Balancing the Roles of Paid Employment and Unpaid Caregiving

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ABSTRACT

The dissertation provides an in-depth examination with regard to working caregivers’ perceptions of their experience of combining paid employment and unpaid caregiving responsibilities by studying a sample with diverse caregiving responsibilities within an Australian context. Many studies on informal caregiving and paid employment, the interaction between work and family domains, and the impact of combining work and caregiving, focus on caregivers who provide care to people within a specific group, such as individuals with dementia, or the elderly. This research focuses on the experience of working caregivers rather than the specifics of the illness or disability of the person for which care is provided.

A case study approach using primarily a semi-structured, face-to-face interviewing method was employed for the present study. Seventeen people who were employed at the time of interview while concurrently holding an informal caregiving role, participated in interviews designed to explore the experience of being a working caregiver, to reveal the strategies adopted by working caregivers to deal with challenges arising from balancing work and family responsibilities and to identify the impact of being a working caregiver.

Being a working caregiver is a complex experience that is influenced by many aspects, such as inherent demands imposed by both work and family domains and relationships between working caregivers and their care recipients, other family members and friends. In contrast with the widely acknowledged impact of caregiving on employment, in terms of taking different forms of alternative work arrangements (for example, reducing work hours, moving away from full-time employment or exiting from the workforce), participants of this research were keen to maintain their current employment status for as long as possible. However, all working caregivers in the study had to alter their lives significantly in order to accommodate the challenges at hand.

The current study found that balancing the roles of paid employment and unpaid caregiving was manageable due to informal flexibility granted at the workplace as a result of long
tenure, rather than support from friends, colleagues and use of formal programs. Self-imposed silence in the workplace about caregiving and a disinclination to share stories about the challenges of being a working caregiver are dominant themes.

The research contributes to the literature in relation to the interface between work and family domains by providing a range of perceptions of the experience of being a working caregiver. Findings from this study have implications for employers, policy makers within organisations, health professionals and the wider society.
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And finally, I would like to thank the people who participated in this research for their time and generosity. I thank them for allowing me to share their stories in this dissertation and enhance our understanding of being a working caregiver.
DECLARATION

This thesis:

• Contains no material which has been accepted for the award to the candidate of any other degree or diploma, except where due reference is made in the text of the examinable outcome;

• To the best of the candidate’s knowledge contains no material previously published or written by another person, except where due reference is made in the text of the examinable outcome;

• Has met all the requirements of the Ethics Approval from the Swinburne University of Technology (refer to Appendix 3.9 and 3.10); and

• Professional editorial intervention was restricted to: standards D and E which is in keeping with the Swinburne research higher degrees policy and procedure section 24.7

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# Table of Contents

ABSTRACT ............................................................................................................................... i

ACKNOWLEDGEMENTS........................................................................................................ iii

DECLARATION ....................................................................................................................... v

CHAPTER 1 – INTRODUCTION ............................................................................................ 1

1.1 Chapter Overview ....................................................................................................... 1

1.2 Statement and Background of the Problem............................................................... 1

1.2.1 The increased need for informal caregiving provision .................................... 2

1.2.2 The decline in the availability of family caregivers ........................................ 4

1.2.3 The high prevalence of the working caregiver ................................................ 5

1.3 The Purpose of the Study ......................................................................................... 6

1.3.1 The significance of the current study .............................................................. 6

1.3.2 The aims of the current study ....................................................................... 9

1.4 An Overview of the Structure of the Thesis .......................................................... 10

1.5 Definition of Terms .............................................................................................. 11

1.6 Summary .............................................................................................................. 13

CHAPTER 2 – REVIEW OF LITERATURE ................................................................... 14

2.1 Introduction ............................................................................................................ 14

2.2 The Nature of Caregiving .................................................................................... 14

2.2.1 Caregiving for children without a disability .............................................. 14

2.2.2 Caregiving for a dependant ....................................................................... 15

2.3 Types of Caregiving ........................................................................................... 16

2.3.1 Formal and informal caregiving ............................................................... 16
2.3.2 The differences between formal and informal caregiving ............................................. 18

2.4 Multiple Roles .................................................................................................................. 20

2.4.1 Social identities and social roles .............................................................................. 20

2.4.2 Role-related stress and the effects of performing multiple roles ..................... 22

2.4.3 Role strain and work–family conflict .................................................................... 25

2.4.4 Role enhancement and work–family enrichment .................................................. 33

2.5 Paid Employment and Unpaid Informal Caregiving .................................................. 36

2.5.1 Paid employment versus unpaid informal caregiving ....................................... 37

2.5.2 The consequences of combining paid employment and unpaid informal caregiving ................................................................. 42

2.5.3 The support needed in combining paid employment and unpaid informal caregiving ................................................................. 46

2.6 Justification of the Doctoral Study ............................................................................ 47

2.7 Summary ....................................................................................................................... 51

CHAPTER 3 – METHODOLOGY ...................................................................................... 52

3.1 Introduction .................................................................................................................... 52

3.2 Research Paradigm ....................................................................................................... 52

3.3 Research Design ........................................................................................................... 54

3.3.1 Justification of the methodology and method selected ...................................... 54

3.4 Participants, Recruitment Process and Sampling ..................................................... 58

3.4.1 Protection of human subjects .............................................................................. 58

3.4.2 Gaining and maintaining access to industry partners ....................................... 58

3.4.3 Sampling strategies .............................................................................................. 60

3.5 Data Collection ............................................................................................................. 63

3.5.1 Interview models .................................................................................................. 63

3.5.2 Semi-structured interviews ................................................................................ 64

3.6 Data Management and Analysis ................................................................................. 71

3.6.1 Data management and preparation ...................................................................... 72
Appendix 3.1 – Information Statement ........................................................................... 323
Appendix 3.2 – Study Flyer ........................................................................................... 325
Appendix 3.3 – Participant Recruitment Letter ............................................................. 327
Appendix 3.4 – Informed Consent Agreement for Participation in Research ............... 329
Appendix 3.5 – Semi-structured Interview Schedule .................................................... 330
Appendix 3.6 – Samples of Invitation Letter (via email)............................................... 333
Appendix 3.7 – People Who Have Been Interviewed ................................................... 334
Appendix 3.8 – Final Sample for Case Study ................................................................. 335
Appendix 3.9 – Ethics Clearance ................................................................................... 336
Appendix 3.10 – Ethics Clearance for Modified Protocol/Extended Project ............... 338
CHAPTER 1 – INTRODUCTION

1.1 Chapter Overview

The main objective of this dissertation is to examine the perceptions of the experience of being a working caregiver\(^1\), that is, a person who is in paid employment while simultaneously acting as an informal caregiver to a family member. This includes caring for a person with a disability, chronic health problems or a terminal illness, or a frail elderly person (Miller-Keane & O’Toole 2005). This chapter sets the context for the current research by providing background information and discussing the significance and purpose of the study. The research is set in an Australian context, and the statistics included in this dissertation, unless otherwise specified, are drawn mainly from Australian sources. The theories and conclusions from the literature in this thesis derive from studies conducted in a range of countries, including Australia. An overview of the thesis structure and a summary of definitions of the terms used conclude this chapter.

1.2 Statement and Background of the Problem

Working caregivers are expected to become more prevalent as more people, both women and men, are attending to the welfare of people (mostly family members) of all ages who are in need. The need for caring provision is likely to increase in the years to come, and formal caregiving systems are unlikely to keep up with the demand. In addition, the availability of family caregivers, especially non-working caregivers, is diminishing as women increasingly engage in paid employment and able older people continue to work as economies tighten and superannuation opportunities narrow. Hence, it is important to understand the experience of those who combine the roles of paid employment and unpaid caregiving, their ways of coping with the challenges they face, and their need for support.

\(^1\)There are various ways of referring to a person who has caring responsibilities, for example, carer or caregiver. While those terms are used interchangeably in the literature, for the purpose of this thesis, caregiver will be used except in quotes from other studies.
1.2.1 The increased need for informal caregiving provision

The need for informal caregiving provision is likely to increase as the number of disabled people and frail elderly who are in need of care continues to grow. Australia’s population, like those of other Organisation for Economic Co-operation and Development (OECD) countries, continues to age due to the combination of greater life expectancy and the onset of old age for the baby boomers (defined below).

With respect to greater life expectancy, combining factors include increasing technological capacity, widening access to information, and advances in public health and medical technology. Over the past 20 years, life expectancy at birth has improved by 6.0 years for males and 4.3 years for females. Based on current mortality rates, a boy born in 2007–09 can expect to live 79.3 years, while a girl can expect to live 83.9 years (Australian Bureau of Statistics 2009). By 2051, these figures will be 84.9 for males and 88 years for females (Australian Bureau of Statistics 2006).

In terms of the onset of old age for the baby boomers, the situation of population ageing will become more apparent as this cohort age. The term ‘baby boomer’ is widely used to refer a person who was born during the demographic post–World War II baby boom between the years 1946 and 1964 in Australia, the United States and the United Kingdom in particular. Hence, the proportion of the population aged 65 years and over (‘65+’) increased most sharply from 2011 when people born in 1946 turned 65. This trend will continue throughout the lifetime of the baby boomers (Australian Bureau of Statistics 2006).

The mere elongation of life expectancy does not, however, guarantee that older people will live actively and independently. In fact, an acute event, such as a car accident, chronic illness or impaired function as a result of ageing, can reduce an older person’s independence. The higher prevalence of chronic illness among older age groups, in particular dementia and associated disability, increases the need for informal caregiving. The number of older (those aged 65 and over) disabled Australians is expected to grow by 150 per cent, and the number of very old (aged 85 and over) by 200 per cent over the next 25 years (Lymer, Percival & Harding 2006). Demand for care for disabled (of any age) and
the elderly population is projected to grow significantly over the next 25 years (Lymer, Percival & Harding 2006).

The increased need for informal caregiving is also due to the increasing number of children with a chronic illness as a result of advances in scientific knowledge and technology (Gibson 1995). While the risk of having a child with a birth defect increases for women who have children at old age, advances in medicine make it possible for children who are born premature or with birth a defect to survive. This, in turn, contributes to the prevalence of developmental disabilities. The data from a recent study carried out in the United States shows that the prevalence of developmental disabilities (DDs) has increased 17.1% – that is, there were about 1.8 million more children with DDs in 2006–08 than a decade earlier. The prevalence of autism increased 289.5% over the same period (Boyle et al. 2011).

Developmental disabilities are defined in that study as a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help and independent living. Developmental disabilities begin any time during development up to 22 years of age, and usually last throughout a person's lifetime (Boyle et al. 2011).

According to the results of the Survey of Disability, Ageing and Carers (SDAC) (Australian Bureau of Statistics 2009), almost four million people in Australia (18.5% of the population) reported having a disability, and needed ongoing assistance in 2009. Of all Australians with a disability in that year, 290,000 (7.2%) were children aged 0–14 years (Australian Bureau of Statistics 2012). Approximately two-thirds (67%) of children with a disability required assistance with day-to-day activities and around half (48%) required assistance with cognitive or emotional activities, such as decision-making or thinking through problems, coping with feelings or emotions, and making friendships, maintaining relationships or interacting with others (Australian Bureau of Statistics 2012). According to the ABS (2012), nine in ten children with a disability (91%) were receiving informal assistance from family members or friends.
1.2.2 The decline in the availability of family caregivers

While it is predicted that the need for the provision of informal caregiving will increase, the availability of family caregivers, in particular non-working caregivers, has declined. The average size of a family has decreased over recent decades due to reduced fertility and improvement in contraception, the delay in starting a family and increased rates of relationship breakdown. According to the Australian Bureau of Statistics (2010), in 1961 each woman in Australia had an average of 3.5 babies. By 1981, the number was 1.9, and by 2001 it was 1.7. Also, the median age of all mothers who registered a birth in Australia in 2010 was 30.7 years (ABS 2010) compared to 25.6 in 1968 (ABS 2008). Thus, in future, most people will have fewer siblings with whom to share their caregiving responsibilities. The data from a US study indicates that women born in 1910 and 1935 started their childbearing at the youngest ages, with a media–age at first birth of 21 years. The median age at first birth among the 1960 birth cohort was 23 years (Kirmeyer & Hamilton 2011).

In addition, the increasing participation of females in the labour force (Jenkins et al. 2003) will have an impact on the availability of non-working caregivers. There has been a traditional expectation that caring for children with a disability or looking after frail elderly family members would be undertaken mainly by women. This stems from two perspectives. The first is the perceived strong commitment of women to expressive activities (Crano & Aronoff 1978), and to providing emotional support and nurturing activities that ensure the smooth running of the family (Bernard 1981; Hochschild & Machung 1989; Thompson & Walker 1989). The second is that until the latter part of the twentieth century, a much greater proportion of men than women in Western countries were in paid employment. Rightly or wrongly, women were consequently perceived to have more time and flexibility to fit in such caregiving activities. Women provide the bulk of informal caregiving in European countries (for example, approximately 60 per cent in the United Kingdom), the United States and in developing countries, such as China (Eaton 2005). In Australia, over two-thirds of primary carers (68%) were women (Australian Bureau of Statistics 2009).
The availability of non-working caregivers in Australia is further affected by such variables as changes in superannuation law and the ongoing economic consequences of the 2008 global financial crisis. The trend of earlier retirement has recently reversed. People are staying in the workforce longer in order to rebuild financial security for their lives after retirement. Along with demographic changes, this means that in the future the availability of non-working caregivers will decrease. As a consequence, according to Carers Australia, the ‘caretaker ratio’ – the ratio of people most likely to provide care to the number of people most likely to need care – is projected to decline substantially, from 2.5 in 2011 to less than one in 2050 (Carers Australia 2010). Demand for informal caregiving is expected to substantially outstrip supply over the next 40 years or so (Carers Australia 2010).

As a result of the high participation of women in the labour force, the difference in the proportion of men and women involved in the caring role is getting smaller (13% of women compared to 11% of men) (Australian Bureau of Statistics 2009). While women still outnumber men in this role, the number of male caregivers is significant and is likely to increase. For this reason, the research described in this thesis includes both male and female participants, and gender differences are not explored. There is a need to understand the play between paid employment, informal caregiving and other roles, for both men and women. The stresses of and interactions between multiple roles need to be understood if effective policy and support is to be developed for all caregivers, men and women, and those they look after.

1.2.3 The high prevalence of the working caregiver

Many people aged 65 years or older, especially those with a functional disability, are in need of some form of long-term care. As a result of an escalating effort by governments in the Western world, there has been a shift of the provision of care for dependants (elder care and care for people with disabilities) away from formal institutionalised care towards community-based and informal family care (Tolhurst 2001). The majority of care for dependants is still provided by a family member, especially when the carer perceives that a significant decline in the functional abilities of the person receiving care has occurred (Cicirelli 2000). Thus the shift has increased the number of people who assume a
caregiving role. Australia has a similar situation: the imbalance between demand and supply and the availability of formal caregiving may be impacted by the shift from institutional to community care, but without a corresponding shift in the level of funding for community care, as well as the resulting time fragmentation and complex systems (in terms of transferring patients from a formal caring system to a community-based system) (Department of Health and Ageing 2009). A shortage of formal care services will increase demand for informal caregiving.

In Australia in 2009, 2.6 million people were providing care for family members and friends, with most caregivers being middle-aged (35 to 54 years) (Australian Bureau of Statistics 2009). Of this group, 29% were primary carers (Australian Bureau of Statistics 2009). The number of carers and primary carers is increasing at some 2% per year (Carers Australia 2010). The Survey of Disability, Ageing and Carers (SDAC) found that 56.1% of carers participated in the workforce (that is, they were employed on either a part-time or full-time basis or were looking for work) (Australian Bureau of Statistics 2009). More and more people, both females and males (13% of women and 11% of men) (Australian Bureau of Statistics 2009), are taking up a caregiving role while retaining their paid job.

1.3 The Purpose of the Study

1.3.1 The significance of the current study

The key objectives of the doctoral study reported in this thesis are to provide a better understanding of the experiences of working caregivers in Australia and the challenges working caregivers are facing, and to explore working caregivers’ perceptions of the interface between family and work domains. This research is an additional component to the ‘Redesigning Work for an Ageing Society’ (RW4AS) project, an undertaking funded by the Australian Research Council (ARC) and supported by a number of industry partners across the nation, including public and private sector organisations. The central aims of the larger project are to identify and respond to challenges to the health and well-being of workers as they age, and to develop an Australian framework and guidance materials for the promotion of work ability and for managing an ageing workforce. While the ARC project is merely about ageing, this thesis has taken the research beyond the boundaries of
the larger project by studying caregiving for the disabled and the frail elderly. In conjunction with the ARC project, the findings from this doctoral study will shed light on how issues arising from combining the roles of caregiving and paid employment can be tackled more effectively within an Australian context. They will provide government and employers with valuable information in relation to the design of more appropriate programs or initiatives in order to assist working caregivers.

This thesis is important for a number of reasons, and the decision to choose this topic for research is discussed below. First, as the proportion of the elderly and dependent adults or children requiring care steadily increases, it is unrealistic to think that the task of caring for adult dependants can be managed through community and professional sectors without the contribution of informal caregivers (Carers Australia 2010; World Health Organization 2002). In 2012, for example, informal carers, both primary and non-primary, provided an estimated 1.3 billion hours of care in Australia (Carers Australia 2010). Caring for a person who is frail and aged will become as big an issue as child care has been in the community (Carers Australia 2005). Recent conservative estimates show that in 2010 the total replacement cost of informal caregiving (a measure of the additional care that would need to be provided each year by the formal economy to replace the work done by informal carers were their services no longer available) was approximately $40.9 billion (equivalent to 3.2% of GDP and 60% of other formal health care) (Carers Australia 2010). Unpaid informal care was the major provider of community care services, delivering 74% of all services to people needing care and support (Carers Association of Australia 1998). The significant contribution made by informal caregivers to the health and well-being of the recipients of care, as well as to the wider community and the national economy, is widely acknowledged. According to Carers Australia (2010), the value of informal caregiving is around $6.5 billion per annum even using the most conservative ‘opportunity cost’ method. The opportunity cost is another measure that can be used to value the time spent by carers as it reveals the resources that are diverted each year from production in the formal economy to informal care.
Second, recent data indicate that 85% of carers in the United Kingdom have provided informal care during their working lives (Henz 2006). Most primary carers in Australia are of workforce age (75% are aged between 15 and 64 years) (Australian Bureau of Statistics 2009). More importantly, many carers, if not most, are working full-time (Gallagher & Gerstel 2001; Johnson & Climo 2000). More people are likely to experience growing tension between their desire to retain a paid job and their family obligations (Kinsella & Velkoff 2001). Issues in relation to combining employment and informal caregiving responsibilities are becoming crucial to individuals, employers and the government. According to the World Health Organization (WHO 2002), the number of women and men involved in providing care is increasing. Both women and men will increasingly encounter the reality of handling simultaneous demands and face challenges regarding how to manage multiple roles, in particular, unpaid caregiving provision and paid work. The increase in informal caregiving has an impact not only on those who engage in it, but also on the wider community (Amirkhanyan & Wolf 2003; Pavalko & Woodbury 2000; Scharlach 1994; Schulz et al. 1995). It may also have a detrimental effect on the efficiency of the workplace. There are risks to staff morale, team building and skill retention. Issues related to combining work and caregiving may result in high labour turnover, an increase in the cost of training replacements, and reduced productivity (Brody et al. 1987; Frone, Russell & Cooper 1997a; Scharlach & Boyd 1989).

Third, it is revealed by researchers in the United States that there is a lack of caregiver-specific and caregiver-related programs and initiatives that incorporate the means by which the overall demands from the domains of both family and work might be addressed (Fredriksen-Goldsen & Scharlach 2001). While support for caregiving and caregivers should be a national priority for the government, employers and the wider community, programs and policies should be focused not merely on increasing employees’ availability for work, but on attending to the overall issue of work demands versus family needs (Fredriksen-Goldsen & Scharlach 2006). The scarcity of policies and programs can be seen in Australia as well. In particular, there are differences in the use of work arrangements, including flexible time, rostered days off, working from home, and informal arrangement with
employers, to assist working caregivers holistically in tackling the overall issue of work demands versus family needs (Gray & Hughes 2005).

Last, limitations have been identified in previous studies, especially those that rely heavily on analysing aggregated data rather than the perspectives of individuals and the differences between them (this will be discussed more in chapter 2).

While monitoring caregivers’ activities or involvement in changing practice in organisations is not the focus of the current study, providing information that may be helpful to working caregivers is one of the objectives of this research. The research described in this thesis will show that even in the most ideal workplaces, conflicting demands between work and caregiving can be stressful. Both the government and employers need to be aware that access to services for informal caregiving may become as important to their employees in the future as access to child care services is today. Decision-makers and employers can make a real difference by initiating reforms, and programs should aim to enhance workforce participation rates while stimulating the availability of caregiving arrangements and improving outcomes for caregivers.

1.3.2 The aims of the current study

The primary goal of this doctoral research is to examine the perceptions of the experiences of those who are unpaid informal caregivers to adult or child dependent family members while simultaneously holding a paid job, and to examine how working caregivers cope with the challenges they face in life. This research aims to:

- explore the impact on working caregivers’ lives of simultaneously holding multiple roles;
- raise awareness among employers that informal caregiving is an issue for their employees, and therefore, for them as employers;
- shed light on how the caregiving issue might be addressed and alleviated most effectively, by providing information about possible support programs which can be tailored to individual preferences.
The research presented in this thesis focuses on the following main research question:

*What are working caregivers’ perceptions of their experience of combining paid employment and unpaid caregiving responsibilities to a dependent adult or child?*

The associated sub-questions are:

1. *How do participants describe their decisions to engage in the caregiving role?*
2. *How do participants describe their experiences of being working caregivers?*
3. *What kinds of strategies do working caregivers adopt in order to deal with the challenges arising from juggling work and family responsibilities?*
4. *What kind of effects does carrying out multiple roles appear to have on the lives of working caregivers?*

The research questions listed above are of a kind for which a qualitative case study approach is an appropriate research method. The most central characteristic of qualitative research is its emphasis on the perspective of the individual being studied (Bryman 1989). Given the importance of addressing the questions of ‘what’, ‘how’ and ‘why’, a case study approach has been used in this research (Stake 2005). The reason behind the decision to use a case study approach will be discussed further in chapter 3.

