerations for spousal caregivers. CDA is an interpretive method, which can be a complex and technical process. Focusing on techniques of CDA accepted as being accessible to researchers from social science backgrounds enabled this method to be utilised successfully, however it requires acknowledgement that the researcher does not have a background in linguistics. It should also be noted as a limitation to this research that this analysis is specific to the Australian context. Although many developed countries have engaged neoliberal ideas to managing population ageing, contextual differences may limit the transferability of these findings to other locations.

The emergence of individual choice within policy has created an inequity for caregivers, who are not afforded the same degree of choice as other older Australians. The three documents analysed clearly demonstrate neoliberal motives to encourage individual responsibility for ageing, as a means to address the predicted fiscal gap of a rapidly ageing population. Conspicuous by its absence is the lack of consideration to the impact of this on informal and spousal caregivers. There is a clear distinction in these documents between aged consumers and their ageing caregivers, specifically evident in the language around choice and responsibility. Consumer directed care delivers a focus on the older care recipient, seemingly at the expense of choice for their caregiver. It is also clear that choice in this context is about access and control, which although beneficial when considering access to services, fails to consider the fundamental choice to provide informal care or not.

There are many assumptions evident in the documents analysed, primarily that family caregivers have and will continue to provide care. This assumption is so

strongly held that both the Productivity Commission Inquiry and subsequent aged care reform are based on this premise. It is presented that family will provide care out of love, and largely because there is no other alternative available. Researchers such as Cahill (1999) have found that caregiving can and does take place in the absence of love and affection, so it cannot be assumed that love is the underlying motivation behind duty to care, when the primary issue is a lack of choice. By enforcing the dominant cultural and moral discourse of "loving caregiver", there is an ongoing attempt to promote the preferred policy solution of increased familial and spousal responsibility for care.

This focus on independence is essentially shifting the burden of care from the public arena to private homes, creating a greater dependence on spousal caregivers and other family members (Fine, 2012). While there is a preference for at home care, it is crucial to consider that the carers themselves will also be ageing, with the largest growth in numbers of informal carers projected to occur amongst older persons (Percival & Kelly, 2004). By 2031, older carers will contribute 56% of all care (Percival & Kelly, 2004) at a time when both carer and care recipient live well into old age and with the complexity of their own health needs.

As the number of older people with a severe or profound disability is projected to grow, their care needs will increasingly be more complex. This combined with decreased availability of informal carers will mean that government policy can no longer rely on the future availability of informal care (Hughes & Heycox, 2010) or that ageing partners will assist in filling this void over time. While research has considered the implications of intergenerational care, very little has considered the unique situation of spousal care in older couples.

A significant absence evident in the discourse of caregiving is that of family members and spouses who do not take on the role of informal caregiver. A sense of moral or social responsibility provides the cultural context for many Australian families, increasing the likelihood that people may not readily disclose their true views in order to provide socially desirable responses (Burridge et al., 2007). So while a modern society may portray a sense of choice, decisions that do not fit within cultural norms and expectations may actually diminish the real value of choice in these situations.

Policies are affected by ideological influences such as neoliberalism, which essentially attempts to transfer economic principles and values to the social world. While this might seem logical to governments attempting to escape predicted financial strains of population ageing, it is crucial that we do not lose sight of the human factor, and of the impact these policy directions have at the individual, family and community level. Espousing choice for an ageing population and creating systems of individual control and consumer directed care cannot come at the expense of equity, rights and wellbeing of spouses and other informal caregivers. The challenge for social work is that we maintain an awareness of how these discourses and ideologies are filtered into social policy and subsequently practice. Given the changing context of community values, attitudes and

structures, it is important that we consider grounding policy for an ageing Australia in social reality if it is to work well (Bartlett, 2003).

There are a number of implications of this for the social work profession. Within both policy and practice arenas, there is a need for increased equity of choice for caregivers, especially in the delivery and provision of consumer focused care. At the practice level, it is critically important that social workers investigate the ability of spouses to provide care and continue to argue for better care packages for older people. Equally carers advocacy organisations need to challenge inequities to ensure all older Australians are supported and afforded choice. This is particularly important when we consider the possible implications of the deteriorating health of carers who may be unwilling to continue in caregiving roles.

At the broader policy level, social workers need to be aware of significant sociological changes being observed internationally which will challenge well-established traditions. The inadequate policy offerings serves to create a sense of gratitude by caregivers that they are being acknowledged, yet this does little to address the fundamental imbalance of power and inequity at play here. Rectifying this cannot be adequately managed at the family level alone. This disequilibrium needs to be considered as a concern of the welfare state and can be enacted through new social policy (Esping-Andersen, 2009). Thus policy directives should focus upon the causal connection between stages of the life cycle and provide solutions that do not focus entirely on population ageing as the social problem. This will foster societies better equipped to identify and rectify the underlying driving forces that are producing these challenges over the long term (Esping-Andersen, 2009).

Finally, more research is needed to identify how choice is facilitated within direct practice environments and to understand the experience of choice from the perspective of caregivers themselves. As a profession who strives toward equality of human rights, there is an ethical responsibility to consider the equity of traditional role assignments in the face of increased choice in all other areas of policy and consumer driven care.

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Summary of chapter

The findings in this chapter addressed the first research question of this thesis: *How is choice portrayed in contemporary social policy with regard to informal caregiving?* The findings revealed how policy uses emotive language to promote discourses of informal care as a relational act of love. The strong assumptions surrounding both the availability and willingness of family members and spouses to provide care underpinned all three policy documents analysed. Submissions were received by carer advocacy groups during the Productivity Commission Inquiry and consultations with caregivers also occurred during the development of the National Carer Strategy. These findings, however, continued to highlight the absence of choice in the way informal care is constructed within social policy.

This analysis also demonstrated the strong influence of economic principles on choices and supports for caregivers within the care system. The economic rationale underpinning decisions to support informal caregivers was justified as a means to avoid the financial repercussions to government if the provision of informal care was reduced. This primary focus of caregiver supports being to sustain continuation of care demonstrated an example of how power can be maintained through discursive strategies. These overt statements justify economic rationale at the expense of potential social and financial exploitation of caregivers. This is particularly relevant to the study of vulnerable groups such as informal caregivers, where there is a general acceptance of dominance by broader health and care systems dependent on their cooperation and contribution. These findings are important both in the contribution these insights make to knowledge, but also as a foundation to build subsequent stages of research within this thesis.

It was key that the method of analysis specifically enabled the critical and contextual focus of the thesis methodology to be enacted. While discourse analysis has long been utilised within linguistic studies to explore the function and structure of language (Marston, 2004; McCloskey, 2008), critical discourse analysis (CDA) enables social researchers to move beyond the linguistic level to critically review the impact of policy language on social phenomena and within the context of changing social and political environments (van Dijk, 1993; Wodak & Meyer, 2009). This also increases the accessibility of discourse analysis to social researchers, providing a method to analyse language use within its social and political context (Marston, 2004; Fairclough, 2010). Of particular relevance to this study was the ability for CDA to analyse how discursive strategies can maintain social inequality and power imbalance and how this inequality may be, sometimes covertly, communicated in language and text (van Dijk, 1993); how power can be exercised in social settings through the use of language and texts to promote specific ideological agendas (Fairclough, 2010); and how policies can reveal assumptions and subject positions (Marston, 2004).

While the critical and contextual abilities of CDA offered significant benefits to social work research, it is worth noting the potential challenges of this approach for social researchers. Emerging from a linguistic field, navigating CDA literature can be incredibly daunting for a newcomer to the complex linguistic jargon inherent in this space. Despite extensive texts discussing principles and examples of CDA, the theoretical concepts of discourse analysis are complex, making it difficult to establish a common understanding or systematic approach

(McCloskey, 2008). There is also a dearth of direction around how to design and approach analysis in a practical sense. Despite these challenges, the benefits of this critical and contextual method made this adventure worthwhile. Being able to consider the impacts of policy language on practitioners and resources enabled a much richer appreciation of the policy context and reforms that would not have been evident at any superficial level of reading. As a social worker, the analytic skills developed through use of this method are an invaluable contribution to the social work toolkit, with the capacity to apply this lens to the many texts encountered within social work practice, education and research.

The critical discourse analysis undertaken in this thesis provided an insight into the complex and conflicting ideologies co-existing within social policy and aged care reform. The findings of this policy analysis were then used to inform the second stage of data collection, which sought to understand the translation of these policies into health and aged care practices. The next chapter will discuss how practitioners navigate the translation of these policies into their work with older community residing couples.

CHAPTER 5: Stage two findings – Exploring choice in practice

Introduction

This chapter presents the findings from the second stage of the study. It explored the second research question of this thesis: *How do practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities?*

Practitioners represent a critical junction for the implementation of reforms in the health and aged care sectors. As key facilitators of access to formal service systems, as well as enactors of social policy, this stage set out to understand the role of these central players in the care system. The analysis of individualism and familialism within stage one of the thesis presented an important foundation for this second stage, which sought to understand how these conflicting ideological paradigms play out in the provision of services to older couples.

In order to capture the depth of discussion required to achieve this aim, focus groups were devised. The questioning route was designed to guide practitioners through a critical reflection of their personal views and professional practices with older community residing couples. This method of data collection was successful in capturing the many personal and professional dilemmas in practitioners' translation of policy and highlighted the significant impact this can subsequently have on service recipients.

The contributions to authorship of this paper are as follows:

Author	%	Contribution
Belinda Cash	60	Prepared focus group and recruited participants Conducted focus groups with practitioners Analysis of focus group transcripts Completion of first draft of article Reviewed and responded to track changes and feedback from co-authors on each version of manuscript Prepared and submitted article to journal Responded to and addressed reviewer feedback
Suzanne Hodgkin	25	Peer discussion of transcripts, codes and emerging themes during data analysis Provided feedback on manuscript
Jeni Warburton	15	Provided feedback on manuscript

Practitioners' Perspectives on Choice for Older Spousal Caregivers in Rural Areas

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Abstract

Recent shifts toward individual choice and consumer-directed practices largely conflict with traditional expectations of familial obligation and informal caregiving. The research reported on in this paper aimed to understand how practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities. Seven focus groups were conducted in rural and outer regional areas of North East Victoria, comprising 42 practitioners who work with older couples who reside in the community. Thematic analysis revealed practitioners' personal values and constraints of the direct practice environment impact on the experience of choice for older Australians. This discussion considers the problematic nature of choice in policy and practice for older people and their caregivers in light of these findings.

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Population ageing has prompted significant review of social and economic policy, resulting in an array of new policy and practice initiatives in health and aged care (Hughes & Heycox, 2010). Neoliberal values of financial independence and self-reliance are encapsulated in recent policy directives, which highlight key values such as choice, independence, and self-determination (Cash, Hodgkin, & Warburton, 2013). These values have manifested in policy changes such as consumer directed care and a renewed focus on ageing in place, with changes also shifting the expense and locus of care provision from government to private households (Hodgkin, 2014). This dynamic and changing policy environment creates challenges for practitioners, who can become caught between policy directives, conflicting social norms, and the reality of practice. These challenges can be further exacerbated for practitioners in rural and remote areas, whose practice environments are frequently at odds with policy developed for metropolitan contexts. The rural practice environment is of increasing relevance, with a higher ratio of older people living in regional and rural areas than in major urban locations and projections are that this will continue in the future (Australian Bureau of Statistics, 2008; Australian Institute of Health and Welfare, 2007; Edwards, Gray, Baxter, & Hunter, 2009).

Using critical discourse analysis, we have previously highlighted assumptions and expectations of informal care embedded in key policy documents (Cash et al., 2013). Here we argue the language associated with familial care and its emphasis on obligation to care remains pervasive. While consumer directed care and

individual choice are heavily promoted, these are absent from policies directed at informal caregivers (Cash et al., 2013). This absence has been discussed by others such as Pickard (2010), who identified the tension between policies that advocate individualism and others that promote familialism. So it is pertinent then to consider how this tension in social policy is played out in the rural practice environment. This paper examines how practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities. This insight has the potential to increase understanding of the impact practice has on choice for spousal caregivers and to inform practitioners and health services in rural areas how choice for older caregivers can be better understood and enabled in practice.

Background

Recent shifts within policy and practice have increased focus on community-based care, healthy and active ageing, individual responsibility for ageing, and increased consumer choice (Hughes & Heycox, 2010). Although these are frequently marketed as providing individual choice for ageing consumers, the reality of inadequate resources forces reliance on informal support in health and aged care. This inequity is apparent in a growing body of research where marital, familial, and emotional obligations, or a lack of other available alternatives are frequently identified as reasons people provide informal care (Australian Bureau of Statistics, 2008; Burridge, Winch, & Clavarino, 2007; Cahill, 2000; Duner, 2010; Kuscu, Dural, Yasa, Kiziltoprak, & Onen, 2009). So while additional choice is promoted to ageing consumers, this appears to occur at the expense of choice for their ageing caregivers. It is important to note this consideration of choice is not about critiquing the essence of caregiving, rather it is about critically considering how it is constructed and employed in political rhetoric and social policy (Hughes & Heycox, 2010).

Choice is theorised as enabling greater individual freedom and control, subsequently improving wellbeing and increasing satisfaction with services (Arksey & Glendinning, 2007; Markus & Schwartz, 2010). Within health care, it is based on the assumption that consumers have the capacity and willingness to readily select their preferred option by trading off the costs and benefits of available choices (Foster, Earl, Haines, & Mitchell, 2010). Conversely, it has also been argued that concepts of choice do not necessarily translate effectively to public and welfare services, where it can increase anxiety and stress and further exacerbate inequities for some healthcare users (Arksey & Glendinning, 2007; Markus & Schwartz, 2010). It is also important to note that support for this concept has focused almost exclusively on choices made in the absence of contextual factors (Markus & Schwartz, 2010), thus the promise of choice does not take into account the various values, social norms, and internal conflicts that underpin these decisions (Arksey & Glendinning, 2007; Foster et al., 2010). For caregivers specifically, research demonstrates their decisions are socially situated within families and wider social and cultural expectations (Arksey & Glendinning, 2007; Egdell, 2013) and involve a complex combination of emotion and relationship

(Rummery & Fine, 2012). Older caregivers in particular experience restricted choice due to longstanding relationship obligations and a struggle to align with practitioners' emphasis on individual choice (Pickard, Shaw, & Glendinning, 2000). So while social policy initiatives emphasise a focus on consumer choice, there is a multitude of complex factors impacting how this is translated into practice.

Beyond the challenges of choice for caregivers themselves, it is important to understand the role of health and aged care professionals in facilitating choice. Social workers and other practitioners play a key role in frontline work, supporting decision making and negotiating community and residential care systems with older persons and their families (Hughes & Heycox, 2010). However, a key challenge is that the current climate within health and aged care is one of dependence on the availability of informal care, so much that formal care is essentially the supplement and safety net to the unpaid work of partners, family, and friends (Hughes & Heycox, 2010). Financial constraints, eligibility criteria, and waiting lists for formal services force practitioners to "choose" who will receive services according to organisational criteria and available resources (Arksey & Glendinning, 2007). These shortages are often more apparent in rural areas with a lack of available, adequate, affordable, and accessible health and social services being attributed to the health disadvantages of rural residents when compared to their urban counterparts (Byles, Powers, Chojenta, & Warner-Smith, 2006; Davis & Bartlett, 2008; Edwards et al., 2009). These create significant challenges for practitioners attempting to balance the needs of older people and their caregivers, with frontline practitioners ultimately responsible for translating policy objectives that strive for community based care at the practice level with limited available formal supports (Hughes & Heycox, 2010).

With the assumption of informal care evident across social policies, it is important to consider the role of healthcare practitioners in further enabling or limiting choice for older people. Also, it is crucial to consider the integral challenges of drawing on choice within ageing and caregiving, which are founded on longstanding familial care traditions. These relationship obligations are particularly relevant to the experience of spousal caregivers, who make up 83% of caregivers over the age of 65 and whose cohabitation increases the likelihood they will become the primary carer of their ageing partner (Australian Bureau of Statistics, 2008; Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2009). A systematic review of studies on caregiving willingness suggested that "for healthcare professionals, acknowledging reluctance may complicate the process of allocating scarce resources if the caregiving role is rejected" (Burridge et al., 2007, p. 17). The implications of overt dependence in the health and aged care systems on informal carers can complicate ethical decision making for busy rural practitioners, who are often faced with limited alternative resources to offer. This dependence increases the risk of professional complacency in assuming caregiving willingness, raising an important ethical consideration for healthcare practitioners working with older people.

Research Methodology

This study addressed the question of how practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities. The study involved a series of focus groups with healthcare practitioners working in rural and outer regional areas of north-eastern Victoria. Ethics approval was sought and obtained prior to commencement of research (La Trobe University, Faculty of Health Sciences Human Ethics Committee, FHEC12/177).

The study location included five local government areas in North East Victoria, with each location varying in both size and access to available health and community supports. The region was selected as a population with a higher proportion of older people than the state average, with projections suggesting this ratio will continue in the future (Victorian Department of Health, 2013). It also comprises both regional and rural health services, with participants recruited across these services to present a broad picture of practitioners in the region. Seven health services in the identified region were invited to participate, comprising either the sole health service within a rural locality (n = 4), or a regionally based organisation providing acute or outreach services to these rural locations (n = 3). The first researcher worked with a contact in each service who invited all staff who met the inclusion criteria. Criteria included being a healthcare practitioner, working in a rural or outer regional area providing services to a rural population, and being engaged in work with older community residing couples. This achieved the diverse mix of services and practitioners required in focus group research (Krueger & Casey, 2000). The sample comprised 42 practitioners, with groups held at each of the seven health services. The professional background and gender of participants are presented in Table 1, and their roles are presented in Table 2. The diversity of backgrounds is consistent with literature on rural practice (Dellemain & Warburton, 2013).

Table 1 Participants by Professional Discipline

Discipline	Female	Male	Total
Nursing	22	1	23
Social work	3	2	5
Physiotherapy	4	0	4
Occupational therapy	3	0	3
Other professional background	6	1	7
Total	38	4	42

Table 2 Participants by Role

Service Provided	No. of participants
Aged Care/HACC Assessment	10
Direct nursing care (inpatient)	7
Direct nursing care (community)	5
Allied health (discipline specific)	8
Social work specific	4
Senior/coordination role	4

Community case manager	2
Other role	2
Total	42

The focus group methodology was important in this study as it incorporated both participants' language and views on a topic, as well as the benefits of interaction between participants, allowing them to explore and clarify their views on complex topics in greater detail (Krueger & Casey, 2000; Liamputtong & Ezzy, 2005; Morgan, 1997). In the present study, it was anticipated that focus groups would enable a reflective means to engage in discussion about choice, which might also permit an exploration of normative assumptions (Kamberelis & Dimitriadis, 2008). Although focus groups are useful in the context under study, it is important to note that some individuals are constrained in a group setting (Morgan, 1997). Thus it is important to be cognisant of this potential weakness and ensure space is provided for all participants to express their views.

Each focus group ran for approximately one hour and was facilitated by the first author. As recommended by Krueger and Casey (2000), discussion moved from introductory questions to more specific topics. Specific questions included, for example: How are decisions made about what care and support will be provided? How and when are these choices offered? Do you think choice for caregivers is actively considered by practitioners? The focus groups were audio recorded and transcribed verbatim, with personally identifiable information removed from the transcripts to protect participant anonymity. Transcripts were analysed using an inductive process of thematic analysis, with assistance of data management software NVivo. Co-coding and regular peer discussion of emerging themes took place between the second and third author, to increase interpretative rigour (Liamputtong & Ezzy, 2005). A comparative analytics method was used to ensure that as new themes emerged in second and subsequent transcripts they were revisited in the first and so on (Krueger & Casey, 2000). Analysis then identified the sequence of emerging ideas before key themes were determined and exceptions identified. This allowed consideration to not only the emerging themes, but the evolving and reflective nature of discussions both within and across groups.

Findings

This research sought to understand how practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities. The interactions between practitioners moved discussion from initial "gut" reactions that often reflected personal and social values and norms, to a reflection of their professional practice and the constraints within which they work. There followed a discussion on how these constraints impacted on the experiences of older couples within their community.

Love and Obligation: Contradictions of Caregiving Motivation
Initial responses by practitioners in this study reflected a powerful moral discourse based on assumptions that those who care do so out of love (Cash et al., 2013). Many expressed surprise at use of the term "choice" in relation to spousal care. Their response reflected traditional assertions about marriage such as: "I think it's what they sign up for" (FG3, nurse) and "Well there's the wedding vows, till death us do part" (FG7, nurse). Other comments reflected expectations of caregiving within a spousal relationship, "there is a higher expectation from the person who needs the care that their spouse will continue to fulfil that role" (FG7, social worker). These comments are consistent with social expectations and norms of spousal care, and perhaps indicate a lack of critical thought within this practice domain.

Practitioners across several of the groups also discussed "the promise" couples had made as a demonstration of caregiving as love and commitment. Many stories were shared of couples who had made "the promise" to provide support at home rather than consider residential care, struggling to relinquish care roles despite adversity and difficulties in continuing to do so. Stories often reflected couples experiencing guilt and distress in their struggle to maintain the promises made to one another, demonstrating that practitioners are well aware of the highly emotional ambivalence of choices made in this context.

