



University of  
**Southern  
Queensland**

THE INFLUENCE OF VALUES ON CAREGIVING FOR OLDER ADULTS IN RURAL  
AND URBAN AREAS

A Thesis submitted by

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## **ABSTRACT**

In rural areas there is often a perceived expectation that individuals should be self-sufficient, and self-reliant (Fuller et al., 2000; Vayro et al., 2020), whereas, in urban communities it is suggested that accessing support services is more convenient resulting in greater accessibility to services and more help-seeking behaviours (Orpin et al., 2014). There is relatively little empirical research about the influence of values on caregiving for older adults in rural and urban settings. Thus, it is important that this topic is further explored in the literature as rural communities have been identified as a vulnerable in having poorer access to health and support services for older adults (Shevchenko, 2018). The aim of the present study is to understand the influence of values on the experience of caregiving. In this study an older adult who requires caregiving, is seen as an adult over the age of 65 who suffers from a chronic long-term illness, physical impairment, or disease. Seventeen caregivers from both urban and rural Australia who lived in the states of Victoria, New South Wales, and the Australian Capital Territory participated in semi-structured interviews about their caregiving experience and the role of values in influencing the caregiving. Thematic analysis was applied to the interview transcripts and led to identification of themes of love, reciprocity, aged care stigma, obligation, appreciation, and community. The findings of this study are consistent with past research and literature across the rural/urban divide of caregivers. Moreover, this study has led to the identification of a novel theme regarding community. This a novel finding and has implications for future research regarding community support as it is in direct contrast to the view that those in rural communities are struggling and isolated from services. This has significant implications as future research, in how community as a value may help to identify specific targeted community supports to reduce isolation and disconnection for rural and urban caregivers.

## **CERTIFICATION OF THESIS**

I Siobhan Melvin declare that the master's thesis entitled The Influence of Values on Caregiving for Older Adults in Rural and Urban Areas is not more than 40,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references, and footnotes. The thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Date: 04/10/22

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## **TABLE OF CONTENTS**

ABSTRACT.....	i
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CERTIFICATION OF THESIS.....	ii
ACKNOWLEDGEMENTS.....	iii
LIST OF TABLES.....	v
LIST OF FIGURES.....	vii
CHAPTER 1: INTRODUCTION.....	1
1.1. Older Adults with Chronic Illness.....	1
1.2. Rural and Urban Populations.....	1
CHAPTER 2: LITERATURE REVIEW.....	3
2.1. The Differences in Rural and Urban Areas.....	3
2.2 The Caregiving Role.....	6
2.3 The Role of Values in Caregiving.....	8
2.4 Informal and Formal Supports for Caregivers.....	9
2.5 The Sociocultural Stress and Coping Model.....	12
2.6 The Present Study.....	14
CHAPTER 3: METHOD.....	15
3.1 Reflexive Statement.....	15
3.2 Participants.....	16
3.3 Interview processes.....	19
3.4 Data Analysis.....	19
CHAPTER 4: FINDINGS.....	22
4.1 Deductive and Inductive Themes.....	22
4.2 Love.....	26
4.3 Reciprocity.....	27
4.4 Obligation.....	28
4.5 Aged Care Avoidance.....	29
4.6 Appreciation.....	30
4.7 Sense of Community.....	32
CHAPTER 5: DISCUSSION.....	34
5.1 The Sociocultural Stress and Coping Model.....	34
5.2 Deductive Themes.....	35
5.3 Inductive Themes.....	38
5.4 Implications for Future Research and Practice.....	41
5.5 Research Limitations.....	42
CHAPTER 6: CONCLUSION.....	43
References.....	44

Appendix A .....62

**LIST OF TABLES**

Table 1 *Caregiver Demographic Data* .....18  
Table 2 *Description of Themes* ..... 23



**LIST OF FIGURES**

Figure 1 *Sociocultural Stress and Coping Model* .....14



## **CHAPTER 1: INTRODUCTION**

### **1.1. Older Adults with Chronic Illness**

The number of older adults who suffer from chronic diseases and ailments, resulting in a reduced ability to care independently for themselves will increase as the age of population in society steadily rises (Knight & Sayegh, 2010). The Australian Bureau of Statistics (ABS) projects that the number of older Australians is predicted to reach between 28.3 and 29.3 million people by 2027, and between 37.4 and 49.2 million people by 2066 with particularly high growth rates in those 85 years and older (ABS, 2017-2018). Furthermore, 78% of older aged 65 or over report at least one of nine types of chronic illnesses, including arthritis, asthma, coronary heart disease, chronic obstructive pulmonary disease, depression, type II diabetes, high blood pressure, osteoporosis, or stroke (ABS, 2017-2018). Hence, the need to care for those who are chronically ill will become a more common experience, as more and more individuals will be taking on the role of caregiver (Pinquart & Sörensen, 2003). With the population aging internationally (Shevchenko, 2018), the topic of caring for older adults is a pressing issue globally and an empirically based understanding of the role of values in caregiving is vitally needed. Previous research has supported the view that values can influence caregiving (Ehrlich et al., 2015; Fuller et al., 2000), and this research is vital given the limited research on values on caregiving, particularly in urban and rural contexts.

### **1.2. Rural and Urban Populations**

The population in rural areas, as identified in developed countries, tend to be older and have an increasing age demographic than urban areas (Australian Institute of Health & Welfare, 2007). Most significantly, rural populations have poorer access to healthcare and less specialist services than their urban communities (Innes et al., 2011). It has been established that rural caregivers often do not avail of professional services due to inappropriate service models, access difficulties, distrust, stoic self-reliance and/or fears of stigma (Berry et al., 2016; Collins et al., 2009; Pollock et al., 2002). In contrast, in urban

communities accessing formal support services is said to be more convenient resulting in greater accessibility to services and there are more help-seeking behaviours (Orpin et al., 2014).

The Australian Statistical Geographical Standard (ASGS) is a geographical classification which defines locations in terms of remoteness. Major Cities of Australia are assigned as urban areas in the remoteness structure as areas where geographic distance imposes minimal restriction upon accessibility to the widest range of services (Australian statistical geography standard (ASGS), 2021 – 2026). Rural areas have a degree of imposition due to geographical distance and include inner regional areas, outer regional areas, remote Australia, and very remote Australia regions. Inner Regional Australia is defined in the remoteness structure as areas where geographic distance imposes some restriction upon accessibility to services (ASGS, 2021 – 2026). Outer Regional Australia is defined in the remoteness structure as areas where geographic distance imposes a moderate restriction upon accessibility to services (ASGS, 2021 – 2026). In this study, participants were recruited from inner and outer regional rural locations and from urban metropolitan locations.

## **CHAPTER 2: LITERATURE REVIEW**

There is relatively little empirical research to date about the influence of values on caregiving for older adults in rural and urban settings. This literature review will examine the differences in caregiving in rural and urban areas, while reviewing the complexity of the caregiving role, and the role of values in influencing caregiving. The importance of informal and formal supports for caregivers will be discussed, including the differences in the influence of informal and formal supports for caregivers in rural and urban areas. The literature review will conclude by discussing the guiding theory for this research which is the Sociocultural Stress and Coping Model by Knight and Sayegh (2010). This model identified the role of group specific values as influences in the stress and coping process for caregivers of older adults (Knight & Sayegh, 2010). It is important that this topic is further explored in the literature as rural populations have been identified to have poorer access to health and support services for older adults (Shevchenko, 2018).

### **2.1. The Differences in Rural and Urban Areas**

In urban communities accessing social supports is reported to be more convenient, but as the population is higher and denser community relationships in urban areas are weaker (Herron et al., 2016; Glasgow, 2000). In contrast, in rural communities there are more informal supports from relatives or neighbours and there is a stronger sense of community (Bushy, 2000; Orpin et al., 2014). Nonetheless, there are noticeable differences regarding population, with the average age in rural communities said to be much higher with the migration of younger adults in search of further work or educational opportunities (Dal Bello-Haas et al., 2014; Glasgow, 2000). Life in rural areas is different to urban areas in relation to age demographics, and there are also variations in accessibility to public transport, health care and specialist health treatment which suggests that the experiences of caregivers in rural and urban areas may be different (Herron & Rosenberg, 2019). Many support services are not available or accessible in rural areas because of the cost of providing services in

geographically isolated areas with low population density (Fuller et al., 2000; Herron et al., 2016). The accessibility of health services is also an issue for rural populations internationally, as professionals employed in these areas tend to be more present in cities and metropolitan areas (Knight & Winterbotham, 2019).