### 1.4 An Overview of the Structure of the Thesis

The organisation of the thesis is as follows. Chapter 1 provides the background statement and discusses the significance and purpose of the study. Chapter 2 provides a thorough review of the literature relating to the interface of work and family, in particular, in the context of being involved concurrently in paid employment and in unpaid informal caregiving. The effects of holding multiple roles and the consequences of competing demands on working caregivers’ lives are also discussed in chapter 2. Chapter 3 presents an outline of the research design. The chapter explains why the case study approach and face-to-face interviewing are the appropriate means of data collection for this research. Nine
information-rich cases are presented in chapter 4. Chapter 5 highlights the findings of the current study, and presents the themes that emerged across all interviews. Guided by phenomenography, meta-analysis in chapter 6 uncovers the meaning and essences in the experience being studied and provides rich, in depth, descriptive and interpretive information that promotes greater understanding of the phenomenon of being a working caregiver. Finally, chapter 7 summarises the contributions, implications and recommendations made by the current research. The boundaries of the current study and suggestions for future research are also included in this final chapter.

1.5 Definition of Terms

Before proceeding, it should be emphasised that some terms in the literature pertaining to multiple roles and role interference are not used consistently. For the convenience of readers, some frequently used terms, including those specifically used for this research (without references), are briefly defined as follows:

- **Activities of daily living (ADL)** This is a concept of functioning – activities of daily living are basic activities that are necessary to allow independent living, including eating, bathing and toileting. This concept is associated with several assessment tools to determine an individual’s ability to perform an activity with or without assistance (World Health Organization 2004).

- **Adult or child dependant** In this thesis the term refers to a person who needs help because of disability, old age or chronic health problems.

- **Caregiver/carer** this term equates to ‘working caregiver’ (see definition below).

- **Direct costs** These are the additional expenditures that must be made to meet the special needs of the person being cared for and the additional costs that are associated with caring; for example, the purchase of special equipment, health services, respite and other support services (Carers Association of Australia 2000).

- **Disability** For the purpose of this study, and in line with the definition employed in the Survey of Disability, Ageing and Carers (SDAC), a disability is defined as any limitation, restriction or impairment that restricts everyday activities and has lasted or is likely to last for at least six months (one of the selection criteria for participating in the
The examples of disability range from hearing loss that requires the use of a hearing aid, to difficulty in dressing due to arthritis, and to advanced dementia requiring constant help and supervision.

- **Ethics (relational)** This term is used to describe the balance of fairness within relationships that are concerned with offering support, help or recognition, or showing due concern for another (Boszormenyi-Nagy & Krasner 1986).

- **Frail elderly** Individuals over 65 years old who have functional impairments, or any adult over 75 years old (Miller-Keane & O’Toole 2005).

- **Informal caregivers** These are people who provide informal caregiving to others in need of assistance or support. Informal caregivers provide this service free of charge and outside the boundaries of ‘formal’ government services. Typically, an informal caregiver is a family member or a friend of the person receiving care (Australian Bureau of Statistics 2000; Australian Institute of Health and Welfare 2008).

- **Informal caregiving/informal assistance** This is the type of help or supervision (usually unpaid) that is provided to people by family, friends or neighbours (who may or may not be living with them in a household) (World Health Organization 2004).

- **Instrumental activities of daily living (IADL)** This term refers to activities with aspects of cognitive and social functioning, including shopping, cooking, doing housework, managing money and using the telephone (World Health Organization 2004).

- **Mainstream parenting** In this study, this refers to the caregiving responsibilities related to rearing healthy children and/or children without a disability.

- **Multiple roles** While the focus of this dissertation is the perception of the experience of balancing the roles of paid employment and unpaid caregiving (the duality of the roles), working caregivers in the current study are taking up other roles in their lives. Thus, the term ‘multiple roles’ is used throughout the thesis.

- **Psychological strains** These are referred in many studies, as well as the current thesis, and are defined as depressive mood or symptoms such as depression, anxiety or life distress due to high demands and low ability to control these demands, rather than a clinical depressive disorder (Osipow, 1998; Osipow & Spokane 1987).
• **Self-imposed silence in the workplace** One of the main themes emerged from this research, this refers to a strong desire to not to reveal the extent of informal caregiving, for various reasons.

• **Strain** This occurs when demands are high, but the ability to control them is low. Strain is an unhealthy state that can lead to fatigue, anxiety, depression and negative somatic symptoms (Karasek 1989).

• **The replacement valuation method** This is a calculation based on the cost of buying the equivalent number of hours of informal care from the formal care sector (Carers Australia 2010).

• **Work–family conflict** This has been defined as ‘a form of inter-role conflict in which the role pressures from the work and family domains are mutually incompatible in some respects’ (Greenhause & Beutell 1985, p. 77).

• **Working caregivers** This term refers to informal caregivers who are working with or employed by one of the industry partners. Only two out of 17 interviewees were part-time workers, hence the focus of this thesis is on the full-time working caregivers.

### 1.6 Summary

This chapter began with the introduction of the research background for the thesis followed by the outline of the importance and purpose of the current study. The primary research questions and the organisation of the thesis were presented prior to the provision of the definitions of the terms that will be used in the thesis. The following chapter will provide a review of the literature in the field of work–family research, in particular, ideas and theories that are important to the current study.
CHAPTER 2 – REVIEW OF LITERATURE

2.1 Introduction

Research into caregiving and multiple roles has grown considerably over the past two decades in response to the rapidly expanding population over 65, and the increasing participation of women in the labour force. The first part of this chapter reviews relevant literature by providing an overview of the nature of caregiving with an emphasis on caregiving for a dependent child or adult. The second part includes an examination of the types of services that are available in caregiving for a dependent child or adult and the differences between those services. The third part introduces various theories in relation to multiple roles; the effects of handling multiple roles are explored broadly, as well as the context of caregiving. The fourth part discusses the impact of combining employment and caregiving on caregivers’ life. The chapter concludes with the justification for conducting the current study. The reasons for excluding certain people from the research (such as professional caregivers) are presented throughout the chapter.

2.2 The Nature of Caregiving

Caregiving is defined as an act of providing direct care, and is an evolutionary human life experience within the circle of health–illness wherein connections are co-created and expressed in actions of concern, responsibility and attentiveness (Mitchell 1990). People who are in need of caregiving include children without a disability (normal nurturing), or a dependant (a person who needs help because of disability, frailty in old age or chronic health problems). Just as the activities involved in providing caregiving to different people vary, so does the experience of caregiving.

2.2.1 Caregiving for children without a disability

Child care can be viewed as encompassing caregiving activities with respect to children. In practice, the activities of looking after one or more children are typically operationalised (Frone, Russell & Cooper 1992a; Gutek, Searle & Klepa 1991; Scharlach & Boyd 1989). Balancing the responsibilities of nurturing and employment is not an easy task (Greenhaus
& Parasuraman 1997). The challenge stems from the fact that raising a child is expensive and consuming in terms of time, focus and energy.

The Child care Affordability Index (Taskforce on Care Costs 2007) shows that the cost of child care in Australia has gone up by 65% since 2002 compared with a rise of 17% in net disposable household income. The increasing cost means that child care is becoming less affordable in the context of the average household disposable income. Most people are forced to return to the workforce once the period of maternal or parental leave to which they are entitled is over if they decide to use child care service. As a result, fathers and mothers who have a paid job have less free time than employees who are not parents. Employed parents experience greater time pressures and stress than employed non-parents (Friedman & Greenhaus 2000). More and more people are facing the challenges of being in paid employment and raising a young family simultaneously. Other stresses that working parents experience are partly associated with the concern about the negative effects of non-parental care, including the impact on a child’s emotional and intellectual development when sending a child to a day-care centre or a place where family members or relatives provide caregiving (Hertz 1997).

2.2.2 Caregiving for a dependant

Caregiving for a dependant, on the other hand, is generally undervalued as there is no productive goal seen to be associated with it (Connell 2003). Unlike caregiving for children without a disability, which follows a fairly predictable schedule, providing care to a child with a disability or a long-term health condition due to accidents, environmental factors or being born with a particular disorder (Australian Bureau of Statistics 2009) has no definitive end in sight and often goes unrecognised. A similar situation applies to caring for an adult dependant. Older people are sometimes labelled as unproductive, dependent and a burden to the society in which they have long been contributing and independent members (Upreti 2008). The stereotypical image of the elderly as old and crippled due to illness and disability associated with the ageing process is deepened unconsciously in our society (Connell 2003). Caregiving for a dependant is considered by some scholars as an unexpected career (Aneshensel et al. 1995).
While people with a chronic illness or disability do not necessarily face acute, life-threatening situations, 60 per cent of the 3.9 million people with a disability in Australia reported needing assistance to manage their health conditions or cope with the activities of everyday life (ABS 2009). Caregiving for an adult or child dependant, therefore, is defined as the provision of substantial assistance with at least one activity associated with daily living (ADL) or an instrumental activity of daily living (IADL) to a physically or mentally impaired person (Aneshensel et al. 1995).

2.3 Types of Caregiving

2.3.1 Formal and informal caregiving

There are two primary types of caregiving: formal and informal. Formal caregiving is classified as paid services provided by licensed or unlicensed outsiders under the umbrella of a formal health care system (Abel 1986, 1991; Brody 1981; Stone, Cafferata & Sangl 1987). According to the Australian Institute of Health and Welfare (2008), this definition also includes care provided by volunteer or foster care arranged by a formal service. Formal caregiving is further divided into institutional care (provided in acute care and long-term care facilities) and community-based care (World Health Organization 2004). The latter is viewed as the blend of health and social services that allows individuals who suffer from some mental or physical incapacity to live at home but receive the care they need for the purposes of promoting, maintaining or restoring health or minimising the effects of illness and disability (World Health Organization 2004). The services provided in the community sectors usually include professional services (nursing, physiotherapy, occupational therapy and speech therapy), home support services (cleaning, laundry and grooming), and personal care (bathing, toileting and transferring) (Department of Health and Ageing 2006).

Informal caregiving is a term that has emerged within studies on ageing. A review of caregiving literature, while it does not provide a single, clear definition of informal caregiving, it does indicate that similar definitions have been used in different countries. For example, in the United Kingdom, the term ‘informal caregivers’ refers to those who look after a relative or a friend who needs support because of age, physical or learning
disability, or illness (including mental illness) (Department of Health 2006a). Only those parents who look after children with disabilities fall into the category of informal caregivers (in line with the way in which the term is defined for this study).

In Australia, in contrast to formal caregiving, informal caregiving, according to the ABS (2000), is characterised as services that are not organised or provided within the framework of professional social care. Rather, it is a type of service provided by family members such as spouses, adult children and friends to assist with ‘everyday types of activities’, to people with disabilities or long-term conditions, or people who are frail elderly individuals. These activities include communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self-care and transport. The definition provided by the AIHW (2008) emphasizes that informal caregiving provided by informal caregivers is regular, ongoing assistance without payment being made for the care given.

Long distance caregiving is a special type of informal caregiving, in that the people who provide assistance (caregivers) do not live in the same household as those who receive help (recipients). While some people may not consider themselves to be caregivers in this situation, this form of informal caregiving places additional burdens on caregivers as it creates a new set of challenges. These include maintaining regular and effective communication with the recipient of care and attempting to balance time with and away from care recipients.

Research conducted in other countries, such as the United States, has demonstrated that the major human resource for the support and maintenance of the frail elderly population is the family (Brody 1981; Himes 1992; Stoller 1983; Stone, Cafferata & Sangl 1987). Partners, sons and daughters are the most common providers of help to older people and people with a disability. Family caregivers are the backbone of long-term care provision in the United States (Wolff & Kasper 2006).

In Australia, as a result of structural change in the health, aged care, disability services and child welfare sectors since the early 1990s (mainly the shifting from institutional and
residential models of care to a more broadly based system that emphasises the principles of community), the landscape of human services delivery and the expectations placed by family members on each other have changed significantly (Department of Human Services 2006). According to the ABS (2009), there were 2.6 million carers who provided some assistance to those who needed help because of disability or old age in 2009, 29% of whom were primary carers. The National Health and Hospital Reform Commission (2009) identifies family caregivers as vital to the long-term sustainability of the health system because they provide caregiving to family members who would otherwise need to be cared for in the health and aged care sectors.

Caregivers are not only filling the growing ‘care gap’, but are also making a contribution to the community and the national economy. The provision of unpaid care by family members helps to subsidise the formal health care system, thereby containing the cost. According to the first Australian study of the economic value of the informal care provided by unpaid family carers (undertaken by Access Economics and commissioned by Carers Australia), the annual ‘replacement value’ of informal care was $30.5 billion (Carers Australia 2005). This figure increased to exceed $40 billion per annum in 2010, 33% higher than in 2005 (Carers Australia 2010), due mainly to the ageing demographic and the growth in the replacement cost of care (from $25 per hour on average in 2005 to $31 per hour in 2010).

2.3.2 The differences between formal and informal caregiving
The principal difference between formal and informal caregiving (usually family caregiving) is that informal caregiving involves interaction between people who already had a social link with each other before the need for care arose. The social relationship between caregivers and care recipients is the key characteristic of family caregiving. In addition to the social connection, other key elements of informal caregiving, as mentioned previously, are its unpaid nature, its frequent invisibility and its duration and intensity over and above normal care. The central concern is the long-term care of a person during an illness (Melnyk et al. 2001). Thus discussion about informal caregiving, especially when combined with paid employment, is considered an important but previously neglected debate. Caregivers make an enormous sacrifice, giving up substantial time and energy that
could otherwise be used to pursue their hobbies and other social activities. This sacrifice and the associated potential health risks deserve the attention of employers and employees alike.

In addition, the amount and intensity of caregiving changes, and usually increases, over the course of a caregiving episode. In reality, caregiving, in particular in-home care, often extends across a prolonged period of time; it encompasses demands and situations that reach beyond measurable variables into the ‘distinct and complex interpersonal experiences’ of the real world of the persons involved (Gubrium 1991, p. 17). Moreover, a caregiver often continues to provide supplementary or ‘invisible’ care after an impaired family member has been placed in a formal institution (Wilson 1989).

The duration and intensity of family caregiving can be interpreted or described in different ways, and is worth exploring further. What is the separation point for defining long-term caregiving? How should intensity be defined? Should this be based on the time devoted to the caregiving role or on the actual activities provided? The Dutch National Organisation of family caregivers (LOT) and the Organisation of Voluntary Home Care and the Assessment boards have determined the dividing line between occasional care and long-term family care to be three months, based on the assumption that family carers usually experience social, physical and emotional problems after a three-month period (Beneken et al. 2004). The same approach was found in the 1994–95 British Family and Working Lives Survey (Department of Education and Employment 1997; King & Murray 1996), a large-scale data set with longitudinal information about both employment and informal caring from a national representative sample of the British population. The question used to identify informal carers was ‘Do you currently or have you ever regularly looked after someone, for at least three months, who is sick, disabled or elderly?’

In Australia, according to the ABS’s definition, informal assistance provided by a carer has to be ongoing (or likely to be ongoing) for at least six months (Australian Bureau of Statistics 2009). This definition was utilised as one of the selection criteria for the participants in the current study. The provision of caregiving is an ongoing process, so it
was important that participants had a long-term commitment to their caregiving role in order to be able to describe their experiences fully. Selecting participants who had taken up the caregiving role for a substantial period also increased the researcher’s capacity to observe. Furthermore, chronic work–family conflict seems to be particularly appropriate to an examination of health consequences because these effects are likely to be cumulative over time (Greenhaus, Allen & Spector 2006).

There is no clear definition of the intensity of caregiving. Measurements used to obtain information for this variable varies from the number of hours devoted to caring to the actual numbers of activities provided. While the intensity of caregiving is likely to have some impact on the caregiving experience, the main objective of the present study is to examine perceptions of the experience of being in a context of having paid employment and an unpaid caregiving role. Hence, the focus of selection of participants in this doctoral study was on those in the dual roles of paid employment and unpaid caregiving role.

Given the definitions of informal caregiving and informal caregiver in Australia and the United Kingdom, it is easy to understand why the following scenarios were considered to be outside the scope of the current study. Individuals who provided mainstream parenting activities were excluded from this study (more details will be provided in the section on justification for the doctoral study). Individuals who provided caregiving on a voluntary or foster basis, or over a short period, were also excluded from this study, as it is assumed that this kind of responsibility or activity can be withdrawn easily. Furthermore, paid caregivers, such as nurses and social workers, were not included in this study, although it could be argued that professional care workers are facing significant challenges, in particular, how to set clear boundaries between their paid and unpaid caregiving roles.

2.4 Multiple Roles

2.4.1 Social identities and social roles

Social identity theory (Ashforth & Mael 1989; Hogg 2006; Tajfel & Turner 1986) and identity theory (Burke & Reitzes 1991; Stets 2006; Thoits 1991) have been said to occupy a ‘parallel but separate universe’ (Hogg, Terry & White 1995, p. 255). However, they hold in
common that role identities are socially defined, though identity theory focuses more on the examination of the implications of individuals’ identification with various roles they may occupy. According to social identity and identity theories, roles such as work and family form the basis of a person’s self-identity. Individuals who participate in a variety of social roles have multiple identities (Ashforth 2001; Burke 2003; Thoits 1991).

In addition, the more salient the role identity, the more meaning, purpose and behavioural guidance individuals should derive from its enactment and the more that identity should influence an individual’s psychological well-being (Thoits 1991, 1995). According to Simon (1995), work and family roles have different meanings for men and women. Men tend to carry a large share of the responsibility to provide financial security for the family, while women tend to be more responsible for caregiving. In her open-ended interviews with 40 employed married parents (men and women) residing in Indianapolis in the United States, Simon found that almost all of the men interviewed believed that providing economic support was a key component of their family roles, and was synonymous with being a father and husband. Of all the interviewed men, 80% also emphasised the negative consequences for a man’s self-image of not making a contribution to his family.

The situation was different for women. Most women in the study believed that being a ‘good’ mother or wife involves more than providing economic support. In fact, only 25% women believed that they should have an economic obligation through which their husband’s financial pressure could be reduced. Of the women interviewed, 35% expressed the view that their family roles did not include the provision of economic support. The third group, comprising 40% of the women interviewed were ambivalent about the relationship between work and family roles. Nevertheless, all of them viewed work as an additional responsibility to their primary obligation, that is, to provide emotional support and nurturing to their children and spouse, and to maintain a warm and harmonious home. These findings were consistent with other studies carried out in the United States, for example, Friedman and Greenhaus (2000) found in their research that the family role was more salient to women and the work role was more salient to men.
Roles, as dynamic aspects of social positions, refer to the expectations as well as the actual behaviours of individuals. Roles are prescribed and sanctioned by a group or society (Fredriksen-Goldsen & Scharlach 2006). ‘Role salience’ (Thoits 1991), ‘role identification’ (Lobel 1991) or ‘role identity’ (Rothbard & Edwards 2003) each variously represent an important component of an individual’s life role, thus influencing the experiences of individuals of the work–family interface (Carlson, Kacmar & Williams 2000).

2.4.2 Role-related stress and the effects of performing multiple roles

Social role performance is impacted by the context and setting within which roles exist. Individuals differ in their responses to certain roles and types of stress, which can be explained by a number of theoretical approaches.

The contextual approach assesses the stressor by taking into account a person’s plans and other circumstances surrounding the stressor (Brown 1981; Brown & Harris 1978). Turner and Avison (1992) take a further step on this approach by suggesting that a crucial context for understanding the meaning and impact of an event is whether or not issues around that event have been resolved. The authors define resolved events as those from which individuals derive positive meanings for themselves in terms of providing opportunities for learning and personal growth.

While the contextual approach is deemed to be a more objective approach in which researchers impose meanings according to contextual information, the interpretive approach focuses on subjective factors, mainly the interpretation by, and interpretive processes of, individuals. Scholars in this tradition employ different methodologies, for example, standard appraisal scales (Folkman 1984; Folkman et al. 1986; Lazarus & Folkman 1984) and narrative analysis (Pearlin & Schooler 1978; Riessman 1990; Silver & Wortman 1980) for their research. Such scholars argue that the meanings and significance of stressors are based on a cognitive process in which people actively try to make sense of their life difficulties and search for adaptive strategies to cope with certain undesirable events (Janoff-Bulman 1992; Silver, Boon & Stones 1983; Downey, Silver & Wortman 1990).
A third approach, the value and beliefs approach, maintains that people’s general value and beliefs produce variability in a role and determine the meaning of stressors (Davis et al. 2000; Janoff-Bulman 1992; Pearl 1989; Simon 1995; Wortman & Silver 1989). Scholars of this approach attribute individual and group differences in vulnerability to individual and group differences in beliefs.

Nevertheless, the meanings that individuals themselves attach to their roles have not been directly assessed but rather through inference in all three approaches mentioned above, with the exception of Riessman’s (1990) work (narrative analysis). Most of the research was based on highly structured quantitative analysis of survey data. This emphasises the importance and appropriateness of the approach utilised in the current study as the meaning, purpose and guidance that people gain from role identities were not assessed indirectly through time and energy spent in roles (Stryker & Serpe 1994), or salience rankings (Thoits 1995). The case study approach and face-to-face interviews used within the doctoral research allowed me to research the meanings that participants attach to their role identities and behaviours, which may differ from those identified by me, but are essential in terms of my understanding of their responses and their coping strategies.

One of the challenging issues in social science research is that stresses rooted in people’s lives, such as the demands of multiple roles, do not always have undesirable emotional consequences. There are two competing main views in relation to the effects of multiple roles: the scarcity approach and the expansion approach. These opposing approaches make conflicting predictions as to the consequences of an individual performing multiple roles.

The scarcity approach (Goode 1960; Greenhaus & Beutell 1985; Greenhaus, Allen & Spector 2006) perceives an additional role to be detrimental, and believe that a person’s experiences in work and family roles are mutually incompatible. They take the view that competing roles are a source of stress and have negative outcomes. In contrast, the expansion approach (Greenhaus & Parasuraman 1999; Frone 2003; Greenhaus & Powell 2006; Marks 1977) acknowledges the positive connections between work and family roles, and attributes benefits from multiple roles to positive outcomes. However, conflict and
facilitation are not necessarily in competition with each other. The possession of multiple roles or identities may provide people with several possible sources of gratification and self-esteem (Marks 1977; Sieber 1974; Thoits 1983, 1986).