Following these initial responses, participants began to reflect on social obligations and marital expectations as strong driving forces motivating spouses to provide informal care. Practitioners felt choice was inhibited significantly by social expectations and pressures, with one noting "I think there are a couple of disincentives to abandon being a caregiver. One would be your neighbours, what sort of bastard are you?" (FG3, nurse). This response is perhaps particularly relevant to those living in rural areas where communities are smaller, neighbours are more aware of what is happening, and there is stigma attached to formal support (Dellemain & Warburton, 2013).

> When you are going back to these small rural areas, there is some pressure … you've got to show that you've done your best before you put your partner in care … you've got to travel the journey of a dutiful wife (FG7, social worker).

However, choice within care is a highly complex phenomenon, as noted by the following participant:

> I'm not sure in many circumstances that people do have a choice. There are certain assigned things that you take on in life and I think this is probably one of them. Realistically, from a physical sense, the choices are out there. You can put your rellie in care if you decide to, that is your choice. But the choices in your head or from an emotional sense, I think are quite different really. I'm not sure that choice is there yet (FG3, nurse).

These conflicting views of motivation to care, love versus obligation, highlight the complexity underpinning this situation for both ageing caregivers and for practitioners. This is compounded for spousal caregivers, who face additional normative assumptions about care within relationships. This can contribute to

practitioners being reluctant to intrude within spousal relationships and caregivers self-imposing constraints about accepting support that arise from feelings of obligation (Arksey & Glendinning, 2007). Thus, choice in this context is highly complex.

Exceptions to Care as Love

As discussions continued, practitioners began to engage in deeper reflection about the exceptions: partners who did not want to provide care to a spouse. They used descriptive terms such as "caught in a trap" and "crisis point" to highlight the bind between marital obligation and the reality of care. Observations included, "really don't want to do the care but caught in that trap of hey, I'm married … " (FG3, allied health) and "they think that's what is expected of them and they will do it for a long time, but they don't want to do it and they resent it" (FG7, social worker). While their initial reaction was normative, many began to unpick the notion of spousal care as an accepted social norm. However, few openly considered the quality of the relationship and its relevance to willingness to provide care. One participant captured this concern, stating:

> Some people do it willingly and gladly and that's what they want to do and they are so committed to each other and that's good, but it depends a lot on relationship … What people forget is that domestic violence and issues can occur in young people and they are just the same sort of mix of relationships spread across older people. They don't just suddenly all work out hunky dory, just because you're old (FG7, social worker).

The majority of practitioners reflected on the impact of stress on decision making, with repeated discussion across all of the groups highlighting that caregiving situations often reach a crisis point before services are accessed. While caregiving was perceived as a norm, there was a degree of dissonance between expectations of this role and the crisis that often follows. Many practitioners identified that caregivers are often emotional, anxious, and distressed during these crisis presentations, which was seen to significantly inhibit their ability to make informed choices. This highlights potential challenges of consumer-directed practice, and the implications of older people making decisions at a time of personal turmoil.

Participants also noted a duality in the way spousal caregivers discussed their caregiving. Several participants across the groups used the expression "the quiet word" to reflect on the frequent occasions they found themselves approached by caregivers following meetings to convey concerns. One participant captured the discrepancies of this talk, saying "you've spent an hour and a half hearing one version and then in ten minutes it turns the whole thing upside down" (FG4, nurse). Being able to provide a safe environment, usually away from the care recipient, to talk openly about the care role and their willingness to undertake this was identified as important to enabling freedom to speak openly and honestly. There was a strong sense that in many instances, caregivers are reluctant to admit they are struggling or do not want to continue in their role in front of their partner or during meetings with multiple staff. At no point was "the quiet word" seen as

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standard practice or an organisational requirement in establishing care or discharge for older persons. Despite this, it appeared to be accepted as a frequent occurrence without significant critical consideration of this phenomenon and why it occurred outside more formal discussions.

Value of Critically Reflective Practice

Although participants were well aware of social expectations around spousal care, some were more able to critically reflect upon their implicit role in promoting marital obligation. For instance, one participant openly commented that "I think professionals expect that of spouses, and they expect children to do that as well. To provide a certain level of care" (FG7, social worker).

Several practitioners also noted that care is not static. One suggested that "you might only start with helping them with something little and gradually this person is deteriorating, so you are getting more and more responsibilities" (FG7, allied health). On a more concerning level, some practitioners openly stated it was not their concern if someone identified unwillingness to care.

> How often do we come across where once this acute illness occurs, the partner will take that opportunity to say well I'm not having them home any more. Well, wait a sec, we're not into marriage counselling here, but you know, they think we are going to solve the problems for them. Well unfortunately you're going to end up taking them home again (FG7, nurse).

While few discussed unwillingness to care, others highlighted the imbalance in needs between older people who wanted to return home and family caregivers who resisted this. This disparity between the needs of client and caregiver was evident on several occasions, yet very few practitioners noted any attempt to identify appropriate alternatives for caregivers in these circumstances. Overall, the result was an ongoing reinforcement of familialism and its subsequent implications for caregivers over time.

Challenges of Direct Practice

Multiple factors were identified that impacted on the reality of choice in practice. In almost every instance, participants stated "we're consumer focused" and "we're client focused," yet there was also evidence of contradiction. Some comments alluded to consumers "coming around" to a particular suggestion or practitioners "chipping away" at a preferred solution. Despite the clear identification with consumer-focused practice and many practitioners speaking of the flexibility and diversity of supports able to be offered, this was contradicted by frequent acknowledgment of limited resources. One practitioner noted that "it's all very well to say you can have whatever you want, but what if whatever you want just doesn't exist in your area" (FG5, nurse). The lack of available alternatives for both consumers and caregivers in rural areas contributes to a practice environment that significantly limits practitioner's ability to actually offer choice and be consumer directed in practice. For many, the reality of rural health care meant they were the only health service within a particular area.

> As far as I know there isn't anything, there isn't another choice. So from a consumer's point of view, I don't know whether it's important to them or not to have the choice of whether they come here or somewhere else. But the reality is they actually haven't (FG1, allied health).

Barriers created by geographic distance were raised across all of the focus groups. Distance had the most extensive impact on both individuals and organisations, affecting access to services and specialists, severely limiting packaged services, increasing travel time and expenses, and ultimately restricting choice for consumers. Participants identified that no allowance was made in consumer funding packages or in service funding to reflect the considerable distances travelled to provide services for older people wishing to remain at home. At a service level this impacts on waiting lists, ability to see more clients in a day and a reduced ability to provide services more regularly across the region covered.

A further constraint related to health literacy, with system complexity seen as a barrier that significantly impacts consumer and caregiver choice and consumer directed care.

> People are really confused about what's available … They struggle with the language, they struggle with the terminology that is used, they struggle understanding what are the services, how do they pay for that and how is that going to impact on their pension … Sitting down and making those decisions is really, really, really difficult sometimes (FG6, nurse).

While issues of health literacy and limited resources were identified by practitioners as barriers to choice and service accessibility for older Australians, it is important to acknowledge the complexity of translating choice in practice extends across practice constraints to the impact of social norms on both couples and practitioners, making the limited choices that practitioners have available potentially undesirable or unrealistic for older couples in the community.

Discussion

By exploring the concept of choice in relation to rural spousal caregiving, this research contributed to our understanding of the complexity of practice in these contexts. Findings comprise two key areas impacting on choice for rural caregivers: the impact of social norms on practitioners' own personal values and practice decisions and the constraints of direct practice environments. Initial reactions from practitioners across all professions highlighted social norms around marriage and care with regard to choice. Once encouraged to reflect more on this notion, it was clear that the concept of choice is complex and presents huge challenges to practitioners in the contemporary environment of care. Growing numbers of older people, challenges of geographic and social isolation, and major service challenges due to the tyranny of distance provided additional challenges to the rural and regional practitioners in this study (Davis & Bartlett, 2008; Winterton & Warburton, 2011). The views of practitioners clearly demonstrate they were well aware of these challenges in their practice settings and these findings suggest that many were struggling with how to implement choice when little or no choice exists.

The concepts of choice and consumer directed care are readily drawn on within policy and practice without due consideration to the complexity and problematic nature of these ideas for older persons and their caregivers (Arksey & Glendinning, 2007; Markus & Schwartz, 2010). This study supports these concerns that choice is problematic, with practitioners' initial lack of critical reflection regarding choice demonstrating the tendency to overlook the complex dynamics and feelings of obligation often inherent in caregiving relationships (Arksey & Glendinning, 2007). The general supposition that spouses will provide informal care despite the risks and complexities also transfers from policy into practice. While it may be assumed most caregivers willingly undertake this role, research clearly demonstrates this assumption cannot be made of all caregivers. The majority of practitioners in this study demonstrated acceptance of caregiving obligations, which has important implications for their direct practice with family caregivers.

As discussed by Hughes and Heycox (2010), this competing demand to enact community care policy objectives while balancing the needs and preferences of caregivers places practitioners in a difficult bind. A study into choice for caregivers in the UK found that although practitioners generally used appropriate reasoning in decisions about what is acceptable for caregivers, this was often based on implicit assumptions rather than something actively discussed and explored with the caregiver themselves (Pickard et al., 2000). This was also evident in the present study, by the ad hoc manner in which caregivers were afforded individual opportunity to discuss their willingness to commence and continue in a caregiving role. Although the majority of participants in this study reflected empathy and genuine concern for the wellbeing of caregivers, familial assumptions appear to reduce the likelihood of practitioners actively asking questions about willingness or capacity to care. In light of literature that identifies significant concern for caregiver's social, financial, and emotional wellbeing (Hodgkin, 2014), it is important that practitioners regularly review what each caregiver's role constitutes and ultimately whether this is reasonable (Pickard et al., 2000). Important reforms in the UK now provide caregivers with legal rights to carer assessments and support, significantly improving meaningful opportunities for engagement and choice (NHS, 2015). This commitment to caregiver wellbeing remains absent in Australian aged care reforms.

Practitioners in the present study also acknowledged how pervasive societal and marital expectations of caregiving are and how difficult it therefore becomes for spousal caregivers to relinquish care. Through observations of "the quiet word" and other examples, they recognised the difficulty for caregivers in admitting an inability to cope in front of a spouse. This supports findings of a systematic review of caregiver reluctance by Burridge et al. (2007), who identified that long-established social and cultural traditions can reduce the likelihood people will readily disclose their true thoughts on providing care. Practitioners' own acceptance of these norms can further reduce the likelihood that caregivers will feel able to disclose concerns. Research in the UK by Pickard et al. (2000) compared the experiences of health care between service providers and older

couples. They found that although nurses claimed to offer choice, caregivers identified feeling obliged to be involved in the provision of care (Pickard et al., 2000). Within the informal care context, social traditions constrain caregivers to the point that the concept of choice is arguably rendered meaningless.

In addition to complex personal and social considerations, this study found the facilitation of choice is also constrained by organisational contexts, which combine to limit what practitioners can offer clients by way of meaningful choices. It is important to note the concerns raised regarding limited health literacy of older persons, which places frontline practitioners in a particularly powerful position of enabling and facilitating choice and access to services for consumers who may have limited awareness of alternatives or the personal resources to navigate these systems (Arksey & Glendinning, 2007). Practitioners acknowledged that the real value of choice for spousal caregivers was often diminished by the multitude of structural and social factors identified, which was exacerbated by issues of rurality. In order to be able to offer meaningful choices to older persons and their caregivers in rural areas, significant fundamental changes are required to overcome the structural and planning barriers to rural service provision.

There are some clear messages for practice stemming from this research. Although it is evident that changes are required at structural and organisational levels, an increased focus on supervision and critical reflection at the practice level might reduce the impact of practitioners contributing to feelings of caregiver obligation. In the present study, few practitioners demonstrated insight regarding how their own values, language, and practices might reinforce obligation for spouses.

However, many became increasingly able to reflect on the challenges of social norms and contextual issues as discussions evolved, supporting arguments that more critically reflective approaches could improve practice for both social workers and practitioners of other professional backgrounds. This might assist practitioners to move beyond simply iterating choice, to engaging meaningful strategies that enable caregivers' opportunity to openly discuss their fears, concerns, and doubts without concern for being judged by "social norms." The implications of practitioners reinforcing familialism are significant and this change can happen in the absence of other policy or organisational changes. However, it is necessary to acknowledge that not all services, particularly in rural areas, have the luxury of employing social workers. This raises the need to consider knowledge translation to other health professions involved in supporting older couples. Interesting observations of diverse practitioner backgrounds were noted during the evolution of the group discussions though were not conclusive enough to warrant inclusion in the findings. It would be of interest to further examine the impact of professional training on how practitioners utilise systemic context and critical reflection when facilitating choice in practice.

At a more macro level, this study supports previous findings about choice within policy not aligning with contemporary social contexts (Cash et al., 2013). While a small body of research has considered caregiver reluctance, investigation into how

this is affected by practitioners and direct practice itself is largely absent. The timeliness of these findings becomes more pertinent in light of plans to shift community support packages within the Australian Home Care system to consumer directed care models from July 2015 (Department of Social Services, 2014). This study highlights the challenges of facilitating choice within the current practice context. Practitioners require access to adequate and appropriate resources and options to ensure that spousal caregiving is not the only alternative made available for older couples who wish to remain in the community. The findings of this study suggest that within the constraints of policy and organisations, practitioners are currently able to do little to facilitate choice for caregivers at all.

It should be acknowledged that there are limitations to this study, particularly around the size, scope, and nature of the project, which restricts the ability for these findings to be generalised to the broader population. The study offers a practitioner perspective of the caregiving experience and does not reflect the views and experience of those providing or receiving informal care. Practitioners in this study identified a number of important factors that impact on the experience of choice at both the practice and broader social and policy levels which warrant further consideration. Future research to understand the issue of choice from the perspective of caregivers themselves would be valuable in working toward this outcome.

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Summary of chapter

The findings in this chapter addressed the second research question of this thesis: *How do practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities?* Social workers and other health professionals entrusted with enacting social policy provide a crucial gateway between services and the older Australians and caregivers accessing these supports (Hughes and Heycox, 2010). Informed by the findings of the CDA, this stage set out to explore both the practicalities and challenges of enacting choice in practice, as well as any potential impacts of practitioners own normative assumptions of care within marriage.

The findings of these focus groups with health and aged care practitioners revealed important insights into the complexities of enacting individualised policies and practices into familial contexts. The disparity between the needs of care recipients and spousal caregivers was emphasised in both the conceptual and practical barriers identified by practitioners. Importantly, these findings also revealed unexpected insights into the significant influence of social norms and personal perspectives on professional practice. This provides an empirical demonstration of how the ideological conflicts identified within policy manifest within the practice arena. Strongly held beliefs about care within marriage and assumptions about the wishes of couples provided crucial insight into the weight of social norms on practitioners own perspectives and subsequently their practice.

The use of focus groups at this stage of the study encouraged discussions that explored participants' language and views about the provision choice for spousal

caregivers. This method of data collection provided the additional benefit of capturing interaction between participants as they explored and clarified both their practices and their underlying attitudes toward normative assumptions of marriage and care (Kamberelis & Dimitriadis, 2008; Liamputtong & Ezzy, 2005; Morgan, 1997; Krueger & Casey, 2000). This interactional aspect was particularly beneficial in this study, as it quickly became evident that very limited critical reflection of spousal care had occurred prior to participation in the focus group discussions. With the evolution of discussions across each focus group, practitioners moved from rote replies espousing consumer directed practice to a deeper exploration of these views. As discussion evolved, participants became more able to consider the issues of social and relationship context on choice, revealing considerable new depths to practitioners' own personal views on their practice with older couples. Limitations enforced by time and resource constraints also restricted choice and further constrained the often unheard words of caregivers during assessment and service planning. In addition to the gathering of data for this thesis, focus groups also raised awareness about spousal caregiving within the practice domain; providing the opportunity for practitioners to critically reflect on their own role in facilitating and restricting choice for caregivers.

Focus groups with practitioners provided an insight into the complex translation of choice into practice with older community residing couples. These findings were then used to inform the third stage of data collection, which sought to understand how normative assumptions of care within marriage are experienced

by caregivers themselves. This third and final stage of the thesis will be discussed

in the next chapter.

CHAPTER 6: Stage three findings – Exploring the experience of caregivers

Introduction

This chapter considers the third research question of this thesis: *How do expectations of informal care impact spousal caregivers in later life?* The first two stages of this study revealed the strong influence of normative assumptions of care within marriage on policy and practice. With contextual considerations of care examined, this stage of the research sought to explore how older spousal caregivers perceive caregiving within the social context of long term marriage. This third and final stage therefore set out to explore how these contextual factors were experienced by caregivers themselves. This final stage of data collection presented the important opportunity to capture the lived experience of caregivers themselves.

To understand the experience of choice and decision making for spousal caregivers within this context, individual interviews explored the experience of providing informal care within the context of long term marriage. Ten interviews were conducted with older adults providing care to their partner at home. Brief vignettes of these caregiver stories are provided in Appendix Seven as a contextual overview of participants.

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Author	%	Contribution
Belinda Cash	60	Prepared interviews and recruited participants Conducted interviews with caregivers Analysis of interview transcripts Completion of first draft of article Reviewed and responded to track changes and feedback from co-authors on each version of manuscript Prepared and submitted article to journal
Jeni Warburton	25	Peer discussion of transcripts, codes and emerging themes during data analysis Provided feedback on manuscript
Suzanne Hodgkin	15	Provided feedback on manuscript

Expectations of care within marriage for older couples

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Abstract
Objectives
This study explores the intersection of marriage and caregiving among older spousal caregivers in regional Australia. Specifically, we address the research question "How do expectations of informal care impact spousal caregivers in later life?"

Methods
These comprise interpretive qualitative in-depth interviews; in order to understand the lived experience of caregiving within the context of long term marriage.

Results
Findings highlight the complexity and diversity of marital relationships as the context of informal care. Individual and social obligations were evident in key themes, demonstrating how spouses automatically assume and continue in caregiver roles in later life.

Conclusion
Caregiving is an expectation of couples in long term marriages, regardless of relationship quality and willingness to care. Normative expectations also impact decision making around future care planning and transitions away from home based care. These are important considerations for both policy and practice with older adults and their caregivers.

Introduction
Spousal caregivers are significant providers of community based support to older adults in Australia, with 76 per cent of caregivers over the age of 65 providing care to their partner (1). Informal care between older spouses can be motivated by a range of complex factors, including altruism, love, reciprocity, obligation, guilt and commitment to the marital relationship (2, 3). In addition to these individual motivations, unpaid support is often a necessity for older adults wanting to maintain independent living. The health and aged care systems in Australia rely heavily on informal caregivers to support older members of the population (4), making spousal care a valuable social and economic commodity.

Previous studies have highlighted that kinship is strongly associated with feelings of obligation to provide support when a family member requires care in later life (5). Familial obligations have been associated with adverse effects such as

emotional stress and negative health impacts for the caregiver and reduced quality of care for the care recipient (5). While some literature has highlighted the importance of identifying positive aspects of providing informal care (6), research has more commonly demonstrated negative impacts on caregivers' physical, psychological and financial wellbeing arising from the stressful nature of co-resident care (7-9). Little research, however, has considered how expectations of marital relationships themselves impact the care situation. This study explores caregiving within marriage among a diverse sample of older caregivers living in regional Australia, to better understand the question "how do expectations of informal care impact spousal caregivers in later life?"

Literature Review
The experience of both marriage and care are impacted by wider social, familial and cultural expectations (10, 11). An example of these expectations is the gendered nature of marriage and caregiving, where traditional roles have long reinforced unpaid care of children and older family members as "women's work" (12). These roles are key contributors to socioeconomic disadvantage across the lifespan, which significantly impacts financial security, health, independence and quality of later life for women (13). Although women perform higher overall percentages of spousal and other care, the most significant contribution by men to informal care in Australia is care of a partner in later life (1). This is somewhat explained by qualitative explorations of gender and care, which have shown that although normative roles of women as caregivers are embedded across the life course, marital intimacy creates an interdependence where care and commitment are normative for both men and women (14, 15).

Relatively few studies, however, consider the unique nature of spousal relationships as the context of care. One study analysing the British Household Panel Survey explored individual and geographic factors in the formation of care networks (16). This research highlighted that care relationships are usually familial, forged by prior exchanges that create a social insurance of expected reciprocity should there be future adversity (16). This is particularly evident in spousal relationships and is reflected in the findings of in-depth qualitative studies such as those conducted in the Netherlands by Boeije and Van Doorne-Huiskes (17) and the United Kingdom by Ray (2). These studies identified care was strongly linked to reciprocity and marriage vows and was largely viewed as an inevitable duty of marriage.

These expectations of care, however, appear to come at significant personal cost. A large body of research has repeatedly demonstrated significantly higher incidence of psychological disorders, levels of stress and poorer wellbeing in caregivers when compared to non-caregivers (8, 19, 20). These risks are exacerbated for spousal caregivers, with age and co-residency found to increase health and wellbeing risks at a time when their own health needs are becoming increasingly complex (8, 9).

Motivational theories can help understand why someone might engage in a particular behaviour, though motivations to care are often complex and emerge from both internal and emotional drivers as well as external and social pressures

(3). Recent studies suggest caregiver wellbeing is impacted by whether an individual is motivated to care based on intrinsic or extrinsic drivers (3, 20). This is an important consideration for spousal caregivers, whose motivations are likely to be influenced by wider expectations of social norms and perceived relationship obligations.

Expectations of spousal care in rural areas is also impacted by geographic availability of and access to transport and services (21). Respite and other formal service use is a significant concern in rural communities, with fear of stigma, social connections with service providers and a heightened sense of responsibility to provide care evident in older rural caregivers (21).