It has been suggested that urban people are out of touch with the realities of rural Australia in what was named the urban-rural divide (Botterill, 2009). In Australia in particular a combination of bushfires, drought, insufficient water allocations and the Covid-19 crisis is likely to have further contributed to increased psychological distress in rural and regional communities. Furthermore, there is a high rate of suicide in rural Australia which has been related to increased psychological distress regarding lack of available support services in rural communities (Judd et al., 2006). In addition, national policy making, planning and improvements tend to be based upon studies conducted in urban communities, and there is a lack of awareness regarding the experiences of caregiving in rural locations and their subsequent needs (Ehrlich et al., 2015). Berry et al., (2016) suggested that agrarian values are alive and well in rural Australia. The term country mindedness has been used to emphasise the rural–urban division to display the differing worldviews experienced by farmers towards those based in the cities (Duncan & Epps, 1992). A lack of help-seeking behaviours has been found within rural populations that has been associated with disparaging attitudes regarding accessing support in rural areas (Pollock et al., 2002). Collins et al., (2009) found evidence of self-reliance as an ingrained part of rural Australian culture that acted as a barrier to men’s help-seeking behaviours.

Socio-cultural beliefs affect provision of, and access to, care in rural settings, and it has been identified that rural caregivers are mistrustful of services provided by outsiders and uncomfortable in dealing with bureaucracy (Herron & Skinner, 2013). Earlier studies have identified that caregivers in rural areas tend to use fewer community-based services due to competing priorities such as farm labour, socio-cultural barriers originating from social

norms regarding stigma and confidentiality issues in relating to accessing support (Forbes et al., 2006; Morgan et al., 2002). However, more recent research indicates that there is an increasing demand for formal supports in rural communities by caregivers (Herron et al., 2016; Herron & Rosenberg, 2019). Furthermore, in many rural areas' programmes and support services for caregivers of older adults are difficult to find or often non-existent and this can be particularly challenging and isolating for caregivers (Forbes et al., 2012; Wiersma & Denton, 2013; Saunders & Groh, 2019).

Regarding potential differences between values in rural and urban areas, it has been suggested that those in rural communities are stoic and self-sufficient and endure their problems (Ehrlich et al., 2015). Similarly, it is proposed that those in rural communities' view health as being able to work independently and productively, and rely more on family than health professionals, and hold greater self-responsibility for health problems than those in urban areas (Judd et al., 2006). In contrast, in urban communities it has been suggested that accessing health and support services are more convenient resulting in greater accessibility to services and there are more help-seeking behaviours (Tommiss et al., 2007). Values in relation to self-sufficiency have been identified in older adults in rural communities who may recognise difficulties are related to their own psychological distress, but decide to address their problems individually, instead of seeking support (Knight & Winterbotham, 2019). Fuller et al., (2000) South Australia study established that a perception of self-sufficiency had developed out of geographic isolation and produced an environment where signs of weakness were not permitted, and individuals were not encouraged to be honest about how they felt. Thus, distinct rural values may influence the way that rural caregivers experience caregiving. Furthermore, mental health and stress was viewed as something to be endured in rural areas and help seeking behaviour was viewed as weakness (Staniford et al., 2009). Knight and Winterbotham (2019) established that self-sufficiency was a barrier to accessibility of services in regional areas. Hence, considering the differences between urban and residential

communities, it is likely caregiving values from urban and rural areas may differ regarding accessing support.

## **2.2 The Caregiving Role**

Caregiving can be defined within the context of caring for any family relative, friend, or partner or another important person in the caregiver's life who the carer has a significant relationship with (Hudson, 2011). Chan et al., (2013) defines informal caregivers as individuals who are not paid or compensated to provide care. The informal caregiving role has been described as transformation in the direction, amount, and necessity of help provided by caregivers that extends to increasing amounts of assistance required for the survival of the care recipient (Arruda & Paun, 2017; Seltzer & Li, 1996). The caregiver's role includes providing care and aiding with the physical, social, and psychological needs of the older adult in a caregiver's life who may be experiencing a life-threatening chronic disease, physical impairment, or incurable illness (Shelton et al., 2017). Thus, the role of caregiving for an older adult can be very challenging given the dynamic and often unpredictable nature of chronic illness and diseases, and due to the variety of changing needs of the care recipient.

The transition to caregiver includes a significant life transition and consists of taking responsibility for complex tasks that an individual may have never had experience with before, such as symptom assessment and management, helping with instrumental activities of daily living such as shopping, making appointments, and providing transportation, and medication administration (Schultz et al., 2012). There is considerable empirical evidence to suggest that caregiving is highly demanding, exhausting, and burdensome (Arruda & Paun, 2017; Chan et al., 2013; Pinquart & Sorensen, 2003; Schultz, et al., 2006; Vick et al., 2019). Negative consequences associated with caregiving for older adults can include impaired physical and mental health (Losada et al., 2010; Taylor & Quesnel-Vallée, 2017). Being a caregiver has also been associated with a range of adverse outcomes, including increased levels of mental distress (Givens et al., 2014), higher stress levels (Gilhooly et al., 2016; Pinquart & Sorensen, 2003; Pinquart, & Sörensén, 2011), financial hardship (Chiao et al.,

2015), and social isolation (Schultz et al., 2012). Caregiver distress is associated with increased depression, lower levels of life satisfaction and even higher mortality rates (De Fazio et al., 2015; Vitaliano et al., 2003). Hence, caregivers are often expected to assume a complex caregiving role and becoming a caregiver of a dependent older adult can influence a wide number of domains in a caregiver's life including finances, family, and social relationships and mental and physical health (Anderson & White 2017; Burton et al., 2006; Kasper et al., 2015; Vitaliano et al., 2003).

While the challenges associated with caring for dependent older adults are evident in past research, it also has been identified that caregivers can also experience a variety of positive emotions and satisfaction associated with feeling needed and useful in their role (Lloyd et al., 2016; Tang & Chan 2016; Tretteteig et al., 2017). It has been suggested that the experience of caregiving is multi-dimensional and contextual with positive and negative effects often co-existing rather than moving along a single dimension (Kimball, 2015; Zhang et al., 2022). There are positive aspects and rewards also associated with caregiving, and carers who identify with positive perceptions and experiences reporting fewer adverse health outcomes (Carbonneau et al., 2010; Zarit, 2012). It has also been suggested that the positive experiences of caregiving, may well buffer negative effects (Tang & Chan, 2016; Yu et al., 2018).

Most caregivers experience a variety of positive emotions and satisfaction associated with feeling needed and useful in their role (Tretteteig et al., 2017). Carbonneau et al., (2010) identified positive aspects of caregiving to include: the quality of the relationship between the carer and recipient, the ability of the carer to find meaning in their role, and the carer having a sense of accomplishment. Further, positive experiences relating to the caregiving role included satisfaction, emotional rewards, personal growth, competence and mastery and spiritual growth (Lloyd, et al., 2016; Peacock et al., 2009). Past research has identified that positive aspects of the caregiving experience such as appreciation for the closer relationship,

rewards and gratifications from the caring role are associated with greater subjective well-being and less depressive symptoms (Pinquart & Sörensen 2003; Quinn & Toms 2018; Yu et al., 2018). Thus, caregiving values may play a role in individual meaning and the sense of caregiving as an accomplishment or an effectuation.

### **2.3 The Role of Values in Caregiving**

Values are individual beliefs that influence and guide human behaviour and motivate people to act in certain ways (Mc Cleary & Blain, 2013). An individual's upbringing can contribute to their values that rationalise and justify themselves taking on a caregiving role (Knight & Sayegh, 2010). Individuals are often predisposed to adopt the values of the environment that they were raised in as they tend to believe those values are in line with their view of what is important to them and can influence coping and interpersonal meaning. Positive self-affirmation values have been associated with more resilient and better coping styles and enhanced psychological and physical health outcomes (Creswell et al., 2013). Knight and Sayegh (2010) identified the role of values as influences in the coping process for caregivers of older adults and suggested that distinct values may affect caregiving and influence caregivers remaining in the caregiving role. Thus, the impact of values on caregiving is an important topic that needs to be further explored in research.