Factors that contribute to the effect on performing multiple roles, especially gender differences in mental or psychological health consequences, have been of interest to many researchers. In the United States during the 1970s, while it was widely assumed that there were no gender differences in mental health, some researchers believed that women in modern Western industrial societies experienced higher levels of psychological distress than men, simply due to their willingness to admit and seek help (Gove & Tudor 1973). A decade later, however, a more general consensus was reached by social scientists in the United States, that is, differences in mental health between men and women were largely due to their societal roles and ‘social structural factors’ (Gove 1984; Kessler & McRae 1984; Marcus, Seeman & Telesky 1984; Reskin & Coverman 1985; Ross & Mirowsky 1984). It was argued that highly structured or ‘fixed’ roles that are typically occupied by men tend to be causally linked to good mental health. On the other hand, the nurturant roles likely to be taken up by women tend to impose a strain and hence are associated with poor mental health (Gove 1984). It was also believed that social structural factors, such as gender inequality in the family and workplace in terms of the division of household labour and labour market inequality, were the main cause of the difference in mental or psychological consequences between men and women (Kessler & McRae 1984; Reskin & Coverman 1985; Ross & Mirowsky 1984).

A study carried out by Simon (1995) provides another explanation for gender differences in mental or psychological health. The author suggests that the meanings that men and women attach to their roles vary, as does their perceived interrelation among roles. This, in turn, causes the differences between men and women in terms of the feeling of role conflicts, as well as their mental or psychological health. In the context of work and family domains, work and family roles have different meanings for men and women. While women are likely to view work and family roles as independent of one another, men, on the other hand, have a tendency to perceive the roles as being interdependent. These differences may
partially explain why the mental health advantages of combining work and family roles are fewer for women (Rosenfield 1992; Rosenfield, Vertefuille & McAlpine 2000).

The effect of performing multiple roles is also associated with an individual’s ability to establish and maintain role boundaries between family and work domains (Ashforth, Kreiner & Fugate 2000; Clark 2000; Nippert-Eng 1996). Segmentation and integration are two concepts that are related to the boundary management. They are regarded as opposite ends of the same continuum (Ashforth, Kreiner & Fugate 2000; Kreiner 2006; Nippert-Eng 1996). Individuals vary in their preferences in integrating or segmenting work and family life (Kreiner 2006; Rothbard, Phillips & Dumas 2005). In general, individuals who prefer segmentation are keen to keep family and work separate from each other by maintaining highly impermeable boundaries around work and family domains. On the other hand, those who favour integration tend to merge or blend various aspects of work and family by maintaining highly permeable or blurring boundaries around family and work domains (Glavin & Schieman 2012; Kriener 2006). In addition to individual preferences, the decision of segmentation or integration is influenced by factors such as the provision of resources and conditions in the workplace.

**2.4.3 Role strain and work–family conflict**

Role strain and work–family conflict can be explained by the scarcity approach of multiple roles, which takes the view that human time and energy is limited so that each additional role taken on by an individual further depletes a finite supply of personal resources (Coser 1974; Goode 1960; Slater 1963; Voydanoff & Donnelly 1999). Individuals who take on multiple roles may be unable to meet the totality of their role responsibilities.

Role strain, ‘the felt difficulty in fulfilling role obligations’ (Goode 1960, p. 483) derived from multiple roles, is inevitable for a number of reasons. Each of the roles that an individual takes on will entail somewhat different obligations, and requires contradictory performance that has conflicts in time, place or resources. In addition, an individual who takes on multiple roles is likely to engage with different people in several role relationships.
While the scarcity views of Coser (1974), Goode (1960) and Slater (1963) are more based on theory, there are empirical studies that appear to be grounded in the scarcity approach, in particular, dealing with the conflicts between occupational roles and familial and marital roles (Cuber & Harroff 1965; Edgell 1970; Komarovsky 1976). In her study of 62 seniors at an all-male Ivy League college in the United States, Komarovsky (1976) isolated six key factors to describe the phenomenon of role strain. According to Komarovsky (1976), role strain is the result of, variously, role ambiguity, role overload, role conflict or the scarcity of resources that are necessary in order to fulfil the responsibilities of multiple competing or conflicting demands. An individual’s knowledge and technical skills are considered to be resources upon which the successful performance of a particular role depends. The nature of the familial relationship and issues of reciprocity are included in the first key factor – ambiguity, which refers to the lack of clarity about a particular role.

Over the past 25 years, researchers have produced a substantial body of literature on the interface between work and family lives (Barling & Sorensen 1997; Barnett 1998; Greenhaus & Parasuraman 1997, 1999; Greenhaus & Powell 2006; Pocock, Skinner & Williams 2008; Powell & Greenhaus 2010; Skinner & Pocock 2010) motivated by the increasing proportion of women in the workforce. Given the fact that care is more likely to be provided by women (Australian Bureau of Statistics 2010), appropriately measuring and valuing the care provided by informal caregivers, many of whom are women simultaneously holding the roles of paid employment and unpaid caregiving to children with disabilities and elderly individuals, remains a challenge (Baird & Williams 2010). Work–family conflict, or work–life conflict (Pocock, Skinner & Williams 2008), a type of inter-role conflict (Barnett & Gareis 2006; Greenhaus & Beutell 1985) and role strain dominate the field of work–family interface research for reasons discussed below.

First, the increasing proportion of dual-income couples and single parents in the workforce means that more people than ever before are experiencing challenges in terms of juggling family and work domains. Second, long work hours, control over work scheduling and increased job pressure (workload and work overload in particular) indicate that it is the work that tends to garner more and more attention, and increasingly intrudes on personal
and family life (Milliken & Dunn-Jensen 2005; Skinner & Pocock 2008). Third, the literature has consistently revealed that people who have multiple roles suffer a wide variety of negative consequences (Allen et al. 2000; Bellavia & Frone 2005; Eby et al. 2005; Frone 2003). In particular, when hours of work are the same, those with caring responsibilities have worse work–life outcomes than others (Skinner & Pocock 2010).

Greenhaus and Beutell (1985) identify three types of work–family conflict: time, strain and behaviour-based conflicts. The time-based conflict occurs when the time demands associated with one role restrict the amount of time that can be devoted to another role, as the roles are generally performed in different locations. As a result, functioning in one role, such as a paid job, reduces the time available to spend in the other role, for instance, an unpaid caregiving position. Dedicating long hours to work may reduce an individual’s performance in the family role or roles, or even make it impossible for the individual to assume the family responsibility, and vice versa.

Greenhaus and Beutell (1985) define strain-based conflict as the situation that develops when the stress arising in one role is carried over or transferred to the other role. This view is supported by other scholars, such as Bolger et al. (1989), Linville (1987) and Repetti (1987b). The authors believe that the experiences of stress and satisfaction associated with any given role are not always confined to that domain. It is possible for experiences, thoughts, and feelings in one role to spill over and to influence the experiences, thoughts and feelings in another. For example, an unpleasant mood and the consequent strain symptoms, such as anxiety and irritability from work, may reduce the effectiveness of an individual in the caregiving role and vice versa.

According to Greenhaus and Beutell (1985), behaviour-based conflict usually occurs when a behaviour that is proper and effective in one role is inappropriately applied to the other. For example, the manner used by a chief executive officer when chairing a management meeting may not be suitable for communication with a nurse in a hospital or a clinic officer when the same person takes their frail parents for a medical appointment.
Greenhaus, Allen and Spector (2006) have added a fourth mechanism, energy-based conflict, into the existing typology of work–family conflict (that is, time, strain and behaviour). This form of conflict could appear in a situation in which an individual may need to rest mentally or physically after the completion of one role in order to recover and prepare for the other. The energy-based conflict is likely to be seen among older employed spousal caregivers as a person’s health and functional capacity, especially physical functional capacity, deteriorates with age. This, in turn, increases fatigue and slows down the recovery process.

The challenge for an individual, then, is to discover mechanisms that can reduce strain and determine ways to effectively maximise one’s abilities and energies in order to minimise the effects of role strain on performance. The decision process underpinning strain-reducing mechanisms can be compared to that associated with the economic decision: the allocation of scarce resources – role energies, time and emotions among alternative ends, which are role obligations imposed on an individual. One of the suggestions made by Goode (1960) is to select a set of roles that are mutually supportive and create minimal conflict, over which, on most occasions, an individual has no control. This study is an example in which most of the working caregivers have no choice but to assume the caregiving role.

The majority of research in relation to spillover between social roles has been conducted in European countries, Canada, the United Kingdom and the United States, and focused on the intersection of employment and family life. Research suggests that spillover between work and family roles can indeed occur in both directions (work to family or family to work). In addition, the effects of spillover can be positive or negative (Bolger et al. 1989; Frone, Barnes & Farrell 1994; Pocock, Skinner & Williams 2008).

In a similar vein, in Australia there is a significant interest in work–life issues. In 2007, a group of Australian scholars introduced a new measure of work-to-life interaction, the Australian Work and Life Index (AWALI) to conceptually measure the negative effects of work on the rest of life (Pocock, Skinner & Williams 2008). AWALI is a national survey of Australian workers collected in 2007, 2008 and 2010 through computer-assisted telephone
interviews (random digit dialing) and offers a quantitative measurement of the perceptions and experiences of individuals about work-to-life interactions. Despite the fact that AWALI provides a single-direction measure of interaction that focuses on the negative spillover from work to the rest of life, it does present a snapshot of the work-life relationship experienced by Australians. Analysing the data collected in 2007, the authors report that work significantly affects workers’ lives beyond the workplace, and 20 to 25 per cent of working Australians experience frequent work-to-family conflict (Pocock, Skinner & Williams 2008). However, the nature of relying on self-reported data from a limited set of questions (each year’s data collection includes five core questions, as well as a few questions that pursue specific themes) prevents the researchers from producing subtle and nuanced analysis.

The literature also reveals that commitments to other roles can have varying impacts on job performance. While Graves, Ohlott and Ruderman (2007) and Ruderman et al. (2002) report that commitment to non-work roles had a positive effect on the job competencies and performance of women managers and executives, the findings from Weer, Greenhaus and Linnehan’s study (2010) are different. Attempting to find out whether those findings could be generalised to non-managerial employees, Weer, Greenhaus and Linnehan conducted a study among an understudied population (secretaries rather than those in managerial positions) in 2010. The main objective of their study is to determine whether the relationship between the non-work role and work performance is better explained by a conflict perspective (a belief that high levels of commitment to the non-work role require time and energy from individuals, and drain resources away from work, thus reducing job performance) or an enrichment perspective (a belief that resources acquired through extensive commitment to non-work roles can be transferred to the work domain, thus enhancing job performance).

The study involved 182 pairs of legal secretaries (obtaining information about their commitment to non-work roles, non-work role demands and non-work role resource acquisition) and their managers (acquiring information about secretaries’ job performances) in five law firms located in the mid-Atlantic region of the United States. While the authors
found that an extensive commitment to non-work roles had both positive impacts on job performance (through resources acquisition) and negative impacts (due to emotional energy spent on non-work roles or strain symptoms produced by non-work roles that were carried over to work), and that emotional energy demands had a stronger effect than resource acquisition on job performance. In short, the participants’ psychological commitment to non-work roles was more likely to hinder rather than enhance their job performance.

While it is generally accepted that work–family conflict is bi-directional (Allen et al. 2000; Carlson, Kacmar & Williams 2000; Frone, Russell & Cooper 1992a), the discussion of whether conflict is from family to work domain or work to family domain is not the focus of the present study. While the discussion about bi-directionality may be outside the scope of the current study, it is important to recognise that regardless of the direction of the interference, work–family conflict is triggered by simultaneous pressures or demands from both roles. Conflict usually occurs when responsibility in one role interferes with meeting the requirements and achieving effectiveness in the other (Edwards & Rothbard 2000; Greenhaus & Beutell 1985).

**Role strain and work–family conflict in the context of informal caregiving**

The research on work and family topics has expanded in scope during the first decade of the twenty-first century (Bianchi & Milkie 2010). The focus of such research is no longer narrowly on the ‘working mother’, as the challenges of juggling work and family responsibilities have been extended to all types of families, not just two-parent, dual-earner families.

Role strain in the situation of employees who take on an informal caregiving role refers to the degree to which individuals perceive that they have been experiencing physical, financial or emotional strains as a result of shouldering caregiving responsibilities (Fredriksen & Scharlach 1999). It has been conceptualised as a function of an imbalance between demands and carers’ resources (Fredriksen-Goldsen & Scharlach 2006).
Beitman et al. (2004) used the Job Caregiver Role Strain Scale (JCRSS), a survey instrument based on the Job Family Role Strain Scale developed originally by Bohen and Viveros-Long (1981), but amended the scale as necessary to validate Komarovsky’s role strain theory among working adults who also cared for a frail elderly person. The JCRSS questionnaire was distributed to 11 males and 34 females who worked for at least 20 hours per week in a small town in Indiana in the United States, and who identified themselves as the primary carer of a frail elderly person.

Data analysis yielded four factors that were related to role strain. The key factor was termed ‘time management and arrangement’, which referred mainly to the competing demands between work and caregiving time, as well as the constant worry for the recipient of care while at work. This factor accounted for nearly 40% of variance. The authors also confirmed that role strain patterns for female employed carers were different from those observed for male employed carers. For example, female carers seemed to be less able to separate their emotions from their responsibilities than their male counterparts, as the females took fewer personal breaks from the caring routine. Thus, the caring experience was deemed more burdensome for females than for males.

However, the study was carried out in a place where the majority of participants had very limited access to external resources. This might explain the skewed results (that is, increased role strain). In addition, one of the criteria for inclusion when selecting samples was that individuals must be from among ‘those who identified themselves as primary carer of a frail elder and worked at least 20 hours per week’. This criterion took no consideration of the ‘demands’ of caring in terms of the actual time spent on, and the duration of, the caring role. Furthermore, using a Likert scale survey among a relatively small sample (45 people) without follow-up not only limited the weight on the comments on gender differences, but also precluded the authors from obtaining qualitative information and capturing the experience of being employed carers.

Utilising a conceptual multi-factorial resources and demands model, the key objective of the study conducted by Fredriksen-Goldsen and Scharlach (2006) was to examine the
The caregiving strain experienced by employees caring for disabled adults and the accommodations made by employees to cope with the challenges. The authors believed that the caregivers’ background characteristics, the demands imposed by caregiving and workplace, and resources were the primary factors impacting upon strain. Data collected from a sample of 1146 employed caregivers at the University of California at Berkeley, defined as currently assisting an adult family member or friend who had a health problem or a disability while employed at least 50% of the time, were used for analysis.

The study reveals that family and work demands were the principal contributors to caregiving strain. Involvement in caregiving (in particular, the number of hours of caregiving provided, whether as a primary or a secondary caregiver), was associated positively with caregiving strain and caregiver depression, and the level of impairment of care recipients (behavioural problems have a greater impact on caregiving stress than functional limitations) was linked to strain. Consistent with other studies (Burke 1986; Frediksen & Scharlach 1997), the research finds that the demands of work and work overload were connected positively to caregiving stress and conflict between work and family responsibilities. In addition, the authors claim that the strain of caregiving was greater for respondents who were female and in poorer health.

However, the self-report and cross-sectional design made it difficult to examine the impact of dynamic changes in caregiving and the workplace over time. A longitudinal design and a qualitative approach would make it possible to obtain in-depth information. Although the size of the sample was reasonably large, the fact that the sample was selected within a single university setting means that the findings can not be generalised beyond the specific workplace. The study might also underestimate the strain of caregiving because the university’s human resource policies usually embraced an extensive array of family-support programs and benefits. Access to programs and benefits, while commonly provided in many large employers, is not available to the vast majority of people in the workforce. This circumstance pertains to one of the objectives of the current study, which is to provide employers with some information about possible programs that would enable employees to cope with the challenge they are facing.
2.4.4 Role enhancement and work–family enrichment

In the mid-1970s, Marks (1977) and Sieber (1974) were sceptical about the scarcity approach after studies began to reveal that some multiple-role players did not suffer from role strain or struggle with role conflicts (Nelson 1966; Rainwater 1964). The authors were convinced that there was a need for a more comprehensive theory, instead of focusing merely on the spending and the drain metaphors (scarcity theory). They suggested that the advantages of pursuing multiple roles would likely outweigh the disadvantages, and proposed an expansion approach.

The supporters of the expansion approach to multiple roles take an optimistic view of human energy levels and believe that activities are not necessary to stabilise the production of human energy. The approach views the available supply as abundant and expansible. Different from Goode’s (1960) consumption view that energy saved by using less in one role can be used in a more demanding role, Marks’ (1977) and Sieber’s (1974) social production view assumes that some roles may be performed without any net energy loss at all. It is argued that activity in one domain ‘creates energy for use in that role or other role performances’ (Marks 1977, p. 926), and that the resources acquired in one role as a by-product of social relationships may be reinvested in other roles. Coser (1974) further suggests that multiple roles will automatically protect a person from being ‘absorbed’ by a single role through some social structure. The author believes that an individual should have ample energy for all role activities, and that feelings of being drained and exhausted are likely linked to an individual’s commitment to an activity. Commitment is considered by Marks (1977) to be the factor that will decide whether or not some form of strain or overload will be experienced by a multiple roles player.

As a consequence, there is an interest in, and a call for, a more balanced approach to the study of the work–family interface (Frone 2003; Greenhaus & Parasuraman 1999). A number of concepts have been employed to examine the positive relationships between work and family lives: positive spillover (Hanson, Hammer & Colton 2006; Stephens, Franks & Atienza 1997; Sumer & Knight 2001; Voydanoff 2001), enhancement (Ruderman et al. 2002; Tiedje et al. 1990), enrichment (Carlson et al. 2006; Greenhaus & Powell 2006;
According to theories of positive spillover, occupying multiple roles may be beneficial for individuals (Barnett & Gareis 2006; Barnett & Hyde 2001; Sieber 1974).

Positive outcomes can be produced through three different paths when a person is participating in multiple roles. First, experiences in multiple roles can have additive effects on an individual’s physical and psychological well-being (Barnett & Hyde 2001), happiness, satisfaction with life and perceived quality of life (Rice, Frone & McFarlin 1992). Individuals who are involved in, and satisfied with, multiple roles experience greater well-being than those who participate in only one role. Second, participation in multiple roles can also prevent individuals from suffering distress in one of those roles. Individuals may compensate for failure in one role by falling back on gratification in another role (Sieber 1974). Third, experiences in one role can produce positive experiences and outcomes in the other. This can be achieved either through reinventing the resource obtained in one role in other roles, or using the energy created from one role in other roles. It can also be achieved simply because individuals who participate in multiple roles become more tolerant.

In addition to the participation perspective, Greenhaus and Powell (2006), and Hanson, Hammer and Colton (2006), took a different approach in studying the positive relationship between work and family. The authors examined the positive spillover from a resource perspective. Five types of resources identified by Greenhaus and Powell (2006) that are generated in one role and may be applied to another, and that have the capacity to promote work–family enrichment, are skills and perspectives, psychological and physical resources, social-capital resources, flexibility and material. Building on Greenhaus and Powell’s findings, Hanson, Hammer and Colton (2006) specify two mechanisms through which resources generated in one role can promote performance in, and have positive effects on, another. The instrumental path refers to the mechanism through which different types of resources (for example, values, skills and behaviours) acquired or nurtured in a role of one domain are directly transferred to another role, thus improving performance in the latter.
role. The affective path refers to a situation in which individuals transfer positive effects, such as a positive mood and happiness, from one domain to the other.

**Role enhancement and work–family enrichment in the context of informal caregiving**

Although there is an increasing interest in the positive effects that work and family lives can have on each other, research on employment and caregiving, in particular the positive perspective, has been less impressive. The lack of a comprehensive theoretical framework to examine the positive effects of combining work and family roles (Frone 2003) has hindered research in this area.

Employed carers function within both the family, one of the primary centres of role involvement (Goode 1960), and the occupational sphere from which individuals derive various levels of social status, personal esteem and economic resources (Pearlin 1983). Research in the area of the work–family interface has demonstrated that the employment role has generally been shown to have positive effects on carers’ well-being (Aneshensel, Frerichs & Clark 1981), or at least the positive effects of employment outweigh the negative (Scharlach 1994). Meanwhile, some aspects of the caring role can be sources of satisfaction and can even be associated with positive emotions and moods (Miller 1989; Stephens & Franks 1995; Stephens, Franks & Townsend 1994).

In one of the few studies that aimed to examine the ways in which positive and negative experiences spill over from one role to the other and the effects on caregivers’ psychological well-being, Stephens, Franks and Atienza (1997) in the United States assessed spillover between the roles of parental care and employment. Eligible participants were women who were carers of an ill or disabled parent and who were also employed (at least 10 hours per week). The respondents reported that having a successful day at work not only put them in a good mood to assist their parents, but also prompted them to have greater and more positive feelings about themselves because of their experiences in paid employment. In the same vein, knowing that parents were being well cared for gave individuals greater confidence at work. The authors found that positive spillover, mainly good moods, spread in both directions (from work to family and family to work). The
findings from the Stephens, Franks and Atienza (1997) study have contributed to research on women’s multiple roles, especially caregiving and employment, in several ways. For example, they extend previous research in this area by suggesting that spillover has implications for caregivers’ emotional health. However, the limitations with regard to the cross-sectional design make it difficult for the authors to explain whether spillover was more likely to be a consequence of role stress and role satisfaction or a precursor.

The positive experience from one role to the other has also been examined from different perspectives by other authors in the United States. For example, a study carried out by Dunkin and Anderson-Hanley (1998) discusses the positive outcomes of caregiving in terms of ‘carer gain’, which is conceptualised not merely as the absence of negative outcomes such as burden, but rather as the presence of feelings of satisfaction, personal growth and the idea that caregiving can provide enhancement of a carer’s life. Scharlach (1994) reports that positive aspects of combining work and caregiving roles, such as a sense of accomplishment and enhanced interpersonal relationships, were apparent for the majority of the participants in his study.