While these studies provide important insights into the many impacts of care on both caregivers and relationships, it is not clear how these unwritten social obligations are experienced by and impact on caregivers in later life marriage. In order to address this gap in knowledge, the current research explores caregiving obligations on older spousal caregivers in the Australian context.

Method
This is the third stage of a multiple methods project exploring spousal care in regional Australia. Previous stages of this research examined policy and practice in relation to spousal care, demonstrating significant normative assumptions impacting caregivers at structural and organisational levels (22, 23). The current study therefore aimed to explore the lived experience of these assumptions on caregivers themselves, via the research question *"How do expectations of informal care impact spousal caregivers in later life?"* A qualitative methodology was identified as best able to capture the richness of caregivers' personal experiences and perspectives in their own words (24).

Data collection occurred via in-depth interviews conducted by the first author, who is an experienced social worker and academic with the specialised interviewing skills required to achieve the required depth of exploration. Ethics approval was obtained prior to commencement of research (La Trobe University, Faculty of Health Sciences Human Ethics Committee, FHEC12/177).

Sample
Purposive sampling in qualitative research seeks to recruit participants who can best contribute depth of understanding to the phenomenon being studied (24). This study focused on the care context, necessitating diverse respondents as demonstrated in Table 1. Inclusion criteria comprised being either male or female; aged over 65 years; live in regional North East Victoria, Australia, and be or have recently been a co-resident caregiver to a spouse or partner. Participants were recruited via non-probability self-selection sampling, where individuals responded to written advertisements displayed in health care centres and caregiver support groups. Although this approach can lead to sampling bias where only people with a specific interest will reply (24), it enables better protection of potential participants from coercion to participate. Although not a requirement of the sampling frame, all participants who elected to participate were in long term marriages (mean 44.9 years). As interview analysis began at completion of the

first interview, the sampling strategy continued until it became clear that although new interviews provided diverse participant stories additional themes ceased to emerge, suggesting theoretical saturation had been reached (25).

Table 1: Participant demographics

Pseudonym	Gender	Carer Age	Spouse Age	Married (years)	Reason for care	Length of care
Carol	Female	69	84	34	Frailty	1 year
Richard	Male	65	60	40	Huntington's Disease	3 years
Ken	Male	84	86	55	Alzheimer's Disease	7 years
James	Male	66	67	45	Multiple Sclerosis	7 years
Maureen	Female	73	75	50	Dementia	4 years
Susan	Female	74	77	54	Motor neurone	4 years
Alice	Female	70	72	40	Dementia	3 years
Charlie	Male	74	66	44	Stroke, aphasia	2 years
Joan	Female	77	76	30	Frailty, cognitive decline	5 years
Robert	Male	79	78	57	Cognitive and psychiatric	5 years

Interviews

Semi structured interviews were conducted in participants homes (n=7), the office of the researcher (n=2) and a local health service (n=1). Interviews varied between one to two hours in duration and were audio recorded with participant's permission. Participants were asked open ended questions about how they came to provide care to their partner, including questions about other supports available to them. These open questions encouraged reflection on the experience of becoming a caregiver to their partner, with further clarifying questions utilised as required throughout the conversation. This type of open ended interview encouraged participants to tell their stories, enabling the emergence of meaning and interpretation during this process.

Analysis and Interpretation

The analytic purpose of this study was to explore how older spousal caregivers perceive caregiving within the social context of long term marriage. Data were

analysed using an inductive thematic analysis technique, based on Braun and Clark's six stages of analysis (26). Interviews were transcribed verbatim, with identifying information removed to protect participant anonymity. Transcripts were then coded initially via an inductive open coding process to broad categories with the assistance of data management software NVivo. Analysis was then revisited across all interviews, identifying key themes and exceptions. Regular peer discussion of transcripts, codes and emerging themes occurred with the second author, to increase interpretative rigour so that interpretations and conclusions accurately reflected data (24). Reliability was further enhanced through comparative analysis, by revisiting previously analysed interviews to recheck transcripts against themes emerging in later interviews (27). Key themes were then considered in relation to broader social context and previous literature (26).

Results

This paper reports on two key themes that emerged from analysis of interviews. The chosen themes present a new contribution toward understanding the complex and diverse expectations of care experienced by spouses in later life. These two themes highlight how marriage impacts expectations of care at both individual and structural levels, as well as presenting new insights into the dilemma of when care expectations within marriage cease.

Other themes, not elaborated on here, demonstrated how participants in this study exhibited stress and angst consistent with the vast body of existing knowledge on caregiver strain and burden (7-9). In order to provide a brief snapshot of the dyads in this sample, participant descriptions of their motivations to care, relationship quality and other variables that impacted decisions to care are summarised in Table 2. This data highlights that in some cases, the rural location of participants reduced availability of both formal and informal supports to assist with care. Despite this, caregivers were generally very positive about their access to additional and alternative supports in their communities.

Table 2: Summary of participant descriptions of their relationship quality, motivations to care and availability of other supports

Pseudonym	Relationship Quality	Motivations for spousal care	Other factors identified by participant as impacting care
Carol	Very poor relationship; "do not love one another"; live apart together	Obligation; sense of duty; perceptions of friends and family	Children live distantly and are not in close contact. Financial and social reasons for staying together.
Richard	Difficult and distant. Live together, though "not as husband and wife"	Obligation; marital duty	Some in home supports accessed; complex care role causes significant distress. No children or other informal supports available.
Ken	Close; loving; committed	Love; "devoted husband"; work together as a team	4 children all live distantly; no formal supports; health services as needed. Has own physical health issues.
James	Close; loving	Willing to care; marital commitment	2 adult children, supportive but geographically distant. Accesses specialist services; significant financial issues from early retirement to provide full time care.
Maureen	Close; loving relationship.	Wanted to care; extension of long and positive relationship	Supportive children, though not in local area. Husband recently admitted to residential care due to rapid deterioration and inability to manage risk at home.
Susan	Close and positive; open communication (including challenges of care on Susan)	Willing caregiver; acknowledges no alternative had she wanted one.	Twice daily in home support, extensive informal care required; respite and carer support services accessed.
Alice	Strained; not close.	Marital responsibility; religious faith	2 adult children, live distantly. Husband recently admitted to residential care (increased aggression and disorientation)
Charlie	Generally good	Marital duty; responsibility; would prefer not to but resigned to role.	Adult children and good social networks nearby; past history as nurse, so expectations higher of ability to provide care.
Joan	Generally good, a little distant.	Marital responsibility; doesn't enjoy role but feels obliged to care.	One child lives nearby and provides support. Has formal services in home to support care needs. Has own physical health concerns; significant emotional strain from care role.
Robert	Positive; becoming difficult due to nature of illness.	Duty; marital responsibility; role as husband	3 adult children who live nearby and are supportive. Experiencing own significant physical health issues.

Caregiving as an expectation of the marital contract

All participants in this study identified spousal care as a central component of their marital relationship. These associations were often influenced by societal notions of marriage, with several referring specifically to the fulfilment of marriage vows. While the impact of social norms on assumptions of care was unsurprising, the depth of influence these unwritten expectations had on spousal caregivers provided new insight into the complexity of marital obligations to care.

For half of the caregivers, supporting their spouse was an extension of a long and reciprocal relationship. This was demonstrated by Ken and Mary, who have been happily married for 55 years. Ken described his role as "*devoted husband*" rather than caregiver, depicting his reasons for care as being about love and commitment. *"She says, why are you doing this? I say, look, I married you for better or for worse… and I really meant that"* (Ken). This commitment was also evident for Susan, who after 54 years of marriage to Sam identified the quality of their relationship as the reason she can continue to provide the extensive and complex care he requires for them to stay together in their home.

Most participants, including Ken and Susan, struggled to articulate how commencing spousal care had not been a conscious decision. James noted *"No one ever thought it would be anything else… It just never occurred to us, certainly never occurred to me"*. James described the changes following his wife's diagnosis of Multiple Sclerosis as a continuum of their strong marital relationship. Although none of the participants openly welcomed the caregiving role, an optimistic attitude was more evident in couples who described a positive marital relationship.

Although generally content within their relationships, caregivers such as Charlie and Joan clearly identified spousal care as an obligation rather than a choice. While Joan identified her obligations as stemming from gendered roles as wife and mother; Charlie's pre-retirement career as a nurse increased expectations about his capacity to provide care at home after his wife's stroke. He described some resentment of returning to caregiving in later life, *"I wanted to get away from it, that's all… I'd done that sort of stuff for so long. You retire and you start doing it again"* (Charlie). Charlie, Joan and Richard all reflected on their own parents' provision of spousal care in later life; attributing familial modelling as an influence on their own perceptions of care as a responsibility of marriage.

Marital responsibility was surprisingly also evident for caregivers who described unhappy relationships. Carol's story, for example, revealed care expectations were an unwelcome burden in a long marriage characterised by emotional abuse from her "*controlling and ungrateful*" husband. Carol overtly identified the absence of love between them, but continues to care in order to demonstrate to her children and the wider community that she is "*not an awful person*".

For caregivers in difficult relationships, such as Carol and Richard, choices to care were further constrained by shared financial assets with their partner. Carol described how she sought advice from a counsellor about her options to leave Frank, though fear of financial insecurity contributed to her decision to instead

stay in an unhappy situation. Richard's frustrations also echoed structural realities of co-resident caregiving. *"At times I've really wanted to just take off. Then you think, where am I going? What am I going to do?"* (Richard). The social and financial interdependence created by marriage also emerged in positive care relationships. James, for example, experienced serious financial hardship after being forced to sell his business and enter early retirement when Anne required full time support. These practical realities clearly impacted the experiences and options surrounding care for these older couples.

The uncertain end of expectation
Despite overt costs and challenges in providing spousal care, interviews captured the struggle caregivers demonstrated around considering residential care alternatives. Two caregivers in this study, Alice and Maureen, participated in interviews soon after making this difficult decision. Both women had reached a point where their respective husband's dementia care needs had become too difficult to manage at home, yet they experienced this transition differently.

Alice continued to struggle with change and loss, tearfully attempting to justify her decision on many occasions as she recounted her story. This difficult transition was complicated by the negative reactions of David's family, who openly criticised her reduced involvement in providing care after his transition to a residential facility. Alice subsequently felt guilty that she should have provided care at home for longer, despite its impact on her own wellbeing.

Maureen, however, reflected with hindsight on stages of denial that lead to her agreeing to residential support for Ron.

> *I knew deep down... I was basically in denial that it was happening... I had hoped that he would come back... But looking back, it was probably never going to happen (Maureen).*

Maureen's safety had become a major concern, with Ron's deteriorating dementia resulting in aggression toward her. *"I feared for my life. It was that bad"* (Maureen). Despite this, the decision to transition Ron to residential care was made reluctantly and largely due to pressure by concerned health care professionals. Although others supported and encouraged this transition, Maureen was reluctant to break her promise to Ron that she would care for him at home as long as possible.

Only one of the remaining caregivers, Joan, had begun to plan for Tom's future care needs. After lengthy consultations with her husband and family, they decided to place Tom on a waiting list for residential care. For all of the other caregivers, the future remained unknown; threatened by the unthinkable possibility of their partner needing more care than they would be able to provide at home. Both James and Robert demonstrated significant reluctance to dwell on the prospect of increasing care needs despite their wives progressive illnesses. Robert reflected on his commitment to continue providing care as long as he can, before declaring, *"I'm not going to walk away".*

Most caregivers in this study demonstrated commitment to ongoing care, regardless of relationship quality or satisfaction with the care role. This reluctance to transition away from care at home has important implications for wellbeing of caregivers and care recipients, as well as implications for services and practitioners when these situations ultimately become untenable in a crisis situation.

Discussion

This study addressed the question, *"how do expectations of informal care impact spousal caregivers in later life?"* Consistent with prior literature on marital care obligations (2, 17), all participants in this study identified an unquestioned and unconscious transition into care roles because of their co-resident marital relationship. For three female caregivers, this was overlaid with gendered expectations, and in one case a history of abuse and financial vulnerability. Despite this, both men and women in this study viewed spousal care as an expectation of their marriage.

Beyond these anticipated associations between marriage and care, in-depth interviews enabled a more nuanced understanding of spousal care expectations than has been previously explored. This study extends knowledge beyond individual care motivations to provide an analysis of how wider societal expectations and structural factors impact caregiver choices and decisions.

Four caregivers in this study demonstrated little intrinsic motivation or satisfaction deriving from their care role; instead drawing on social, financial and logistical incentives to provide ongoing care. This is an important finding, as extrinsic motivations for care have previously been correlated with greater stress and anxiety for informal caregivers (20). Interdependence of resources posed fewer challenges for willing caregivers in this sample, though the risk of financial or housing insecurity in later life was a factor that overtly forced ongoing provision of care for at least one caregiver in this study.

It is also noteworthy that seven of the ten caregivers within this rural sample had no family in the local area available to provide additional informal care. Spousal care was the only option available for ongoing community based care for these couples. This lack of informal alternatives forced decisions toward formal supports and residential care alternatives when at home care became too complex. The migration of retired adults to rural areas, as well as out migration of young people for education and employment is an ongoing contributor to this phenomenon (28).

In part, these findings support previous research suggesting reciprocity over the long term of a marriage counterbalances short term challenges of providing spousal care (2, 17). This was not evident across all participants however, with several spouses planning to continue providing long term care despite unhappy relationships, considerable burden and resentment of the care role. This is contrary to existing literature suggesting spouses who see caregiving as burdensome and unsatisfying are less likely to adopt or persist in this role (29), or

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that commitment to caregiving is based on previously positive marital relationships (30).

Of particular note were findings highlighting the intersection of marital care obligations with transitions away from home based care. Expectations of care appeared to outweigh individual choice in both the minds and structural realities of older spouses. For those struggling with and dissatisfied by the caregiving role, expectations to commence and continue providing care did not appear negotiable. Although most participants acknowledged there might come a time in the future where they would be physically or emotionally unable to continue in their role, self-imposed commitment to ongoing care at home suggests this is likely to culminate in a crisis rather than a planned approach to exploring alternatives. These findings, together with our prior research from the perspective of health practitioners, highlight the critical point that spousal caregiving often reaches a crisis point before services are accessed (23).

Conclusions
This study has implications for individual caregivers and their families, as well as for practice with older community residing couples. Findings demonstrate diverse experiences amongst caregivers, and specifically that not all spouses are happy with either their relationship or the caregiving role. Comprehensive assessments with older couples should provide both parties opportunities to openly discuss their expectations and experience of care away from their partner. Regular review of the changing nature of care with both parties might also assist to identify alternatives before a crisis stage is reached. The combined influence of social norms, practical barriers and emotional relationship context, however, can make this difficult in practice. This can be further compounded by the multitude of social and structural factors combining to limit what practitioners can offer couples by way of meaningful choices (23).

The diversity of caregivers in this sample extends knowledge beyond the experience of dementia and other specific care types. Although diverse in care types, it should be noted as a potential limitation that this study relies on a small sample. The in-depth interviewing technique, however, enabled a deeper and more nuanced exploration of caregivers' experiences. Many participants reflected gratitude at the opportunity to speak openly about their experiences, as they felt the topic of spousal care was not one they could usually discuss.

Individual and social obligations of care within the marital relationship were demonstrated in this study to override even unhappy relationships and risks to the caregiver. Despite risks being well-established, contemporary social policies continue to be developed assuming traditional models of familial caregiving (22). This assumption was problematic for spouses in rural areas, many of whom had no other available family supports in the local area. The significant impact of normative care expectations in this study resulted in automatic assumption of care roles and impacted decision making around future care planning. These are important considerations for both policy and practice with older adults and their caregivers.

Impact Statement

This paper highlights complex individual and social factors compelling older adults to provide spousal care. Systemic reliance on spouses to provide care reinforces self-imposed obligations, increasing the likelihood of crisis situations and risk of harm to caregivers due to the challenges of transitioning to alternate care arrangements.

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Summary of chapter

The findings in this chapter addressed the third research question of this thesis: *How do expectations of informal care impact spousal caregivers in later life?* Informed by the findings of the CDA and focus groups with practitioners, this stage set out to explore the lived experience of care within marriage.

In order to hear the stories of caregivers themselves, in-depth interviews were determined to be the most appropriate method of data collection. Affording participants privacy to speak openly about a deeply personal experience was a key methodological consideration. Semi-structured interviews enabled in-depth exploration of social norms and expectations of marriage on participants' experience of spousal care. Open-ended questions encouraged participants to explore their decisions around caregiving and to understand the experience of choice and responsibility from a personal perspective, using their own terms (Liamputtong & Ezzy, 2005). This enabled the emergence of meaning and interpretation during this process, which was particularly helpful as it quickly became clear that participants had never really considered the meaning of their role as both spouse and caregiver prior to the interviews. As such, these discussions provided an opportunity for both interviewer and caregiver to analyse this experience together. This is common in this type of qualitative interview, which acknowledges the dually inductive and deductive approach that not all relevant questions are known prior to the research (Liamputtong & Ezzy, 2005).

These interviews revealed a diverse range of both relational and structural complexities that contributed to spouses commencing and continuing in care roles. These findings demonstrated how assumptions of spousal and familial care were not only structurally expected of caregivers, but also self-imposed by their strong sense of obligation and marital commitment. Caregivers in this study demonstrated diverse personal and social circumstances, yet all identified unconscious transition to caregiving roles. This suggests that this experience is not only extremely common, but independent of other factors. Not all couples were in loving relationships, with motivations for providing care including conformity to social expectations of marriage and a lack of personal resources limiting other opportunities. Complex interpersonal relationships, grief and loss; and the conceptual and practical challenges surrounding future transitions away from primary care in the home also impacted caregiver experiences. The weight of social obligations were forefront in these findings, demonstrating how spouses' persist in the provision of care despite personal costs and complexities inherent to the caregiving role.

These interviews with caregivers highlighted that despite the significance of individualism through policy and practice, this was largely absent from the discourse of caregivers. Instead, the weight of social and relationship obligations motivated spouses into an automatic assumption of caregiving. These findings provide an important new insight into the complexities of translating individualised and choice oriented policy and practice within familial care contexts. The integration of these findings with previous stages of the study will be discussed in the next chapter.

CHAPTER 7: Integration and discussion of findings

Introduction

A particular strength of this thesis is its conceptual framework, which drew on critical and systemic foundations to guide design and implementation at each stage of the research. The multiple methods design also allowed the most suitable methods of data collection and analysis to be applied to each level of the care system. A key aspect of systems theory however, is its consideration not only of individual parts of a system, but also of the interactions between systems and the overall fit for people within their environment. This is a particularly important aspect of this thesis, which weighs into debate at a time of significant change in aged care policy and practice.

This multidimensional approach to research allowed development of a systemic approach to examine the issues facing spousal caregivers. This is an innovative new way of exploring care, which opened up a greater understanding of how different layers of the care system interact with and impact on one another.

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Suzanne Hodgkin	25	Provided critical review and feedback on manuscript
Jeni Warburton	15	Provided critical review and feedback on manuscript

A transformative approach to systems theory in caregiving research

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Abstract
This paper illustrates how systems theory can be used in social work research design to understand the systemic issues associated with spousal care in rural Australia. Spousal caregiving is embedded within multiple formal and informal systems, including family, community, health and aged care practice, social policy, and social and cultural norms. It is therefore a complex phenomenon to explore in social research, with each of these systems interacting with and influencing other aspects of the care system. The purpose of this paper is to provide an illustration of a research design that explores this systemic complexity. The design is conceptually underpinned by the transformative paradigm; a critical approach that reflects social work principles of social justice. The methodology is based on an ecosystems approach to assessment, using multiple methods to explore interactions between systems of care at policy, practice and individual levels. This application of systems theory to research presents an innovative opportunity for social work research to reflect long established practices of understanding complex phenomenon within its sociocultural context.

Introduction
Population ageing continues to ignite social and economic debates around the globe as policy makers, service providers, family members and older adults themselves consider how the care needs of an ageing population will be met. In Australia, as in other western countries, extensive literature highlights the preference of older adults to remain in their home environment as they age (Vreughdenhil, 2014; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). This preference dually serves the interests of older adults themselves to maintain greater autonomy in later life, while alleviating the fiscal pressures on governments to support a rapidly ageing population (Department of Health and Ageing, 2012a). Although ageing in place is both a popular and efficient means of supporting an ageing population, the majority of older adults will require some level of support in order to maintain independence and community living in later life. Within Australia, this support is provided across a range of formal and informal systems in both community and residential care settings. This system of support, however, relies heavily on the availability of unpaid spousal and other informal caregivers, who provide more than 80% of care required by older Australians (Productivity Commission, 2011).

The complexity of the spousal caregiving role originates by virtue of the distinctive social relationship created by marriage. Marital relationships are often characterised sociologically by the established roles, responsibilities and patterns of reciprocity that are present in the relationship before the commencement of

caregiving (Bruhn & Rebach, 2014; Ray, 2006). This micro level relationship is also influenced considerably by macro social and cultural expectations of care within marriage and families (Arksey & Glendinning, 2007; Costello, 2009; Egdell, 2013; Ray, 2006). The spousal relationship is therefore one that has embedded expectations, multiple internal and external influences, and the nature of a couple's pre-existing relationship all impacting how the care role is experienced. These expectations are also reflected in contemporary policy and practice directions, which both promote and rely on familial and community based care (Australian Bureau of Statistics, 2012; Colombo & Mercier, 2012; Productivity Commission, 2011).