There is considerable literature to suggest that values that motivate caregiving include love, closeness, and affection (Joling et al., 2017; Lloyd, et al., 2016; Orpin et al., 2014; Shim et al., 2013; Williams et al., 2014), reciprocity (Gilbert & Powell, 2005; Reid et al., 2005) faith and religious ideologies (Sanders, 2005) and strong feelings of duty and obligation (Murray et al., 1999; Ribeiro & Paúl, 2008). In Gallego-Alberto et al.,'s (2016) study, an adherence to personal values in caregiving was associated with lower anxiety, and a commitment to family values was associated with lower levels of depression for caregivers of older adults with dementia. Furthermore, caregivers who reported experiencing contradictory values and simultaneously feeling both positive and negative emotions when caregiving had



increased levels of depressive symptoms and identified with strong feelings of guilt (Gallego-Alberto et al., 2016). It was also found that negative values associated with caregiving indicated increased levels of psychological distress in dementia caregivers (Romero-Moreno et al., 2013). Values associated with a negative feeling of caregiver obligation and duty have also been found to have had a negative impact (Knight & Sayegh, 2009). Thus, past research has evidenced the significant and influential role that values can have in caregiving.

Tretteteig et al., (2017) described how meaningful relationships with the care recipient motivate caregivers to act in accordance with their values and goals. Past research has established that family motivations regarding feeling obliged to provide care for older adults are ingrained in family values (Pharr et al., 2014). The most common motivation or reason for taking on a caring role was a sense of family responsibility (70.1% of all primary carers) (Verdugo, 2019). An older adult's spouse or next generation relative such as the older adult's daughter or daughter-in-law tend to be the most likely family members that take on the role of caregiving (Schulz et al., 2012). When the caregiving experiences of spouses and adult children was compared, Pinquart and Sörensen (2011) established spousal caregivers describe having smaller informal support networks, having a duration of more care hours provided per week, described worsening physical health and depressive symptomology than adult children caregivers. However, adult child caregivers experienced increase role conflicts and disputes within their family and career relationships, which led to more heightened risk for role overload and burden. Therefore, it is important to note that although group differences have been noted between adult children and spousal caregivers, researchers have rarely looked at values to explain these disparities in rural and urban contexts.

#### **2.4 Informal and Formal Supports for Caregivers**

There is evidence of distinct rural cultural values which may influence the way that rural caregivers experience caregiving via their use of formal and informal supports (Ehrlich et al., 2015; Fuller et al., 2000; Saunders & Groh, 2019). Informal support for caregivers

includes relationships such as family members, friends, neighbours or others in the community or social network who provide social support such as home visits, or phone calls (Aldeman et al., 2014). Perceived informal support is viewed as the amount of support the caregiver feels they have in their own social network, which has been found to be a strong predictor of individual well-being (Siedlecki, 2014). Formal support for caregivers includes professionals or employees from health services in paid employment, such as personal care assistants in facilities such as aged care homes (Shiba et al., 2016). The relationship between formal and informal supports and caregiving values is important, as caregivers identify with having informal social supports in their community, and who receive formal support professional services have been found to experience reduced caregiver burden (Aldeman et al., 2014; Shiba et al., 2016, Ward-Griffin et al., 2012). However, previous studies have indicated that caregivers identify with caregiver burden, and with having many unmet needs including a lack of informal supports due to social isolation, and limited formal supports from professionals such as counselling, or support from services in managing concerns about the disease/illness, and a scarcity of financial support due to being unable to sustain employment (Chen et al., 2016; Hashemi et al., 2017).

Despite the considerable level of burden that can affect caregivers' daily lives and health, the availability of informal and formal supports has been found to function as protective mechanisms that can prevent caregiver burnout (Gray et al., 2016). Furthermore, the perception of at least one form of informal support was also found to show lower caregiver burden (Shiba et al, 2016). Past research notes however, that caregivers with high levels obligation are unlikely to perceive informal supports as available (Knight & Sayegh, 2009). It has also been established that caring for a longer duration of time, being female, and increased use of formal and informal resources is associated with greater resilience and as having a more positive influence in the caregiving role (Joling et al., 2015). Lin et al., (1999) suggested that informal support has a more positive influence on psychological well-being

than formal support, and Pinquart and Sörensen (2007) established the benefits to a caregiver's well-being from receiving ongoing informal support in caring. There is less research about formal supports for caregivers of older adults, and the influence of formal supports on values in caregiving is an important area that will be further explored in this study.

There is a common belief that rural elderly persons have a large informal network of family supports and that they have more contact with their adult children than urban elderly; however, this perception has not withstood the test of scrutiny (Kroust, 2015). It has been identified that the primary informal helping network for elders in urban and rural areas is family, but it is important to note that families may be comprised of only one individual (Conley & Burman, 1997). McKenzie et al., (2010) systematic review of urban versus rural comparisons examined three outcomes for carers including caregiver service use, health promotion behaviours such as implementing self-care strategies and mental health including caregiver stress, burden, and depressive symptoms. The review found no significant differences in the three outcomes between caregivers in urban and rural locations.

Previous literature on the differences between rural and urban experiences of informal and formal supports in caregiving has been quite mixed. For example, Kim et al.,'s (2006) study found that caregivers in urban settings had a higher carer burden, distress, and isolation than caregivers in rural settings. In contrast, Tommis et al., (2007) study established that the male caregivers of older adults with stroke or dementia in urban areas identified in having better support and access to mental health services, in contrast to the mental health of male caregivers in rural areas.

Bien et al.,'s (2007) study found that rural caregivers of older adults identified with higher psychological distress and negative impacts of caregiving than urban caregivers. Rozario and DeRienzi's (2008) study identified no significant differences in perceived stress for urban versus rural caregivers but found rural carers to exhibit lower depressive symptoms

than urban carers. Furthermore, differences between rural and urban experience of care burden in Japanese caregivers of older adults established that negative caregiving aspects were higher for caregivers in urban communities than in rural (Imaiso et al., 2012).

Nonetheless, McKenzie et al., (2012) identified that past research has been conducted across a variety of countries and health care settings, and this may help to explain the diverse nature of results in the comparisons of rural versus urban experiences of caregiving in past literature.

In summary, past studies that have looked at rural caregiver's experience indicate that there is a greater reliance on informal rather than formal support services in rural areas (Imaiso et al., 2012; Tommis, 2007). There tends to be more informal supports in rural communities from relatives or neighbours and there is a stronger sense of community (Bushy, 2000, Orpin et al., 2014). Thus, due to rural areas feeling unsupported by specialist services, informal supports such as family, and friends in rural communities are likely to hold a more important role in supporting rural caregivers, compared to urban caregivers. Previous research has also identified that in urban communities it has been suggested as the population is higher and denser community relationships tend to be weaker (Glasgow, 2000; Imaiso et al., 2012). However, there is limited research addressing the influence of values on caregiving in rural and urban areas in Australia and this is an important topic that will be further explored in this study.

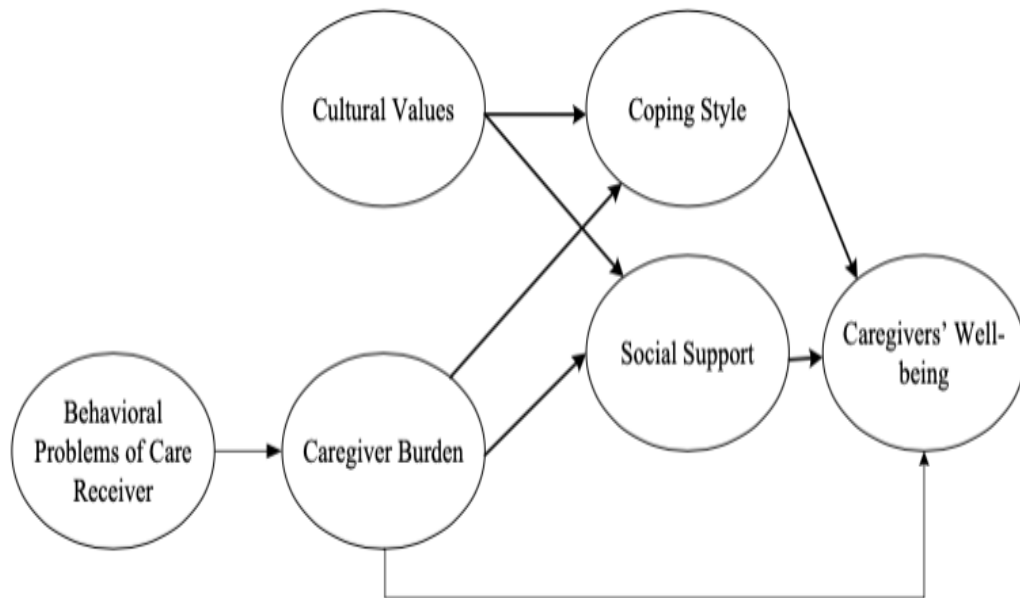
## **2.5 The Sociocultural Stress and Coping Model**