Nevertheless, the most consistent findings from the studies mentioned above relate to the detrimental effects of negative spillover on caregivers’ well-being. For example, negative spillover is identified in Dunkin and Anderson-Hanley’s study (1998). The authors report that being exhausted and unable to concentrate at work, as well as having work interrupted, were the interferences from caregiving on work. The lack of time available and the subsequent lack of attention to the caregiving role were what constituted the interference with caregiving caused by work. This adverse effect will be discussed in more detail in the next section.

2.5 Paid Employment and Unpaid Informal Caregiving

The policy of encouraging older people to be cared for in the family home is very attractive to governments, due to the considerable potential savings to the public purse. Unpaid care provision by family members at home helps to subsidise the formal health care system. However, it may well have serious implications for employees with caregiving
responsibilities. Caregivers as a group report poorer health and well-being and often feel exhausted, isolated and burdened by their responsibilities (Carers Australia 2010).

Caregivers often provide assistance at great physical, emotional and financial cost to themselves. Issues confronted by caregivers include financial costs and economic disadvantages, changes of employment status and the decision to take early retirement, risks to physical health, and threats to emotional well-being.

This is particularly true in the situation in which caregivers provide frequent and intensive assistance of long duration to a chronically ill individual, a disabled elderly person or a child with a disability, as the effects of chronic work–family conflict are likely to be cumulative over time (Greenhouse, Allen & Spector 2006). This is not to deny the effects of temporary commitments from volunteers on their employment or health, but rather suggests that the effects of short-term commitment may not be as severe as those of long-term commitments.

2.5.1 Paid employment versus unpaid informal caregiving

Paid employment is important to caregivers, given that it is often the only thing that prevents them from living in poverty. Income from a paid job is crucial for financial security (Couch, Daly & Wolf 1999). Paid employment may also provide opportunities for friendship, confidence, a sense of identity and a break from caregiving (Greenlee & Scharlach 2001).

Research indicates that employment has no direct connection with the desire to assume a caregiving role. Data obtained through four municipalities in the southern part of the Netherlands suggest that living near a parent is a key determinant of becoming a caregiver (Dautzenberg et al. 2000), a finding that is consistent with a number of other studies undertaken in the United States (Stern 1995, 1996). Other research carried out in the United States reveals similar results. Research by Pavalko and Artis (1997) found that employed women were equally likely to start a caregiving role as unemployed women. Further, Moen,
Robison and Fields (1994) confirmed that there was no difference between working and non-working women in terms of entry into the field of caring.

While research reveals that whether or not an individual is employed has no direct link with the decision to take up the caregiving role, findings with regard to the employment arrangement after assuming responsibilities of informal caregiving are inconsistent. Nonetheless, an increase in hours in caregiving may be negatively associated with the number of hours in paid employment (Spieβ & Schneider 2003). The main adverse impact may be in the form of reducing in work hours or exiting the workforce (Pavalko & Artis 1997; Pavalko & Henderson 2006).

Studies carried out among women in the United States (Moen, Robison & Field 1994; Robison, Moen & Dempster-McClain 1995) and 12 European countries (Spieβ & Schneider 2003) found that carers reduced their hours of paid employment rather than stopping paid employment. These findings contradict the results released by Pavalko and Henderson (2006) in the United States, as well as a study carried out by Henz (2004).

Using data from the 1995–2001 waves of the National Longitudinal Survey of Young Women, Pavalko and Henderson (2006) realised that women who started in a caregiving role were more likely to terminate their employment than those who did not start in a caregiving role (the likelihood of remaining in the labour force was reduced by 50%). For those who remained employed, carers were not more likely to reduce their work hours than non-carers. The findings suggest that if carers make changes in their employment when combining work and care responsibilities, they typically exit the labour force completely rather than reducing hours.

Similar findings were presented by Henz (2004) following an analysis of longitudinal data of the Great Britain 1994–95 Family and Working Lives Survey. The author revealed that approximately one-third of all informal carers said that caring had no effect on their employment arrangements. Another one-third reported that caring had one or several effects on their employment. The most common decision taken by informal carers was to
stop working. The data also revealed that part-time workers were more likely than full-time workers to reduce their hours of paid employment once they started in a caring role.

Analysing the data collected in 2008 for the second national assessment of work–life interaction (Australian Work and Life Index), Skinner and Pocock report that five out of ten men and women have a mismatch between actual and preferred hours. Most of those with a mismatch, 79.4 per cent of men and 70.7 per cent of women, want to work less (Skinner & Pocock 2010). There is no exception for people with caregiving responsibility. Data from the survey commissioned by the Taskforce On Care Costs in Australia reveal that 49% of people with caring responsibilities for someone with a disability or long-term health condition would reduce their work hours in the future due to the cost involved in obtaining services for their caring responsibilities, and the time and energy needed to cope with the multiple roles (Taskforce on Care Costs 2006). Research by the Taskforce on Care Costs has clearly demonstrated that the financial cost of care affects caregivers’ employment decisions. In particular, in the situation in which the cost of caregiving is perceived as being ‘too high’ (for example, the purchase of care services from the private market), income from paid employment cannot compensate for the cost of caregiving (Taskforce on Care Costs 2006). Caregivers are forced to take the option of leaving the workforce rather than having the choice of accommodating and balancing paid employment and unpaid caregiving.

Other factors that have an influence on employment decisions are occupational position and the level of dependency of care recipients. Research has demonstrated that semi-routine and routine manual workers report the strongest effects of caring on employment (Henz 2004), and employed caregivers in non-professional occupations have more difficulty combining their work and family responsibilities (Neal et al. 1993). The decision to leave the workforce is more common among employees without career-related benefits and with low incomes (Henz 2004). Furthermore, individuals who are in a ‘family-friendly’ workplace culture supportive of both flexible working arrangements and other conditions that facilitate a good relationship between work and life are more likely to remain employed (Eby et al. 2005; Pavalko & Henderson 2006). It is worthwhile to mention that flexibility is not
equivalent to employment status. Carers who work part-time do not necessarily have more flexibility than those who work full-time. The assumption that part-time employment is a good indicator of job flexibility and the notion that it is easier to combine caregiving responsibility with a part-time job than with a full-time job are not supported by Henz’s study (2004).

A caregiver’s propensity to leave the workforce is also associated with the level of severity of a care recipient’s disability. The results from an analysis of a large-scale data set with longitudinal information show that exiting the workforce occurred predominantly during the first year of caring in response to the increasing level of dependency of care recipients, during which time caring duties were quite intensive (Henz 2006).

In addition to the main adverse impact of caregiving responsibility on employment arrangements, other reported negative impacts of caregiving on work life, while few, are related to the increased stress trying to maintain full-time employment. In a study carried out in Australia by George et al. (2008), eight females and three males who were working full-time or equivalent while caring for a child with chronic illness were interviewed. The authors found that participants had to rearrange their working hours, use their leave entitlements, work unsatisfactory hours, sacrifice their careers and even change their jobs in order to balance their dual roles (George et al. 2008). These findings concur with other studies in Australia and the United States (Leiter et al. 2004; Vickers 2005).

The reality of combining caregiving and employment raises concerns over whether or not workplace policies can ease the great strains imposed by multiple roles. Do workplace policies that provide job flexibility, arguably the most important aspect of employment in coping with caregiving demands alongside paid work, make a difference? Once again, findings have been inconsistent. Some studies have shown that job flexibility, such as taking unpaid family leave and working at home, lowered the negative effect of caring on work (Fredriksen-Goldsen & Scharlach 2001; Neal et al. 1993; Scharlach, Sobel & Roberts 1991), and was associated with a stronger work commitment (Kossek & Ozeki 1998). In their report for the second national assessment of work–life interaction, Skinner Pocock
(2010) stated that differences in access to flexibility have a significant effect on work–life interaction. The flexibility was examined by asking participants about how much flexibility they have over when they work and how much control they have over working times to meet their requirements. A healthy work–life interaction, according to the authors, was associated with a high level of flexibility (Skinner & Pocock 2010). The study also found that the majority of employees (56.1 per cent of surveyed) were working unsocial hours (weekends, nights or combine of both) have low flexibility (Skinner & Pocock 2010). This view is, to some extent, in line with the work done by Henz (2006) who found that job flexibility did not provide significant benefits in terms of helping to ease the burden imposed by combining employment and caregiving.

Some researchers have studied the importance of job flexibility by comparing different occupational groups. In the study of Neal et al. (1993), people in professional and managerial occupations found it easier to combine work and caregiving. While remaining in work, they provided caregiving to more relatives than people in other occupations, due to the fact that people in professional and managerial occupations have greater autonomy in arranging work and family responsibilities than those who are in semi-routine and routine occupations (Henz 2004). Income level was not been looked at in any of the studies mentioned above.

Whether or not working caregivers will benefit from initiatives implemented in the workplace also depends on the content of programs. If the primary purpose of policies and programs is to keep costs down, or to increase employees’ flexibility and availability for work, that is, employer-orientated flexibility (Heron & Charlesworth 2012), rather than attend to the overall issues of work demands versus family needs, the likely result will be to increase the strain in meeting multiple work and family responsibilities (Fredriksen-Goldsen & Scharlach 2006) as many workers with caring responsibilities do not have a firm basis from which to seek adjustments to their working hours (Charlesworth et al. 2012). Employers who can provide more employee-orientated (Skinner & Pocock 2010) or employee-centred (Charlesworth et al. 2012) flexibility will enable better work–life interaction for their employees. Another aspect of workplace policies and programs is that
policy-makers and employers should be mindful that having formal access to workplace policies and programs is different from taking advantage of them. The actual usage of policies and programs is influenced by a mix of factors including organisational knowledge and negotiation flexibility (Diamond, Baird & Whitehouse 2007). Thus, being aware of discouraging factors that prevent carers from utilising policies and programs is equally as important as making policies and implementing programs (Fredriksen-Goldsen & Scharlach 2006).

### 2.5.2 The consequences of combining paid employment and unpaid informal caregiving

Alongside issues such as stopping work or working fewer hours, and therefore, earning less money, the financial burden imposed by the shift of care from institutional to community and family is often considered to be a significant problem for many families. The ongoing expenses involved in meeting the special needs of care recipients, such as the purchase of items of special equipment and medication, the costs of parking and frequent dining out, and health services including respite and other support services, are unsustainable, according to the report by Taskforce on Care Costs (2006). Economic strains related to out-of-pocket expenses and lost wages are often associated with family breakdown (McClelland & Green 2003).

Whereas short-term economic disadvantages such as lost wages are visible, the long-term economic impact should not be overlooked. Caregivers are likely to receive little or no superannuation because they are on low incomes (Corti, Laurie & Dex 1994; Evandrou & Winter 1992), in part-time jobs (Evandrou & Winter 1992; Martin & Roberts 1984) or on government pensions. This could present a significant problem when it comes to funding caregivers’ own retirement or future care needs.

It is important that non-monetary costs, physical and psychological, are not understated as they place additional pressure on carers. There is strong evidence that providing care to an adult dependent or child with a disability has a substantial impact on a caregiver’s health and well-being, both physically and emotionally (Jenkins 2004). Indeed, work–family experiences can shape an individual’s emotional and physical health through different
venues. Work overload, insufficient work and/or a low-income job that is often connected to economic hardship and financial insecurity all have an impact on an individual’s emotional health and family relationships.

In particular, conflicts between work and family are strongly linked to emotional strain, depression, somatic symptoms, physical exhaustion and burnout (Allen et al. 2000; Skinner & Pocock 2008). Conflicts could arise from long working hours, lack of control over working schedule (time-based conflict), work overload (strain-bases conflict) (Skinner & Pocock 2008), the perceived difficulty of trade-offs (Barnett & Gareis 2000), clash of schedules between work and family, irregular scheduling as a shift worker (Barnett & Gareis 2006; Barnett, Gareis & Brennan 2008; Davis et al. 2008; Perry-Jenkins et al. 2007), or time deficits (Nomaguchi, Milkie & Bianchi 2005; Roxburgh 2004). Given its potential dual pathways, namely, increasing work hours and contributing to feelings of strain and exhaustion, work overload has been identified as one of the strongest and most consistent predictors of work–life conflict (Geurts & Demerouti 2003). This is confirmed by Australian Work and Life Index collected in 2007. The authors report that ‘while long work hours and a lack of control over work scheduling demonstrated small to moderate associations with work–life, work overload clearly emerged as the strongest predictor of work–life conflict’ (Skinner & Pocock 2008, p. 311). Conflicts could also be the result of caregivers’ negligence of their own health – one of the two consequences of juggling multiple roles according to the qualitative study conducted by Essue et al. (2011). The authors of that study report that carers often miss their own appointments with specialists due to the responsibilities associated with their caring role.

It is worthwhile to emphasise that in many studies as well as the current research, the term ‘psychological strain or emotional health (well-being)’ is referred to as depressive mood or symptoms such as depression, anxiety or life distress. These are not the same as a clinical depressive disorder, although there is evidence suggesting that almost 85 per cent of those who score high on the Center for Epidemiologic Studies Depression (CES-D) scale tend to be diagnosed as having depressive disorder after an in-depth structured interview with a psychiatrist. The CES-D scale, developed by Radloff in 1977, is still one of the most
commonly used screening tests in helping individuals to determine their depression quotient.

While studies using cross-sectional design have suggested that carers consistently had higher rates of depression than non-carers (Amirkhanyan & Wolf 2003; Frone, Russell & Cooper 1997a; Stephens, Franks & Atienza 1997), results from the analysis of longitudinal data have provided less consistent support for a relationship between work–family conflicts and depression. Using a one-year time lag for their study in a national sample of 234 dual-earner couples in the United States, Hammer et al. (2005) found no relationship between work–family conflicts and depression. This result was inconsistent with what was then revealed by another study in the United States. Using the data collected in a two-year interval from a nationally representative sample of young US women, Pavalko and Henderson (2006) report that women who started in a caregiving role had greater increases in psychological distress than women who did not assume such a role. Some studies discovered that role interference was associated with other aspects of psychological strain, such as anxiety and life distress (Noor 2004; Parasuraman, Greenhaus & Granrose 1992; Schieman, McBrier & Van Gundy 2003).

The existence of psychological strain can be predicted by the demands of and the support needed for a caregiving role. The level of severity of the functional, cognitive and behavioural disability of care recipients (Ory et al 1999; Starrels et al. 1997), the level of assistance required, the extent of the individual caregiver’s responsibility (that is, whether or not a person is a primary carer), the relationship between carers and care recipients, the availability of help from others including family members, supervisors/colleagues and the society at large are all predictors.

Pearlin et al. (1990), in developing the Stress Process Model, predicted that ‘elements of emotional distress are likely to surface first and if they persist, they may be eventually detrimental to physical well-being’ (p. 590). Research has shown that some caregivers tend to delay seeking, or are never willing to seek, support when they are experiencing...
emotional and psychological stress symptoms that may result in physical symptoms (Kroenke 2003).

Demonstrated negative effects of caregiving on physical health, while documented, are less inclusive. These include physical limitations, physical exhaustion (Schofield et al. 1997), chronic conditions, poorer immune system function and a resulting increase in viral illnesses (Pavalko & Woodbury 2000; Scharlach 1994), more disease symptoms and health care usage, and increasing use of medication (Schulz, Visintainer & Williamson 1990). Nevertheless, researchers could find no strong evidence of an increased risk in formally diagnosed illness among carers (Taylor, Ford & Dunbar 1995; Falloon, Graham-Hole & Woodroffe 1993).

Negative emotions have been associated with self-reported health problems, such as cardiovascular disease (Greenglass 1996; Lovallo 1997; Spector, Dwyer & Jex 1988; Spector & Jex 1998). According to the ‘health consequences of work–family conflict’ model developed by Greenhaus and his colleagues (2006), negative emotions including depression, anxiety, frustration, resentment and anger are believed to be the immediate psychological pathway through which psychosocial factors directly influence physical health. Various psycho-neuro-immunological channels probably play the mediated roles. A negative emotional state may affect an individual’s physical health by undermining their immune or hormonal responses, which in turn influences their susceptibility to various physical forms of morbidity (Cohen & Herbert 1996). Continued exposure to events that induce negative emotions can impair an individual’s physical health through excessive stimulation of both hypo-thalamic-pituitary-adrenal and sympathetic-adrenal-adrenocortical systems (Frankenhauser et al. 1989). Negative emotions may also affect an individual’s physical health indirectly through unhealthy behaviours, including problem drinking (Frone, Barnes & Farrell 1994; Frone, Russell & Cooper 1997a; Grzywacz & Marks 2000), tobacco use (Burton et al. 1997; Ng & Jeffery 2003), and less participation in regular physical activities (Grzywacz 1998).
2.5.3 The support needed in combining paid employment and unpaid informal caregiving

As a result of having limited choices in terms of taking up an informal caregiving role, and concerns about the short-term and long-term impacts of their caregiving role on their employment prospects, labour market attachment and financial situation, many carers want or need to combine paid work and informal care (Carmichael et al. 2008). However, combining the roles of paid employment and unpaid caregiving becomes increasingly difficult, not only because of time constraints, but also because of caregivers’ particular needs that employers are sometimes unwilling or unable to meet (Carmichael et al. 2008). Thus, it is imperative for working caregivers to be given the support they need in order to manage the challenges they face.

A study undertaken by Carmichael et al. (2008) in north-western England reveals that the majority of participants (twenty-five out of thirty) agreed that the lack of flexibility in work hours and practices was a particular problem. On the other hand, studies have shown that flexibility in the workplace is associated with a number of positive outcomes. It can increase productivity, reduce absenteeism and employer-employee relationships in the workplace. In addition, flexibility can lower work–life conflict, thus, reduce stress and have positive impact on employee’s physical and emotional well-being (Pocock 2011, reported by Price-Robertson). Organisations are perceived as being more supportive of families when they offer family-friendly benefits, especially in the situation where employees use those policies (Allen 2001). The use of benefits could create perceptions of support for, and control of, work–family matters and generate more positive work attitudes (Allen 2001; Thomas & Ganster 1995; Thompson, Beauvais & Lyness 1999).

Moreover, creating a family-supporting culture within an organisation has a positive impact in helping working carers combining work and family commitments (Behson 2005). Workplace cultures matter a great deal to work–life interaction and unsupportive cultures are strongly linked to poorer work–life interaction (Skinner & Pocock 2010). A family-supportive culture is defined by Thompson, Beauvais and Lyness (1999) as one that has general managerial support of family-related needs, does not penalise employees for
devoting time to family, and has norms that are not excessive regarding the appropriate amount of time devoted to work. Managerial support, or first line supervision, is critical for employees to successfully integrate work and family domains, and thus may foster affective commitment from employees and reduce the intentions to leave the workforce (Wayne, Randel & Stevens 2006; Skinner & Pocock 2010). Friedman and Greenhaus (2000) believe that the mechanism through which a family-supportive environment has a positive effect is the creation of resources, such as time, flexibility and advice, as well as psychological resources such as self-acceptance.

In the same vein, the availability of support in the family domain, in particular social support, is the key element that leads someone to feel loved, cared for and valued (Greenhause & Powell 2006; King et al. 1995). The types of social support that have attracted most attention and have received empirical validation are instrumental and emotional support (King et al. 1995). The former refers to behaviours and attitudes of family members aimed at assisting day-to-day household activities, such as relieving the employees of household tasks or otherwise accommodating the employee’s work requirement (King et al. 1995). The latter refers mainly to the expression of feelings to enhance others’ behaviour (Erickson 1993). It is suggested that emotional support received in the family, such as from a spouse, can reduce workplace stress (Noor 2002). Receiving support either at work or in the family is likely to have a positive impact on one domain that enhances the quality of life in the other (Grzywacz & Marks 2000).

2.6 Justification of the Doctoral Study

The review of literature indicates that research in the area of the work–family or work–life interface has attracted scholars in a wide variety of disciplines, including labour studies, psychology, health economics, women’s studies and public health (Pocock, Skinner & Williams 2008), and employers over the last three decades in response to the rise of the dual-earner household as the dominant family form (Jacobs & Gerson 2004; Kalleberg 2008), as well as shifts in the value placed on greater life balance (Greenhaus & Powell 2006). Despite the proliferation of research on the work–family interface and accumulated documentation of correlations between variables in relation to work and family, the two
crucial life domains, the existing literature is almost entirely survey based. The majority of studies was frequently limited to a single firm, and was cross-sectional in design. The methodological limitations of study designs not only yield the inconsistent findings, but also preclude the interpretation of any causal relationship. Researchers have been over relied on situational predictors and a lack of intention to individuals’ differences, thus preventing a more complete understanding of the integration of the roles of employment and caregiving responsibilities. Studies using longitudinal information from large population have other limitations such as missing crucial data or lack of accuracy.

There is also a tendency to utilise and analyse aggregate state or national data from previous research. It is possible, under these circumstances, that some constructs may not be adequately represented or directly assessed. Even with a designed measurement, such as the Australian Work and Life Index (AWALI) – a short, simple and user-friendly instrument that aims to capture the work–life relationship experienced by Australians, it tends to be difficult to provide nuanced analysis that may be produced from qualitative studies (Pocock, Skinner & Williams 2008). What is needed now is research into the differences between individuals, such as dispositional characteristics, their preferences for work and their actual needs in meeting the challenges imposed by combining the roles of paid employment and unpaid caregiving. A qualitative case study approach and the use of face-to-face interviews for data collection would enable the researcher to examine the extent to which working caregivers can keep pace with the increasing demands of work and family. The approach allows the researcher to study a phenomenon through wide-angle lens and understand and interpret social interactions (Johnson & Christensen 2008; Lichtman 2006).

The literature review further reveals that the majority of existing studies tend to examine one aspect of the phenomenon of combining caregiving and employment, for example, the effect that caregiving for a child with a disability may have on parents, families and siblings (Clements, Copeland & Loftus 1990; O’Brien 2001), the difficulties of employment in terms of the work–family challenge (Clark 2000, 2001; Edwards & Rothbard 1999), or the effect of each type of work–family conflict (time-, strain-, behaviour- and energy-based) on
health problems. This shows there is a need to examine the experiences of being working caregivers holistically, and the meanings these experiences hold for caregivers themselves (Dal Santo et al. 2007).