This reliance of the care system on unpaid caregivers further complicates the spousal caregiving role. Research by Dow and McDonald (2007) highlighted that although unpaid caregivers are central to the provision of aged care in Australia, they occupy a marginal status within this system and are not considered members of the care team nor are they consistently included in the care-planning decisions that impact their lives. This utilisation of informal caregivers as a resource rather than an equal or contributing member of the care team is found in research both in Australia and elsewhere (Linderholm & Friedrichsen, 2010; Williams, 2012). In current reforms undertaken by the Australian government, there are attempts to move the aged care sector toward consumer-directed care by promoting principles of autonomy and choice in a consumer-led market (Department of Social Services, 2015a). While promising much for the individual recipient of care, it remains to be seen how these reforms will impact on other aspects of the care system in Australia, in particular informal caregivers.

In Australia, systems to assist caregivers include provisions for income supplements, respite services and other instrumental and emotional support (Commonwealth of Australia, 2015). These systems of support, however, are recognised as being complex and difficult to navigate (Productivity Commission, 2011). Challenges for informal caregivers include the inadequacy and inconsistency of carer payments (Maker & Bowman, 2012) and the need for greater availability of adequate, affordable and flexible respite services (O'Connell, Hawkins, Ostaszkiewicz, & Millar, 2012). The home care system is also plagued by limited availability of support packages; a challenge exacerbated by the absence of a central waiting list and lack of clarity around prioritisation processes for care recipients (Low, 2015). These unmet care needs are associated with adverse outcomes for both care recipients and caregivers (Low, 2015), with informal caregiving having long been the subject of extensive research that demonstrates significant risks to the social, emotional, physical and financial wellbeing of caregivers (Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2009; Hammond, Weinberg, & Cummins, 2014; Hirst, 2005; Lavela & Ather, 2010; Pinquart & Sorensen, 2011; Thomas, Saunders, Roland, & Paddison, 2015).

These systemic complexities for spousal caregivers are further compounded by broader social factors, which suggest the sustainability of a care system that relies on informal caregivers is problematic. Factors such as smaller family sizes, greater geographic mobility, rising female workforce participation and a reduced propensity to provide care are contributing to falling numbers of family members

available to provide care to older generations and a widening of the gap between care supply and demand (Deloitte Access Economics, 2015; Hugo, 2007). The growing complexity of medical conditions will also require higher levels of formal care into the future, yet imminent workforce challenges have been identified in both residential and community care in Australia (Hodgkin, Warburton, Savy, & Moore, 2017; King et al., 2012). Conservative modelling highlights that this workforce will need to triple in order to meet future care needs (Department of Social Services, 2015b). The average age of entry into residential care in Australia is increasing, with an average age of admission at 84.5 years and the majority of residents classified as high dependency (Australian Institute of Health and Welfare, 2017). This combination of factors suggest that informal caregivers are providing more complex levels of care.

It is increasingly important in this climate of social, demographic and policy change in ageing and aged care, that critical and socially located research is undertaken within the Australian context. In order to understand the complex relationship between micro, meso and macro issues that impact on spousal caregivers, this research draws on systems theory to explore these multiple layers of the care system. The current study therefore set out to address the research question: How do social, cultural, policy and practice systems interact with and impact on spousal care? The aim of this paper is to provide an illustration of how systems theory was used in this social work research design, to explore complex phenomenon within its sociocultural context.

Theoretical Framework
Social work is often distinguished by its focus on understanding and addressing complex social issues, with significant value placed on understanding people within their environment. This is evident in the prevalence of systems based approaches in social work theory and practice, which have been influential in the profession as far back as the 1930s (Healy, 2005). As with many issues studied by social researchers, the Australian care system is both complex in itself and complicated by the many social, political and economic systems that surround it. Research conducted within this intricate system requires a sound conceptual and methodological framework in order to be explicit about the underlying theories and values underpinning research and to ensure clarity about the potential influence of these on the research process. The strong theoretical foundations of the social work profession are discussed in depth in several theory focused texts (such as, Allan, Briskman, & Pease, 2009; Healy, 2005; Payne, 1997), as is the translation of these theories into social work practice (see for example, Connolly & Harms, 2013; O'Connor, Wilson, Setterlund, & Hughes; Trevithick, 2012). Of interest to this paper, however, is the relationship of these theoretical underpinnings with social work research design.

In a discussion of theoretical frameworks in research, Anfara and Mertz (2015) noted that qualitative research tends to focus on the ideological perspectives of the researcher or the deductive application of theory to research findings, often failing to consider the role of theory in research design. The current project, however, set out to design research that was explicitly informed and guided by social work theory at both conceptual and practice levels.

The decision was made to situate this research within an ecological model, enabling spousal caregiving to be analysed within its social environment, rather than focusing on any one aspect of the interconnected care system. There have been many interpretations of systems theories in the social sciences, however the work of Carel Germain and Alex Gitterman is perhaps the most recognised of these subsequent approaches. Their life model of social work practice was developed to bring together both systems and ecological concepts, drawing on ecological metaphors that consider transactions between people and their environment (Germain & Gitterman, 1996). A key principle of the ecosystems approach is that problems arise from a poor fit between a person's environment and their needs, capacities, rights and aspirations (Germain & Gitterman, 1996). The strong influence of systems theories enables the social work profession to understand and address issues of social and structural inequality, through examining the interactions both within and across systems and contributes to the enduring popularity of systems approaches in social work (Connolly & Harms, 2013; Healy, 2005).

An ecological approach enables spousal care to be conceptualised as a series of interrelated systems that encompass the micro aspects of the individual caregiver's immediate home and social environment; the meso practice environment and the macro values, policies and legislation that all impact upon informal care. It was identified early in the development of this research that a critical perspective would be key to understanding the complexities of these interrelated systems, including how dominant ideologies and social institutions such as the family impact on caregiver's lives (Allan et al., 2009). This research therefore draws concurrently on the transformative paradigm, which presents a philosophical framework for conducting critical research that focuses on the role of oppressive social structures on marginalised groups (for a comprehensive discussion of the transformative paradigm, see Mertens, 2009). The transformative paradigm recognises that there are multiple perspectives of reality, which are socially constructed and influenced by societal values and privileges (Mertens, 2009). Consideration of these multiple realities was well suited to a study of informal care, which is located within a complex network of family, community, cultural, organisational and policy factors (Arksey & Glendinning, 2007; Costello, 2009). The integration of critical and systems based approaches therefore provide the opportunity to design research that draws on the well-established foundations of these approaches in social work practice, to create a holistic and contextualised understanding of spousal care.

Systems based approaches to research
With the intention of identifying exemplars of research designs utilising systems approaches within the Australian context, a comprehensive review was undertaken of the literature in two key academic social work journals, Australian Social Work and Qualitative Social Work. The search specifically sought to identify articles that utilised systems theory or similar systems based approaches in the design of research.

An audit of the social work research literature over the past ten years found surprisingly few articles that drew explicitly on systems theory in research design. Of the 685 articles reviewed, only one article explicitly identified systems theory as informing research design. This was a large practice based research project by Bawden and McDermott (2012), who used distinct studies to explore the micro, meso and macro aspects of social work across the largest state health service in Victoria, Australia. Although not specifically identified as informed by systems theory, other studies did demonstrate innovative uses of multiple methods, case study and ethnographic designs to explore multiple perspectives of complex issues, suggesting the profession is drawing on other approaches to capture the contextual complexity of social issues being researched. An example of this included a case study methodology utilised by Drake (2014) to explore the deinstitutionalisation of boarding house residents in Australia. This study involved interviews with past and current residents, boarding house proprietors and staff of both government and community based organisations. Dearden and Mulgrew (2013) also sought multiple perspectives of organisations, practitioners and individuals experiencing eating issues via the use of mixed method surveys to explore men's experiences of eating disorders. These studies highlighted the value of analysing multiple systems in order to gain a broader understanding of the social issues being researched.

Similarly, a wider review of studies focused on spousal care revealed limited consideration of broader systems in research. The largest body of research on spousal caregiving centres on caregiver burden and the impacts of providing care on marital relationships. These studies consider a range of variables, though tend to utilise single research methods such as interviews (Boeije & Van Doorne-Huiskes, 2003; Davies, 2011; Ray, 2006), surveys (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Butterworth et al., 2009; Hirst, 2005) or literature reviews (Braun et al., 2009; Evans & Lee, 2014; Lavela & Ather, 2010; LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005; Pinquart & Sorensen, 2011; Pozzebon, Douglas, & Ames, 2016). Although this body of research highlights the breadth and depth of challenges that impact caregiver wellbeing and relationships, single perspective designs and literature reviews often do not capture the contextual complexity surrounding informal care. Much of the work in this space is also focused on specific subgroups of caregivers, such as those providing support to a spouse experiencing dementia. This can make it difficult for research to then be translated back into the policy and practice contexts in which these individual experiences occur.

Fewer studies have drawn on mixed or multiple methods to explore the phenomenon of care, though exceptions tend toward mixed methods of questionnaires and interviews to capture qualitative and quantitative data from a single source or perspective (De Vugt et al., 2003). One of the few studies that captures multiple perspectives of care was by Pickard, Shaw, and Glendinning (2000), who examined the dual perspectives of both informal caregivers and formal service providers around the shared care of an older adult with dementia. These dual perspectives widened and enriched the understanding achieved and demonstrated the benefit of exploring multiple perspectives of the care situation from different layers of the care system.

As with the review of social work research, theoretical frameworks were not always explicit in these published studies of care. Of those that did overtly draw on theoretical perspectives, there was greater evidence of feminist perspectives, which reflects the highly gendered nature of care. These studies tended to predominantly employ qualitative methodologies based largely on interview or focus group data. For instance Calasanti and King's (2007) study of gender and spousal care utilised interviews and observation from a structural feminist perspective. There have also been some older studies designed to quantify and measure care, utilising social exchange theory to explore marriage and caregiving (for example: Raschick & Ingersoll-Dayton, 2004; Thiede Call, Finch, Huck, & Kane, 1999; Wright & Aquilino, 1998), though these too fail to consider the macro impact of social norms and service systems on this relationship exchange. Some small scale studies that involved interviews with spousal caregivers have considered the marital relationship as the context of care (Boeije & Van Doorne-Huiskes, 2003; Davies, 2011; Ray, 2006), though no studies captured this phenomenon within wider social and service systems.

Recognising these shortfalls, the present study sought to develop a research design that would enable the micro experience of spousal care to be explored in relation to the meso and macro contexts in which it occurs. The critical conceptual framework specifically considers the interrelationship of care systems, capturing multiple perspectives in order to enrich understanding of the caregiving experience.

Methodology
The following presents an illustration of applying an ecological approach to the examination of informal care. This methodology is based on an ecosystems approach to assessment, using multiple methods to explore interactions between systems of care at policy (macro), practice (meso) and individual (micro) levels. Ethics approval was sought and obtained prior to commencement of research (La Trobe University, Faculty of Health Sciences Human Ethics Committee, FHEC12/177). As this research was designed from the outset to capture multiple systems of care, all stages of the study were approved within this same ethics application.

While systems theory is widely recognised as offering a framework for understanding and responding to complex social issues, it has been criticised for failing to adequately reflect individual factors and issues of structural injustice (Healy, 2005). Within the current study, these concerns about systems theory are addressed by the critical conceptual framework underpinning this research.

The social justice focus of the transformative approach, most often attributed to the work of Donna Mertens (2007, 2009, 2010, 2012), aligned with the epistemological principles underpinning this study. The ontological beliefs of the transformative paradigm recognises the diverse social constructions of reality; commonly embracing multiple methods in an attempt to unearth these different perspectives in relation to the social issue under study (Mertens, 2009). In the current study, the use of multiple qualitative methods enabled data to be collected

and analysed across macro, meso and micro systems; capturing the perspectives of multiple stakeholders and that of caregivers themselves. Combining multiple qualitative methods in a single study is also recognised as adding rigor, breadth, complexity, richness and depth to the inquiry, in order to fully understand a phenomenon (Denzin & Lincoln, 2011).

The transformative paradigm is designed to advance the needs of underrepresented or marginalised populations (Creswell & Plano Clark, 2011) and considers not only people who experience discrimination and oppression, but also studies the power structures and discourses that perpetuate social inequalities (Allan, 2009; Mertens, 2010). This underlying philosophy provides a critical lens to understanding how macro policy filters down to impact practice and individuals. This dually provides a conceptual platform that is well suited to exploring the needs and experiences of informal caregivers in a changing social and policy environment, as well as addressing the need for greater critical social gerontology research in Australia (Asquith, 2009). This transformative philosophy also aligns well with a systems approach, which recognises individual experience always occurs in a context of both direct and indirect social influence, so no one system can be interpreted without understanding those around it (Harms, 2010). This research design therefore enabled the complexity of the issue to be examined across individual, practice and structural levels, while ensuring the central focus of the study remained on how these layers of the care system impact the experiences of informal caregivers.

As with social work practice, an assessment of the presenting issue was undertaken as the primary task. Unlike practice, which frequently starts with the individual, this systemic approach commenced at the macro systems level, to consider the social and cultural constructions of ageing and caregiving. These macro considerations formed the point of referral through each of the subsequent systems within the study, to ensure that each stage of the research would be conducted with a clear consideration of real world context. This was key to ensuring that the collection, analysis and interpretation of findings was not conducted in isolation from sociocultural and political context. The cultural dimensions of the macro system provide a social blueprint of sorts, which shape beliefs and ultimately set priorities and limitations on acceptable behaviour within society (Harms, 2010).

As well as analysis of the macro system, the study also included both the service and practice environment (meso system), as well as the views of individuals providing spousal care (micro system). The most appropriate methods of data collection were then considered, and are discussed with brief findings in the following section. Details of findings from the macro and meso stages of this project have already been published (Cash, Hodgkin, & Warburton, 2013, 2016).

Stage One
The first stage of the study involved a critical discourse analysis of key policy and legislative documents relating to aged care and caregiving (Cash et al., 2013). These documents included the Productivity Commission Inquiry into Aged Care

(2011), the subsequent Living Longer, Living Better reform package (Department of Health and Ageing, 2012a) and the National Carer Strategy (Commonwealth of Australia, 2011). This provided a range of policy level perspectives about spousal caregiving, including reforms providing the basis for new aged care legislation in Australia through the Aged Care (Living Longer, Living Better) Act, 2013. The critical analysis of discourses revealed embedded assumptions about both the availability and willingness of informal caregivers within the aged care sector. It also demonstrated the economic reliance on informal caregivers, with the intent of prolonging their ability to provide ongoing care. These economically driven strategies highlighted the ideological conflicts of responsibility and choice dually applied within social policy, where choice within the system seemingly excluded the carers' choice to provide care. These analyses provided foundational understanding of the macro system of care to inform the subsequent stages of data collection and analysis.

Stage Two
The findings of this policy analysis were then used to inform the second stage of data collection, which sought to understand the translation of these policies into health and aged care practices (Cash et al., 2016). Seven focus group discussions were held with practitioners who work with older couples in the community. These discussions explored the views and practices of health and aged care professionals around spousal caregiving and decision making. Findings demonstrated that although practitioners' verbalised consumer focused practice preferences, they recognised that, in effect, the reality of resource constraints translated to limited meaningful choices being available to older caregivers. This was particularly evident in rural locations, where services were limited and access to options considerably constrained by geographic distance and its associated costs. These findings also highlighted a broader challenge with regard to the influence of familial care assumptions being made in the practice space. The discussions revealed limited critical reflection being employed in relation to the wider personal and social obligations that impacted older couples living in the community or of the impact practitioners own views and assumptions had on practice. This was particularly evident in practitioners' assumptions about care willingness by spouses, based on social concepts of marital obligation and care as a demonstration of love within the relationship.

Stage Three
The final stage of data collection involved in-depth individual interviews with spousal caregivers, which provided valuable insights into the lived experience of care within long term marriage. A diverse group of older caregivers were recruited via a purposive self-selection method, with advertisements displayed in rural health services and caregiver support groups. The spouses interviewed had a mean age of 73.1 years and had provided informal care for between one and seven years; with care recipients requiring support for a range of cognitive and physical conditions. Interviews were transcribed and analysed using an inductive thematic technique, which revealed relational and systemic complexities for caregivers that had not been captured in previous stages of the study.

Systemic findings revealed that the majority of participants had no other family living nearby able to assist with the provision of care. This was highlighted by Alice, who said "I never really anticipated that there was any option actually... His family don't live nearby and our daughters [live far away] so there wasn't a family option". This lack of family supports was common to both couples who had raised their families in rural areas, as well as those who had relocated to their current location in later life. Most spouses interviewed received some type of formal support to assist with caregiving, such as nursing or allied health services, home cleaning and personal care. Despite limited available choices regarding these services, as well as the extensive travel required by some couples to access geographically distant specialist services, caregivers in this study were generally positive about the supports available. Their gratitude reflected expectations of the care system that establish spouses as the primary provider of care, with formal services as a supplement if and where they were available.

Findings also revealed relational complexities, which demonstrated how assumptions of spousal and familial care were not only structurally expected of caregivers, but also self-imposed by their strong sense of obligation and marital commitment. Caregivers in this study represented diverse personal and social circumstances, yet all identified unconscious transition to caregiving roles. This suggests that this experience is not only extremely common, but independent of other factors. Not all couples were in loving relationships, with motivations for providing care including conformity to social expectations of marriage and family. Complex interpersonal relationships, grief and loss; and the conceptual and practical challenges surrounding future relinquishment of care also impacted caregiver experiences. The weight of social obligations were forefront in these findings, demonstrating how spouses' persist in the provision of care despite personal costs and complexities inherent to the caregiving role.

Integration of findings
The methods utilised within this study each investigated a stage of the informal care system, so were constructed and conducted as three distinct stages of a larger study. This design utilised a cyclic data collection technique, which allowed the findings from each stage of the care system to inform the next (Mertens, 2012). In order to achieve a truly systemic analysis of spousal care, the project concluded with the integration and analysis of findings from across each of the three layers within the identified system of care.
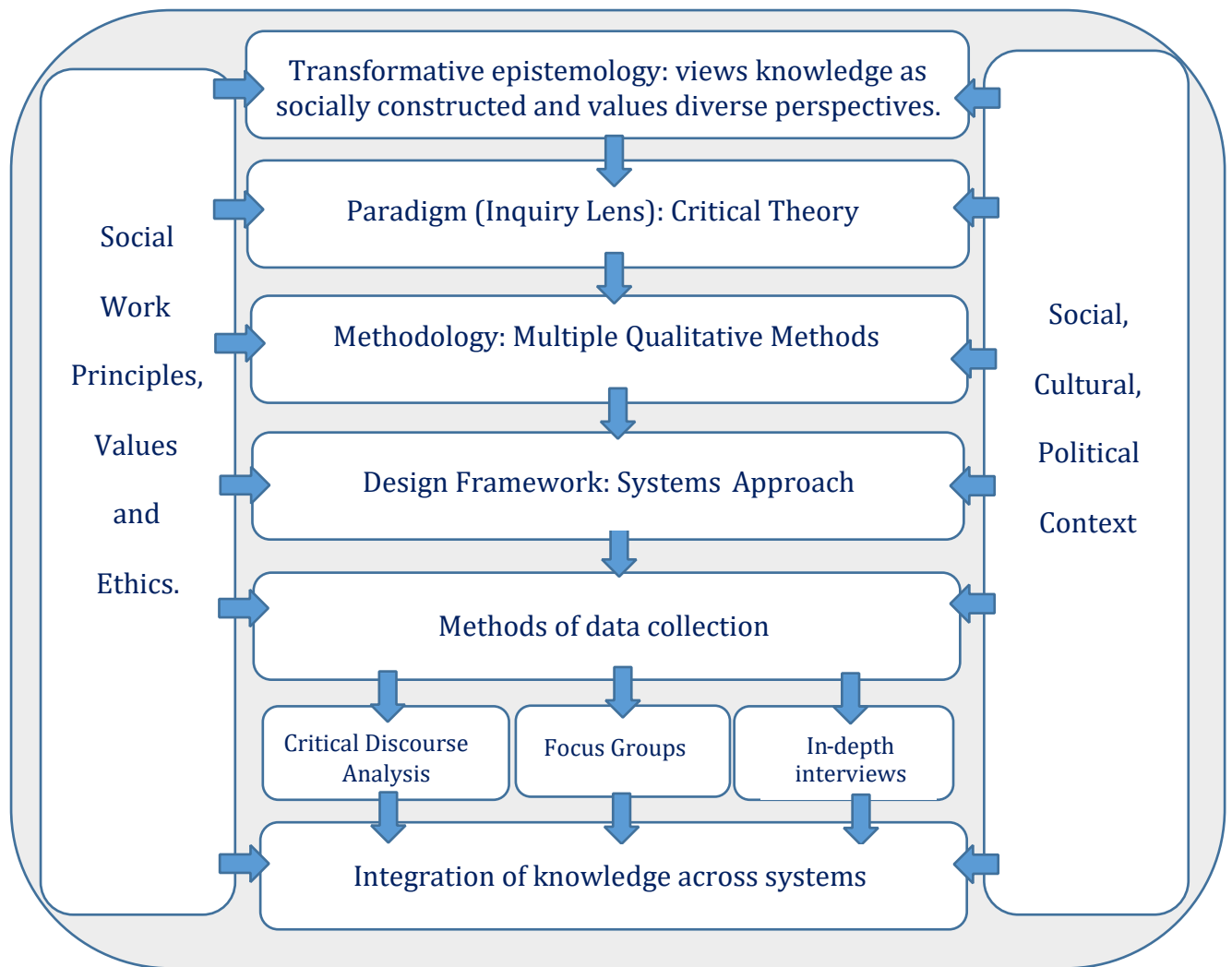
Figure 1: Research design framework

Discussion

The multiple methods utilised within this study analysed the micro, meso and macro aspects of the informal care system; capturing the experience of spousal care within its social, political and practice environments. This design focused dually on understanding each layer of the care system, as well as the interaction between these systems. Approaching research in this systemic way enabled critical consideration of the inter-relationship between these systems, including how changes at macro policy levels can filter down to impact practice and ultimately to individuals. This enabled significant new depth to the findings that may not have become evident analysing systems in isolation from one another.