The guiding theory for this research is the sociocultural stress and coping model by Knight and Sayegh (2010) please see below Figure 1. This model identified the role of group specific values as influences in the stress and coping process for caregivers of older adults (Knight & Sayegh, 2010). The model outlined how cultural backgrounds can influence caregiver health, caregiving support, caregiving coping styles and caregiver burden (Knight & Sayegh, 2010). The model is also relevant across cultures and identified that social support can impact caregiver health. The sociocultural stress and coping model (Aranda & Knight,

1997; Knight & Sayegh, 2010) has been adapted from the general coping model of Lazarus and Folkman (1984). The coping model by Lazarus and Folkman outlined a framework for understanding how positive and negative emotions co-occurred even in the most difficult caregiving situations and incorporated an understanding of the role of values in promoting meaning-focused coping and positive emotions. Thus, according to the sociocultural stress and coping model cultural and group specific values may improve or increase the impact of stressors on caregivers' well-being. Knight and Sayegh (2010) established in the sociocultural stress and coping model that caregiver burden can have a direct effect on caregiving coping style and social support which can then impact caregiver well-being. It was also found that higher levels of caregiver burden appraisal were associated with worse health outcomes for caregivers (Knight and Sayegh, 2010). In the sociocultural stress and coping model, distinct group cultural values had a direct influence on coping and social support, which, subsequently, also had an influence on caregiver health. As such, the sociocultural stress and coping model highlighted the importance of group specific values in influencing caregiving wellbeing. Thus, groups have distinct values that affect caregiving providing support for the possible differences in the values of rural and urban caregivers.

### **Figure 1**

*Sociocultural Stress and Coping Model (Knight & Sayegh, 2010)*



## 2.6 The Present Study

The aim of the present study is to understand the influence of values on the experience of caregiving and how values may influence caregiving for older adults. Qualitative research explores people's complex behaviours, practices, and experiences, to gain a deep understanding of the subtle nuances of people's thoughts and feelings in a way that is difficult to achieve through other methods (Rohleder & Lyons, 2015). This method is particularly useful when exploring the personal experiences of people whose views have not been recorded before, as it allows for more open response from the participants. Qualitative research was used with thematic analysis applied to explore the experiences and values of the participant carers. A reflexive thematic analysis methodology was applied with in this study with a hybrid process of inductive and deductive analysis. Thematic analysis is used for identifying, analysing, and reporting patterns or themes within data and each theme captures something important about the data in relation to the research question (Lapadat, 2010). A critical realist approach was taken in looking for explanations of the participant's experiences and meanings that are influenced by the broader social context in which they are located (Braun & Clarke, 2021). The following research questions are proposed for this study:

1. What are the values of rural and urban caregivers of older adults?
2. How do those values influence caregiving for older adults?

## **CHAPTER 3: METHOD**

### **3.1 Reflexive Statement**

The primary goal of reflexivity is to be aware of how research biases can influence the outcome of the study and how bias has the potential to undermine the rigour of the research, due to researchers being unable to be entirely impartial to their own biases (Morrow, 2005). As such, I acknowledge my own reflexive stance with regards to growing up in a rural community in the west of Ireland, and my own experience in supporting my

mother in caregiving for my grandmother who suffered from Dementia and Parkinson's. I took steps to be aware of and balance reflexivity by keeping a reflexive journal, and by implementing critical realist theory when completing the analysis to ensure the caregivers experiences, were influenced by the broader social context in which they are located.

I was quite aware that when interviewing participants that I needed to remain neutral, setting aside my own views and reactions and to listen from the perspective of a researcher. It was, however, difficult when I heard a story from a participant that I felt connected to as it reflected some of the aspects of my own personal experience of caregiving for my grandmother. I became aware of the connection I felt by internally reflecting on the research process through journaling and I realised that I had taken an insider position with this story. I recognised through journaling that to be totally objective as a researcher I must set aside my personal experience and I realised that to ensure objective positioning I had to request funding for a research assistant to independently code the data and review the participant interviews from the study. I also referred to practice-based literature for recommendations regarding managing with participant stories that can reflect your own experience in practice.

### **3.2 Participants**

Knight and Sayah (2010) identified that well-designed qualitative studies with smaller groups of participants are the next steps required in discovering further themes and patterns in the group-specific values of caregivers. Ethics was approved by University of Southern Queensland Human Research Ethics Committee (HREC) H18REA256 for this study. To be eligible, participants needed to provide some level of care for an older adult or have provided some level of care for an older adult in the past. Participants were eligible if they had provided care in the past and there was no time frame limit regarding when they had previously provided care or acted in the caregiving role. Retrospective caregiver accounts were included in this study to allow for potential differences in caregiver narratives and further reflection regarding the caregiving experience. Caregivers defined themselves as caring for a close family relative, or partner who they had a significant and close relationship



with. There was no lower limit on amount of care provided as a caregiver to qualify for the study, because caregivers' roles are highly variable due to the fluctuating timing of entry into the caregiving role, and the often-unpredictable duration of time spent in the role in the overall life course of the caregiver.

Participants were purposely selected after they volunteered for the study, and self-identified as wanting to discuss in further detail their individual experience of caregiving and wanted to contribute to current research on the topic. In this study an older adult who requires caregiving, is seen as an adult over the age of 65 who suffers from a chronic long-term illness, physical impairment, or disease. Participants were recruited online through the Carers Victoria and Dementia Australia websites where the research study was advertised online. Dementia Australia provide practical and emotional assistance to caregivers across Australia, from pre-diagnosis onwards, and Carers Victoria is recognised and funded as the leading support service for caregivers in Victoria. Interviews occurred online over Zoom and were between 40 – 50 minutes in length in total. Interviews were recorded via Zoom following consent for recording being received. Consent for recording was a requirement to be included in the study.

This study recruited 17 participants (female  $n = 16$  male  $n = 1$ ) in total from both rural and urban areas in line with sample size recommendations for a master's research project (Terry et al., 2017). The Australian Statistical Geographical Standard (ASGS) is a geographical classification which defines locations in terms of remoteness. Under the ASGS, urban areas are classified to include major cities in Australia, and rural areas include inner regional areas, outer regional areas, remote Australia, and very remote Australia regions. Major Cities of Australia are defined as urban areas in the remoteness structure as those areas where geographic distance imposes minimal restriction upon accessibility to the widest range of goods, services, and opportunities for social interaction (Australian statistical geography standard (ASGS), 2021 – 2026). Inner Regional Australia is defined in the remoteness

structure as those areas where geographic distance imposes some restriction upon accessibility to the widest range of goods, services, and opportunities for social interaction (ASGS, 2021 – 2026). Outer Regional Australia is defined in the remoteness structure as those areas where geographic distance imposes a moderate restriction upon accessibility to the widest range of goods, services, and opportunities for social interaction (ASGS, 2021 – 2026). In this study, 10 participants were recruited from inner and outer regional rural locations and 7 participants were recruited from urban metropolitan locations. Most of the carers lived in the state of Victoria, three participants were from New South Wales, and one participant from the Australian Capital Territory.

Demographic information was also collected from the participants in relation to gender, age, location, and the duration of time they have been a caregiver for (please see Table 1). Other demographic data collected during the interview process included the diagnosis of the older adult that they were caring for, which included a range of diseases and illnesses consisting of Parkinson’s Disease, Dementia, Prostate and Lung Cancer, Stroke and Diabetes. Information regarding daily caregiving tasks was also collected and comprised the following areas including grooming/showering/personal hygiene, dressing, toileting/continence, transferring/ambulating, supporting with eating, attending, and transporting to medical appointments, and medication management including administering and collecting prescription medications.