A qualitative case study approach would also allow the researcher to explore other aspects of the informal caregiving phenomenon, including the caregiver’s age, occupation and cultural background; and the relationship between caregivers and care recipients, and caregivers and other family members. These dynamics are likely to have an impact on caregivers’ decisions to assume a caregiving role, their experiences and perceptions of being a working caregiver, their adopted coping strategies, their physical and psychological health well-being, and their financial situation and life in general. Thus, this research can provide a more holistic and better understanding of the structural barriers and opportunities in combining informal caregiving and employment (Fredriksen-Goldsen & Scharlach 2006).

As mentioned in the previous section, the interface between work and family has been widely investigated due to recent demographic trends such as the rise in single-parent families and dual-earning families, and an increase in women’s participation in the workforce. As a result, a considerable amount of previous work–family conflict research focuses on married or partnered couples with mainstream parenting responsibilities in countries such as the United States, the United Kingdom and Australia.

However, mainstream parenting is not the focus of the current study for a number of reasons in addition to the one mentioned above. First, the process of rearing a child without a disability has an anticipated or desired goal in the nurturing, and is considered to be making a great contribution to the society (Gray & Hughes 2005). Second, the importance of parents having access to work arrangements that enable them to care adequately for their children is widely recognised and accepted by employers and the wider community in Australia (Gray & Hughes 2005). It is revealed by Gray and Hughes (2005) that policies and programs, such as providing breastfeeding facilities, are implemented in most companies and public places to support people with ‘normal’ nurturing responsibilities. Furthermore, the authors also report that managers or supervisors and colleagues are very
supportive in terms of providing flexible employment arrangements in the workplace to those with caring responsibilities for children. While the data used by the authors is based on a survey collected in New South Wales, the authors assume that there is no particular reason to think that ‘the pattern of the results will fundamentally differ in other states of Australia’ (Gray & Hughes 2005, p. 7).

On the other hand, there is a need for research into the problems of employees with caring responsibilities to a cohort with special needs, including adult dependants, children with a disability or family members with chronic illnesses. More people than ever before are looking after people with special needs due to the greater life expectancy and an increased number of children being identified as living with a chronic illness (Gibson 1995; Isaac & Sewell 2003).

Much attention should also be given to understanding the fit between the work environment and workers’ needs, interests and desires, as well as the importance of creating workplaces that allow employees to provide care for people with special needs. Issues in relation to coordinating work and caring responsibilities are liable to increase the unresolved work–family conflict as a result of recent demographic changes and social trends. This is more important in Australia due to the changes in superannuation law and a likely outcome of the broader shift in care provision for dependants back to families and communities (Vickers & Parris 2005).

Many employers increasingly attempt to provide their employees with greater flexibility as they recognise that there are benefits for both employees and employers (Hill et al. 2010). Australia has recently enacted a right for some parents to request changes in the hours, patterns and location of work, that is, the Fair Work Act 2009 includes a new ‘right to request’ (Skinner & Pocock 2011). However, only those who are parents or carers of a pre-school-aged child or a child under 18 with a disability may ask their employers for a change in working arrangements. Despite the fact that employers and the government make an effort to support employees seeking flexibility, the right is only available to a small group of people. Those caring for older Australians and those caring for a person with long-term
illness or disability are not included in the group who are entitled to the ‘right to request’. This creates a conflict between the Australian government’s aim to increase female participation rates and the needs of workers who have caring responsibilities for elderly, many of such workers being women (Baird, Williamson & Heron 2012). Studies that examine the needs of those with special caregiving responsibility will shed some light on how to address the issues related to manage multiple roles.

This doctoral research further examines whether an individual’s behaviour, attitudes and well-being are determined jointly by personal needs and resources provided by the surrounding environment (Edwards, Caplan & Harrison 1998; French, Rodgers & Cobb 1974). This includes the exploration of whether an individual’s aptitudes, skills, training, time and energy may congregate to meet demands from work and family domains and role expectations; and whether the resources in the environment can complement individuals’ needs. This, in turn, can help employers and other government bodies to implement effective policies, programs or initiatives that can assist working caregivers.

2.7 Summary

This chapter reviewed appropriate theories and practices in relation to the interface of work and family, in particular, paid employment and unpaid informal caregiving. It also provided examples of methods that other scholars have employed in an attempt to study the issues derived from combining multiple roles, while discovering the limitations of previous studies. Furthermore, the chapter introduced the original framework that was used as the reference at the stage of developing the interview schedule.

The review and discussion have not only contextualised the extent and significance of the thesis, but also set the foundation for understanding why the methodological approach and the means of data collection are appropriate for the current study. This leads to a full description of the research design developed for the current project in the following chapter.
CHAPTER 3 – METHODOLOGY

3.1 Introduction

This chapter describes the methodological approach utilised in the study. It consists of three main sections. First, the research paradigm that guides the study is discussed. Second, the design of the study is detailed, in particular, the reasons for selecting a case study approach and the methods of data collection. Third, the emergent nature of the research plans and the actual process of achieving and maintaining access to the field throughout the course of the inquiry are described. This section also covers sampling issues and decisions. The chapter continues with an outline of the various strategies employed during the interviews and finally addresses how the data are managed and analysed. The role of the researcher and the issue of rigour are discussed in the last section. This chapter sets the foundation for the presentation of the nine case studies in the chapter 4, as well as the findings in the chapter 5.

3.2 Research Paradigm

Scholars have chosen different terms to describe philosophical ideas. For example, Creswell (2009) uses the term philosophical worldview while others use the terms paradigm (Lincoln & Guba 2000) or epistemologies and ontologies (Crotty 1998). Maxwell (2005) notes that the term paradigm derives from the work of historian of science Thomas Kuhn, and refers to a set of very general philosophical assumptions about the nature of the world (ontology).

A paradigm has been defined as a basic set of beliefs that guide action (Guba 1990). A paradigm encompasses three elements:

- epistemology, which asks questions such as ‘how do we know the world?’ and ‘what is the relationship between the inquiry and the known?’;
- ontology, which raises basic questions about the nature of reality;
- methodology, which focuses on how we gain knowledge about the world (Denzin & Lincoln 2000).
Arguably, research paradigms form the basis of any decision-making related to research. They guide investigators, not only in choices of methodology and method, but also in ontologically and epistemologically fundamental ways. Paradigms are critical in justifying the theoretical foundation of any study. The position of a given paradigm has significant implications for the practical conduct of research, the interpretation of findings and the influence in policy-making. Thus, researchers should have a clear view of which paradigm informs and guides their approach prior to engaging in any research (Guba & Lincoln 1994).

According to Denzin and Lincoln (2005), there are currently five competing paradigms informing and guiding qualitative research, namely, positivism, postpositivism, critical theory and related ideological positions, interpretivism and participatory inquiry. Each paradigm has its own epistemological and ontological position and is different from another in terms of methodological approach, as well as the means used for data collection.

Guba and Lincoln’s interpretivism paradigm is a comprehensive eclectic framework. This position assumes a subjective or transactional epistemology in which knowledge is subjective, constructed and transacted between researchers and researched. The world we know is particularly a product of human construction. In addition, it assumes a relativist ontology in which reality is viewed as socially and societally embedded. Reality is dynamic and multiple. While this paradigm has been given different terms by various authors (Crotty 1998; Lincoln & Guba 2000; Neuman 2006; Schwandt 2007), namely, constructivist, interpretivist, respectively, it denotes an alternative paradigm whose breakaway assumption is the move from ontological realism to ontological relativism (Guba & Lincoln 1994). The goal of this position is to understand the complex world of lived experiences from the point of view of those who live it.

It must be understood that the human world is different from the natural, physical world, and therefore, must be studied differently. The decision in favour of the interpretivism/case study approach makes it possible to fulfil the objectives of the study and to provide answers to the research questions.
3.3 Research Design

According to Creswell (2009, p. 3), research designs are ‘plans and the procedures that span the decisions from broad assumptions to detailed methods of data collection and analysis’. The decision to select a specific design for a research project is influenced first by the worldview assumptions that a researcher brings to the study, then by practical issues related to a research project (for example, time constraints and a researcher’s preferred ways of working), then, most importantly, by the appropriateness of a methodology and inherent methods for the given topics.

This study aims to examine the meanings that people attach to their caregiving experiences and how they, as working caregivers, balance the roles of paid employment and unpaid caregiving, as well as manage the challenges from both roles. A case study approach using primarily a semi-structured, face-to-face interviewing method was adopted in the study. This approach allowed the researcher to gain a sense of each context through interviewing, and more specifically, gain an understanding of how working caregivers perceive the demands from family and work domains and their responsibilities of paid employment and unpaid caregiving. The dissertation consists of nine case studies which present multiple constructions of the perceptions of the experience as an employee with informal caregiving responsibilities. The interpretivism/case study approach was chosen for the study in order to emphasise the voice of the individual working caregiver’s life within the context of work and family rather than monitor their actions or involvement in changing an organisation’s practice. Phenomenology was utilised in chapter 6 to describe, interpret, and understand lived experience in an effort to discover meaning rather than to explain and predict (Morse 1991). The appropriateness, benefits and issues of employing the methodology and method selected will be fully discussed in the section below, as well as in the section on ‘data collection’.

3.3.1 Justification of the methodology and method selected

A case study is a common approach of qualitative inquiry (Stake 2005). It is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances (Stake 1995). This approach is widely utilised in research and it
makes possible in-depth examination of social settings, situations or events as experienced by individuals (Berg 2009; Creswell 2013; Leedy & Ormrod 2010). The data, when analysed, can provide rich insights into human behaviours, and assist the researcher in understanding human behaviours through referencing to the meanings and purpose attached to human actors (Denzin & Lincoln 2000). This approach also facilitates an understanding of participants’ own perspectives on their words (van Manen 1990), and thus permits unexpected themes to arise.

Creswell (2007) states that a case study approach has systematic procedures for the conduct of an inquiry. One of the three types of case study identified by Stake (2000) is intrinsic case study design. It is a type of case study that is suggested to be used when the intent of research is to better understand the case, rather than understanding some abstract construct or generic phenomenon or building theory (Stake 1995). Case study designs, especially intrinsic case study approach, draw researchers towards an understanding of what is important about a particular case within its own world. The design aims to develop what is perceived as a case’s own issues, context and interpretations (Stake 2005). A case study approach encourages researchers to provide readers with good raw materials. The emphasis is on ‘thick description’ (Geertz 1993) and critical description (Green 2002). In other words, the goal is to go beyond the ‘what’ questions and seek responses to more challenging questions such as ‘how?’, ‘why?’, ‘what for?’, ‘what if?’ and ‘in whose interests?’ (Green 2002). Qualitative case study researchers let the case ‘tell its own story’ (Carter 1993; Coles 1989) as far as possible by seeking out emic (insider) meanings held by the people within the case (Guba & Lincoln 1994).

This methodological approach fits with the interpretivist theoretical perspective/paradigm, the essential elements of the assumption upon which it is based is that researchers need to know what people think in order to understand why they behave in the ways they do (Schutz 1962). This approach reflects my belief about social reality and how it should be studied. It allows me to explore working caregivers’ experiences of social reality through the interpretations and perspectives of individuals.
One of the advantages of using a case study approach is the possibility it provides for studying the complexity of a phenomenon in a number of contexts or backgrounds. This approach emphasises the uniqueness of each case, but also commonalities across cases. Case study researchers put effort and time into reflecting on their cases, trying to understand their complexities and encapsulating complex meanings into reports. They enter the scene expecting, even knowing, that certain events, problems and relationships will be important, yet discover that some of them at times will be of little consequence (Parlett & Hamilton 1976; Smith 1994). An example from this study is that I expected that support networking would be important for working caregivers to cope with the challenges in their lives; however, the data revealed that the majority of the participants in this study had virtually no support from their extended family members and friends, or their workplaces and colleagues.

Another advantage of employing a case study approach is its potential to provide a mechanism for the transfer of knowledge from one setting to another (Guba & Lincoln 1994). Stake (2000) also makes this point and notes that case studies are of value in helping to establish the limits of generalisability or what is referred to by Schwandt (2007) as analytic generalisation, differentiating from statistical or propositional generalisation. Case study researchers believe that people can learn much from single cases, and form generalisations from their experiences.

Arguably, qualitative methods such as interviewing, observation, writing journals and reviewing artefacts and documents tend to be more appropriate for research in the social sciences, especially human-behaviour related study that is not easily quantified but is effectively described in detail (Green 2002). While I understand that direct observation, in some circumstances, is an effective way to gain access to everyday life, the realisation of the time constraints and the nature of the final sample meant that using face-to-face interviewing was more effective as the primary method of collecting data. Because of the geographical locations of the industry partners from which the participants were recruited, the identified cases for the study were spread across several states. Also, the majority of the
participants resided in geographical states other than the one in which I was based. Thus, it was impossible in this context to observe the activities of work and caregiving.

Another reason for selecting face-to-face interviewing as the key method of data collection is related to the proposed research questions. As outlined in the Introduction chapter with regard to the main research question and the associated sub-questions, gaining an in-depth understanding of working caregivers’ perceptions of their experiences of combining paid employment and unpaid caregiving and identifying the challenges that working caregivers are facing are main objectives of the study, although solutions and recommendations for addressing these issues are also suggested. I sought to examine deep meanings and interpretations of the experience of being a working caregiver from the individual perspective of each participant. A face-to-face interaction, more specifically relying on verbal accounts of social reality, was deemed both necessary and desirable.

The value of using face-to-face interviewing for data collection has been acknowledged by many scholars. It is one of the main methods of finding out ‘what is in and on someone’s mind and to gather their stories, to capture how those being interviewed view their world, to learn their terminology and judgments, and to capture the complexities of their perceptions’ (Patton 2002, p. 348). In-depth interviews elicit a range of themes and enable exploration of the unexpected (Sekaran 2000; Zikmund 2010).

The phenomenological research method is a ‘systematic, explicit, self-critical, and intersubjective study of its subject matter, of lived experience’ (van Manen 1990, p. 11). This approach allows the researcher to go beyond the aspects of life taken for granted and ‘to uncover the meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized or sentimentalized’ (Benner 1985, p. 6), and search for essentials, invariant structure (or essence) or the central underling meaning of experience’ (Creswell 1998, p. 52). It is an approach that enables some aspect of our lived world and experience more understandable and intelligible through reflecting on the linguistics of the described phenomenon (van Manen 1990).
3.4 Participants, Recruitment Process and Sampling

3.4.1 Protection of human subjects

To assure the protection of human subjects, a proposal package that included an ‘Application for Ethic Clearance’, an ‘Information Statement’, an ‘Informed Consent Agreement for Participation in Research’, and so on (refer to the appendices) was submitted to the Swinburne University Human Research Ethics Committee (SUHREC) for approval in November 2006. The ethics clearance from SUHREC was received in February 2007, granting approval for data collection to be conducted between March 2007 and November 2008. An extension was sought and granted in October 2008 so that the data collection phase could be extended to April 2009.

3.4.2 Gaining and maintaining access to industry partners

_Negotiating access to participants through gatekeepers in the involved organisations_

As this study is located within a wider project, negotiating access to potential participants was initially undertaken through formal gatekeepers among the industry partners. The engagement occurred in the project meetings between the research team and the industry partners in the early stage of the wider project, during which I gave a brief presentation about the study to managerial staff. Each participating organisation expressed great interest in tackling the issues related to its ageing workforce, in particular, increasing the retention rates of older workers. Thus, it initially seemed relatively easy for me, as a member of the research team, to establish trust with, and obtain support from, the people in management positions.

The next step in the preparation prior to the fieldwork was the development of the ‘Research Information Kit’. The package consisted of an ‘Information Statement’, a ‘Study Flyer’, a ‘Participant Recruitment Letter’ and an ‘Informed Consent Agreement for Participation in Research’ (refer to appendices 3.1, 3.2, 3.3 and 3.4). The ‘Information Statement’ outlines the relationship between the wider project (RW4AS) and the doctoral study (Working Caregivers’ Study), the aims of the doctoral study, and how the privacy and
confidentiality of participants would be strictly protected. The ‘Participant Recruitment Letter’ provides answers to some most frequently asked questions about the Working Caregivers’ Study. The one-page ‘Study Flyer’ offers a snapshot or overview of the Working Carers’ Study, for distributing to staff via their pigeonholes, posting on noticeboards or including in newsletters or on the company’s intranet. The kit was distributed to managerial staff members through the formal respective gatekeepers for the purposes of raising awareness of the importance of the doctoral study, and obtaining support from management.

The fieldwork did not proceed as planned for a number of reasons. The main reason was that the full-scale employee survey for the wider project (RW4AS) took place in two phases (June to July and September to October 2007). I was told that the study had to be in line with the schedule of the main project, and that it must commence after the second phase of the data collection (after October 2007). As a result, the reengagement/formal engagement with the industry partners was resumed in March 2008.

The initial sampling decision was to recruit participants within all four of the industry partners that were involved in the wider project (RW4AS). However, the plan had to be altered as people who had completed the employee survey in the third organisation were all contractors and had limited connection with the organisation. While the contractors did have their regular fortnightly meetings, the focus of those gatherings was to report issues or difficulties and to seek solutions. Time was critical to those contractors who had no interest in things other than work-related difficulties. My attempt to include this organisation in the study was unsuccessful.

Major restructure and reform had occurred within the fourth organisation that was involved in the main project during the years when it was carried out. At the time that the doctoral study began, there were no formal or informal gatekeepers whom I could contact to pursue the study. Getting interviewees became a very difficult task. As a result, the final sample for the doctoral study consisted of people from two industry partners, numbers 1 and 2.

**Different ways of accessing industry partners**
The first- and second-round invitations for the doctoral study were constructed by me and delivered to the whole community of industry partner 1, where teaching was the main task, via official emails by the Director of Personnel Relations. The purpose of using this tactic, which Patton (2002) refers to as the ‘known sponsor approach’, was to establish my legitimacy and credibility through ‘individuals in an organisation that have the power to withhold access to people or situation for the purpose of research’ (Burgess 1984, p. 39).

While email was the key mode of communication within industry partner 1, delivering messages through the organisation’s hierarchy in regular face-to-face meetings was the main means of communication among employees in industry partner 2. The doctoral study was introduced and promoted to all managers by the liaison person, Kyle (pseudonym), during a weekly management conference.

Potential suitable people who were interested in the study were encouraged to contact me directly for more information, and to clarify any questions they might have. A total of 11 people from across various campuses within industry partner 1 expressed a desire to share their stories and their experiences via either email or phone. Most of the people who were interested in being a part of the study within industry partner 2 were from the branches in a state that is not the state where I reside. Thus I need to organise an interstate trip for data collection, which was much more difficult than organising data collection locally. The preparation prior to the fieldwork included obtaining approval for the trip from authorised personnel, and countless telephone calls and email messages to confirm and coordinate the date, the location and time for interviews.

3.4.3 Sampling strategies

According to Patton (2002), the term purposeful sampling refers to the selection of information-rich cases (those from which a researcher can learn a great deal about issues) for study in depth. The information-rich cases are those from which ‘one can learn a great deal about issues of central importance to the purpose of inquiry’ (Patton 2002, p. 230). Purposeful sampling enables researchers to select cases that are relevant to the research questions, analytical framework and explanations developed in the research (Schwandt
Case study researchers are reminded that selecting cases that potentially provide opportunities to learn is the most essential activity in conducting a study, although variety in cases is also important.

There are many types of purpose sampling strategies. For example, Patton (2002) discusses 16 different strategies, including homogeneous sampling, deviant case sampling and so on. Maximum variation (heterogeneity) and critical case sampling were employed in this doctoral study (Creswell 2009; Maxwell 2005; Patton 2002).

The aim of using maximum variation sampling is to capture and describe central themes that cut across a great deal of variation, such as age, role, ethnicity and so on. Efforts were made in the early stages of recruitment to maximise the heterogeneity of the sample and to yield a wide range of case variation in dimensions of interest (Patton 2002). For example, every attempt was made to include male and female, young and old, and blue- and white-collar caregivers from multiple places and different industries in the study, given that literature suggests that men and women perceive their primary roles differently and there are gender differences in the mental or psychological health consequences when performing multiple roles. This approach could also provide the opportunity to understand, or at least raise questions about, how gender, age and occupation might influence the nature of the caregiving experience, and to facilitate comparisons of caregivers’ social action to show whether they are the same, similar or different.

The sampling decisions were also based on an estimate of which individuals would be most useful for a study (Marshall & Rossman 2011), that is, using the critical case sampling strategy. According to Patton (2002), critical cases are ‘those that can make a point quite dramatically’ (p. 236). In terms of the current study, most participants had a long tenure with their current organisations, were in fairly senior positions and were enjoying relative flexibility at the workplace at the time of the interviews. Thus, it is reasonable to argue that if these people found it difficult juggling work and caregiving, it is likely that people with less autonomy at work would face even greater challenges.
People who had expressed an interest in participating in the study were followed up with telephone screening to further assess their eligibility. As the current study only targets a selection of the population, namely those who have caregiving responsibilities for a dependent adult or child while holding a paid job, potential participants needed to meet the selection criteria listed below in order to be included in the study.

The final sample consisted of 17 participants who were in paid employment (either full- or part-time) while being informal caregivers to one or more dependent family members, either a child or children with a disability, or family members who were elderly and/or had a chronic illness or a terminal illness for longer than six months at the time of the study. The majority of participants, 15 out of 17, had a full-time paid job. Caregivers did not have to reside with care recipients. The assistance that caregivers provided could be in the form of activities of daily living (ADL) and/or instrumental activities of daily living (IADL). All participants were recruited from two industry partners (industry 1 and 2, refer to appendix 3.7).

While the researcher of the current study acknowledged the relatively small size of the sample, the decision to end the data collection was in line with the guiding principles of qualitative research. That is, the data collection process should be discontinued when the researcher reached saturation point (Glaser & Strauss 1967) – when the collection of new data does not shed any further light on the issues under investigation. According to Bryman (2004), Creswell (2013), Minichiello, Aroni & Hays (2008) and Patton (2002), the appropriate time to stop adding new cases is the point at which incremental learning is minimal (Glaser & Strauss 1967).
3.5 Data Collection\textsuperscript{2}

3.5.1 Interview models

As discussed in an earlier section, face-to-face interviewing was the primary method utilised for data collection. Interviewing, as defined by Green and Thorogood (2004, p. 87), is

\textit{conversation that is directed more or less towards the researcher’s needs for data … and can be seen as a specific kind of interaction, in which the researcher and the interviewee produce language data about beliefs, behaviour, ways of classifying the world, or how knowledge is categorized}

Kvale (1996) states that the models of interviewing fall along a continuum on which fully structured interviewing sits at one end, and unstructured in-depth interviewing is located at the other. More specifically, the three models are:

- structured interviews;
- focused or semi-structured interviews;
- loosely structured or unstructured interviews.