An example of this was evident with regard to the prevailing influence of social norms across the micro, meso and macro systems of care explored in this study. The reliance of aged care systems on informal care was embedded through all of the policy documents analysed in this study, reflecting strongly held social expectations around familial care. These familial care assumptions are artfully

constructed within policy via emotive and persuasive discourses; introducing language that underpins subsequent practice guidelines.

These macro findings set the context for the next two stages of the study. Without an existing critical and contextual understanding of policy directions, a study of practice would more likely have focused on practical, rather than conceptual, implementation of reforms. Although focus group discussions in stage two did reveal practice issues resulting from geographic and resource constraints, findings highlighted that social norms of familial care also influence practitioner's perspectives of spousal caregiving (Cash et al., 2016). Critical analysis techniques further revealed the unquestioned manner in which policy directions are being enacted in practice, despite practitioner's awareness of the inequities and inherent challenges these practices and norms presented for spousal caregivers. This deeper exploration revealed how implicit social norms and embedded constructs of familialism and long term marriage shifted focus away from discussions of capacity and willingness to provide care. A key example of this was a common theme of "the quiet word", where practitioners frequently reflected on occasions caregivers sought private conversations away from their spouse following assessments and meetings. This occurrence was widely observed by practitioners, yet mechanisms to ensure caregivers were afforded opportunities to openly communicate concerns away from their spouse remained absent in both policy and practice systems. This demonstrated the dual complexity of navigating social expectations for both caregivers and for practitioners.

Informed by this macro and meso knowledge, interviews with caregivers were then able to enquire about the individual experiences and social contexts of caregiving spouses. These interviews further revealed the social obligations experienced by spousal caregivers, which often outweighed personal considerations, reluctance to care and even hostile relationships. This crucial micro stage of the study highlighted how relational obligations were the dominant influences on decision making and experiences of care for spouses. These findings demonstrated the considerable effort required by spouses to overcome these socially and self-imposed pressures, with the act of reaching out to practitioners via the "quiet word" taking on greater significance.

This brief example demonstrates how examining the multiple perspectives and priorities of stakeholders within the aged care system can bring greater depth and breadth to the analysis of social experiences such as caregiving. Although it would have been possible to study this phenomenon using a range of other approaches, it was the systemic lens that ensured each stage of this process was contextualised both in its broader sociocultural context, but also in relation to other systems of care.

Existing research on caregiving in Australia has tended not to take systemic or critical perspectives. In 2009, sociologist Nicole Asquith identified this oversight as problematic in the present climate of social, demographic and policy change in ageing and aged care. Unlike studies that focus primarily on analysis of a single aspect of the care system, the approach taken in the current study enabled insights into the interactions between the macro, meso and micro aspects of spousal care.

These insights highlight the consequences of conceptual and practical discrepancies between layers of the care system and the subsequent translational and equity issues that can emerge as a result of these conflicting social ideals.

This empirical design builds on caregiving research within the United Kingdom, where critical researchers such as Arksey and Glendinning (2007) have examined the conceptual challenges of informal caregivers within increasingly individualised aged care environments. The current research also extends the findings of Pickard, Shaw and Glendinning (2000), whose research highlighted the assumptions and obligations of formal care staff in their work with spousal caregivers. The current research design builds on the multiple perspectives captured by Pickard et al. (2000), adding the analysis of macro social policy perspectives to spousal caregivers. This unique methodological approach captures the complete picture of spousal caregiving in the Australian context within a single project.

The desire to consider wider social and structural factors was reflected in the transformative paradigm, which provided the conceptual foundation of this research design. This critical lens captured how power can be exercised within social and political contexts, exposing and analysing the macro social discourses and ideologies that underpin spousal care in contemporary policy and practice environments. The transformative lens highlighted ways the care system both overtly and inadvertently takes advantage of caregivers via their limited voice in this space, the unquestioned assumptions of care willingness, the use of language to promote preferred familial care solutions and the structural pressures that work in ways to enforce their "voluntary" commitment to care.

While there are many benefits to this systemic approach, it must be acknowledged that potential challenges might arise with this framework through constraints to time and funding to conduct research of significant systemic size or scope. Critical social workers such as Halfpenny (2009) have highlighted challenges of contemporary settings, where the focus on evidence and outcomes that continues to drive government funding can force social workers into "complying" with policy agendas. This might subsequently result in contexts that do not support research exploring the social and contextual aspects that are valued by and integral to social work.

Conclusion

In this paper, we have set out to illustrate the application of an ecological systems approach to understanding spousal care in rural Australia. The current study contributes both critical and systemic findings that extend knowledge about spousal care in the rural Australian context, as well as providing a methodological approach that can be applied in other social work research to achieve much needed critical and systemic understanding of social issues. Utilising such an approach increases the translatability of the research findings, as they have been captured and analysed within real world contexts at macro, meso and micro levels.

The transformative paradigm illustrated in the current paper suited the interpretive and critical methods of data analysis for this particular social phenomenon, however the systems framework has the flexibility for researchers to draw on other theories, methods or approaches most appropriate to their own topic of research. This systemic methodology could therefore be applied across the breadth of social work fields and with both mixed and multiple method approaches.

The systems framework presented here demonstrates a research design that reflects what social work theory and practice have long known; that considering a person within their environment is essential to the development of meaningful policy and practice that can be applied in the real world. This provides an opportunity to highlight the critical mismatch that can occur between macro goals and implementation of these within practice and individual contexts. The systems framework allows a methodological pluralism that overcomes the challenges of having a singular focus on any of these levels.

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Summary of chapter

This chapter has provided an integrated discussion of the key findings of this thesis. In keeping with the conceptual framework of the thesis, this discussion has focused on the critical and systemic interactions impacting spousal caregivers in Australia. This discussion has highlighted a number of important implications for policy, practice and caregivers. These, along with theoretical and methodological implications of this thesis, will now be presented in the final chapter.

CHAPTER 8: Implications and conclusions

Introduction

This thesis critically examined spousal care within the complex and changing system of care in contemporary Australia. As highlighted in Chapter One, spousal caregiving is an important component of the aged care system that supports Australia's ageing population. The social and economic importance of spousal and other informal care is reflected in the design and funding of formal aged care services in Australia, which presume and rely on the existence of informal supports to provide the majority of care to older adults in the community (Chomik & MacLennan, 2014). This contribution to the Australian aged care system has become increasingly important in recent years, as the care needs of a rapidly ageing population have become forefront of government responses to health and social policy.

The sustainability of an expanded community based care sector, however, depends very much on the availability of spouses and other informal caregivers. This is particularly the case in rural areas, where long-term trends of inter-generational relocation are altering rates of ageing and the availability of informal supports in rural and regional areas of Australia (McDonald, 2016). Many studies in recent years have demonstrated the individual pressures and consequences of home-based care on informal caregivers (for example, Butterworth, Pymont, Rodgers, Windsor & Anstey, 2009; Butler, Turner, Kaye, Ruffin & Downey, 2005; Hirst, 2005; Lavela and Ather, 2010). This study widens the scope taken in

previous explorations of care, to incorporate an understanding of issues and impacts on spousal caregivers from structural and societal levels.

This thesis, therefore, specifically set out to explore how social, policy and practice systems interact with and impact on spousal caregiving in rural Australia. Three systems of care, focusing on policy (macro), practice (meso) and individual (micro) levels were examined via a series of sub questions, answered in the preceding chapters and published papers within this thesis. The three papers within Chapters Four, Five and Six present and discuss the findings from each of the respective systems of care studied. The fourth published paper presented in Chapter Seven demonstrates how and why these aspects of the care systems were analysed using this systems based approach to research.

The exploration of care in this multidimensional way enabled spousal caregiving to be analysed and understood within the complex and changing social and political environment in which it occurs. This final chapter will explore how integrating the knowledge captured across these different systems of care facilitates a more complete understanding of spousal caregiving in the Australian context. First, this chapter will present a summary of the findings from each element of the study, before bringing them together to show how this thesis has made an overall contribution to knowledge, by answering the overarching research question of this thesis. These findings will then be used to discuss the implications of this knowledge on policy, practice and caregivers. The chapter closes with a discussion of the strengths and limitations of this thesis, suggestions for future research and concluding statements.

Summary of key findings

In order to examine the contextual complexities of spousal caregiving, data was collected and critically analysed at policy, practice and individual levels of the care system. This was achieved through the use of multiple research methods to analyse the micro, meso and macro aspects of the informal care system. This design provided a dual focus on understanding each layer of the care system, as well as the interaction between these systems. This approach, therefore, enabled critical consideration of how changes at macro policy levels can filter down to impact practice and ultimately individuals, enabling significant new depth to the findings that may not have become evident analysing systems in isolation from one another.

The following tables present a summary of key findings that emerged at each of these stages of the project. A discussion of these findings will then demonstrate how these three stages culminated in answering the overarching research question of this thesis.

Research question one:

The first research question explored in this thesis aimed to understand how choice for caregivers was constructed in social policy. This was achieved via a critical discourse analysis (CDA) of three of the key policy documents available at the time this analysis was conducted; the Productivity Commission Inquiry into Caring for Older Australians, the Living Longer, Living Better Aged Care Reform Package (LLLB) and the National Carer Strategy.

In the time since this CDA was completed, rapid reform has continued in the Australian aged care system. The reforms analysed in this thesis have continued to roll out and expand, bringing a strengthened focus to community based care and home based care funding (Department of Health and Ageing, 2012a). Despite this ongoing and rapid program reform, the findings of this CDA remain relevant due to the focus of analysis on the broader ideologies and language of the policy documents, rather than the details of specific programs.

Research question one: How is choice portrayed in contemporary social policy with regards to informal caregiving?
Finding: Choice as market-based access and control • Policy identifies that the increased focus on choice in aged care reflects requests for and expectations by older adults of greater autonomy and control in later life. • The term *choice* is used within policy in reference to options within the market-based service system. • The use of the word choice in this market-focused manner leaves room for misinterpretation by consumers of services who might interpret this to mean free choice.
Finding: Caregivers are not afforded the same choices as other older adults. • Throughout each of the policy documents analysed, the language used both overtly states and assumes availability and willingness to care by family caregivers. • Policy documents demonstrate a complete absence of consideration to potential impacts of greater choice for care recipients on informal caregivers.

- There is an assumption that caregivers agree with older adults decisions about care (e.g. remaining at home with family support).
- There is a complete absence of discussion about choice for caregivers in policy.
- Discourse in relation to caregivers uses words like *responsibility* and *duty* to distinguish positioning of caregivers within the care system.
- No consideration in policy for family members or spouses who may not wish to provide at home care nor mechanisms to identify types of care they are willing to provide.
- The invisibility of caregivers is emphasised in examples such as discussions of respite within the documents analysed. Although increased respite is presented as an opportunity to give care providers a break, this is framed in terms of giving care recipients greater choice about how respite services are delivered to them.

Finding: Support for caregivers is based on economic rationale

- Overt acknowledgement in policy that the primary reason to support caregivers is to reduce pressure on publicly funded services.
- This rationale presents an individual level solution to a macro level economic problem, weighting economic outcomes against social and financial exploitation of individuals and personal risks to caregivers. Caregiver support is identified as not intending to decrease caring load, rather to enable caregivers to continue in unpaid care roles.
- This implies that the wellbeing of caregivers is only of value if it reduces financial burdens on the government.

Finding: Language is used to promote familial care as the preferred solution

- Dual discourses of individualised care and familialism coexist within policy.
- Repetitive messages about *reliance*, *dependence* and caregiver's *fundamental* role in the care system is used to justify assumptions of familial care.
- The language used within policy promotes moral discourses of "loving caregivers"

- Emotive language is utilised in policy to deflect from lack of real choice to care. For example, placing an emotive comment (care as love) immediately before a negative comment (demand exceeds supply, so there is no alternative but to care).
- The use of emotive discourses of love as the motivation for care fails to consider the complexity and expectations of caregiving, instead playing on the powerful moral expectations of familial solidarity.
- Phrases "no other alternative" and "willingness to care" are used as euphemisms to "no choice" and "unwilling to care"

Research question two:

The second stage of this research set out to explore how the conflicts identified in policy were navigated in practice. As discussed in Chapter Five, a series of seven focus groups, comprising a total of 42 participants, were conducted with health and aged care practitioners who worked with community residing older couples across North East Victoria. These focus group discussions sought to understand the translation of policy directives and organisational guidelines around choice into direct practice with spousal caregivers. These discussions presented opportunities for practitioners to reflect on their views and practice approaches when working with older couples in the community.

Research question two:

How do practitioners' perspectives of spousal caregiving obligations impact on choice in rural communities?

Finding: Social norms influence practitioner perspectives of spousal care.

- Practitioners demonstrated significant influence of social norms on their perspectives of spousal care (e.g. care as love; assumption spouses would want to provide care in order to remain living together at home).

- Practitioners demonstrated surprise at use of the word choice in relation to spousal care.
- Acknowledgement of social pressures and the perception of others as motivating spouses to care.

Finding: Marriage as a complex context for care

- Deeper reflection revealed many examples of spouses who didn't appear to want to provide care but who practitioners felt did so because they were caught in a bind between love, marital obligations and care needs.
- Many stories emerged of "the promise" couples made to continue providing care to one another and the subsequent distress and struggles to consider alternatives to in-home care that arose because of this.
- Frequent observations of crisis points being reached before support is sought - high levels of distress at this point impact on decision making.
- The "quiet word" was frequently observed as a demonstration of spouses being constrained in ability to speak openly about care to both partner and practitioners.
- No mechanisms in practice to ensure a caregiver assessment or opportunity to discuss care away from partner is routinely provided.

Finding: Limited critical reflection about care roles and relationships evident within practice

- Considerable variation in evidence of reflective practice across participants.
- Adoption of new policy language with limited critical consideration of the complexities of enacting these constructs within familial care contexts.
- Discrepancies and contradictions between verbalisation of "consumer focused" practices and examples of practice that included comments about "chipping away" at preferred solutions and of couples "coming around" to practitioners views.
- Very few practitioners reflected on the impact of relationship quality or the changing nature of care and increased demands on spouses.

Finding: Practical barriers impact ability to offer choice in practice

- Ability to enact market-based choices is limited in rural areas by a lack of market, with many locations offering only single services.

- The most significant barrier to choice in rural areas was geographic distance, which impacted individuals providing and receiving services, caregivers and organisations.
- Ability to access preferred and specialist services was impacted by geographic, financial and transport considerations.
- Funding packages restricted choice in rural areas due to costs associated with travel, and costs charged by providers.
- Service users did not always have adequate health literacy or understanding of the system to navigate this independently – increased role and power of practitioners in guiding and decision making as a result of this.

Research question three:

The third stage of this research set out to understand how spousal caregivers themselves experienced the wider expectations and pressures to care that had been identified in the preceding stages of this research. As discussed in Chapter Six, ten in-depth interviews were conducted with individuals over the age of 65 years who were providing or had recently provided spousal care in their home. These interviews sought to understand the lived experience of choice within the social context of long term marriage. The nature of in-depth interviews presented the opportunity to capture the lived experience of caregivers themselves by exploring their experience of choice and decision making.

Research question three:

How do expectations of informal care impact spousal caregivers in later life?

Finding: Care is an unquestioned expectation of marital relationships

- Commencement of care was automatic and unquestioned by all participants.
- Many caregivers associated obligations to care with their marriage vows.

- Care was frequently associated with a sense of reciprocity within the relationship.
- Some participants noted gendered and familial role expectations and the modelling of these by previous generations as influences to care.

Finding: Contextual factors constrain choices and options relating to care

- Social and financial interdependence restricted ability to consider alternatives to providing spousal care.
- Conformity to social expectations of marriage impacted decisions to care due to concern for what others in the family or wider society might think of declining to care.

Finding: Spouses provide care regardless of relationship quality

- Significant diversity in relationship quality evident across the sample.
- Some spouses identified care as an extension to long and happy relationships.
- An optimistic attitude toward care was more evident in couples who described a positive marital relationship.
- Some spouses continued to provide care despite very poor relationship quality.
- Some spouses continued to care despite reporting they did not want to and did not enjoy providing care.
- Some spouses identified care as an obligation, not a choice.

Finding: Spouses struggle to consider alternatives to in-home care

- Spouses often made promises to provide ongoing care in the home and were very reluctant to break this promise.
- Few spouses had actively considered or planned for future changes in care needs.
- Spouses demonstrated a strong commitment to continuing to provide care despite physical and emotional risks to self.
- Different experiences of participants who had made the decision not to continue with in-home care (family backlash against decision versus supported and encouraged decision).

Integration of findings

This thesis set out to explore the research question: *How do social, cultural, policy and practice systems interact with and impact on spousal care in the rural context?* As highlighted in the findings above, the systems of care surrounding spousal caregivers were analysed at policy (macro), practice (meso) and individual (micro) levels. A systems approach also extends beyond the macro level of influence, to also consider sociocultural contexts (Healy, 2005). Ensuring consideration to these exosystemic factors at each stage of this project enabled the analysis to be conducted within its real world contexts of rural Australia.

In order to address this overarching research question, however, it is necessary to look beyond these individual stages of analysis and to consider the interaction between these layers of the care system. When considering these findings as a whole, new insights are revealed into how these systems interact with and impact on spousal caregivers in rural Australia.

The influence of social expectations surrounding spousal care were established as central concepts early in this research. It was anticipated that, consistent with existing literature on informal care, the nature of familial relationships would contribute to discourses of obligation and expectations to provide care within marriage. The impact of normative care assumptions, however, emerged as a significant factor across and between each of the care systems analysed.

Assumptions of informal care at the policy level were both overt and actively reinforced through linguistic mechanisms. The linguistic analysis of policy demonstrated government discourses that dually argued the economic rationale underpinning the value of informal care, while concurrently utilising emotive language to promote care as a demonstration of love. These competing discourses were interwoven through policy with no clear resolution evident as to how these might be enacted within practice. At the individual level, caregivers acted out these normative assumptions without question, deferring to marital vows and promises to care as central motivators. Contrasting with the suggestions of policy, however, expectations of care within marriage at the individual level were not necessarily associated with love and willingness. The complexity of interpersonal relationships was secondary to the weight of marital expectations, with some caregivers commencing and continuing to provide care despite significant dissatisfaction with both their relationships and the care role.

A significant new insight into the interaction of care systems emerged at the practice level of the care system. Practitioners were clearly caught between macro organisational and policy driven directives and the micro level needs and wishes of older adults and their caregivers. The influence of policy-led language in the practice domain was pronounced, with practitioners readily espousing consumer-led decision making and the facilitation of choice as guiding paradigms in their practice with older couples. The translation of these stated intentions, however, was compromised by their own discourses of care as love and individual socialisation surrounding care as a normative spousal obligation. The potential impact of practitioners' own values and assumptions influencing their language

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and practice decisions is particularly concerning. This has significant potential to reinforce the social obligations already present for caregivers, as highlighted in the micro stages of analysis and imposed at macro policy levels.

A particularly concerning observation across all levels of the care system was the lack of opportunities for caregivers to contribute to discussions and decision making about care capacity and willingness to provide care. Caregivers feeling unable to disclose concerns about providing care in the presence of their partner was a particular example that highlighted the influence of normative expectations on individual decisions relating to care. It was evident throughout each stage of this research that there has been little consideration given to the potential impact of an increasingly consumer-focused care systems on spousal caregivers.

The integration of these key findings presents a holistic understanding of spousal care and enabled the overarching research question of this thesis to be addressed. These integrated findings, however, raise a number of significant implications for policy, practice and caregivers themselves. The implications of these findings are presented and discussed below.

Significance of the study

This research makes a number of significant contributions to knowledge, as discussed below.

Firstly, the design of this PhD as a thesis containing publications has enabled timely dissemination of findings as each stage of the research was completed. Unlike a traditional thesis, this process afforded the insights of anonymous reviewers and journal editors through the development of this study. This has provided invaluable feedback to the development of this thesis and its associated publications.

A key contribution of this research is its methodological innovation. A systematic review of theory use within social work research was conducted as part of this thesis. This review revealed that despite a strong emphasis on systems theories within social work practice, the systems approach has been largely overlooked as a potential framework for guiding research. This thesis has designed and successfully implemented a framework for the use of systems theory in relation to a significant social issue, spousal caregiving.

This research also raises and analyses an important social issue that has been largely overlooked in recent aged care reforms in Australia. Building on a small body of existing literature that expressed concerns with choice-oriented directions in health and welfare contexts, this research contributes significant empirical knowledge toward understanding the context of policy reform on both practitioners and informal caregivers. Importantly, this contribution highlights the significant challenges and inequities of implementing increasingly individualised policy reforms into practice within contemporary social contexts.

A further contribution of this research is its insights into practice with older community residing adults. This study provides an empirical demonstration of the challenges experienced by practitioners attempting to promote the individual rights of consumers within the context of familial social norms. This raises important implications for both the effective translation of these directions in practice and of the need for greater critical reflection and supervision of direct care staff.