**Table 1**  
*Caregiver Demographic Data*

Sample Characteristics	<i>N</i>	<i>%</i>	<i>M</i>	<i>SD</i>
Gender				
Female	16	94.2		
Male	1	5.8		
Age			61	11.1

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Location				
Urban Caregivers	7	41.2		
Rural Caregivers	10	58.8		
Duration of years as a caregiver			12.7	7.9
Current Caregivers	6	35.3		
Retrospective Caregivers	11	64.7		

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*n=17*

### **3.3 Interview processes**

Data was collected through semi-structured interviews which were conducted in English online via Zoom between participants and I. Interviews were scheduled at a time suitable for the participants. Participants were permitted to talk with a minimum amount of interruption or constraint by the interviewer to allow for uninterrupted discussion within the interview, as well as providing a complete record for transcribing and data interpretation. The participants were asked questions about their caregiving experience, who they cared for/or had cared for in the past, the reasons they had become a caregiver, and how their values influenced how they provided care. Participants were also asked about their social supports, and whether they felt caregiving would have an impact on their future.

### **3.4 Data Analysis**

The writer adopted a critical realist approach where the participant’s experiences, meanings and realities are situated in and influenced by the broader social context in which they are located (Braun & Clarke, 2021). Thematic analysis was used to explore the experiences of the participant carers, to find out what influence their values may have had on

their caregiving experience. Thematic analysis is used for looking for and reporting patterns or themes within data and each theme identifies an important aspect about the data in relation to the research question (Braun & Clarke, 2021). A reflexive thematic analysis methodology was used with the data collection with a hybrid process of inductive and deductive thematic analysis undertaken concurrently. Reflexive thematic analysis is an approach that acknowledges an inductive data-focused process, and a deductive theory driven orientation to coding while capturing semantic and latent meanings, and theme development and the potential for flexibility around the theory that frames the research (Braun & Clarke, 2019). A deductive thematic analysis approach was used with guiding theory from previous research that was expected to be reflected in the data. An inductive approach was then implemented with three themes identified in the data that did not fit inside the theory.

The process of deductive analysis is outlined in a step-by-step approach by Braun and Clarke (2006). I was the principal investigator for this study, and in the first stage of thematic analysis I transcribed all the Zoom interview recordings in this study. This included firstly saving all the files securely and then de-identifying the transcripts using a name generator that created random pseudonyms for each participant. I then read the transcripts three times, and initial ideas were recorded and noted down on the second and third readings. In the second stage of analysis, the transcripts were read through again and coded using the qualitative software program NVivo 12 (QSR International, Doncaster, Australia). In the second stage of the analysis, a research assistant was assigned to read over all the transcripts independently and to independently code the transcripts for themes using NVivo. I met with the research assistant initially to discuss my interpretive analysis of the data and the theoretical assumptions of the analysis. The researcher and I subsequently independently coded the data in a systematic fashion as the transcripts were read, with data relating to each code saved to that code, noting that some data could be allocated to several codes in this stage. In the following third stage of the analysis, the codes were gathered into possible

themes, with related codes grouped together into each theme. To further explore the meaning of the narrative in each code, the research assistant and I discussed the codes and converged themes in this third stage of analysis. In this stage, I additionally met with my supervisors to discuss the potential codes and themes in the analysis to ensure the codes and themes were consistent and appropriate to the purpose of the research. Convergence occurred between the research assistant and I by narrowing down the codes into potential themes and subsequent development of themes was guided by a critical realist stance.

In the fourth stage of the analysis, the codes within each theme were reviewed again by the research assistant and I to ensure the codes reflected each theme accordingly and that the themes reflected the data. In the fifth stage, the themes were further refined and named respectively to best suit the themes that had been coded; data were removed from any theme that didn't fit the data appropriately, and the theme was renamed following this stage to reflect accurately the data in the theme. The final stage included the writing of this document and selecting extracts from the transcripts that best reflected each theme, with respect to the original research questions and to represent each of the participants' views accurately. An inductive approach was also implemented which is a data driven approach that includes a process of coding the data without trying to fit it into a pre-existing coding frame (Braun & Clarke, 2006).

## **CHAPTER 4: FINDINGS**

### **4.1 Deductive and Inductive Themes**

This study identified particular interests in, group specific values in influencing the caregiving of older adults, based on previous quantitative research (Knight & Sayegh, 2010) and the sociocultural stress and coping model. Six themes were identified from the interviews: love, reciprocity, obligation, avoidance of aged care, appreciation, and sense of community (please refer to Table 2). The themes of love, reciprocity, and obligation originated from previous work and the sociocultural stress and coping theory during the deductive approach of this research. The themes of avoidance of aged care, appreciation and

sense of community were inductive and were identified during the inductive process under the reflexive thematic approach used in this study. The quotes illustrating themes are identified with the pseudonym given the caregiver, and relationship to the care recipient (for exp. rural/urban caregiver, current/retrospective, spouse, family member).

**Table 2***Description of Themes*

Theme	Caregiver Pseudonym	Urban/ Rural	Relationship	Current/ Retrospective	Quote
Love	Tara	Rural	Spouse	Retrospective	“He was the person that I loved more than anyone and I knew he always felt the same about me, I still believe this now even after he is gone, it brought us closer together, it was unconditional love”.
Reciprocity	Grace	Urban	Daughter	Current	“I believe my mum would have done anything for us growing up, so, I will do anything for my mum”.
Aged Care Avoidance	Ann	Urban	Daughter	Current	“I don't think anyone else can read her like I can so that gives me peace of mind because she knows that somebody is always there with her, and she can ask me for help and be listened to”.
Obligation	Hannah	Rural	Spouse	Retrospective	“You make a commitment to support each other until the end really and this was his end. There's no other reason than that really. It was just what had to be done and that is just what I did”.



Appreciation	Wendy	Urban	Daughter	Retrospective	“It was a constant memory lane when we were together just reliving memories of childhood and old times, I feel like I got a lot out of those experiences with my dad”.
Sense of Community	Susan	Rural	Spouse	Current	“I didn’t have any social relationships until I joined the local carer group. That was a great relief, you walked into a room, and everyone knew what you were talking about. That feeling of just being with similar people”.

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*n=17*

## 4.2 Love

The most common reason provided for being a carer for the frail older adult was love. The act of providing love in caregiving is embedded in and motivated by strong feelings of devotion and affection on behalf of the caregiver towards the care recipient (Park & Schumacher, 2013; Streck et al., 2020). For these carers love was conveyed unconditionally as a positive value motivating their caring:

*Kate (rural caregiver, spouse)* “because he was my partner, so I found that strange because you do what you can until you can no longer do it and that’s just my ethos, so there was no question really about it for me”.

*Eva (urban caregiver, daughter)* “It’s all about the love and it’s a privilege, it’s special, it’s intimate, it draws on the heart strings a lot, I loved my parents to death and would have done anything for them”.

*Louise (rural caregiver, daughter)* “I think when you love somebody, you want to care for them. It’s just not something that you plan. I think it’s not something that you just suddenly decide, but it’s not a chore because you love them”.

*Natasha (urban caregiver, spouse)* “In one respect you’re the equal and a loving spouse, and you want to spend time with them and look after them, because you love them”.

Love as a value for spouses was expressed as a natural progression in the sense of wanting to continue the unconditional love provided in the spousal relationship through caregiving. For adult child caregivers, love as a value was viewed as the unequivocal positive regard held for parents and the immediate desire to provide love and affection to parents by looking after them in caregiving. While these were uncomplicated positive expressions of love for current caregivers that appeared to make caregiving easier, for other retrospective carers there was clearly a suggestion that at the time of caregiving there may have been a sense of interpreting the value of love differently.

*Susan (rural caregiver, spouse)* “I miss him now and our life as it was. I now feel the love we had. I now understand why I went through hell to make sure he still felt cared for”.

*Tara (rural caregiver, spouse)* “He was the person that I loved more than anyone and I knew he always felt the same about me, I still believe this now even after he is gone, it brought us closer together, it was unconditional love”.

For these retrospective caregivers, there was a sense that love as a value was interpreted differently after bereavement in the sense of reflecting on the unconditional love that was felt during the caregiving experience for the family member who had passed away. Unconditional love was recognised as being felt both during the caregiving experience and afterwards during bereavement for retrospective caregivers, where there was a sense of noticing and missing the love felt during caregiving. This suggests that at the time of caregiving current caregivers may have made sense of the value differently compared to retrospective caregivers. Nonetheless in these interviews, love was identified as an integral value that influenced caregiving and was interpreted by both current and retrospective carers in different ways.