Structured interviews, also known as standardised or survey interviews, are predominantly used in surveys or opinion polls (Minichiello, Aroni & Hays 2008). Surveys usually comprise standardised questions with multiple answers with ‘yes’ or ‘no’ as the opinions. Focused or semi-structured interviews involve the development of an interview guide or schedule that lists a predetermined set of topics or issues to be explored during an interview (Minichiello 1995). Essentially, this type of interviewing model provides a more valid explanation of participants’ perceptions and constructions of reality (Minichiello, Aroni & Hays 2008). Loosely structured or unstructured interviews are those that are reliant on the

\textsuperscript{2} A decision was made by the supervisors and the candidate to use first person language to present the sections describing the rationale for interviews as this helps to avoid any confusion between the researcher of the current study and researchers in previous research.
interaction between interviewers and participant/informants (Minichiello, Aroni & Hays 2008) rather than on the use of ordering of question or formal interview schedules.

Both structured and unstructured interview approaches were deemed to be inappropriate for the current study. The former reduces the possibility of enquiring about individual differences and circumstances. The time and resource constraints make it impossible to use informal conversational interviews (Patton 2002) or loosely structured or unstructured interviews (Minichiello, Aroni & Hays 2008). Also, informal interviews risk being unfocused or not gaining data related to questions for a study.

The focused or semi-structured alternative was employed for the doctoral study. This tactic ensures that the same basic lines of inquiry are pursued with each person interviewed. Logical gaps in the data collected can be anticipated and closed. On the other hand, the semi-structured approach provided me with opportunities to word questions spontaneously and allowed the discussion between participants and me to be more flexible, conversational and situational. This method also made it possible for me to freely explore, probe and elucidate particular topics or subjects, and to pose questions about new areas of inquiry that were not originally anticipated in the development phase, that is, to enable the unexpected to rise. This approach also allowed individual participant’s perspectives and experiences to emerge.

The benefits of employing a semi-structured approach, as discussed above, are evident in the current study. For example, the view of ‘out of pocket expense’ was expanded to include costs related to ‘hire’ someone (family members) for temporary ‘respite’ and to include expenditure attached to travel in the long-distance caregiving responsibility. The individual’s perception about ‘financial burden’ emerged, which added another dimension to the notion of ‘out of pocket expenses’.

3.5.2 Semi-structured interviews

The development of the initial semi-structured interview schedule
The development of the early version of the interview schedule was guided by the research questions of the doctoral study. A substantial proportion of the questions were purposely incorporated to examine the difficulty of simultaneously handling the roles of paid employment and unpaid caregiving, to explore the possible solutions and strategies that working caregivers employ to cope with the challenges, and to find out the effect of being a working caregiver on a person’s life.

A thorough search and review of literature on family caregiving, multiple roles, work–family conflict and work–life balance also contributed to the development of the initial interview guide or schedule. While beginning data collection without full investigation of the existing literature is a traditional and generally understood aspect of qualitative research, there is a shift back to seeing the value in reviewing the literature as a source of stimulation and/or sensitisation (Charmaz 2006; Silverman 2000; Strauss & Corbin 1998).

Furthermore, the development of the initial interview schedule was also influenced by my belief that the power lies primarily with the participants, who are the experts on the matter of being a working caregiver. I was mindful of the fact that the more open-ended the questioning, the better the chance that I would elicit information about what people say or do in their life settings.

Once I have developed the main research questions, I compiled a list of issues and concerns that I wanted to cover and discuss with interviewees in face-to-face interviews. The preliminary interview schedule (see the following section) was used in the pilot interviews.

**The pilot interviews**

A pilot study can be seen as a form of action research in that the intention is to learn and to change future action, that is, to find out how to conduct a project more effectively (Gudmundsdottir & Brock-Utne 2010). These authors emphasise the importance of having a pilot study by stating that piloting methods in the preparatory process enables researchers to reduce mistakes in the main research design. Sampson (2004) suggests that researchers, especially those who undertake qualitative and ethnographic studies, should carry out pilot
work prior to immersing themselves in the field. Researchers use a pilot study for various reasons. This includes refining and developing research instruments (Gillham 2000), assessing degrees of observer bias (Hammersley 1993; King 1993), collecting background information and adapting a research approach (Fuller 1993; Hammersley 1993).

The initial interview schedule used in the pilot interviews covers these areas:

- the caregiver’s current work and family life;
- the caregiver’s knowledge of and competency in their work and caregiving role;
- the caregiver’s perspectives on handling and balancing the roles of paid employee and unpaid caregiving, and their ways of managing the potential conflict roles;
- the effects of juggling between a paid employment and an unpaid caregiving role;
- the support that working caregivers need in order to meet the challenges inherent in playing the two roles;
- demographic information such as age/age group, occupation, marital status and ethnic group.

The pilot interviews proved to be a valuable experience and the four pilot interviews were beneficial for a number of reasons.

First, the pilot test provided me with an opportunity to test, amend and refine the provisional interview protocol to ensure the adequacy and utility of the interview questions. More specifically, it enabled me to identify questions that should be retained or omitted in the formal interview.

Second, the pilot study helped me to develop an in-depth interviewing skill. It highlighted the need for, and benefit of, taking a flexible and adaptive approach in conducting an interview according to the situation and context. This will be discussed in more detail in the next section on formal interview. Another aspect of this point was the awareness that special consideration required with regard to various and appropriate means of collecting sensitive data, such as background information, whether or not to include a mini-survey in
the interview schedule, the point at which to collect that information during an interview and handling special circumstances. This study could be viewed as fairly sensitive research in which the reminiscence of an unpleasant scenario or intrusion into personal experience might occur during an interview.

Third, the pilot interview gave me an opportunity to practise organisational aspects of interviewing, for example, tape-recording an interview, note-taking and so on.

The pilot study thus allowed me to reflect on the contents and process of the interviews. This, in turn, helped me to improve the quality of data collection before the formal process.

**The formal interviews**

Data collection occurred through 17 face-to-face interviews of about 45 minutes to an hour in duration, during which I was able to ask individual participant about the ways in which they organised their respective lives and managed the challenge of combining the roles of paid employment and unpaid caregiving. The face-to-face approach enabled ‘communication-like’ dialogue in which both interviewer and interviewee played an important role. In addition, this approach focused on participants’ perspectives; the individual account was being sought and was highly valued.

Most interviews took place during the participants’ working hours, and at a place that was convenient to them, either in their office or at a quiet venue near their workplace (such as a meeting room in a library). All interviews were audiotaped to ensure the accuracy of the data collected, and later transcribed verbatim and in full.

Organising an individual face-to-face interview, in terms of selecting a venue and a time that suited the participant, was a complex task. The assignment became even more challenging for interstate interviews. Planning to interview as many participants as possible in a short interstate trip proved to be fairly demanding. The difficulty was compounded by the reality that some of the participants were shift-workers at the time they were interviewed. Thus, fitting their schedules in with those of other participants was extremely
hard. Nevertheless, the process of engaging with potential participants sometimes involved numerous telephone calls and email messages which helped to build and establish a rapport and trust between the participants and me. I felt that I knew the participants well by the end of each interview.

There is no doubt that being friendly and demonstrating good social skills helped me to build a rapport with the participants. Furthermore, my belief that the thoughts and experiences of the people being interviewed were worth knowing, and my appreciation of those who were willing to share their stories and experiences, certainly helped me to establish and develop a relationship with the participants. Developing a rapport with individual participants has been the dominant theme in the literature on interviewing (Berg 2009).

Whereas recruiting participants is deemed to be a difficult process, interviewing people is definitely a rewarding experience. It is challenging but stimulating, and it provides an opportunity to enter another person’s world for a short period of time, as well as testing the researcher’s social, intellectual, emotional and physical abilities (Patton 2002).

**The flow of the interview**

I usually began an interview by thanking the participant for agreeing to participate in the study, then obtaining a signature on the consent form from the participant. This confirmed the participation and enabled the interview to be audio-recorded. The participant was given the interview schedule prior to the commencement of the interview. While the interviewees skimmed through the questions, they were briefed about the importance and the purposes of the study, and were reassured about privacy and confidentiality. The procedure of firstly sending an ‘information statement’ to potential participants, and then a briefing prior to an actual interview, was designed to give participants enough information to decide whether or not they truly wished to participate (O’Leary 2005).

Although an interview schedule was handed to the participant during each interview, it did not necessarily determine the order of the conversation. I was mindful that relying too
heavily on the interview schedule might yield data of little depth rather than uncovering new ideas. I was open to unexpected clues. In fact, individual interviewees were expected to have their own unique experiences and special stories to tell, and to describe an episode, a linkage or an explanation (Stake 1995).

I commenced the formal interview with the questions that were the least demanding and required minimal recall. Those questions were usually related directly to the caregiver’s work and caregiving roles, and were fairly easy to respond to, as the interviewees basically described routine activities in their daily life. As the participant began to engage in conversation, I guided them towards more specific issues such as the challenge of combining multiple roles. The approach is referred to as ‘funnelling’ by Minichiello, Aroni and Hays (2008) and refers to a process of questioning in which the interviewer controls the flow and type of information being asked for by starting the interview with questions of a general and broad nature (p. 94).

On other occasions, an alternative strategy termed ‘story telling’ was utilised. I asked questions in such a way that the participant felt comfortable responding with a story. I confirmed the approach proposed by Askham (1982) and described by Taylor and Bogdan (1998) as an appropriate and effective way of conducting the interviews – an approach that enabled interviewees to share their stories at their own pace and in their own preferred order. This practice maximised the opportunities I had to hear and to become familiar with specific stories before asking more probing questions about the perceptions and meanings that the participant attached to the lived experiences of being a working caregiver. Caregivers told their stories by providing examples to illuminate the emotional side of caregiving and the impact of caregiving on their social life, as well as on their employment. For example, when asked ‘how is your caring role’, Haidi started the conversation by telling me the routines of her daughter, and her daughter’s interactions with other children, including her siblings. She expressed the emotional impact by telling the story of being asked to pay a fee that is equivalent to the cost of a private school education in order to keep her daughter in a government school. The conversational/story telling style created a relaxed atmosphere, allowing the interviewee’s perspectives and experiences to emerge.
During an interview, I often nodded my head or offered other non-verbal acknowledgments to reassure the interviewee that their responses were supported, and to encourage continued talking. Effective listening involves giving feedback to the participant in a normal social conversational form (Minichiello, Aroni & Hays 2008). I understood that an interview should be operated as a two-way communication, an ‘interactive practice’ (Holstein & Gubrium 1995).

I would run on alternative questions to the interviewee if their responses did not really answer the initial question, or there was a need for clarification or further articulation on an issue or an activity. Furthermore, I would ask a few questions that were likely to yield the same or similar data to ensure the accuracy of the interviewee’s perspectives.

When approaching sensitive questions, such as those related to support in the workplace for their caregiving role or the plan for their future career, some interviewees expressed concerns about how the data would be used, although the issue of confidentiality and privacy had been addressed on several occasions. However, interviewees became more relaxed when they were assured that the doctoral study was my own personal project, undertaken with the aim of providing a better understanding of their experiences of being a working caregiver. Anonymity and confidentiality were assured so that interviewees realised that what they had shared with me would not be reported back to their respective organisations. The trust, rapport and interaction that we had established enabled me to explore, probe, ask questions freely and pursue certain questions in greater depth.

Background and demographic information were obtained at the end of each interview by asking the interviewee to tick relevant boxes in a mini-survey. However, in most cases, this information was gained during the course of an interview (for example, the information about marital status was obtained through asking questions such as ‘do you have children to look after?’; and information about a participant’s education status could be obtained when they described their current position).
My role during a semi-structured interview was mainly that of a facilitator aiming to maintain control and enhance the quality of responses. I reminded myself constantly during all of the interviews that it was important to keep the balance between being a sympathetic, patient and non-judgmental listener and being a passive interviewer who might lead to participants to feel unacknowledged. This approach reflects the fundamental principle of in-depth interviewing, that is, ‘to provide a framework within which informants/participants can express their understandings in their own terms’ (Minichiello, Aroni & Hays 2008, p. 85).

I recorded all of the interviews, as I believe that an audio-recorder is an appropriate way to record the modalities of speech. This allowed me to interact naturally with the interviewees without the distraction of note-taking. In addition, tape-recording makes it possible to maintain the raw data aurally and authentically. While I did not use the note-taking method for the interviews, I did jot down everything that was considered worth noting, such as participants’ body language, and I took field notes after the completion of each interview.

3.6 Data Management and Analysis

Data analysis is ‘the process of rigorously and systematically arranging and presenting information in order to search for ideas’ (Minichiello, Aroni & Hays 2008, p. 258). It is considered to be a reflective and ongoing process during which researchers may need to read and re-read all documents, especially the transcripts, in order to work back and forth between data and ideas, for a substantial period. Analysis in qualitative inquiry involves ‘sorting, organizing, and reducing the data to something manageable and then exploring ways to reassemble the data in order to interpret them’ (Schwandt 2007, p. 7).

This section describes the preparation of the interview data and the data analysis process that was used in the research. It covers how data was transcribed, reduced and managed, and how analysis was conducted manually and with the use of NVivo 7 software.
3.6.1 Data management and preparation

All documents related to the current study were kept securely, with access restricted to my supervisors and me. The names of each participant were replaced by a nominated pseudonym and identification number prior to submission to a professional transcription company to transform the record of interview into textual form for coding and analysis. The ‘verbatim’ transcripts were checked against each respective audiotape to ensure they accurately reflected what had been said by the individual interviewees.

The data were managed with the use of NVivo 7 through the creation of a case node for each participant. Attribute data for each case including age (or age group), gender, caregiving role (caring for whom), and paid employment (organisation and employment status) were recorded using the function of classification, were attached to a case node, and then retrieved through casebook, a table in which there is a row for each case and a column for each attribute recording items of information that apply to all the data for a particular case. The case node brought together data from documents, such as journal and interview transcripts, so that I could instantly access everything I knew about a particular participant.

Two common ways of reducing data into meaningful groups, namely ‘conceptual mapping’ and ‘block and file’ (Grbich 2007), were utilised for data management and data analysis. Conceptual mapping is defined by Trochim (2008) as a structured process, focused on a topic or construct of interest, involving input from one or more participants, that produces an interpretable pictorial view of their ideas and concepts and how these are interrelated. This approach was used when I tried to draw linkages between ideas, the relationship between common patterns. It was also a main means that helped my supervisors and me to think more effectively and manage the complexity of ideas as the mapping provided an appealing, visual and logical summation.

Block and file is one of the two methods used frequently to reduce data. Conventionally, responses to a specific question can be underlined, italicised or colour-coded to keep them within the context of the overall interview data. The modified block and file approach was
exploited in the NVivo 7 program. Relevant passages were grouped and placed into TreeNote (in NVivo) under provisional headings and subheadings.

A case study approach uses a bottom-up approach to data analysis, that is, inductive analysis. More specifically, thematic analysis, a common technique for making sense of textual data, is used to analysis texts or words (Grbich 2007; Maxwell 2005; Patton 2002). Schwandt (2007) defines qualitative analysis as ‘working from the data of specific cases to a more general conclusion’ (pp. 146–7). The inductive approach is a systematic procedure for analysing qualitative data where the analysis is guided by specific objectives. The primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant or significant themes inherent in the raw data, without the restraints imposed by structured methodologies (Schwandt 2003).

Inductive analysis begins with the inventory and definition key phrases, terms and practices that are special to the people who participate in the study – the emic (Pike 1954) analysis; in other words, it seeks the indigenous categories (Patton 2002). The term emic (insider) refers to the language and categories used by the people researched. It is then followed by etic (outsider) analysis through which researchers develop terms to describe inductively generated categories – sensitising concepts (as opposed to purely indigenous categories or concepts). I am taking an etic stance in analysing the data.

Researchers use inductive analysis in order to make inferences from data, and to establish clear links between research objectives and the summary findings derived from the raw data. Conclusions are drawn from a sample that covers a reasonably wide variety of circumstances. One of the key elements of this approach is that data analysis is an ongoing process. In other words, while ultimately full analysis of all data will be carried out, researchers analyse the data during the phase of data collection. Researchers use the early findings to amend their research designs and inform the way in which the research process continues (Green 2002).
Qualitative analysis consists of writing up separate cases followed by cross-case analysis with the objective of searching for patterns and themes that cut across individual experiences. The initial focus of this process is on fully understanding individual cases before those unique cases are combined and aggregated thematically. This helps ensure that emergent categories and discovered patterns are grounded in specific cases and their context (Glaser & Strauss 1967).

Due to the word limit for this dissertation, it was impossible to write up all cases in the form of a case study report. The selection of cases to be included in chapter 4 was a most difficult task. Nine individuals were selected to be represented as full case studies as they are all full-time employees (with diverse characteristics), working for different industries with different degrees of control in their workplaces, and providing care for one or more family members with dissimilar needs. Thus, the cases provide rich information in terms of working caregivers’ stories and experiences, as well as their perspectives on issues such as their relationship with care recipients and other family members, colleagues and friends, their need for social support, and so on. There is much to learn from those cases as they are so different from each other. They yield high-quality, detailed descriptions, which are useful for documenting uniqueness.

As the final sample of this study is quite diverse, data collected from all interviews (17) were analysed. Any common or shared patterns that emerge are of interest and value in capturing the core experience and central, shared dimensions of a setting or a phenomenon. They are presented in chapter 5.

Thematic analysis is a common type of qualitative data analysis and is the method employed for this study. The focus of thematic analysis is to identify codes, sections of a text from the transcripts recorded through face-to-face interviews with the participants (or field notes and documents) that appear to contribute to emerging themes. It is a process through which a researcher engages in systematic examination and re-examination of the data. This involves, first, reading each individual transcript and making sense of the interview, and reading the transcript as part of a collective set and making sense of what is
being said by the participants as a group in order to obtain meaningful categories that can be grouped to form a theme or a series of themes. Themes emerged from the experiences of those being interviewed and their views on the issues or phenomenon.

As noted earlier, the NVivo 7 program was used to aid the data analysis process. This computer program enables meaningful chunks of data to be identified, retrieved, isolated, grouped and regrouped for analysis. Following the steps covered in the previous section (data management and data preparation), that is, typing all field notes, submitting the audio-recording for transcription and amending the interview transcripts, detailed analysis with a coding process occurred. While the steps involved in analysing data for the doctoral study are outlined below, it is worthwhile to note that the analytical procedures are not in linear form, but rather a process that is recursive, dynamic, intuitive and creative. It is a process that requires constant inductive reasoning.

### 3.6.2 Data analysis

Rossman and Rallis (1998) describe coding as the process of organising materials into chunks or segments before bringing meaning into information (p. 171). The initial coding process refers particularly to the process of generating free nodes and building tree nodes. The term node is used to indicate either a terminal or a connection in a branching network in an information system. There is no difference in a fully developed NVivo program. Nodes are defined as points at which concepts potentially branch out into a network of sub-concepts or dimensions (Bazeley 2007). They provide the storage area in NVivo for references to coded text. While free nodes serve simply as temporary ‘dropping-off’ points, tree nodes are critical places at which relationships or connections are established, and serve as connecting points for subcategories. Thus, each free or tree node serves as a container for what is known about, or evidence for, one particular concept or category (Bazeley 2007, p. 15).

When I was producing codes, I was mindful of a principle outlined by Minichiello, Aroni and Hays (2008) that codes need to be conceptually based and clearly defined. The devised codes were related to the research questions proposed and fitted into a conceptual scheme.
A coding manual consisting of category names, rules of assigning codes, and examples was developed. Doubts and problems concerning the definitions of categories, coding rules were discussed and resolved with the help from the supervisors. Coding consistency check was carried through numerous supervisory meetings.

The initial coding categories were revised, changed, and combined or deleted as some categories overlapped one another and could be collapsed. Each code (free or tree node) was given a name. Words, sentences or paragraphs were coded into relevant free or tree nodes. The coding process provides not only the information needed for writing up the case study reports, but also the basis for the themes in chapter 5, the findings.

The coding process was followed by the task of constructing the unique cases and telling stories. The nine case studies (to be presented in the next chapter) are at the heart of the doctoral study and the centre for the generation of insight. The case studies aim to describe each individual caregiver’s experience in depth and detail, holistically and in the context of working and caregiving, without pigeonholing or categorising those cases (Glaser & Strauss 1967). The case study report provides richness, depth and meaning, which is the key contribution of qualitative research. The process of writing the case studies enabled me to become familiar with each case as a stand-alone entity. This, in turn, has helped me with the analysis across cases.

Following the completion of the writing of the case studies, the focus was on interpreting and integrating what had been said by different participants – the preparation for constructing the findings chapter. The ‘pattern coding’ (Miles & Huberman 1994) process that aims to search for patterns, themes and relationships was carried out with the help of the NVivo 7 program, and was based on all the interview data, including nine case studies. The process involved encompassing and connecting concepts that come from any two or more of the tree nodes.

While data are both evidence and clues from which knowledge and understanding are drawn, it is the researcher’s responsibility to identify common themes that link issues
together, and ground the analysis in the participants’ understandings (Minichiello, Aroni & Hays 2008). One of the benefits of writing the case study report was that I was forced to look for and explain similarities within groups and intergroup differences, as well as degrees of consistency by making comparisons between cases. The idea behind cross-case searching tactics is to force investigators to go beyond initial impressions, especially through the use of structured and diverse lenses on the data (Eisenhardt 2002).