Finally, this research contributes knowledge to understanding the experience of spousal caregivers in rural Australia. While research has previously demonstrated the significant risks to co-resident spouses providing care, there has been very little consideration of the unique and often long standing nature of their marital relationship as the context of care. This research contributes a unique in-depth insight into the impact of wider sociocultural and systemic influences on the experience of providing care to a spouse in later life. The adoption of a systems approach in this thesis enabled multiple perspectives of the care system to be explored in this single study of spousal caregiving.

Implications for social policy

Social policy has been a central consideration throughout this thesis, with the extensive reform of aged care services found to have both direct and indirect impacts on spousal caregivers and the provision of services. As highlighted in Chapter One, recent policy changes have centred on increased marketisation of the care system. This has contributed to a growing privatisation of care services

and user pays principles, as well as an increased focus on consumer-directed care programs (Meagher & Goodwin, 2015). These changes sought to overcome the complexity of navigating the existing aged care system, by centralising and improving access to aged care services and bringing greater control over decision making to consumers. Accompanying these changes, however, are the major conceptual and practical shifts required by service providers and consumers to implement these transformations in the provision of care.

The concerns raised in this thesis with regard to aged care policy have emerged both via the direct analysis of key policy documents, as well as during exploration of how macro policy directions influence other levels of the care system. Rather than analyse specific programs within the service system, this research has taken a critical approach to analysing the broader discourse and central assumptions that underpin contemporary social policy. This focus ensured that the findings of this thesis would maintain relevance and transferability as new programs emerged during subsequent stages of the reform process. Exploring the interpretation and implementation of these key social and policy concepts in practice and with caregivers also highlighted a number of key issues relating to the translation of policy into real world contexts. The implications for policy emerging from these findings will now be discussed.

Caregivers in social policy

Health and aged care policy in Australia is overt in acknowledging the economic and functional reliance on informal caregivers that is central to these systems of care (Deloitte Access Economics, 2015; Productivity Commission, 2011). With the

replacement costs of formal care precluding it as a financially viable alternative to informal care, it should perhaps not be surprising that this thesis highlighted a number of mechanisms utilised within policy and practice to enforce and maintain familial care obligations.

Although there is some indication that propensity to provide informal care is declining (Deloitte Access Economics, 2015), it is reasonable to assume that both spousal care and individualised care approaches are likely to continue for the foreseeable future. It is therefore imperative that the needs of caregiving spouses as both individuals in their own right, as well as a central part of a care dyad, become more visible within contemporary policy and practice environments. The evolution of both caregiver needs and individualised care have unfolded much earlier in the UK than in Australia. The UK have responded to these challenges with active development of compulsory caregiver assessments and legislation that focuses on the provision of supports and consideration to the individual needs of caregivers (Larkin and Milne, 2014). These significant steps forward in caregiver rights in the UK provide some useful considerations for Australia in more actively advocating for and responding to the needs of caregivers.

Some progress toward this is becoming evident, with the Australian government recently announcing that they will begin introducing a new Integrated Carer Support Service (ICSS) from October 2018. Developed in consultation with and endorsed by Carers Australia, the ICSS aims to centralise caregiver support services via the Carer Gateway and to introduce a range of new carer specific supports (Carers Australia, 2018). These new services are being funded by the

introduction of a means test to cap eligibility for recipients of the Carer Allowance (Department of Social Services, 2018). The announcement of this new caregiver specific initiative is a promising government response to several key issues for caregivers that emerged throughout this thesis. It is, however, important to recognise that these proposed new supports and services continue to reinforce issues raised in findings during each stage of this thesis around supports designed with a primary focus on sustaining care. Increasing early intervention and other practical and emotional supports is, of course, crucial and important for the large numbers of caregivers across Australia who can and want to provide ongoing care to a family member. This thesis, however, has highlighted the unique situation of cohabiting spouses whose contextual realities enforce the provision of continuing care despite considerable adversity and in some cases the desire not to provide ongoing care.

Phase two of the ICSS, set to commence from September 2019, mentions the introduction of "needs assessment and planning" services for caregivers (Department of Social Services, 2018), though it is unclear at this early stage what this might entail or how it will be implemented. The findings of this thesis suggest the introduction of caregiver assessments must be a crucial outcome of this reform process, as this presents the opportunity to resolve a number of key issues that emerged throughout this research. Firstly, these assessments will assist in distinguishing caregiver voices and views from those of the care recipient, rather than making assumptions that there has been discussion and consensus within the dyad relating to care decisions that ultimately affect both parties. This is particularly important in the climate of increasing consumer directed service

delivery and must be conceived as an ongoing process rather than a static assessment at the commencement of care.

This new approach to assessment might open up discussions that better explore key transition points in the care relationship that were observed throughout this thesis to frequently culminate in a crisis. Even with the introduction of caregiver assessments or counselling, the strong reliance on informal and community based care continues to present few meaningful or favourable alternatives for spouses other than respite or residential care. These alternatives have been identified by older adults as options that erode autonomy and self-identity (Stones & Gullifer, 2016). This presented in findings from caregiver interviews as a particularly unfavourable solution to caregiving stressors, drawing attention to the need for more creative care alternatives to better meet the needs of older couples.

The concept of choice in policy

As highlighted in Chapter One, a number of key social gerontologists have expressed concern about the potential challenges of neoliberal economics and its associated individualised principles of choice being applied within health and aged care contexts (Arksey & Glendinning, 2007; Fine, 2012; Markus & Schwartz, 2010; Pickard, 2010). Despite these well documented concerns, the concept of choice has remained central to the reforms undertaken in Australia.

A shift toward choice and autonomy enables active consumers to be responsible for their own health and wellbeing, aiming to overcome previously identified challenges in the system around services being restrictive and lacking flexibility

to respond to individual care preferences. Sociologists such as Susan Pickard (2010), however, have discussed how these shifts concurrently see caregivers, who are autonomous consumers in other aspects of life, being encouraged to fulfil moral and ethical family duties and traditional obligations in order to fulfil the individual care wishes of family members to receive care in the home. This dilemma was evident throughout this thesis, with analysis demonstrating the layering of individualised care and familial discourses within contemporary policies. These dual ideals promote individual choice and expansion of community based care for older Australians, yet notions of individual choice and autonomy are conspicuously absent for caregivers, who are instead offered support to sustain family care responsibilities (Commonwealth of Australia, 2011; Productivity Commission, 2011).

An important contribution of this thesis was the examination of these conceptual concerns in real world practice and care contexts. Within this study, practitioners demonstrated limited consideration of the caregiving spouse's individual needs, often viewing these as secondary to that of the care recipient. Priority of care recipient needs was also evident in conversations with caregivers, who were frequently observed to give precedence to the care requirements of their partner over their own needs and wishes. There are multiple complex reasons for this, stemming from the relational nature of spousal care and compounded by policy and practice approaches that focus on individual care recipients rather than care dyads. This is a complex issue, with the findings of this thesis suggesting that spousal care expectations are deeply embedded in the automatic and unquestioned thoughts and behaviours of both practitioners and caregivers. The

emergence of increased choice for care recipients is an important step forward in the reform of aged care services, though it is important that individualised care does not occur at the expense of those providing care, particularly when extensive research demonstrates the risks and poor outcomes for family caregivers (Butterworth et al, 2014; Hartke, King, Heinemann & Semik, 2006; Hirst, 2005; Lavela & Ather, 2010; Pinquart & Sorensen, 2011).

The individualisation of care will also be challenged by the growing prevalence of dementia within older populations. Dementia is currently the single greatest cause of disability in Australians over the age of 65 years, and is the third leading cause of disability burden (Australian Institute of Health and Welfare, 2012). Projections indicate the number of Australians with dementia is expected to triple by 2050 (Australian Institute of Health and Welfare, 2012), which will present both an increased burden of care on informal caregivers and significant challenges to the practice of consumer-directed care.

Research by Moran et al (2012) in the UK has suggested that greater control by consumers also has the potential to increase choice for informal caregivers. Their exploration of individualised care budgets identified increased caregiver choice and flexibility as positive outcomes, though this advantage required caregivers to provide the additional time required to undertake the necessary coordination of services and supports (Moran et al, 2012). Although there is not currently literature exploring CDC from the perspective of caregivers in Australia, early studies are beginning to emerge around the experiences of CDC from the perspective of care recipients. Gill, Bradley, Cameron and Ratcliffe (2018)

interviewed older adults receiving CDC packages in Australia, revealing that many recipients were unable to describe CDC or what it meant to them, were unable to distinguish it from provider controlled services and demonstrated a reluctance to negotiate services to better suit their individual requirements. These findings highlight a number of concerning challenges for older adults in understanding and navigating the service system as autonomous consumers. Although this study didn't specifically consider the perspectives of caregivers, other studies such as that of Moran et al (2012) would suggest that spouses and other informal supports are likely to be actively involved in this complex experience of decision making and coordination of supports. The central involvement of caregivers in the administration of CDC highlights the importance of actively considering the impact of this transition on caregivers within the Australian context.

It is also important that choice in the care context is not exclusively about decisions relating to selection of formal services. There needs to be both the opportunity to consider what types of care an individual wishes to or does not wish to provide, including the decision to provide no care at all, and the mechanisms in place to support these alternatives to spousal care. Many stories emerged throughout this thesis that demonstrated how social norms and assumptions of care forced caregivers into the provision of care roles. This was maintained at many levels and by a variety of individual, social and structural mechanisms. It is therefore a recommendation of this thesis that social policy better consider the complexity of family based care relationships, not only in a general sense, but specifically with relation to the impact of individualised and consumer directed care approaches.

Implications for practice with older Australians

Practitioners in health and aged care play a central role in facilitating and enabling access to supports and services for older Australians. As has been highlighted in this thesis, however, they are caught in a complex nexus between changing policy directions, organisational constraints and the needs and wishes of older adults and their caregivers. As such, although only one stage of this thesis focused specifically on the perspectives and practices of these professionals, the implications for practice arising in this thesis stem from all three levels of the system analysed.

Research into practice often focuses on the practical implementation or resource challenges of working with older adults. The critical and systemic approach taken within this thesis enabled practitioner roles to be examined from multiple perspectives, from their individual beliefs and practices through to the wider implications of organisational and policy influences on their work with older adults in the community.

The impact of practitioners on the availability of choice

This thesis highlighted that as individuals, health and aged care practitioners are socialised into the same familial expectations of care as other Australians. These personal views and perspectives were demonstrated to present both conceptual and practical issues in practice with older couples. The focus group style discussions used to collect data in this research enabled practitioner views to be

critically explored in greater depth, revealing the underlying complexity of social norms on practice. When encouraged to explore their assumptions further, practitioners were able to identify many examples of situations where spouses felt compelled to care against their wishes and of care being provided for reasons other than love. A particularly concerning phenomenon that commonly arose throughout these discussions were observations of the "quiet word". These frequent occasions of caregivers being unable to disclose concerns about providing care in the presence of their partner highlights the pressure of normative expectations on decisions surrounding care.

This thesis has raised significant issues about the potential impact of practitioners own values and assumptions of familial care influencing their language choice and practice decisions. These influences have potential to reinforce the social obligations already present for caregivers. When considered in light of interviews with caregivers, who did not perceive any choice related to care, the significant effort required by caregivers to initiate these quiet conversations becomes clearer. It is particularly concerning that despite widespread recognition of these normative pressures on spouses, neither policy nor practice demonstrates any structural responses to address this lack of opportunity for caregiver participation in assessment and care planning.

As highlighted earlier, at the time of concluding this thesis, there has been a promising government announcement suggesting that caregiver assessments are intended as a future goal of the ICSS (Carers Australia, 2018). If enacted, this would be a considerable step forward in bringing the needs of caregivers more

overtly and routinely into conversations and decisions surrounding care, as observed following their introduction in the UK (Larkin & Milne, 2014).

These developments, however, only partially resolve issues that arise from the positioning of caregivers within the overall systems of care. Despite being the primary providers of community based aged care in Australia, informal caregivers continue to be regarded as a resource rather than a central component of the care team (Dow & McDonald, 2007). In addition to the introduction of routine caregiver assessments, practice needs to more purposefully engage informal caregivers in case conferencing and planning meetings that occur amongst formal service providers involved in the provision of care. Greater engagement of informal caregivers as central to care teams also needs to ensure appropriate consideration is given to the underlying obligations and pressures to care experienced by spouses and other family caregivers. This complexity must be considered and addressed in these decision making platforms. Informal caregivers should be given an opportunity to discuss their role on the care team, even if this means that the outcome necessitates increased formal service provision if the caregiver decides to change or reduce the amount of direct care provided or wishes to consider alternatives to providing primary care in the home.

Previous research has suggested that reluctance to care is complex and somewhat taboo, with caregivers concealing true feelings in favour of socially appropriate responses (Burridge et al, 2007). Compounding this complexity are concerns that practitioners might avoid conversations about reluctance to care due to the potential complications of having alternative resources available if the caregiving

role is rejected (Burridge et al, 2007). This thesis builds on the concerns raised by Burridge et al (2007), with findings suggesting that in addition to the complexities of inadequate alternatives, practitioners are actively making assumptions about care willingness without overtly discussing this with caregivers. This has important implications for practice with older couples and is not addressed by traditional caregiver support mechanisms that also assume care willingness via their focus on sustaining care for as long as possible. Even without alternative services to offer, there are options available to health practitioners caught in this nexus. Firstly, prioritising the building of relationships with care recipients and caregivers will engender confidence, trust and a greater likelihood of disclosure during conversations about the realities and challenges of care. The inclusion of informal caregivers in conversations about care and decision making can at the very least open up conversations about alternatives and solutions.

The efficacy of reflective focus group discussions with practitioners in this thesis highlighted the potential benefits of greater critical reflection as a practice tool. Critical reflection is discussed by Gardner (2009) as providing a process for exploring and articulating underlying individual and organisational values and assumptions. This process of critical reflection then enables practitioners to actively engage with the dilemmas of practice, bringing clarity and focus on key issues during times of uncertainty and complexity (Gardner, 2009). It is therefore a recommendation of this thesis that greater emphasis is placed on training, supervision and guided critical reflection for practitioners working with older couples in the community. This would dually increase critical attention to the implementation of policy concepts into practice, but also ensure more active

consideration to the potential impacts of social norms on practice and on older adults. While social work places a strong emphasis on professional supervision and critical reflection to address practice challenges, these mechanisms are not always valued by employing organisations and other health professions. The diverse and multidisciplinary nature of the health and aged care workforce would require a wider campaign of advocating these reflective practice strategies across professional disciplines.

It is also important to note here the involvement of professional associations such as the Australian Association of Social Workers (AASW) in prioritising and promoting ageing within social work education. Although the AASW has a Scope of Practice document promoting social work in aged care, the Australian Social Work Education and Accreditation Standards (ASWEAS) guidelines on essential core curriculum content makes no mention at all of educating future social workers in this field. This is concerning given that Australian research has highlighted that exposure to gerontology content in social work programs is associated with both a greater understanding of ageing issues and also an increased interest in working with older adults (Hughes and Heycox, 2006). The critical issues highlighted in this thesis draw attention to the need for a greater response from AASW and other professional bodies to firmly locate ageing on education and practice agendas to ensure practitioners are well informed and critically engaged with issues impacting older Australians.

The challenges of translating policy into practice

This thesis contributes knowledge to a body of work that has found the concept of choice and consumer directed care are readily drawn on within practice without adequate consideration of how complex and problematic these concepts can be for older people and their caregivers (Arksey & Glendinning, 2007; Markus & Schwartz, 2010). In addition to individual practitioner variables on practice, the systemic nature of this thesis contributes a number of important insights into the translation of contemporary policies into practice with older community residing couples. Practitioners in this study consistently described their approach to practice using consumer focused descriptors. Although this adoption of language aligned with contemporary policy directions, further exploration of this description exposed practice approaches that did not always align with stated intentions. Describing the need to "chip away" at individuals, or waiting for them to "come around" to preferred solutions revealed ongoing struggles for practitioners in moving away from traditional roles as experts in decisions around care. These findings reflect the complex and changing context of practice for health and aged care professionals.

The implementation of individualised care requires considerable change from ingrained practitioner led approaches to managing and distributing resources to care recipients. The shifting of power and decision making to service users presented some challenges to practitioners in this study, who discussed concerns of limited health literacy and the need for individuals to understand, navigate and assert their needs within the complex systems of aged care. The introduction of CDC focused programs further increases the necessity for caregivers and care

recipients to understand these complex and changing systems. Although this arguably presents the opportunity for caregivers to have greater choice in the types of support available to supplement their informal care, it also requires the ability to take on further responsibility in a coordinating or case management type of role. Early research on the transition to CDC in Australian aged care has also highlighted challenges for practitioners and organisations, with practitioner values, attitudes and organisational culture identified as key challenges to the implementation of CDC in practice (Laragy & Allen, 2015; Gill & Cameron, 2015; Prgomet et al, 2017).

Although language in the practice domain reflected policy rhetoric of choice and consumer focused care, caregiver needs and wishes were not formalised or overtly considered in practice. Importantly, support for caregivers centred on respite and strategies to maintain ongoing availability to care, rather than on the individual needs of the caregiver or even of the care dyad.

Rural issues

Aged care and other social policy tends to be developed within a primarily metro centric framework. This often results in policies that make broad assumptions about the availability of formal services and of geographically convenient relatives to assist with informal care. The rural Australian context presents both strengths and challenges to caregiving that are distinctly different from the experiences of providing care in metropolitan centres. Although policy reforms acknowledge the complexities for rural Australians, there are few meaningful strategies in place to overcome these structural limitations. These limitations become particularly

apparent when analysing the translation of market-based approaches to care in rural, regional and remote areas of Australia.

As highlighted previously in this thesis, the increase of marketisation is presented within health and aged care by way of promises for greater individual autonomy over care decisions and choice between services and supports. Recent discussion papers exploring the impact of changing policies in aged care, however, have suggested marketisation has a significantly reduced applicability in rural and remote settings (Baldwin et. al, 2015). These challenges were evident within this thesis, which demonstrated many examples of the practical constraints to offering and implementing choice to older couples, and particularly to caregivers in rural areas.

A key example of these translational issues was evident in the challenges of practitioners who grappled with the realities of limited resources or organisational flexibility to provide meaningful choice. Within the rural locations sampled in this thesis, most had only one available service provider, meaning that the choice available was to accept the service or not. This example highlights that despite a change of language suggesting greater choice, the lack of market-based options in rural areas fails to provide the mechanisms and resources required to support these shifting policy directions. These structural limitations were also evident in practitioners and caregivers discussions of how funding arrangements failed to consider the costs and challenges of geographic distances in rural areas. The requirements of travel to provide services in rural areas required significant percentages of package funding to be used for travel expenses. This also reduced

the hours of direct service provided and further constrained the ability to choose alternate service providers. Although this study revealed individual practitioners and organisations creatively responding to these gaps for caregivers in practice, the broader structural issues and lack of consideration to service access in rural areas was a key implication of these findings. It is therefore a recommendation of this thesis that individualised models of funding provide appropriate consideration to the geographic constraints of purchasing support for the growing numbers of older adults in Australia who reside in rural areas.

Implications for spousal caregivers

At the core of this thesis are the growing numbers of ageing women and men providing unpaid care to their spouse across Australia each and every day. While research has previously demonstrated the significant risks to co-resident spouses providing care, there has been very little consideration of the unique and often long standing nature of their marital relationship as the context of care. This research contributes a unique insight into the impact of wider sociocultural and systemic influences on the experience of providing care to a spouse in later life.

Throughout the development of this thesis it became increasingly clear that the individual needs of caregivers have become secondary within an increasingly consumer focused care system. Individualised care represents a positive step forward to increase and expand community based care alternatives for older adults, yet these notions of individual choice and autonomy are conspicuously absent in policy discussions regarding caregivers. The very existence of the "quiet

word" is evidence of the invisibility of spousal caregivers in aged care practices. This thesis provides a multidimensional illustration of how both normative assumptions of spousal care, as well as structural constraints within the care system, significantly impact choices and options for spousal caregivers.

While choice-oriented language dominated the policy and practice analyses within this thesis, consideration of choice was least pronounced in interviews with caregivers themselves. Familial care obligations dominated the discourse of spousal caregivers, who struggled to consider choices around the provision of care. Choice did not enter the dialogue of these caregivers, who viewed themselves as spouses and partners before care providers, automatically assuming care roles as an expectation of their marital relationship. Many of the older spouses who participated in this research were providing care as an extension of a long and happy life together, though this was not an assumption that translated to all caregivers and relationships in the sample. Even those caregivers in unhappy marital relationships or who were challenged by the care role still struggled to reconcile the concept of choice as relevant to their situation. These familial obligations impacted not only the decision to care initially, but also ongoing care decisions around accessing respite and formal supports and particularly in considering transitions away from providing care at home. These findings have a number of significant implications for caregivers.

Firstly, these findings suggest that regardless of policy reform and practice changes, normative expectations are likely to result in spouses continuing to provide unquestioned care to their partner. The automatic role assumptions

described within this thesis reflect the internalised norms of socially appropriate behaviour that arise from a lifetime of being socialised to familial values (Silverstein et al., 2012). Ethicists Ruud Ter Meulen and Katharine Wright (2012) have discussed how the emotional involvement and compelling moral duty that exists between family members greatly impacts the notion that informal care is a personal decision and voluntary action. This was evident through many aspects of this thesis and provided important insight into the findings.