### **4.3 Reciprocity**

Many studies have identified that caregivers value reciprocity, which is the opportunity to provide care and give back to their loved one the care that they also mutually received in the relationship (Jervis et al, 2010; Murray et al.,1999; Peacock et al., 2010). The value of reciprocity in caring for older adults was identified by these caregivers, where caregivers talked about their opportunity to give back to a loved one including a spouse or parent by caregiving.

*Mary (urban caregiver, daughter)* “I feel my parents helped me a lot, so it was only natural that I wanted to help when dad became unwell. Dad was always very supportive of me, so I was always going to care for him”.

*Louise (rural caregiver, daughter)* “Probably for the care that I got from my parents that I wanted to contribute to dad's life in the same way that he has contributed to mine”.

*Kate (rural caregiver, spouse)* “You just do it because you think oh well if I was crook or if I became really unwell, I just know that he would look after me”.

*Grace (urban caregiver, daughter)* “I believe my mum would have done anything for us growing up, so, I will do anything for my mum”.

In this study, reciprocity for caregivers who were adult children was phrased in a positive sense as providing back the care they had received in childhood and adulthood, whereas for spouses’ reciprocity was identified as an integral part of the spousal relationship and commitment to one another. Adult child caregivers exhibited reciprocity in a retrospective sense based on their own individual experience of care from a parent and reflected upon this exchange in the sense of how they were now caring for a parent who had provided them with a high level of care during childhood and their adult years. For adult child caregivers, in Kate’s example, there was also a sense of reciprocity as a value being future focused, in recognising a parent would also reciprocate prospective care. In comparison for spousal caregivers, reciprocity was seen as a value that evolved over the duration of the relationship and it was conveyed with the impression that the loved one receiving care would also provide the same level of care if the situation was reversed. This identifies the importance of caregiver’s own appraisal of reciprocity in the caregiving relationship, and although further research is required, reciprocity was interpreted as a positive value influencing caregiving.

#### **4.4 Obligation**

Obligation as a value in caregiving refers to the degree caregivers feel morally bound and compelled to provide care to the care recipient (Stein et al., 1998). Obligation in term of caring for a loved one such as family member, or spouse refers to the feeling that caregivers seek to provide care for their loved one experiencing health issues or illness, due to normative feelings of obligation, dedication, and devotion (Knight & Sayegh, 2010). For these caregivers obligation was expressed as a value motivating their caregiving:

*Hannah (rural caregiver, spouse)* “You make a commitment to support each other until the end really and this was his end. There's no other reason than that really. It was just what had to be done and that is just what I did”.

*Carol (urban caregiver, daughter)* “In my mind I made a mental commitment to make sure she had all that she needed, and to do the right thing. I could not just care I suppose? but that's not the right thing to do”.

*Zoey (rural caregiver, spouse)* “It was just what had to be done and that is just what I did. I wanted to look after him and I did so in the most incredible way”.

*Ann (urban caregiver, daughter)* “I have a responsibility in looking after my mum, and an obligation to my mum which trumps my obligation to myself”.

For these carers, obligation as a value was identified in a positive sense regarding the commitment towards caring for a family member or spouse. Obligation as a value was discussed in the context of an internal feelings that included the caregiver's personal beliefs regarding their individual commitment to caring for a loved one. However, obligation as a value was also expressed as an external feeling, where caregivers expressed their own feelings regarding how they had felt stepping into the caring role had been the right thing to do. Caregivers discussed an expected obligation from their external feelings in a moral and societal perspective, due to being a close family member such as an adult child caregiver or spouse.

#### **4.5 Aged Care Stigma**

Aged care stigma refers to actively seeking to avoid a planned or unplanned admission to an aged care facility for an older adult. Feelings of comfort and relief from holding the role of primary caregiver were identified in this study, regarding the strong emotional connection and desire to provide primary care for a loved one (Netto et al., 2009; Ribeiro & Paul 2008). For these caregivers' the value of aged care stigma were expressed as a motivation to provide care of a loved one:

*Geraldine (rural caregiver, daughter)* “I know she’s very well looked after because I do it every day, and I’m with her 24 hours a day, and she doesn’t have to sit in pain or silence waiting for someone to come to her”.

*Ann (urban caregiver, daughter)* “I don’t think anyone else can read her like I can so that gives me peace of mind because she knows that somebody is always there with her, and she can ask me for help and be listened too”.

*Deborah (urban caregiver, daughter)* “I think everyone has heard the horror stories of nursing homes I couldn’t bear the thoughts of my parents not being looked after properly, and there is no way I would ever have let that happen”.

*Susan (rural caregiver, spouse)* “It was horrific, but I never wanted him to go into care, I wanted the time to sit with him instead of him barely eating in a home because they wouldn’t have the time to look after him properly”.

For these caregivers there was a sense of aged care stigma influencing their caregiving as they spoke of avoiding their own discomfort and focusing on their own peace of mind by providing primary care of a loved one. Aged care stigma was seen as a negative value in one sense where the caregiver’s stance was predominantly focused on avoiding the perceived negative aspects of aged care, which they did not want the loved one that they were caring for to experience or endure in aged care. Nonetheless, aged care stigma as a value was also seen in a positive sense due to the caregiver viewing their role as primary caregiver to be quite protective of family member they were caring for. This was conveyed in a sense of having peace of mind through being the primary caregiver, with caregivers discussing how they felt they were able to reduce feelings of guilt, uneasiness, or discomfort, they were likely to experience if the family member they were caring for was admitted to aged care.

#### **4.6 Appreciation**

Appreciation is being aware that there are always positive things and aspects of life to be thankful for (Algoe, 2012). Caregivers can often adapt and cope well with the challenges

they face in the caregiving role and can feel appreciative for the caregiving experience (Cohen et al., 2002; Farran et al., 1991). For these carers, appreciation was reflected in the act of caring and recognising the importance and relevance that the loved one cared for already had on the life of the caregiver.

*Wendy (urban caregiver, daughter)* “It was a constant memory lane when we were together just reliving memories of childhood and old times, I feel like I got a lot out of those experiences with my dad”.

*Carol (urban caregiver, spouse)* “It has changed my perspectives and thinking, and I try to live the best life I can now because you have limited time here. The little things in life that used to bother me no longer bother me”.

*Edel (rural caregiver, daughter)* “I'm getting to spend more time and be present with my mum every day, and I'm asking her lots of questions each day. So, I get stories of her life and I'm taking that as a positive”.

*Louise (rural caregiver, daughter)* “My relationship with my dad is much more vibrant and stronger and just being there with him while he is on his journey, I guess we have gotten to know each other in a way we would never have”.

For these caregivers they reported a sense of appreciation, in being able to provide care to the loved one, and experienced positive memories during the focus of their care. Caregivers recognised the subjectivity of caring in changing life perspectives where appreciation became essential as a value in the process of the care undertaken by the family caregiver. There was a sense of appreciation being interpreted as a positive value influencing caregiving, where feeling thankful for being present during the caregiving experience was considered to have been quality time spent in caring for their loved ones. Appreciation was also expressed as a positive value with caregivers discussing developing awareness and acceptance regarding their caregiving role and valuing the beneficial connection and

relationship growth over time, they experienced with the family member they were caring for.

#### **4.7 Community**

Community refers to the experiences of a group of people, where caregivers feel like they have a sense of belonging and feel like they matter to others in their group or community (Omoto & Malsch, 2005). Community as a value was understood in different ways by rural and metropolitan caregivers. Informal supports such as caregiving groups were identified as an important sense of connection to community with rural caregivers, whereas in metropolitan areas urban carers reported disconnection from formal supports and community.

The majority of the rural carers cited sense of community as a value, with eight out of ten rural respondents discussing the meaningful association with informal community support.

*Ann (rural caregiver, spouse)* “It gives carers an opportunity to stop feeling isolated, to communicate with other people and to be able to tell others how they feel without being judged, because only carers of people with Dementia really understand how you feel”.

*Hannah (rural caregiver, spouse)* “I went to a support group and that’s how I made new friends, it helped me to feel normal and it felt like everyone in the group just spoke the same language and understood, and you never felt judged”.

*Susan (rural caregiver, spouse)* “I didn’t have any social relationships until I joined the local carer group. That was a great relief, you walked into a room, and everyone knew what you were talking about. That feeling of just being with similar people”.

*Zoey (rural caregiver, spouse)* “The people who were in the carers group lived close to my house, but I had never met them before, or knew they were dealing with the same issue, and I got great support from that group”.