It is worthwhile mentioning that the themes and patterns are dynamic. This leads to the next step in the data analysis – the revision stage. As thematic structures and overarching constructs emerged during analysis, it was necessary for me to peruse the field notes and interview transcripts many times in an attempt to work from the bottom up and stay grounded. In addition, I had numerous meetings with my supervisors during which patterns and themes were contemplated again and further condensed and organised, culminating in three decisive themes (refer to chapter 5). The amendments were carried out with the use of the ‘set’ feature in NVivo, so that the themes that appeared as key findings were placed under headings. The revising stage also served the purpose of ensuring that final themes adequately accounted for the data across the cases.

I constantly wrote memoranda to record and keep track of ideas about how categories or dimensions interacted and fitted together into a larger theoretical whole (Silva-Smith 2007) throughout the entire process of analysis. In addition, I included the changes that I had made to the coding system and the reasons for doing so in the memoranda. Furthermore, I used the dated memoranda for recording the thoughts about relationships among the data.

Initially, I was reluctant to make changes and attempted to maintain the stability of the coding system as far as possible in the early stage of data analysis. However, I gradually came to a realisation that was stated by Coffey & Atkinson (1996, p. 32):

*codes are organizing principles that are not set in stone. They are our own creation, in that we identify and select them ourselves. Codes are tools to think with, and can*
be expanded, changed, or scrapped altogether as our ideas develop through repeated interactions with the data.

The focus then was on how to balance flexibility in coding with purposefulness and consistency (Bazeley 2007).

3.6.3 The role of the researcher and the issue of rigour

The nature of the researcher’s role is an important aspect of qualitative research. Marshall and Rossman (2011) categorises the issues related to a researcher’s role into two groups – technical and interpersonal. The difficulty involved in negotiating entry and maintaining access to the industry partners can be considered as the issues related to technical. The persistence and patience required to get in touch with potential participants, the importance of building a rapport and trust, the skills needed to be an active and thoughtful listener while having an empathetic understanding of, and profound respect for, the perspectives of others, can be categorised as interpersonal issues. Both technical and interpersonal issues have been covered throughout this chapter.

This section continues the discussion of the researcher’s role by focusing on the issue of rigour, especially those issues related to ethical consideration as well as the strategies that are available within qualitative research to protect against bias and enhance the trustworthiness and authenticity (Guba 1981; Guba & Lincoln 1989; Lincoln & Guba 1985) of findings. Researchers are responsible for anticipating possible ethical issues that could occur at all stages of research from research planning and design to data collection, data analysis and interpretation, writing, and finally dissemination of the findings.

There are two aspects of ethical concern in qualitative research: formal ethics approval and the notion of ‘situated ethics’. While the former refers to the formal documentation and procedures that a researcher must follow in order to obtain official approval for conducting a study, the latter highlights the importance of the need for a researcher to make complex and sensitive decisions in particular cases and settings (Simons & Usher 2000).
As noted in the earlier sections, concerns with regard to reciprocity, obtaining informed consent, and protecting human participants’ anonymity and privacy were thought out carefully during the design stage. These issues were addressed in the documents created for the study, some of which were sent to potential participants, while others were submitted to the Ethics Committee for approval as appropriate (refer to the appendices).

Situated ethics, on the other hand, is local and specific to a particular practice. Thus, it is immune to universalisation (Simons & Usher 2000). All participants in this study were reassured that it would not place them at risk of damage to their professional or employability. I was aware of the possibility that participants might not answer certain questions, or might even provide misleading statements during an interview because of their perception of the purpose of the study as well as ‘different and unexpected interpretations by participants of the meaning of the researcher’s question, depending on the words used’ (Bowden & Green 2010a, p. 109). Thus, as discussed earlier, I had included a few questions or prompts, such as ‘if you could design a perfect job for yourself, at this stage of your life, what would it be?’ that would entail the same or similar responses or answers at various sections in the interview schedule.

I was also mindful of, and vigilant about, the possible reactions from participants when approaching some sensitive questions during each interview. As noted in the early section, participants were also given surety that anything they shared with me, regardless of personal experiences or suggestions or criticism about their current employers, would not be disclosed to anyone or reported to the personnel higher in the work hierarchy. Furthermore, I constantly reminded myself during the writing stage that any information that might reveal an individual’s identity had to be eliminated in order to assure confidentiality and anonymity.

Rigour is an alternative term used by qualitative researchers to indicate that the researcher has taken due care to ensure that the research has been conducted in a fair and rigorous way in qualitative research. Rigour in research requires that the results of the study and any examination of the process of itself can illustrate clearly that the researcher is trustworthy.
Trustworthiness is the extent to which the researcher’s findings accurately reflect the purpose of the study and represent the reality and ideas of the participants (Holloway 1997). According to Lincoln and Guba (1985), trustworthiness has several elements. In other words, researchers can employ a number of strategies to ensure the trustworthiness of a piece of research. One of the methods used in this doctoral study is what the authors refer to as member checking. This technique, according to the authors, involves taking data, analyses, interpretations and conclusions back to the participants (Lincoln & Guba 1985). It is believed that participants should play an important role in directing, as well as in acting in case study’ (Stake 1995). For the doctoral study, it was not feasible to take my preliminary analyses back to the participants due to the constraints related to time and access to industry partners. However, I tended to ask questions in different ways or pose different questions to interviewees about the same topic during all interviews. This approach enabled me to cross-check the information provided by participants and to obtain as accurate an understanding of participants’ interpretations as possible.

Peer review or debriefing was another tactic I utilised to ensure the trustworthiness of the study. The role of peer reviewer defined by Lincoln and Guba (1985) as ‘devil’s advocate’ provides an external check of the research process (Ely et al. 1991; Lincoln & Guba 1985). The strategy was exercised throughout the whole journey of the doctoral study, through supervision meetings, informal conversations with former and current colleagues, family members and friends, and formal colloquia or conferences to find out whether my supervisors and other colleagues arrived at a similar interpretation when shown the data and the analysis (Lincoln & Guba 1985).

While member checking and peer briefing are part of credibility, one of the components of trustworthiness, other elements of trustworthiness include transferability and confirmability. Transferability means that findings in one context can be transferred to similar situations or participants, and rests in the hands of the readers. It could be achieved through purposeful sampling, by providing a thick description and by describing as accurately as possible. The
concept confirmability signifies that the findings are the results of the research, that is, it emphasises the objectivity of the study. However, the quality of research, in particular those involving human participants, can be improved firstly by acknowledging the existence of inherent subjectivity, and secondly through rigorous research practice (Bowden & Green 2010a).

According to Bowden and Green (2010b), there are three different types of voice of the researched/participants. They are the individual voice (individual participant), the collective voice (a combined voice discussed and agreed upon by a group of people), and the researcher-interpreted collective voice. Rigour in research practice includes a researcher’s commitment to make every research action a means for maximising opportunities for the researched to make their own voices heard, and minimising the extent to which those voices are filtered. As noted in previous sections, during each interview I was mindful of the reality that the voice of participants is located in a given time and place of the data collection, and I tried to create an atmosphere that allowed participants to express their perceptions freely. I also made an effort to represent each individual’s filtered voice and/or expressed perspectives as faithfully as possible (Bowden & Pam 2010b, p. 124) when constructing case study reports. Qualitative researchers must also be reflexive and show that the data can be traced back to its origins (Lincoln & Guba 1985). Themes that cross all cases (the collective voice of participants) are presented in the finding chapter. Implications of how the issues related to combining paid employment and unpaid caregiving (researcher-interpreted collective voice) can be addressed are discussed in the final chapter.

### 3.7 Summary

This chapter described the design of the doctoral study. This included the underpinning rationale of choosing a qualitative case study approach for the research; the development of interview schedules; the sampling strategies; the data collection procedures; and data management and analysis.

In addition, a discussion was presented in this chapter about the difficulties involved in gaining the initial access to the industry partners from which the participants were recruited,
and the effort of maintaining that access. Furthermore, the researcher’s role and the issue of
rigour in a qualitative study – in particular, research involving human participants – were
considered.

The findings of the research will be reported in chapters 4 and 5, namely, the case studies
and the findings chapters respectively.
CHAPTER 4 – BALANCING THE ROLES OF PAID EMPLOYMENT AND UNPAID CAREGIVING: CASE STUDIES

4.1 Introduction

This chapter presents the nine case studies that highlight how individuals perceive the experience of balancing the roles of paid employment and unpaid caregiving. The chapter provides a brief description of the research participants, followed by the presentation of the case studies, which reveal both the challenging and the rewarding experiences of working caregivers.

A review of literature, as conducted in chapters 2, reveals that issues related to simultaneously managing paid employment and unpaid caregiving revolve around both work and family domains, especially the demands emanating from work and caregiving responsibilities. The perceptions of the experience of being a working caregiver are also influenced by the overall available resources. These include individuals’ competency about work and caregiving, their education/occupation and personality, as well as whether they receive external support for their multiple responsibilities. The relationship between caregivers and care recipients, caregivers and other family members further influence the perceptions. The impacts of those experiences on the life of a working caregiver, according to the extant literature, include, but not limit to physical, emotional and financial components.

The development of the interview schedule, the strategies employed for interviews and data collection, and the subsequent presentation of this chapter, is guided by the broad reading and thorough review of the existing literature. However, while the cases are introduced and constructed under similar headings and subheadings, the perception of the experience of each individual is shaped by who they are and the context in which they work and live. Each case is presented in a vertical way with a great depth. Thus, the stories show patterns of similarities, but also differences. This contributes to the richness of the data. The aim of this chapter is to present the cases so that the themes can emerge.
4.2 The Caregivers: General Information

All of the participants who were involved in the study were recruited from the two organisations mentioned in chapter 3. At the time when the interviews were being conducted, all interviewees were employed by one of the two organisations while being responsible for looking after one or more family member who was either a frail elderly person, a child with a disability, a spouse with a life-threatening disease or a person with long-term health problems. Interviewees might also have been responsible for providing care for more than one person in any of the above categories.

The majority of participants were employed full-time and had a long tenure in the organisations. Nearly all of them had no intention of exiting the workforce, at least in the short term. Most of them wanted to retain their job for as long as possible, due to short-term and long-term financial burdens. Some of the participants were shift workers and preferred to maintain their current employment arrangements, once again due to financial pressures.

All of the participants were primary caregivers, if not the only caregiver to their family members. Most carers provided informal caregiving to more than one person with special needs. Caregivers spent approximately 25 to 30 hours, excluding weekends, on their caregiving responsibilities. While not all care recipients were living with carers, the unpaid caring role virtually became a 24-hour-a-day ‘career’ for those carers who resided with care recipients.

The nine cases are presented below. For ethical reasons with respect to anonymity, pseudonyms are used for all participants, care recipients and other family members involved, such as a husband or wife and other children in the family. Any demographic information, such as age and marital status, in the following text and in the tables in the appendices, refers to the situation at the time of the interview, from mid-2008 to early 2009.
4.3 The Case Studies

4.3.1 Terri

Snapshot

Terri is a 34-year old full-time librarian who lives alone and has been with her current employer for nine months. Prior to taking up that position she worked for an organisation interstate, where her parents reside. She is the only carer for her parents, who were diagnosed with different forms of cancer one year apart.

Terri stopped working while her mother was bedridden following an operation and after her father underwent surgery. She was in and out of the workforce a few times due to her caring responsibilities. Flying interstate every two or three months for a week or so to help her parents with their medical check-ups and hospital visits constitutes Terri’s current caring responsibility.

The demands of work

Terri works 35 hours a week as a technical librarian. Her work is a combination of information service provision and cataloguing. More specifically, she is involved in cataloguing books, and anything associated with technical services is her responsibility as she is a technical librarian. The duties she performs fluctuate from day to day; work demands vary, and are in line with the organisation’s timetable. Client enquiries and face-to-face demands are minimal at times during the year, but the accumulated backlog of work keeps her busy.

While being a librarian might not be considered physically demanding, one needs to be mentally resilient to deal with the emotions and assorted behaviours of clients of different ages, from 17 onwards. Terri has a Master’s degree in business IT, as well as a librarianship
qualification. She is not only a competent librarian, but also loves her work as ‘it has a lot of varieties and it is stimulating’. She enjoys the pace of her work, which is demanding, but not excessively so. Thus, she feels very fulfilled day to day when she sees clients satisfy the service she provides.

When Terri is at work, she dedicates herself totally to the tasks at hand, and focuses completely on her job; she is able to put aside her home commitments and her personal situation. Terri knows that her parents will make contact with her if there is an urgent issue. In addition, Terri has a good relationship with her parents’ doctors, whom she can contact if she has a concern.

*I have a good relationship with their doctors. If I ever thought that they might be hiding information from me, I will call up their doctors. And I know all their details and I have all their medical records. I have a copy with me as well, and I’m very comfortable now that we have a good understanding of the situation and how we choose to support each other.*

Terri believes that people who have been in a caring situation ‘work very well in a crisis, being able to act and react at a moment’s notice’.

**The demands of the caring role**

**Caring for elderly parents with health problems**

Terri’s parents are in their late fifties. Her mother was diagnosed with cancer and had to have an operation in 2005 when Terri was living and working in the United Kingdom. Terri was informed of the situation a couple of days before her mother underwent the major surgery. Her father could not bear the possibility of not letting their only child see her mother, in case the surgery went wrong. In fact, doctors did not think she would live. Terri was shocked by the news. She quit her job and left her apartment and her boyfriend in a very short time in the hope of seeing her mother for the last time. Terri was thrust into a new environment of hospital and sickness.
Terri’s mother lost her mobility after surgery and was bedridden for a few months, which affected her a great deal emotionally. She learned to be completely dependent on Terri as a friend as well as a daughter with whom she could really talk. Consequently, the mother-daughter relationship was strengthened. However, this did not happen overnight. Initially Terri was upset and kept all of her emotions to herself, and did so for a very long time. When her mother was quite self-sufficient and her health was on the way to recovery, Terri moved interstate to have a break from what she described as the ‘unwell’ environment.

Unfortunately, one year later in 2006, Terri’s father was diagnosed as having cancer (a different form from that of her mother). She was studying in Melbourne at the time. Terri went through a similar process as she had with her mother: transferring her studies, cancelling her lease, packing up her house, and moving back to Sydney as soon as possible. She was by her father’s side while he went through a set of treatments including surgery, chemotherapy, radiotherapy, physiotherapy and various other allied health complementary therapies.

The demands of caring were substantial for Terri as her parents had different oncologists and, therefore, needed to go to different hospitals for appointments with their doctors. She also had to learn how to provide special assistance, such as giving injections and organising the prescribed medication for her father. Their house was occupied by many types of medical equipment, and had to be very sterile and functional. In Terri’s words, the house became ‘very unhomely’ and ‘wasn’t a warm environment’.

Terri’s father experienced extremely intensive chemotherapy treatment, comprising three chemotherapy treatments one week, then four the week after. This cycle occurred for months. He became very weak and his immune system was compromised. He was not supposed to be outside in crowds of people and was very housebound. While Terri’s father was getting used to the chemotherapy, side-effects such as the loss of his hair, and the special diet that he endured, made him emotionally unstable. It was very difficult for Terri and the family. Terri put it this way: ‘I think when something so life-altering comes into your life, there’s a lot to deal with.’
After being a full-time caregiver for a few months for the second time in a year, and while she was living with and providing assistance to her parents, Terri found a job. Six months later, she was ‘forced’ by her father to relocate to another state as he did not want to be a burden for his only child any more. He blamed himself for interrupting his daughter’s career and study.

Neither of Terri’s parents was having chemotherapy at the time of Terri’s interview: they had completed their course of treatment 9 to 12 months earlier. It had been a long wait for Terri to see her parents reach the stage of remission. Nevertheless, her parents were required to have regular tests to ensure that there was no need for further treatment.

**The experience of being a caregiver**

**Hardships and negative elements**

**The impact on emotional well-being/behaviour**

Having both parents diagnosed with cancer, and being around other sick people and doctors, was in Terri’s words ‘really traumatic’. The stage when Terri’s parents were on high dosages of medication was exceptionally challenging for everyone. Terri had to cope with her parents’ changing emotions and the ways in which they responded to everyday life, given that they were on mood-altering drugs. As a result, Terri’s life became a rollercoaster of emotion on a day to day basis. In addition, while she was attempting to concentrate on her job fully, Terri found that her personality and energy levels had changed. She was not as outgoing as she had been previously, and not as cheerful and upbeat.

Terri described the change this way:

> So some days we would be awake all night [because of] a side-effect of the drug. Or someone would be sick all night. And I would always be tired or emotional or upset, and that was just how I was dealing with the situation, and that was the effect. It wasn’t actually who I was as a person.
There were definitely fluctuations in Terri’s emotional health. Some mild symptoms were directly stress-related and were diagnosed by a specialist. Terri said that her doctor told her ‘you are still quite young and it can be very emotionally affecting and often carers can become quite depressed’. She reflected on the situation from her viewpoint: ‘I was at home with my parents, but couldn’t share it with them.’

In addition, the daily routine of a caregiver is greatly affected by the care recipient, mainly because a caregiver goes through much that a care recipient experience. This was the case for Terri. She did not eat if her parents did not eat, and did not sleep if her parents did not sleep.

**The impact on the establishment of new relationships**

When Terri first found out about her mother’s health condition, she did not tell her boyfriend, and did not notify him at all when she left the United Kingdom. She has not felt able to contact him since, and is still feeling guilty about her silent disappearance:

> I didn’t know how to tell someone, ‘I think my mum’s going to die’. I didn’t know how to, I didn’t want to say it. So I couldn’t tell him why I was leaving. So I didn’t tell him, which is really – I feel really bad about it, but …

> I couldn’t do anything at the time. And … many years later, or even a year later, I thought about contacting him, and saying, I’m sorry, I didn’t mean to. But sometimes that makes things worse, to explain it. Hopefully he just forgot about me, or something, or moved on. And I don’t know how you explain to someone all the feelings that you go through when you’re going to lose someone, and when you’re caring for someone.

She wished that the relationship had continued, but being with her mother, and seeing her for perhaps the last time in her life, was her priority at the time.
I didn’t want to stop the relationship but I had to focus on my family. I was far more concerned about losing my mother.

Caring for her parents has been Terri’s main concern. The sense of responsibility for caring for her parents could take over at any moment. She is aware of the difficulty of keeping friendships once people realise that they will never be her highest priority. This is one of the factors that has contributed to her hesitation to start a new relationship. Thus, Terri has not been able to establish a new relationship for the last three years.

Unfortunately, if I could’ve been more sensitive to other people, I would’ve, but I wasn’t in a position to be. It’s very difficult to be in a position where you have to prioritise people. I had to put my parents’ health and wellbeing above my own needs, and above the needs of people in my life. And it’s very difficult to tell someone that they’re ranked lower, that I can’t give them attention. So yeah, that’s very difficult to do.

I think people who I know, who I’m friends with, they understand if I am anywhere in the world, I will always answer a call from them [her parents], and can get on a plane and come back and help them.

While a sense of guilt about leaving her previous partner without communication is still with Terri incessantly, she excused herself by saying that it was the first occasion on which she had had no idea how to handle a situation. However, this was against her primary principle in a long-standing relationship, which is being honest with each other. During the interview, Terri emphasised her belief that there should be no secrets between a loving couple. Thus, hiding one’s responsibilities and obligations from the other party is unacceptable. She was deeply affected by the incident, and has no courage to venture into another relationship.

The impact on career and study
When Terri’s mother first became ill, Terri had three days to quit her job, pack her belongings, and fly for 24 hours from the country in which she was living and working to the place where her parents were residing, otherwise she might have missed seeing her mother. She encountered a similar scenario a year later when her father was diagnosed with cancer, and was required to have immediate surgery. Terri moved from interstate back to be with her parents in an extremely short period.

It is understood that frequent relocation and change of job due to caring responsibilities is an interruption to career and study. This has been the case for Terri. She explained the impact: ‘I am sure professionally it’s not the best thing to do, because … it is hard for someone to become settled in a job and to be able to devote oneself to work.’ However, Terri does not think that she has missed any opportunity for training or promotion at her workplaces because she never told any of her employers that she had a caring role.

On the contrary, Terri considers that, to some extent, being in and out of the workforce provides an opportunity for a fresh start. It is possible that she has been using job changes as a way of avoiding becoming close to other people and to reveal her personal commitment.

Terri recalled the situation that presented itself when she resigned from her previous employer prior to the company she was with at the time of interview:

    So being able to have the opportunity to stop that job and to start a new job allowed me to be me again … to maybe take a little bit of time out of the workforce to concentrate on yourself and to remember who you are as a person, and not just as a carer. And then to re-establish yourself in a new job as the actual person that you are.

The difficulty involved in re-entering the workforce after the completion of a caregiving role is one of the problems that caregivers encounter, and one of the key issues that government or employers attempt to address in initiatives and programs. However, Terri
has different perceptions of being in and out of the workforce, mainly in the aspect of psychological well-being (under circumstance of financial security):

… in fact, it might be a very good way of me dealing with the emotions of – because each time I’ve had to leave a job, or chose to start a new job because it’s a different stage in my parents’ illness. So when I’ve left a job has probably been the lowest point of their health, and then sometimes I’m starting a job because they’re getting better … things are becoming more optimistic …

**Positive elements**

*Improvement in physical health*

While providing care to two parents afflicted with cancer can be emotionally draining, it has also offered Terri a whole new appreciation of her own health. ‘I felt it was important, especially because they’re my parents and there’s a generational gap and a respect gap – I had to lead by example.’

By making sure that her parents had the food that complemented their respective medical diets, encouraging them to have regular gentle exercise, and introducing them to yoga and different forms of preventative medicine, Terri was actually taking very good care of her own health, adapting to a healthy diet habit and exercising regularly. That was something over which she and her parents were able to bond because ‘they felt good that I was getting something positive out of it, and that I wasn’t neglecting myself’.

*Role enhancement*

*Becoming more sympathetic and forbearing at work due to caring role*

Having survived this difficult phase of her life virtually by herself, Terri now empathises with other people who may be going through similar difficulties. She believes that carers are very used to anticipating the needs of a person who is not comfortable asking for help, does not know how to ask for help, or is unwilling to speak at the time. Terri believes that carers have the ability to look at situations, identify issues, and come up with some solutions. She believes that being a carer has made her more tolerant. In her own words:
… often I will look at my interactions with people and be far more tolerant and compassionate …

… But sure, I’m human and you have bad days, and you lose your temper because you get someone who’s taking advantage of you …

… but I’d say for the majority, the majority of times, because I personally have a new outlook on life, and a new appreciation for the immediacy and temporal nature of life.