Commitment to care in marriage is implied both implicitly in the nature of the relationship, as well as explicitly by way of vows. These perceived commitments played on the minds of caregivers in this study, with concerns about "what people would think" if they were to cease caregiving emerging in several participants' dialogue. Practitioners also recognised these social pressures, discussing the need for spouses to be "seen to be trying" and to have "done their best" before being able to contemplate relinquishing care. Despite awareness of these social constraints at all layers of the care system, there remains an absence of mechanisms to ensure the voice of caregivers is captured in interactions with service providers.

Arguably caregivers do have choices, because these constraints are self-imposed. Although ideas of familial obligation are now being challenged by the rise of individualism within health and welfare contexts, this discourse has emerged concurrently with, rather than instead of, the familial foundations of social solidarity. It was evident across the stages of this thesis, that familialism remains the dominant social discourse around caregiving and is subsequently reinforced

by both caregivers, families and wider systems of policy and practice. Caregivers in this study frequently made statements to the effect of "well, who else would do it if not me?" These comments reflect the reality for many older Australians within contemporary Australia, for whom the changing social landscape and increased geographic mobility has seen less connections available to provide informal care. This was demonstrated in this study, with the majority of caregivers having no children or other family living nearby who were able to assist with informal care. For others, although there may be choices available, these were demonstrated to be constrained by financial, geographic and personal factors.

There are also important implications here for the types of services and supports made available to caregivers, with previous research demonstrating caregiver reluctance to use and dissatisfaction with existing respite services (O'Connell et al, 2012; Robinson, Lea, Hemmings, Vosper, McCann, Weeding & Rumble, 2012; Vecchio, 2008). A Canadian study by Keating and Dosman (2009) has also highlighted that family caregivers, particular co-resident caregivers, are the least likely to receive formal help despite providing the highest levels of care. This was attributed in part in delaying help seeking due to their reluctance to request support for care tasks they felt should be their own responsibility (Keating & Dosman, 2009). As highlighted by Timonen et al. (2013), intergenerational caregiving is greatly impacted by socioeconomic factors. Although their intergenerational study was not specific to the experience of care between spouses, the research highlights interesting considerations about the socioeconomic implications of providing care. Familialism is perhaps then more pronounced for couples who cannot afford to engage additional home support

services or consider alternatives such as supported retirement housing options. This is an important consideration within increasingly market-based and user pays systems.

This thesis has demonstrated that spousal care occurs regardless of relationship quality, irrespective of satisfaction with the provision of care and largely without consideration of available alternatives. In short, spouses do not perceive any choice but to provide care to their partner in later life. It is important to acknowledge that it is not quick, easy or even necessarily the desired outcome to change these normative constructions of care. It is, however, important to consider what can be done to better support spouses caught in this bind. Given the focus of currently available caregiver supports on sustaining ongoing care, this is particularly important for those who are struggling with the care role or who no longer wish to continue providing care.

Unmet support needs of caregivers have been associated with increased psychological distress (Temple & Dow, 2018), a known risk factor for neglect and abuse of older adults (Cooper, Selwood, Blanchard, Walker, Blizard & Livingston, 2010). As highlighted in this study, motivations to provide care can alter over time, as the burdens of providing informal care evolve and change. It is crucial that practitioners' are aware of the potential risks involved with reluctance to care, and that regular monitoring of care relationships and caregiver support needs are established foundations of practice.

Throughout this thesis it was demonstrated through the observations of both caregivers' and practitioners' that help seeking tends to be initiated only after a crisis. As highlighted above, Keating and Dosman (2009) identified a reluctance by family caregivers to use formal resources. This often resulted in service use being initiated by service providers in response to a health crisis (Keating & Dosman, 2009). It is therefore recommended that greater consideration be given to the relationships and social contexts of caregiving spouses, to better enable meaningful options, supports and earlier intervention that acknowledge the complex social and personal pressures of home-based care within marriage. Greater efforts to increase the health literacy of older caregivers navigating complex systems and greater promotion of advanced care planning would also reduce the culmination of spousal care in crises.

For spouses who do wish to continue providing care at home, it is important that options are available that suit the specific needs and wishes of both caregivers and care recipients. The findings of this thesis demonstrated a reluctance from some caregivers to utilise respite services or to participate in carer specific activities that excluded their partner. Previous research has highlighted the need for respite and support services that better offer flexibility to address individual needs and consider the financial and personal barriers that might be present for caregivers to access supports (Winterton & Warburton, 2011). For rural caregivers, this might require greater consideration of innovative technologies, such as telephone based group programs (Shanley, 2008) or inclusive social opportunities such as dementia cafes for older adults and their caregivers (Dow, Haralambous, Hempton, Hunt & Calleja, 2011).

Strengths and limitations of the thesis

As addressed in Chapter Seven, a key contribution of this research is its methodological innovation. The critical foundation of this thesis enabled spousal care to be analysed and explored with consideration to the social and political complexities that underpin policy and practice in the contemporary Australian aged care system.

The systematic review conducted as part of this thesis revealed limited adoption of systems theories as a guiding framework for social work research. This thesis has designed and successfully implemented a framework for the use of systems theory in social work research, enabling a comprehensive analysis of the systems of care. Beyond its utilisation in this thesis, this methodological approach has potential for application to other social work research that seeks a critical and systemic understanding of social issues.

Within this thesis, the systems based research design enabled spousal care to be understood within the broader systems of care in which it occurs. This multidimensional framework also provided a methodological pluralism to overcome the challenges of having a singular focus on any of these levels. A key strength of this thesis was its ability to contribute both critical and systemic findings that extend knowledge about spousal care in the rural Australian context, which is essential to presenting recommendations for the development of meaningful policy and practice with real world application.

While this systemic approach was a strength of the research design, it presented some challenges with regard to the limitations subsequently placed on the size and scope of the study to achieve this breadth of analysis across systems. The number of interviews conducted achieved the required level of saturation for the purposes of this project, though had time and resources permitted, a bigger sample size would have enabled the inclusion of more diverse perspectives of the caregiving experience. The diversity of caregivers in this sample extends knowledge beyond the experience of dementia and other specific care types. Although diverse in care types, it should be noted as a potential limitation of this sample that participants had provided care for between one and seven years at time of interview. These findings may therefore not reflect the experiences of longer term caregivers. Although this study relies on a small sample, the in-depth interviewing technique enabled a deeper and more nuanced exploration of caregivers' experiences. Many participants reflected gratitude at the opportunity to speak openly about their experiences, as they felt the topic of spousal care was not one they could usually discuss. The scope of this study at practice and caregiver levels was also restricted to one rural and regional area of North East Victoria and to spousal caregivers. Opportunities to consider other geographical areas and different relationship types would contribute much to this knowledge.

The changing nature of aged care in Australia during the completion of this thesis also presented a number of challenges and potential limitations to this research. It was tempting to analyse specific programs or features of the reform, though the quickly evolving nature of the reform space raised the risk that analysis would

quickly become dated and irrelevant. The decision was made to maintain a broader perspective on the ideologies and language underpinning reforms. This perspective has enabled the findings of this thesis to remain relevant in the face of rapid and ongoing reform at program and meso levels of implementation. The contributions of this thesis, then, offer greater scope to inform issues in a broader sense.

Recommendations for future research

This thesis has contributed to understanding the systemic complexities of spousal caregiving within the rural Australian context. These findings have highlighted several areas that would benefit from further research to expand on and extend knowledge in this area.

At the time of data collection for this thesis, the CDC reforms had only been newly revealed and were not yet being enacted within practice contexts. The findings of this thesis therefore reflect the views of practitioners navigating broader shifts around individualised and person-centred care rather than what has since become known as CDC. At the time of completing this thesis, early research is beginning to emerge around the implementation of consumer-directed care within home and community care environments. This research is highlighting challenges for practitioners and organisations grappling with the complexities of staff values, attitudes and organisational culture as barriers to the implementation of CDC in practice (Laragy & Allen, 2015; Gill & Cameron, 2015; Prgomet et al, 2017). Continuing to actively review and adapt the approaches to translating this

significant shift in practice is an important aspect of this reform process. This is particularly important in relation to research in rural areas, to determine how market-based approaches to service delivery will be enacted in areas recognised as lacking adequate market choices (Baldwin et al, 2015).

The findings of this thesis suggest it would also be useful for research to consider the presence of and opportunities for supported critical reflection in the workplace for practitioners navigating these significant changes to practice. At a practice level, there were some observations within the data of this thesis suggesting a differing understanding of, and engagement with, critical reflection depending on professional discipline. Further research to explore the training and practice of reflective practices might assist in determining how best to implement training and supervision to the multidisciplinary teams of staff involved in working with older couples in the community.

The translation of CDC into aged care should also be explored from the perspective of both care recipients and caregivers. Evaluations in the UK to explore the impacts of individualised funding models on informal caregivers has contributed important insights into the benefits and challenges of these new approaches to care (Larkin & Milne, 2014; Larkin & Mitchell, 2015; Moran et al, 2012). It is essential that research in Australia actively explores and monitors the experiences of care recipients and informal caregivers that emerge from the implementation of consumer-directed reforms. The findings of this thesis highlighted important insights into the relational and structural challenges experienced by caregiving spouses. Research that captures the perspective of care recipients enacting

individualised care decisions within their family environment would provide important new insights in this area. It would also be beneficial to consider the translation of the current study into a metropolitan context, to determine similarities and differences with the rural location of the current study.

Conclusions

Spousal caregivers are a central and crucial component of the aged care system in Australia. Despite this central role, however, consideration of their experiences within the complex and changing system of aged care in Australia is often peripheral.

While many individual Australians have and will continue to make the decision to care for a spouse in later life, it remains important to consider this micro level phenomenon from wider vantage points. The critical and contextual analysis of individuals within their social environments are central to both social work and social gerontology. It was this multidimensional analysis within this thesis that highlighted many serious, structural inequities for spousal caregivers within the contemporary systems of care in Australia.

Research has previously demonstrated the significant risks to co-resident spouses providing care, yet there has been very little consideration of the unique and often long-standing nature of their marital relationship as the context of care. This research contributes the first in-depth insight into the impact of wider sociocultural and systemic influences on the experience of providing care to a

spouse in later life. The adoption of a systems approach in this thesis enabled multiple perspectives of the care system to be explored in this single study of spousal caregiving.

This research also builds on existing literature that expressed concerns with choice-oriented directions in recent aged care reforms in Australia. This research contributes significant empirical knowledge toward understanding the context of policy reform on both practitioners and informal caregivers. Importantly, this contribution highlights the significant challenges and inequities of implementing increasingly individualised policy reforms into practice within contemporary social contexts.

While there are clearly benefits to encouraging and enabling greater options for individual autonomy for older adults, there is a greater need for caution that this does not come at the expense of informal caregivers, for whom there is little choice. Policy solutions that draw on choice to achieve economic goals risk exploiting the familial obligations experienced by spouses and other family members in contemporary society. Framing choice as readily available and the preferred solution in practice fails to meaningfully consider the significant impact of social norms and traditions to which the current generation of older persons adhere. The translation of choice into practice for older couples is enormously problematic.

Contemporary policy highlights 'choice' and 'autonomy' as key commitments in the new era of aged care reform in Australia. In practice, however, aged care

recipients are constrained by an array of financial, procedural, and practical obstacles that require focused supports from professional aged care workers to navigate and negotiate, even as funding for these supports are dwindling versus rising demand. This thesis has demonstrated that such 'choices' and 'autonomy' nominally available to aged care recipients are non-existent for spousal care providers, who exist at the margins of policy and practice whilst providing care at a significant discount to the welfare state.

Appendices

Appendix One: Systematic review of systems theory in social work research

A central consideration in the design of this thesis was the aim of analysing micro, meso and macro systems of spousal caregiving. Preliminary exploration identified very few social work researchers utilising similar critical or systemic approaches in their research design. In order to explore this methodological hypothesis more clearly, a systematic review was conducted, exploring theoretical and methodological social work approaches published during the past ten years in two key social work journals. The results of this systematic review highlighted the use of systems theory in research design is underutilised and reflected the methodological innovation of this thesis.

As highlighted in Figure 1, a total of 685 articles were included in this systematic review. Of these, 11 articles referred to systems theory, most commonly with regard to systems approaches in practice *(n=5)* or as a framework for understanding a social issue *(n=2).* Of the four remaining articles that identified systems theory as part of the research design, three utilised single method approaches, with two papers drawing on systems theory in data analysis and the third formulating interview questions with an ecosystems focus. Only one of the 685 articles reviewed identified systems theory as informing research design, using a number of distinct studies to explore the micro, meso and macro contexts of the topic. Despite the strong influence of systems theory in social work practice, these findings suggest systems theory is seldom overtly utilised in social work research.

Search criteria: All articles published in Australian Social Work and Qualitative Social Work between Jan 2006 – Sept 2016 (excluding editorials, book reviews and commentaries)

Australian Social Work 344 articles

Total of 685 articles included in review

Qualitative Social Work 341 articles

328 excluded (not relevant to RQ)

Aust Social Work 16 articles included

Qual Social Work 7 articles included

334 excluded (not relevant to RQ)

11 included for specific reference to or use of systems theory

Total of 23 articles identified as relevant to RQ

12 included for relevant approach (not identified as systems theory)

- 1 article that utilises systems theory in the design of a large, multi method project
- 1 article that draws on systems theory to guide research questions utilised in individual interviews
- 2 articles using variations of systems theory in data analysis
- 2 articles that discuss a social issue in relation to systems theory (systems theory not used in research design)
- 3 articles that evaluate interventions based on systems theory (systems theory not used in research design)
- 2 articles researching the use of systems theory in practice (systems theory not used in research design)

- 7 articles that utilise multiple methods approaches to understand complex issues from multiple perspectives
- 3 articles that utilise a case study approach to researching multiple stakeholder perspectives
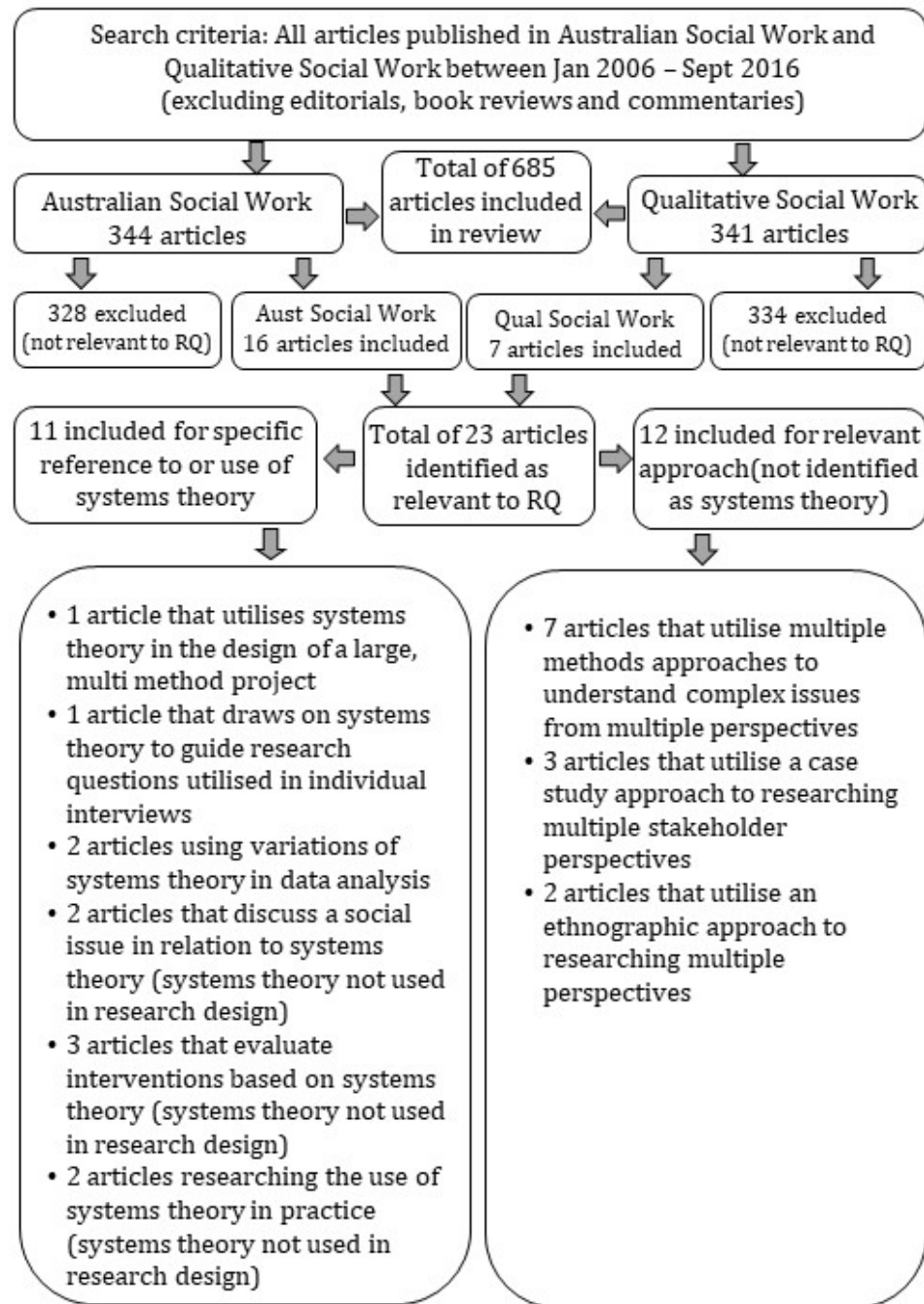- 2 articles that utilise an ethnographic approach to researching multiple perspectives

Figure 1: Overview of systematic review

A further 12 articles were included in this review as they utilised multiple methods *(n=7)*, case study *(n=3)* and ethnographic designs *(n=2)* to explore multiple perspectives of complex issues. While other studies in the search frame utilised case study, ethnography and other multiple method approaches, those included in the review specifically employed multiple methods to collect data across systems rather than from a single perspective or particular layer of the ecosystem. The studies included captured the systemic complexity of the respective topics being investigated, though did not explicitly identify with the theoretical lens of systems theory. This division is made to distinguish that while social research often utilises multiple qualitative methods in order to fully understand a phenomenon (Denzin & Lincoln, 2011), a multiple methods approach does not necessarily aim to or consider the interactions between systems that is inherent to a systems perspective.

The studies included in this review demonstrate the value of understanding context when researching the complex social phenomenon characteristic of many social work research questions. These findings, however, suggest that despite the strong association between social work and systems theories, the systems perspective remains very much underutilised in social work research. The benefits to understanding the influence of and interactions between social systems highlight the potential opportunities for social work research to embrace systems theory in the design of research.

La Trobe University
Faculty of Health Sciences
MEMORANDUM

Dr Suzanne Hodgkin,
Jeni Warburton

TO:

Social Work and Social Policy
Albury/Wodonga

SUBJECT: *Reference:*   **FHEC12/177**

Student or   Belinda Cash
Other Investigator:

In sickness and in health: The experience of choice
Title: **for older spousal caregivers in rural communities**

DATE: 24 October, 2012

The Faculty Human Ethics Committee's (FHEC) reviewers have considered and approved the above project. You may now proceed.

Please note that the Informed Consent forms need to be retained for a minimum of 5 years. Please ensure that each participant retains a copy of the Informed Consent form. Researchers are also required to retain a copy of all Informed Consent forms separately from the data. The data must be retained for a period of 5 years.

Please note that any modification to the project must be submitted in writing to FHEC for approval. You are required to provide an annual report (where applicable) and/or a final report on completion of the project. A copy of the progress/final report can be downloaded from   the   following   website: http://www.latrobe.edu.au/research-services/ethics/HEC-application.htm

Please return the completed form to The Secretary, FHEC, Faculty of Health Sciences Office, La Trobe University, Victoria 3086.

If you have a student/s involved in this project, a copy of this memorandum is enclosed for you to forward to the student(s) concerned.

Owen M Evans, PhD
Chair
Faculty Human Ethics Committee
Faculty of Health Sciences

Appendix Three: Participant information and consent forms for focus groups

The experience of choice for older spousal caregivers

INFORMATION FOR FOCUS GROUP PARTICIPANTS:

This project is being conducted as part of a PhD research program at La Trobe University. The project aims to investigate the experience of spousal caregivers in rural communities. Approval by the La Trobe Human Research Ethics Committee was obtained for this project to occur (Reference FHEC12/177, date of approval 24.10.12).

The research will involve a series of focus groups with health care staff across North East Victoria, in the local government areas of Wodonga, Wangaratta, Indigo, Towong and Alpine. These groups will seek participant views about the processes and practices of rural health practitioners when working with community residing older couples. Particular focus will be given to the provision of choice in these situations.

The data obtained in these focus groups will be recorded, transcribed and analysed. All identifying information from participants will be removed during transcription to protect the anonymity of participants. A thesis will be prepared outlining the full research methodology, analysis and outcomes. Copies of this thesis will be made available to La Trobe University in hard copy and via a digital online thesis database. It is anticipated that this research will be further disseminated via submission for publication in hard copy and/or electronic journals and conference proceedings and presented at conferences or other appropriate forums. Any quotes or participant comments utilised during the dissemination of this research will be allocated a pseudonym and contain no identifying information. All research documents and data will be kept in accordance with confidentiality, privacy and data storage guidelines. Feedback regarding the outcomes of the research will be made available to partcipants on request. This feedback will include a summary of key findings and copies of relevant publications.

Should participants wish to withdraw consent from the project at any time, they can do so via completion of the attached Withdrawal of Consent Form. Please note that individual contributions to group discussions will not be able to be removed after participation in the focus group.