Five out of seven of the urban caregivers cited not feeling connected to community as a value but a negative an unsatisfied one, in the context of feeling disconnected from formal supports, and community.

*Alex (urban caregiver, spouse)* “There is no help. Carers Gateway called me and told me that I’m entitled to one night of respite, you get no help, so you feel like you get nothing and constantly feel like you get nowhere”.

*Charlie (urban caregiver, family caregiver, daughter)* “I don’t have any contact with anyone or any support anymore, just Facebook groups”.

*Marie (urban caregiver, family caregiver, daughter)* “I don’t have any time to do anything, or see anyone, you lose all of your friends, because all I do is caregiving and fighting with the state government and the council, but we still don’t get anything”.

*Linda (urban caregiver, family caregiver, daughter)* “It’s so hard to get any type of help, you ring up and someone rings you back and you don’t know where they’re from, it’s all over the place. I felt dismissed by services, I didn't have any rights”.

There was dichotomy between rural and urban caregivers experience of sense of community, rural caregivers valued connection to informal supports such as caregiving groups in their local communities as a positive value influencing caregiving, whereas urban caregivers reported experiencing isolation and disconnection from community in a negative aspect that had an adverse influence on caregiving. There was also a lot of frustration around lack of access to formal supports for urban caregivers, whereas the rural caregivers cited positive experiences from informal supports. Urban caregivers also referred to feeling isolated and deserted by informal supports which was identified as a negative influence on their caregiving experience.

## **CHAPTER 5: DISCUSSION**

### **5.1 The Sociocultural Stress and Coping Model**

The sociocultural stress and coping model (Knight & Sayegh, 2010) identified the role of group specific values as influences in the stress and coping process for caregivers of older adults. The themes of love, reciprocity, and obligation originated from previous work in relation to the sociocultural stress and coping theory and were identified during the deductive

approach of this research. The present study has answered the research questions regarding what the values of rural and urban caregivers of older adults are, and how these values influence caregiving. Caregivers described the values motivating their caregiving in terms of love, reciprocity, obligation, aged care stigma, appreciation, and community. The study also identified the positive aspects of group definitive caregiving values including love, reciprocity, and obligation. This has theoretical implications as positive caregiving values are aspects of the caregiving experience that have not yet been combined within the sociocultural stress and coping Model, and this requires further research. There are also practical implications as further research will help to identify what service providers can do to encourage shared group specific values as positive influences on caregiving.

The sociocultural stress and coping model identified that specific groups values influence caregiver health, caregiving support, caregiving coping styles and caregiver burden (Knight & Sayegh, 2010). Group specific values had a direct influence on coping and social support, which, subsequently, also had an influence on caregiver health (Knight & Sayegh, 2010). In this study, the value of community, which was expressed by rural caregivers, is related to the group specific values identified in the sociocultural stress and coping model. Community as value, which is a novel finding, has theoretical implications, as fostering community in caregivers in practice, and connection to caregivers in their neighborhoods or areas could influence coping, social support, and caregiver health. However, the value of community and its impacts for caregivers has never been explored in the sociocultural stress and coping model and this also requires further research.

## **5.2 Love**

For current caregivers there were uncomplicated positive expressions of love with strong feelings of devotion and affection expressed towards the family member they were caring for. While for other retrospective carers there was clearly a suggestion that at the time of caregiving there may have been a sense of interpreting the value of love differently. In the aftermath of bereavement, there was a sense of caregivers feeling inspired to search for

meaning and reflecting more on the positives from their caregiving experience overall in particular regarding the loving relationship that existed between the caregiver and care recipient. Thus, love was identified differently for retrospective caregivers as influencing caregiving, which is consistent with past research where it was found that bereaved caregivers can be inspired to search for meaning and can reflect on more positives from their caregiving experience (Shim et al., 2013). This also has potential implications for all formal supports such as therapeutic practice, as it may be clinically appropriate to support both retrospective and current caregivers to reframe their caregiving experience more positively.

The most common reason provided for being a carer for the frail older adult was love, which is consistent with multiple studies to support love as a value that influences caregiving (Joling et al., 2017; Lloyd, et al., 2016; Orpin et al., 2014; Williams et al., 2014). Lloyd et al., (2016) describes the importance of love in the caregiving relationship in influencing positive caring experiences. Joling et al., (2017) found unconditional love to be cited by carers but not by professionals as an essential aspect of endurance in the caring role. Past research has indicated that both female and male caregivers reported engaging in caring tasks increased the sense of love in the relationship (Peacock et al., 2010; Ribeiro & Paul, 2008). Growing dependency in the caring relationship was also identified as bringing greater love and emotional closeness to the caregiving relationship in Murray et al.,'s (1999) study. Thus, the theme of love was the principal motivation in caring for older family members.

### **5.3 Reciprocity**

The value of reciprocity as a motivating factor for influencing caregiving in this study is supported by past research, with these caregivers reporting wanting to repay the care they had received from spouse or parent (Jervis et al, 2010; Peacock et al., 2010). Caregivers talked positively about their opportunity to give back to a loved one by caregiving (Gilbert & Powell, 2005; Lloyd et al., 2016; Reid et al., 2005; Peacock et al., 2010). For adult caregivers' reciprocity was identified in the context of paying back the care experienced in childhood but

also for the ongoing help and support received in adulthood. In comparison, when spouses explained their feelings of reciprocity it was viewed more in the sense of the natural progression of the relationship, and reciprocity was viewed a value that they had committed to as part of the spousal relationship. Kohli (2005) notes that reciprocity as a caregiving value implies that individuals who received support and care from others will likely reciprocate this support and care also in life. Thus, the findings of the present study are consistent with past research where caregivers reported the desire to repay and reciprocate the affection they had received from their spouse or a parent (Jansson et al., 1998; Peacock et al., 2010).

These caregivers discussed reciprocity as a value motivating their caregiving which is also consistent with Lloyd et al.'s (2016) and Ribeiro & Paul's (2008) report of carers identifying reciprocity as a meaningful contributor to a positive experience, when the previous caring relationship had been positive. However, it is important to note that past research has identified that caregivers who previously had difficult relationships with parents reported caring in the absence of reciprocity (Jansson et al., 1998). Nonetheless, reciprocity is an important theme that requires further research in the context of values, as it can be a meaningful contributor to a positive experience in the caregiving role (Ribeiro & Paul, 2008), and further research and understanding of reciprocity in this context could support understanding of the values that can lead positive experiences in the caregiving role.

#### **5.4 Obligation**

The theme of obligation was expressed as a value motivating caregiving in a positive sense. For these caregivers there was a sense of obligation in the caregiving role due to a sense of feeling responsible in caregiving for a loved one, and due to their commitment in the spousal relationship. Family obligations to provide care for older adults have long been rooted in family structures and family upbringings that shape decision-making surrounding the provision of care to a dependent older family member (Pharr et al., 2014). In this study, obligation as a value was identified in a positive sense of holding responsibility towards

caring for a family member or spouse which is consistent with past research regarding caregiver's personal feelings of obligation in provide care for loved ones and family members (Epps et al., 2014; Knight & Sayegh, 2010). The findings of obligation as having a positive influence on caregiving is consistent with past research where it has been established that meaningful and positive relationships with the care recipient can make caregivers feel obliged to act in accordance with their personal values and goals in committing to caregiving roles (Tretteteig et al., 2017).

Furthermore, Jervis et al.,'s (2010) study outlined how adult child caregivers reported feeling obliged in a positive sense to care to for their elderly parents due to feelings of dedication and identified as wanting to spend time in their elderly parents' company. Past research has also identified that in spousal relationships partners often report feeling obliged to take up the caregiving role due to their previous commitment to the marriage and vows they took when marrying (Rollero, 2016). Donovan and Corcoran's (2010) study additionally described how by maintaining their commitment to their partner, the spousal caregiver was enabled to maintain their stamina in the caregiving role. Thus, this study is consistent with Rollero (2016) findings as the caregivers reported a positive commitment in feeling responsible for the caregiving role of a spouse who required caregiving.

Nonetheless, past research has found that obligation can have a negative influence on caregiving (Knight and Sayegh, 2010). Justifications for taking on the role of caregiver can often result in negative feelings of obligation leading to more strain, resentment, and distress (Losada et al., 2006) and reduced life satisfaction (Haley et al., 2003; Pyke, 1996). However, in contrast the interviewees in the present study spoke of feeling morally bound and compelled to provide care to the care recipient and expressed obligation as a value to have a positive influence on caregiving. Hence in this study, negative expressions of obligation were not expressed or reported, suggesting for carers their own sense of obligation was because of their individual values and moral choices.

## **5.5 Aged Care Stigma**

The themes of aged care stigma, appreciation and community were inductive and were identified during the inductive process under the reflexive thematic approach used in this study. Firstly, with respect to aged care stigma, this value was found to negatively influence caregiving. For these caregivers there was a sense of aged care stigma influencing their caregiving as they spoke of avoiding their own discomfort and focusing on their own peace of mind by how they provided care. Past research has identified that family caregivers often consider that there to be no other viable options other than themselves as family members to provide care (Anngela-Cole & Hilton, 2009). The findings of this study are consistent with past research that remaining in the home environment and being cared for by a family or a spouse, is the most preferred option regarding caregiving for both rural and urban caregivers (Szebehely & Trydegård, 2011).

Nonetheless, as the number of individuals needing care is likely to increase due to reasons of demographic ageing, challenges in health care and aged care are increasing, with an increased need for formal supports and services for caregivers (Hajek et al., 2021). Further research is required regarding aged care stigma to understand the sense of caregivers avoiding their own discomfort and providing care to avoid the loved one they are caring for going into aged care. The value of aged care stigma is also an interesting contrast to Knight et al. (2022) research, where caregivers stance regarding never wanting to use aged care for a loved one was cited as culturally specific by ethnic carers, but also recognised as a choice not available in older times for their people (Knight et al., 2022).

## **5.6 Appreciation**

For the caregivers in this study there was a sense of appreciation leading to personal growth from caregiving. Lau and Cheng (2015) identified that the capacity to derive feelings of appreciation from caregiving experiences to be associated with increased morale and a more positive attitude towards coping and managing in the caregiving role. Previous studies

have indicated that caregivers describe their role as resulting in intrinsic personal growth in terms of reporting feeling humbler and more appreciative of life (Netto et al., 2009; Ribeiro & Paul, 2008; Robertson et al., 2007), having more patience (Peacock et al., 2010), and being more self-aware (Sanders, 2005). In Netto et al.'s (2009) study caregivers spoke of being more appreciative of others and placing less value on money and materialistic goods. Thus, the findings of this study are consistent with past research where caregivers spoke of having grown intrinsically due to the experience, being more appreciative of life, and others, being more self-aware and placing less value on money and materialistic goods (Netto et al., 2009; Peacock et al., 2010; Ribeiro & Paul, 2008; Robertson et al., 2007; Sanders, 2005).

Furthermore, caregivers reported how the caregiving experience helped them to reframe how they see things by focusing and being mindful of what is good in life (Lau & Cheng, 2015). For these caregivers they also reported a sense of feeling thankful and experiencing contentment in being able to provide care to the loved one, and experienced positive memories during the focus of their care. This is consistent with past research that has identified that positive aspects of the caregiving experience including appreciating the emotional rewards and gratifications which have been associated with greater subjective well-being (Pinquart & Sörensen, 2003). Further research in this area is of importance, as gaining an understanding of appreciation as a more positive caregiving experience that can influence the caregiving role is important and could contribute to the development of interventions to support carers who are struggling.

## **5.7 Community**

The final value community was identified as influencing caregiving and is a novel finding in Australia and has implications for future research and practice. For these caregivers there was a contrast between rural and urban caregivers experience of sense of connection to community, with rural caregivers conveying their strong connection to informal supports such as caregiving groups in their local communities, whereas urban caregivers reporting



experiencing more isolation and disconnection from formal and informal supports in their community. The findings of this study are novel to Australia, and consistent with previous research from other countries where urban caregivers reported disconnection and isolation from formal and informal supports than rural caregivers (Imaiso et al., 2012; Kim et al., 2006). This is also consistent with previous research, that there tends to be more informal supports in rural communities from relatives or neighbours and there is a stronger sense of community (Bushy, 2000; Orpin et al., 2014). Informal supports such as caregiving groups were identified as an important sense of connection to community with rural caregivers, whereas in metropolitan areas urban carers reported disconnection from formal supports and community. Further research regarding community as a value influencing caregiving in Australia, is of high importance, as the absence of connection to informal supports could be seen as a risk factor when identifying carers who are struggling, and this would help provide more targeted support services.

### **5.8 Implications for Future Research and Practice**

The present study has helped to understand the influence of values on the experience of caregiving and is consistent with past literature regarding the themes of love, reciprocity, obligation, and appreciation influencing the caregiving experience. The findings of this study are consistent with past research and literature across the rural/urban divide of caregivers. Moreover, this study has led to the identification of a novel theme regarding the value of community. This is a novel finding and has implications for future research regarding community support, as it is in direct contrast to the view that those in rural communities are struggling and isolated from services. This finding suggests that having more self-reliance in rural communities is possibly a good thing, as caregivers in rural communities are more self-sufficient in seeking out support and connecting with their local community.

Community as a value indicates that rural caregivers are much more resourceful and self-support by using their informal support networks, whereas urban caregivers appear to have more access to services and formal supports, but the quality or experience from services

were poor and inadequate in meeting caregivers support needs. This has significant implications, as service providers could focus on creating connection for urban caregivers which could additionally influence coping, social support, and caregiver health under the sociocultural model of stress and coping theory. Future research, that explores community as a value for caregivers may help to identify specific targeted community supports to reduce isolation and disconnection for caregivers.

A strength of the present study includes the identification of the positive aspects of group definitive caregiving values including love, reciprocity, and obligation. This has theoretical implications as positive caregiving values are aspects of the caregiving experience that have not yet been combined within the sociocultural stress and coping model, and these positive caregiving values requires further research in sociocultural theory. There are also practical implications as further research regarding positive values will help to identify what service providers can do to encourage shared group specific values to have beneficial influences on caregiving.

### **5.5 Research Limitations**

Limitations of this study included how eleven participants were retrospective carers out of seventeen participants, and six participants were current caregivers. Another limitation is the predominantly female sample, with the inclusion of one male participant with no quotes used from the male participant in the study, which indicates that these values might not be as relevant to, or influential for, male caregivers. It is possible that there are differences between the perspectives of current and retrospective carers, in the sense of retrospective carers having experienced the caregiving role in full and have had time to contemplate and reflect over the duration of their caring role. Whereas the current carers are expressing their subjective experience of the stage of caregiving they are experiencing at the time the interviews in this study were completed. There were also more retrospective rural caregivers than retrospective urban caregivers which may have created an uneven distinction between the interviews. Characteristics of retrospective memory including recall bias, positivity bias and social

desirability bias may have impacted on their recollection of events and emotions relating to their experience of being a caregiver (García-Bajos et al., 2017). Future research could also focus on the values of rural caregivers themselves in more detail, rather than the external perceptions of researchers.

## **CHAPTER 6: CONCLUSION**

There is growing interest on the topic of caregiving for older adults as the age of population in society steadily rises, and more family members or significant others are taking on the role of caregiver. Past research supports the view that values can influence finding meaning in caregiving. Currently, there is a lack of research on the influence of group specific values in the experience of caregiving in rural or urban contexts. This study adds to the qualitative literature on values in caregiving by including caregivers from rural and urban areas in Australia and has identified a novel theme in Australia for sense of community. The present study has answered the two research questions regarding what the values of rural and urban caregivers of older adults are, and how these values influence caregiving. Caregivers described the values motivating their caregiving in terms of love, reciprocity, obligation, aged care stigma, appreciation, and community. The value of community as influencing caregiving is a novel finding in Australia and has theoretical implications due to its sense of a protective factor relating to group specific values under sociocultural model of stress and coping. This study found rural caregivers to be more self-sufficient by using their informal support networks, whereas urban caregivers have more access to services, but the quality of these services were seen as insufficient and poor. Thus, understanding the nature of regional and rural values on caregiving is significant for future research in implementing targeted practice

interventions, and specific targeted community supports to reduce isolation and disconnection for caregivers.

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## **Appendix A**

### **Questions from semi-structured interviews**

1. Can you please tell me about your experience of caregiving?
2. Can you tell me about the reasons you became a caregiver?
3. Can you please tell me about how your values influence how you provide care?
4. What do your social supports or social relationships look like?
5. Can you please tell me if you think caregiving will have an impact on your future