All staff of Alpine Health are invited to participate in this research. The focus group for (organisations) will be held at (time) on (date) at (location). All participants will be required to sign a consent form prior to participation in this research (see attached).

Should you have any further questions regarding this project, please feel free to contact me on the details below to discuss. Thank you in anticipation of your support,

Belinda Cash

PhD Research Student, La Trobe University

b.cash@latrobe.edu.au or

PhD Research Superviso

s.hodgkin@latrobe.edu.au

LA TROBE UNIVERSITY

The experience of choice for older spousal caregivers

Belinda Cash

PhD Research Student

RESEARCH CONSENT FORM (Focus Groups)

I, _____, agree to the following:

I have read and understood the attached information regarding the research project entitled 'The experience of choice for older spousal caregivers'.

- I agree to participate in focus groups as outlined in the attached information sheet.

- I agree to the audio recording of my participation in the focus groups. I understand that the information obtained during focus groups will be transcribed and all identifying information will be removed.

- Transcribed data obtained from the focus groups will be analysed as the basis of a research thesis. This thesis will be used for academic purposes and copies will be available at La Trobe University and electronically via a digital thesis database.

- Dissemination of this information may also include presentations at conferences or other appropriate forums and submission for academic publication as deemed appropriate by the researcher.

- I understand that should I wish to withdraw consent from participation in this project at any time, this can be done by providing the researcher with a written request to this effect. I understand that after participating in the focus groups however, it is not possible for my individual contribution to be removed from the focus group data.

Name:_____

Signature:_____

Date: _____

Appendix Four: Focus group question guide

The purpose of these groups will be to facilitate discussion about the practices of rural health practitioners when working with community residing older couples. Particular focus will be given to the provision of choice in these situations. It is anticipated that group forums with practitioners will elicit opinions and enable open discussion about the policies and practices related to the choices and services received by older people and their caregivers. The group will be posed questions to explore work practices with older couples with regards to the decision making around in home care and support.

Questions:

- Can you tell me about your role in working with older couples?
- Can you tell me about the types of choices offered to spouses when they enter or during their role as caregiver?
- Are there any specific policies or practices in your work that consider the preferences of the partner who will provide care?
- How are decisions made about what care and support will be provided in community based care situations?
- (E.g. By staff, the carer, the care recipient, in consultation?)
- What impact does being in a rural area have on the availability of choice to older couples requiring in home care?
- Do you feel that there is a choice about becoming a caregiver in spousal relationships? Please explain why you feel this way.

Appendix Five: Participant information and consent forms for caregiver interviews

The experience of choice for older spousal caregivers

INFORMATION FOR INTERVIEW PARTICIPANTS:

This research aims to explore the experiences of older spousal caregivers who live in a rural area. This project is being conducted as part of a PhD research program at La Trobe University. Approval by the La Trobe Human Research Ethics Committee was obtained for this project to occur (Reference FHEC12/177, date of approval 24/10/12).

The research will involve a series of interviews with spousal caregivers across North East Victoria, in the local government areas of Wodonga, Wangaratta, Indigo, Towong and Alpine. Interviews will be loosely guided to gain an in depth understanding of the factors underlying the decisions to become a spousal caregiver and of the choices provided at points of contact by service providers.

The data obtained in these interviews will be recorded, transcribed and analysed. All identifying information from participants will be removed during transcription to protect the anonymity of participants. Your name and contact details will not be passed on to anyone else. A postgraduate thesis will be prepared outlining the full research methodology, analysis and outcomes. Copies of this thesis will be made available to La Trobe University in hard copy and via a digital online thesis database. It is anticipated that this research will be further disseminated via submission for publication in hard copy and/or electronic journals and conference proceedings and presented at conferences or other appropriate forums. Any quotes or participant comments utilised during the dissemination of this research will be allocated a pseudonym and contain no identifying information. All research documents and data will be kept in accordance with confidentiality, privacy and data storage guidelines. Should you wish to receive feedback about the outcomes of this research, a summary of findings will be made available at the conclusion of the project to any participants who request this.

Participating in interviews which involve discussing your own personal situation can at times be difficult or upsetting. While all precautions are being taken to minimise any risk of this occurring, the support of a free counsellor will be available to any participants who wish to access this service following their participation in this research. The contact details of this person will be provided at the beginning of your interview should you choose to participate.

Should participants wish to withdraw consent at any time, they can do so via completion of the attached Withdrawal of Consent Form within 4 weeks of participation.

You are invited to participate in this research. All participants will be required to sign a consent *form prior to participation in this research (see attached).

Should you have any further questions regarding this project or if you would like to participate, please feel free to contact me on the details below.

Thank you in anticipation of your support,

Belinda Cash

PhD Research Student, La Trobe University
b.cash@latrobe.edu.au or

PhD Research Superviso
s.hodgkin@latrobe.edu.au

The experience of choice for older spousal caregivers

Belinda Cash
PhD Research Student

RESEARCH CONSENT FORM – (Interviews)

I, _____, agree to the following:

- I have read and understood the attached information regarding the research project entitled 'The experience of choice for older spousal caregivers'.

- I agree to be interviewed as outlined in the attached information sheet, to discuss my experience of being a spousal caregiver.

- I agree to the audio recording of my interview. The information obtained during this interview will be transcribed and all identifying information will be removed.

- I understand that I am able to request particular information regarding my case be changed or omitted from use in the case study.

- Transcribed data obtained from this interview will be analysed as the basis of a research thesis. This thesis will be used for academic purposes and copies will be available at La Trobe University and electronically via a digital thesis database.

- Dissemination of this information may also include presentations at conferences or other appropriate forums and submission for academic publication as deemed appropriate by the researcher.

- I understand that should I wish to withdraw consent from participation at any time, this can be done by providing the researcher with a written request to this effect within 4 weeks of participation.

Name:_____

Signature:_____

Date: _____

Appendix Six: Caregiver interview question guide

Semi structured in-depth interviews will be conducted with people who care for a spouse. Interviews will be loosely guided to gain an in depth understanding of the factors underlying the decisions to become a spousal caregiver and of the choices provided at points of contact by service providers. The questions posed to each participant will aim to explore their decisions for becoming a caregiver to their partner and to understand the experience of choice and responsibility from a personal perspective and with relation to interactions with service providers.

Questions:

- Can you tell me about when you first became a carer to your partner?
- Did you feel that there were many choices available to you when you became a caregiver?
- Can you tell me about any options offered to you and why you did or did not choose these?
- What choices would you like or have you found most useful in your caring role?
- Can you tell me about the factors that influenced your decision to provide care at home to your partner?

Appendix Seven: Caregiver vignettes

Carol's story

Carol is a 68 year old woman who first began providing support to her 84 year old husband Frank five years ago. There was a significant increase in the level of support required a year ago after multiple physical ailments and operations led Frank to cancelling his licence and becoming dependent on Carol for transport and some personal care.

Carol and Frank have been married for 34 years, though Carol states openly that "we don't love each other". She describes a difficult and distant relationship, which has been characterised by long term emotional abuse. Both Carol and Frank have maintained a strong sense of independence from one another and in Carol's words, they "live together apart". Now that their three adult children have left the family home, they continue to live together for financial reasons and to avoid the complexities of dividing assets and leaving the family home. Their children all live in metropolitan cities well away from the family home and are not in regular contact. Carol identifies few close friendships and has no-one to confide in or to access support from in her current situation.

Carol describes feeling unprepared and unwilling in her role as caregiver. She states firmly that she has never been inclined toward nursing and now feels compelled to take on this role. She describes Frank as ungrateful for the support she provides and expects it of her without offering thanks. She feels this in part contributes to her feelings of anger and resentment about the caregiving role which has been thrust upon her.

There are strong currents of social and marital responsibility in Carol's story. She feels she would "be regarded as the most dreadful person" if she chose to end the relationship or refuse to provide care. She instead struggles on, admitting that thoughts of suicide have crossed her mind as a means to escape the situation she is in. Despite this, a strong sense of responsibility for their future wellbeing leaves her working on a five year plan to sell up the family home and move to a retirement village so that additional support would be available for Frank if the role becomes too much for her. Carol says that "if our relationship was different and we loved each other devotedly it would be a different matter. But we don't".

Richard's story

Richard is a 65 year old man who cares for his wife of 40 years, Denise, who is 60 years old. Denise was diagnosed three years ago with Huntington's disease, a complex neurological condition. This genetic disorder causes brain impairment that impacts cognitive, physical and emotional function. Richard and Denise made the decision not to have children because of her family history and the risks of the Huntington's gene being passed on to their children, a decision that still raises heightened emotions for Richard.

Richard and Denise have a difficult and distant relationship and he describes them as living together, though not as husband and wife. Providing care to Denise is complex and he struggles daily with the emotional upheaval of this role. The symptoms of Denise's disorder make it difficult for Richard to engage with her at times, particularly as her cognitive and emotional symptoms worsen. Accessing

treatment and support services for Denise has also been challenging at times, with Richard describing conflict and distress in his interactions with health professionals. He expresses frustration at the lack of information he was provided with during Denise's diagnosis and subsequent treatment and feels that adverse reactions she has experienced to medications have contributed to her rapid deterioration and loss of speech.

Denise can be aggressive at times and Richard is open about discussing the apprehension that he experiences daily due to the unpredictable nature of her behaviour. Richard has recently become involved with local caregiver support services, which he feels have been a helpful outlet to discuss his care role and to learn more about available supports in their local area. He describes himself as "stuck with the care role", as the long term nature of their relationship means they are "just part of one another". The degenerative nature of Denise's illness is something that Richard acknowledges, though not something he is actively planning for. Despite the obvious distress and dissatisfaction with providing care, as well as the lack of a positive relationship between Richard and Denise, he still plans to keep her at home as long as possible.

Ken's story

Ken (84) and Mary (86) live together in a log cabin they built together for their retirement years. They are located in a beautiful, yet isolated rural pocket overlooking a river. They have been married for 55 years and have four adult children who all live distantly, though maintain regular contact. Mary was

diagnosed six years ago with Alzheimer's disease, after Ken had noticed her increasing forgetfulness and failing memory.

Ken and Mary are well connected to social groups in the nearest rural township and Ken continues to be involved in volunteer activities that enable him to take and involve Mary. They speak highly of the local healthcare services that have been supportive and responsive at times when they have needed to access them. Ken has tried though not continued with carer support groups as he didn't enjoy the focus on carers alone, he sees Mary as very much part of the deal and doesn't want to participate without her. Although it has been offered, Ken maintains they do not yet need home care or meals on wheels services. He is open to the idea that they may consider these in home options in the future, reluctantly acknowledging that residential care is something he hates to contemplate but may also be required if their situation deteriorates at home.

Ken is perplexed when asked why it is he who provides care to Mary, firmly stating that he would not have it any other way. "I tell her, I married you for better or for worse and I really meant that". He describes his role as devoted husband rather than caregiver, stating that they work together and rely on each other now as they always have. For the moment, they continue to focus on enjoying one another's company and on remaining actively engaged in life.

James' story

James is 66 years old and provides care to his 67 year old wife, Anne. Anne was diagnosed 6 years ago with multiple sclerosis after many years of symptoms. James and Anne have two adult children who both live considerable distances away with their own families. James describes the relationships with their children as very supportive both emotionally and financially, with their son having provided financial support on occasion to assist with Anne's support needs. Finances have been tight for James and Anne after they were required to sell the family business when Anne became unwell. James describes challenges with Anne becoming increasingly unable to perform at work before her diagnosis and he eventually needing to retire to care for her full time at home. The early retirement and need to sell the business has left James and Anne with the need to significantly adapt their future financial and retirement plans.

Anne's multiple sclerosis has continued to deteriorate over the past few years and she now uses an electric wheelchair for mobility. She experiences significant fatigue and finds it challenging to assist around the home, with James performing all meal preparation and household tasks. While Anne can still currently maintain her personal hygiene needs, James is required to assist with lengthy daily physiotherapy exercises.

Although he acknowledges there are often challenges in being a spousal caregiver, James remains committed to this role, stating that he has never considered anyone else providing care with the exception of the specialist interventions that he is unable to provide. James and Anne have engaged actively with physiotherapy and

local health services and speak very highly of the treatment and support offered in their rural community. They have researched respite options but elected not to utilise these at the moment.

James and Anne maintain a loving relationship, though James does reflect on his role as a caregiver as something which has required significant adaptability and a reassessment of his expectations, his relationship with Anne and of their plans for the future. He notes with some sadness that at this point he chooses not to dwell on the future and the knowledge that there will come a time when Anne will require full support to manage her illness and the uncertainty of what that may bring.

Maureen's story

Maureen is a 73 year old woman who lives in a small rural township. Her husband of 50 years, Ron, was diagnosed with an uncommon form of dementia in 2010 after around 8 years of symptoms. Although the initial onset had been slow and difficult to diagnose, Ron has deteriorated rapidly in recent years. This ultimately culminated in Ron being recently admitted to permanent care.

Maureen reflects on their marriage as a happy time of working, travelling and living together around the world. Maureen and Ron have friends but no family supports in the local area where they chose to retire following Ron's diagnosis. They have two sons, one who lives several hours away and another who lives abroad, both of whom she describes as wonderful and supportive wherever possible. Maureen describes Ron as having always been such an intelligent and

wonderful man and the "boss" within the relationship, making it all the more heartbreaking to witness the loss of his ability to speak as the dementia took hold. She describes drawing on her professional background in occupational therapy to explore creative strategies and supports to maintain Ron's ability to communicate, though smiles ruefully as she admits his strong personality has at times made providing care a challenge.

As Ron's symptoms of dementia became more complex, Maureen began to struggle at home as he became increasingly paranoid and aggressive toward her. During a residential respite admission, Maureen was eventually convinced by the formal care staff that it was no longer safe for her to take Ron home. She describes that despite the immense heartache and loss at reaching this crisis point, she now recognises it was the right decision for them both. Maureen visits Ron frequently and remains actively involved in his ongoing care at the residential care facility.

Susan's story

Susan is a 74 year old woman who lives in a rural community that is 90 minutes from a regional centre and around 4 and a half hours by road to the nearest metropolitan city. Susan's husband, Sam, is 77 years old and was diagnosed in 2010 with motor neurone disease. In the 4 years since his diagnosis, Sam's illness has progressed rapidly. Once an active and mobile individual, he is now confined to a specialised electric wheelchair and has very limited movement in his arms and legs. Local home care staff visit the family home twice daily to assist Sam to and from his bed and wheelchair via an electric lifter, as he is no longer able to

make this transition independently. They assist him to the toilet and to shower during their visit.

Susan performs all other daily care tasks for Sam, including feeding him, assisting with toileting and other home nursing duties to support his breathing and general activities of daily living. She is also now responsible for all of the cooking, cleaning and general upkeep of the family home and garden. Susan is well supported by the Motor Neurone Association, local hospital and healthcare staff from their local community. She is also active within a local carer support group. Susan maintains a social network of friends and accepts offers of respite for Sam to allow her to continue involvement with sporting and social opportunities when the opportunity arises. She is very limited in being able to leave the home due to not currently having a vehicle, but is able to access the local township by foot.

Susan describes her 54 year marriage to Sam in positive terms. Despite tragedies and challenges, they maintain a strong relationship where they can talk openly about the challenges of Sam's illness, the impacts of this on Susan as his caregiver and of their plans for the future with the knowledge of Sam's likelihood of further deterioration. She describes herself as a willing caregiver, though acknowledges there is not really an alternative should she have wanted one. She identifies the support and respite that allows her to maintain some personal activities outside of her caregiving role as essential.

Alice's story

Alice is a 70 year old woman who lives in a rural community. Her husband David (72) was diagnosed three years ago with a frontal lobe dementia after several years of symptoms. Alice never considered there to be any option in taking on the caregiving role. With no other family options nearby, she felt that having been married for 40 years there was little alternative but to assume caregiving when the need arose. David had been the primary manager of household finances and had always been the designated driver in their relationship. They lived out of town on a property that David largely maintained, though his illness soon precluded this. They made the difficult decision to sell the property and move to a unit in the nearby rural township.

David's dementia deteriorated quite rapidly and he became unable to drive and to manage the household finances, which became Alice's responsibility.   She describes feeling worried and apprehensive about needing to drive the car and to take on these financial decisions. As David became increasingly disoriented, aggressive and incontinent she describes feeling unable to cope, feeling unable to relax and on edge. Alice drew on her strong faith during this time and talks of how she prays for guidance and strength.

Alice provided David with in home care and support for the past three years, though recently made the difficult decision for him to move into a residential care facility in a nearby regional centre when she became unable to cope with the caregiving demands. She is fragile and teary as she discusses her decision, all the while trying to reassure herself that this is the right decision. She now travels to

visit David once a week, though describes these visits as highly emotional and difficult. She notes that the supports which were in place to assist David ceased immediately when he moved to care and has left her quite alone. She describes the loneliness and emotional fragility she still experiences.

Charlie's story

Charlie is a 74 year old retired nurse who has provided care at home for his 66 year old wife, Sandra, after she experienced a stroke 2 years ago. Charlie and Sandra have been married for 44 years and have always lived and raised their children in this rural community. Their children, wider family and friends live nearby and are supportive, enabling Charlie to have respite from his caregiving role.

Since her stroke, Sandra has required significant support by various health providers. Charlie assists Sandra to her appointments, provides personal care such as bathing and has also taken on the primary roles of cooking, washing and ironing. Sandra's physical recovery has now plateaued, and she continues to experience some physical instability, significant aphasia and anxiety.

Charlie is very matter of fact in describing his role as a caregiver. He feels it is just part of life and his role as a husband and reflects on the modelling of his own father who cared long term for his mother who experienced dementia. He saw this as something his father just got on with and didn't whinge about and it is now his turn to do the same.

Despite this it is clear that this was not something Charlie anticipated in his future. He describes retiring from nursing to escape the constant day to day provision of care to others only to find now this role has emerged in his marriage as a daily reality.

Charlie has no plans to cease caregiving and sees that as long as he is physically able he will continue to provide care at home to Sandra. As her spouse, he firmly states that it wouldn't occur to him to do otherwise. The gruff exterior wavers momentarily as he pauses to reflect on caregiving and states "it is something I wouldn't choose to do".

Joan's story

Joan is 77, she cares for her 76 year old husband Tom who is experiencing increasing physical frailty and cognitive decline impacting his short term memory. Joan has been providing care in their family home for the past 5 years.

Joan and Tom have been married for 30 years, with one child from their relationship and five children from Joan's previous marriage. Three sons have died in recent years, leaving two daughters in the local area and one who lives distantly. Joan describes one of her daughters as particularly helpful, frequently dropping by to offer support to she and Tom. Joan identifies this family support as crucial to enabling her to continue in the provision of care at home.

Joan compares raising children to her current role as a caregiver, reflecting on the similarities of having cared for her children and now taking on that role for her

husband. She is open in describing the care role as something she doesn't particularly enjoy and that she didn't really want to do. When thinking about the reasons she continues to provide care, she reflects on the expectations of both her gender and her generation. She feels it was something she was bought up to do, that care work was part of her role as a mother and now extends to care for her husband.

Joan recalls the challenges and time it took her to overcome her pride and admit that she was struggling with the caregiving role. She identifies a clear point where she experienced a severe emotional breakdown before she recognised that she was not coping with the strain. Joan is now grateful for the in-home services that assist with caregiving tasks for Tom, though she has found this an intrusion at times. Joan also now accesses carer supports and counselling services to support her wellbeing and ability to continue providing care at home to Tom.

When looking toward the future, Joan accepts that as Tom's needs continue to grow she may not be able to continue supporting him at home. Her own health is becoming increasingly problematic and her arthritis has begun to worsen. She and Tom have discussed with their daughters what the future may bring in light of Joan's deteriorating health and they have put Tom's name on a list for residential care in the future. In the meantime Joan plans to continue accessing respite supports and trying to maintain her own wellbeing.

Robert's story

Robert is 79 years old and lives in a regional centre and is the primary carer for his 78 year old wife, Betty, to whom he has been married for 57 years. Robert has provided care for Betty for the past 5 years since the onset of an acute psychiatric episode which saw her admitted to a secure inpatient facility. Following this episode, Betty has had many ups and downs since this initial admission, and was eventually diagnosed with Alzheimer's disease.

The nature of Betty's illness has been a difficult rollercoaster for Robert, who has a lot of uncertainty around the progression of her illness and what the future brings. He describes with concern how Betty has more recently become aggressive at times and is now unable to be left alone due to concerns for her forgetfulness and the potential risks which arise from this. Despite these growing concerns, he remains firm that he wishes for her to remain at home for as long as possible to avoid her being placed somewhere she would be unhappy.

Robert and Betty have 3 adult children who live nearby and are supportive, though the day to day care of both Betty and their home falls on Robert. Many of their friends and social supports have dropped off, which Robert feels is due to their uncertainty and embarrassment about how to deal with the changes Betty is experiencing. Both Robert and Betty have had a range of physical health concerns during recent years which have added complexity to their situation.

Robert reflects on his caregiving role as the hand of cards that life has dealt him, and pragmatically accepts this role and states that as her husband, he will not walk

away. He uses the terms love and responsibility to describe his dedication to this caregiving role. With some sadness, Robert acknowledges that there might be a time when he is physically unable to continue supporting Betty at home, though he is reluctant to dwell on this. He holds strong to the memories of Betty in better days and feels his sense of humour helps enormously in coping with the day to day struggles that arise.

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