Terri credits her ability to cope well in a crisis, anticipate others’ needs and act and react at a moment’s notice, to the experience of being a carer. She sees it as an asset to any job at any workplace.

*Becoming more competent in caregiving due to the working role*

As nobody in Terri’s family has a background in medicine, it has been difficult for her to digest all of the information, opinions and advice offered by various doctors. Overall, it was a daunting experience for Terri and her parents. In addition, a lot of issues have had to be taken into consideration because of the diseases and the side-effects of the treatments. Being a librarian has helped Terri to research and interpret medical knowledge for her parents, and enhanced her ability to understand what they were dealing with.

*Being positive about life in general*

Terri is positive about all aspects of her life, and is learning to appreciate and respect life even though it is actually quite arduous. The demanding caring role gives new meaning to her life. She realises how important it is to be positive, to make the most out of life, and to enjoy a high quality of life as the following excerpts reveal:

… Yeah. I think if you don’t go into it with a positive outlook, you can’t get anything positive out of it. I was determined – I mean, my mum had a very small percentage chance of living through the actual surgery, let alone the treatment of the cancer.
And I was determined I was not going home to say goodbye to my mum, I was going home to rehabilitate, to give her a new appreciation for life, for her to live and to live well, to have quality of life.

... So I think I will lead a much fuller and happier life because of what I’ve been through. At the same time, I wouldn’t choose it.

Even though Terri’s parents are only in their late fifties, they seem ‘old’ to her now as they have endured life-threatening illness. Although the doctors cannot predict how long her parents will live, Terri continues to have an exceptionally positive outlook, and is pleased with her current life.

Given that both of her parents have survived cancer to date, and the risks involved in surgery and other treatments, life has taken on a completely different meaning for Terri as well as for her parents. Each of them has reassessed what is important and valuable to the family, and what is not worth getting upset about.

**Family relationships**

**Parents – trying to avoid being a burden**

Terri’s parents feel guilty about what Terri has had to take responsibility for in the past few years, and hate to be a burden on their only child. They cannot bear seeing Terri’s life constricted by a routine of hospitals, medication, treatment, restrictive diets and food, and exercise regimes. They encourage Terri to seek and live her own life:

> They wanted me to totally break my caring role and my habit. So they thought a change of scenery for me would help me to change my mind-frame and just be a little bit more positive and have a better outlook ... they were very keen for me to move to another state just for a while ... So, yeah, I think it’s done me a world of good just to have new surroundings ...
Terri acknowledges that it has been incredibly expensive for her parents to go through so much hospitalisation and take so much medication. There was no financial support from the government for the chemotherapy treatments. Although some tests were subsidised, there were still many out-of-pocket expenses. Other costs included petrol, hospital parking, frequent eating out, as well as the extra expenditure on special products. Due to the side-effects of chemotherapy treatments, Terri’s parents became allergic to many regular products, and were ‘forced’ to choose products that cost more:

*When you’re having chemotherapy seven times a fortnight for six months, when you’re at the hospital, it could be one hour, it could be five hours … I know it took us months to work out what foods my dad would like to eat … And there are so many things you can’t eat when you have chemotherapy. And you keep checking ingredients to make sure that you’re not having all these things …

… And then there’s all the tablets that you have, and you become so sensitive. I know that certain fabric softeners used to irritate his [Terri’s dad] skin. So there’s extra lotions and creams and new soap and certain new clothing. Lots of hats for winter, and there’s all these extra things that you don’t budget for, that you need, you absolutely need.*

Fortunately, Terri’s parents have been able to work the financial side out by themselves. They have not been keen to share that aspect of their circumstance with Terri as they consider life has been was strenuous enough for her. However, dedicating herself to her parents’ needs and taking responsibility for looking after them her parents are the priorities in Terri’s life.

**Child – paying back to parents**

Terri’s parents had never asked her to pay any living expenses while she was residing with them. At the same time, Terri strived to contribute as much as possible, not only just being with them and offering emotional support, but doing things such as cleaning the house,
washing and ironing clothes, and purchasing groceries. She recognised what this meant to her parents:

> And it takes a huge pressure off you, because if they both had a bad day and were sick, nothing gets done. So just being in the house and doing as much as possible, that saved them from a lot of extra expense. And so that was the biggest input that I was able to give.

In addition, Terri considers that providing care to her parents has been be a privilege, as well as a way of repaying her parents for looking after her for so long. It was that thinking that first led Terri to decide to assume the caregiving role and to commit to picking up her parents’ phone calls anywhere and at any time. She can stop virtually anything (holiday, work and study) to be with her parents and offer assistance: 'I was willing to do whatever it takes to help them [parents], to support them … to try and help them as much as I could …’

**Support**

*Enduring in silence*

With the massive and challenging demands imposed by the caring role, it was supposed that seeking support would be on the agenda. Surprisingly, there was virtually no support or other sources of assistance used by Terri for her caring responsibilities. None of her colleagues knows about Terri’s situation, and she has yet to become comfortable talking about her life, in particular her caring role, with anyone in her workplace as she is still fairly new to her current company.

Another reason behind Terri’s unwillingness to share her experiences with others is that she believes people can only understand the condition if they have gone through a similar life journey. Furthermore, Terri is not keen to reveal her status as she assumes that many people now have had some interaction with cancer, so she never knows if she will upset someone else.
Terri’s emotional state can be influenced by the emotional fluctuations her parents experience, due to the effects their illness and heavy medication they take. At times she feels very fragile. Terri takes the view that everyone is entitled to have a bad day, but she does not want to be treated as though she is using the excuse of her caring role as a crutch for her behaviour. Consequently, she conceals both the caring role and emotions from others when she finds it difficult to cope with the challenges involved in being a carer.

**Private family**

At the moment, Terri’s parents are living in Sydney, and their health conditions are improving. Terri is happy and confident with the ways in which she deals with the emotional side of life, and handles the demands imposed by both work and caring responsibilities. She sets up her life to meet her parents’ needs, and keeps her co-workers unaware of her other commitments by utilising annual leave, holiday leave and long weekends to fly to Sydney to help with her parents’ hospital visits and routine check-ups.

*If it’s an emergency, I can tell work that it’s an emergency. I can take a taxi straight to the airport, I don’t need luggage. I have a spare wardrobe at their house. I have spare things at their house. It’s only a one hour and a half flight. I can be there. So yeah. There is – if it’s serious I will go no matter what. So there is nothing else that is a bigger need, there is nothing more important that will stop me … Yeah, absolutely, whenever, whenever they need it.*

Terri recognises the caring facilities and home nurses are available, but chooses not to use those services. While she understands that the horror stories revealed on the news about people being abused does not reflect the whole caring services, she does not trust the industry.

Terri has an excellent relationship with her parents. She knows exactly what they like, how they deal with situations, and how they want to be treated. She would leave her parents in other people’s hands only if it was essential. Furthermore, it is impossible for her to anticipate what will happen the next day as both her father and mother have life-threatening
illnesses, which can reoccur despite their health condition is improving. She considers every day as possibly their last in this world, and cannot envisage her parents spending their last days in some sort of home or respite care.

…it would break my heart – I would be so damaged afterwards, it would break my heart. So some minor ongoing discomfort is nothing compared to the long-term emotional consequence of that situation. I wouldn’t be able to deal with it.

…that’s why I think every carer chooses to address their situation in a way that they can live with. So I can live with changing my life and I can live with caring for my parents the way I’ve chosen to care for them. I couldn’t live with neglecting them, and I couldn’t live with passing that responsibility to someone else. So I think we all choose what works for us.

Parents’ personalities
Terri inherited a range of personality traits from her parents. She is private, proud and self-sufficient. Her parents are the same, and will not seek aid if it is unnecessary, even from Terri. They will call a taxi or an ambulance rather than a friend if they need to go to hospital. Keeping things in the family and counting on one another are the ways in which the family deals with crisis. Terri knows her parents so well:

If they needed a really personal level of care, they – I don’t even know if they would ask me for it. I would offer. If I could sense that there was a need, I would offer, and I would say, I’ve got some holidays. I’m coming to see you. Is there anything to help you with?

Terri’s parents rely upon and support each other because they have gone through similar situations. They really understand how difficult it is to ask for help. Thus, one will provide help, even when the other has not requested. They sympathise and care for each other, which strengthens their relationship.
Knowing her parents care for and understand each other, especially in this difficult time of their lives, is a consolation for Terri:

… because as an only child, you’re also worried about how your parents, how they will function as a couple when one is sick, or the other is sick, and that imbalance. So yeah, we make the best of the situation.

In real life, conversations between people will revolve around being unwell if one side knows the other is unwell. Sickness, medication, hospital visits, doctors and recovery are likely to be the principal subjects of conversation. Friendship changes occur as a result of disclosing the private and very emotional side of one’s life to someone who has never been involved. Although Terri prefers her parents to have some friends with whom they can be casual and almost frivolous, and talk about light and upbeat topics, she is more than happy for her parents to save the really challenging issues for her.

**Summary**

Terri’s experience as a working caregiver is deemed by her to have been a difficult but rewarding journey. Terri is unfortunate that both her parents have suffered life-threatening diseases, and she has been ‘forced’ to pause her life (both personal and professional). In addition to the fact that she is the only child in the family, the family is extremely private. Thus, it is nature that she became the primary carer to her parents.

Terri’s life since her parents became ill has revolved around going through everything with her parents: being by their side when they were bedridden, ‘experiencing’ their side-effects from post-operative treatments, visiting hospitals and clinics on a regular basis, living in an environment that was occupied by medical equipment, getting through nights without meals and sleep, enhancing her parents' medical knowledge, assessing advice from specialists, and searching for the best remedies that could expedite her parents’ recovery.

The reality of being a primary and sole caregiver to her parents has had a huge impact on Terri’s personal life. Her willingness to offer assistance to her parents at any time has
prevented her from venturing into a relationship. She is fully aware of the time and the energy required for a stable relationship, and her parents’ needs will always be the highest priority.

In addition to the impact on her personal life, Terri’s career life has been affected since she became a caregiver. She has been in and out of the workforce, and has relocated a few times. However, Terri has an interesting interpretation of those challenging events. She considers the broken career path to have been an opportunity to cultivate resilience, and the time spent on investigating and obtaining medical knowledge to have been worthwhile because it has enhanced her profession as a librarian. The overall journey of being a working caregiver has not only strengthened her relationship with her parents, but also made her appreciate life much more.
4.3.2 Cathy

Snapshot

Cathy is in her late thirties, and has been in a de facto relationship for five years. Since the beginning of their relationship, she and her partner, Kenny, have been sharing the caring responsibilities for Kenny’s son Arthur, who is ten years old and autistic. The caregiving demands have increased in recent years due to the deterioration of Arthur’s health.

Cathy has been working for her current employer for three and a half years. While her official role has been the Team Leader in a showroom since being promoted two years ago, Cathy has been given many projects unrelated to her current position, and the extra work has affected her performance as a team leader. At the time of the interview, Cathy was anxiously awaiting a decision from the company with regard to her request to reduce her working hours from full-time to part-time. She was uncertain about how she could continue to juggle her employment and her complex domestic work.

The demands of work

Cathy is a full-time employee. She was hired as an interior designer, but accepted a promotion to the role of team leader two years before the interview, and has never really found any pleasure in it. The main duty of her current role as a showroom team leader is to lead a team that is responsible for displaying and publicising the company’s products as well as assisting customers to choose the right products for their design and plan.

After promoting her, the company continued to acknowledge that Cathy was qualified in doing interior design and involved her in both company and major clients’ projects. Although Cathy was enjoying, and passionate about, the extra interior design tasks she was
assigned, she found that her job was getting too hard because she had to perform the role of team leader as well as the role of interior designer.

Cathy explained her situation:

… the extra project work that they’d given me was consuming most of my time and was affecting my role as team leader and it was having a massive effect on the team and I basically came to the conclusion that I no longer want to be a team leader.

After initially being delighted by the promotion to the management role, she found that she could not give the team leader role the attention it needed. As a result, Cathy had been under pressure for quite some time, and understood that she could only focus on one role, and her preference was for the role of interior designer. Cathy had formally raised the issue with her direct supervisor, and had expressed her desire to apply for an interior designer position if the company would create such a position. However, the idea was rejected. In addition, the company then stopped giving Cathy any more interior design projects. This made her more discontented because ‘they [the company] want me to stay but to me it feels like they don’t actually care about the person. All they care about is … performing the role.’

Cathy understands that the company has been struggling due to the global financial crisis. In fact, the company had recently made a number of staff redundant recently. The focus of top management has been on how to cut costs rather than create new roles. However, Cathy believes that the company should have long-term strategic plans, and individuals should be valued based on their respective skills, knowledge, qualifications, experiences and the contribution they make to the company.

Cathy expressed her view in relation to the treatment of valued employees:

To me it seems like they’re only thinking about today and not tomorrow and my thinking is if they really valued me as an employee, they would look at ways of
trying to keep me here, but they’re not. All they’re interested in is making sure they’ve got someone supporting the team leader role.

… what is the point of me staying in the industry my entire working career and being qualified for you [the company] to just go and pay me the same as someone who’s not?

Cathy also thought that the existing paid structure was not well designed. She argued that

I know of people who do or have the same title as me and they don’t contribute anywhere near as much as what I do for the company, but you’re not paid accordingly, you’re not given any benefit for it … To me, unfortunately for me to say it, but to me it feels like I’ve been used.

… they basically said well that’s how this company works. That’s how they structure their pay … So to me I think that’s completely unfair. Yeah, the title, not the person.

At the time of the interview, Cathy was anxiously waiting for the response from the company to her second request. Cathy wanted to work four days a week, and use her day off to do household chores. That way she and Kenny would have more time for their social activities. Cathy recalled that she had had a conversation with Kenny in relation to her current job last year:

I said why don’t I just work four days a week, work part-time and then those days I don’t work, I take care of all those jobs [household] so that we then have the weekend free to have a better quality of life.

Cathy would also like to do some private interior design to fulfil her real passion. She hopes that one day she can work for herself – so she is not torn between two or three roles.
However, at this stage of life, Cathy simply cannot take the risk of losing her job to pursue her passion.

Cathy’s plan for her future career is simple:

… if anything was to develop from that then obviously I’d go do it … and I thought that’d be at least a compromise to at least try and have one day off a week where I can start investigating and doing that.

However, such plans continue to be on hold.

The demands of the caring role

A stepson with Autism

Arthur’s parents felt very early on in his life that there was something wrong with their son, as he was not socialising or communicating with other children. He went through various tests, which were inconclusive, but the year before the interview he was diagnosed with Autism Spectrum, a disease that combines Asperger’s syndrome and Attention Deficit Hyperactivity Disorder (ADHD).

As well as having a low level of interaction with other children, Arthur has an intellectual disability. While Arthur knows the letters of alphabet, and can engage with talking and basic counting, what he says is simple and often does not make any sense. He has trouble concentrating and is obsessed with certain things. As Cathy mentioned during the interview, ‘Yeah so he’s very far behind in learning and that’s purely because he has a very poor attention span. He can’t concentrate for very long and he has a lot of obsessive traits, like shopping, food, lollies and money.’ Arthur does not need a lot of assistance physically. He can bathe himself and brush his teeth, though not very well.

The special school that Arthur used to attend did not work out for him, as the children in that school were severely disabled, and he was learning negative behaviours. His parents withdrew him from the school, and enrolled him in a mainstream school where he was
allocated to a particular education unit with eight children, and was watched over by one dedicated teacher and two assistants.

**Current caring demands**

Cathy and her partner, Kenny, share the responsibility for caring with Arthur’s mother (a term used by Cathy). They care for Arthur four days and four nights (from Thursday to Monday) fortnightly. Arthur needs to be occupied and entertained all the time, as he is not interested in toys and cannot amuse himself. Cathy and Kenny often have to take Arthur to places where he can burn off his energy since he can be quite disruptive at home. However, Arthur is very strong-willed and is uncontrollable at times. Cathy described the situation:

> … whatever he wants to do, he has to do it … so you’d always have to take him out somewhere and as soon as you’ve done that thing, he wants to do something else so you’re constantly on the go from the time he gets up to the time he goes to bed.

**An authoritative role**

The fact that Arthur is not Cathy’s own child does have an impact on how she cares for him, as she can only do certain things before overstepping the mark. However, she has to take the role of being authoritative, though she wants Kenny to take more responsibility. She feels that she cannot leave Kenny to handle the situation. Cathy emphasised that Kenny ‘won’t be able to deal with him [Arthur] by himself, so I do have to take on that part, which is hard because he’s not my child, but I don’t have any choice because if he didn’t, he would just completely take over our lives …’

Kenny is very supportive of Cathy taking on a more authoritative role, not only because he gets tired of repeating himself and having to yell at Arthur all the time, but also because he finds it hard to take charge of Arthur. Someone has to take the role of calming him down, otherwise he dominates wherever he goes, and is out of control. This loss of control occurs at school, at after-school care or vocation care, and at his grandparents’ place.

**The experience of being a caregiver**
The impact on health and well-being

Physical exhaustion

Caring for Arthur takes a lot of effort and time as he is an extremely active child. He talks constantly and often asks the same questions repeatedly. Cathy and Kenny feel extremely exhausted by the end of week, and often struggle to go back to work on Monday. The following excerpts portray Cathy’s real feelings:

… yep. His obsessive behaviour just completely dominates your life and because he talks so much and it can just be complete gibberish and doesn’t make sense. It’s so repetitive, you can hear him say things over, over, over, all day long, all weekend long, it just wears you down and it doesn’t ever – it’s never quiet and it just really really wears you down.

Emotional strain

As mentioned earlier, Cathy has not been enjoying her current position for a while. She admitted that being in a management role is emotionally tiring. In addition, her other assignments in interior design are mentally demanding, even though she benefits from doing them. Furthermore, facing Arthur on weekends is wearing. Cathy concluded, ‘life is never ending’.

Both Cathy and Kenny have taken anti-depressants for years. Although the reasons for taking such medication have changed overtime, Cathy and Kenny now rely on the medication to cope with the challenges of being working caregivers.

The impact on the decision about having children

Having their own child together is not on the agenda for Cathy and Kenny, although they have been together for five years. The fear of having a child like Arthur makes Cathy apprehensive about having her own child, and will not allow herself to take the risk. In Cathy’s own words:
Too frightening! Yeah, I couldn’t bear the thought of having a child that’s a baby … we only have him [Arthur] for four days a fortnight and it’s just unbearable. To think of having him every single day, we would not cope.

Another contributory factor to the decision not to have her own children is that Cathy does not want her children to experience ‘unfair’ judgment and treatment in life. Cathy believes that Arthur has been treated differently from other students at school. The school would ring his parents nearly every day to complain about unacceptable behaviours, and request that he be picked up. Arthur’s mother has been pulled out of work frequently and has to take unpaid leave – once for three months and once for six months – because no-one could care for Arthur. Cathy’s view on this issue was that ‘they [the teachers in school] were meant to be professionals that can look after these children’.

Furthermore, Cathy is concerned that if she and Kenny ‘unluckily’ had a child like Arthur, they would have to stop working or take long leave from employment, which would make life very difficult. Although Arthur’s mother took responsibility for the care of Arthur, Cathy stated that the constant worry about Kenny’s stress and the possibility of him losing his job is emotionally draining. Cathy disclosed her concern:

*I mean there’s been occasions where I’ve had to go pick him [Arthur] up after work. It’s more so how it affects you emotionally whilst you’re at work and knowing how much stress it’s causing my partner dealing with him but if he has to go pick him up, I just know how much stress that’s caused him and how much of a drama that’s caused him at work. The more times he has to take off time at work, then the more risk he’s got to his job … he couldn’t [lose his job] because you need the income to be able to look after him [Arthur]… so very stressful in so many ways.*

The reality of the struggle to find people to look after Arthur, and the fear associated with having a child together who might undergo a similar development path, restricts Cathy and Kenny’s daily life and will continue to do so in the future.

**The impact on the financial situation**
Both Cathy and Kenny endure a huge financial burden associated with paying Arthur’s medical bills and supporting Kenny’s ex-partner. The medical expenses include seeing specialists and medications, and other costs included paying someone to supervise Arthur after school. The situation gets worse when Arthur’s mother has to take long periods of leave from work when the school wants to ‘take a break’ from looking after him, or has temporarily ‘had enough’ of him. Cathy explained the situation:

…I mean even though his mother is taking time off work, he still goes to after-school care because for her to try and look after him full-time, she’d end up in a loony bin. She’d break down, which is completely understandable, I would too … I mean obviously Kenny provides financial support to her, but you know, the fact that she’s taking time off work and she’s not being paid as well, you know, Kenny has to provide more financial support.

The enormous financial pressure is one of the reasons Cathy and Kenny have not purchased a house and is behind Cathy’s endless concern about Kenny’s job and her hesitation about quitting her current employment position: ‘I don’t think we could afford to have done that [quit job], so we forgot that idea.’

**Family relationships**

**A mundane life**

The caring responsibility has an immense impact on the relationship between Cathy and Kenny. Their relation is usually on hold on the days (including weekends) when they have Arthur, because just being around him takes all of their attention and emotional strength. The days when they do not have Arthur are normally occupied by household chores, such as vacuuming and cleaning, washing clothes and shopping, because they cannot really do these things when Arthur is with them. Thus, much of their ‘free’ time is taken up with either doing things that are not enjoyable or doing virtually nothing as they are so exhausted. Cathy and Kenny rarely catch up with their friends, and mostly have no time and energy for a movie or a social life. Cathy described the routine as follows:
... we didn’t go out and sleeping all the time – that was the other problem. Kenny was just exhausted all the time, he’d be falling asleep all the time. Every time he comes home from work, he’d be passed out on the couch; on the weekend, had no energy and had just got to the point where you think what’s this all for, you know?

In addition, Kenny is available whenever his ex-partner needs help, and is willing to take Arthur regardless. Cathy mentioned in the interview that Kenny feels the whole thing (having a disabled child as well as the marriage breakdown) was his fault, and that he deserves to be blamed and punished. She did not elaborate on why Kenny has this attitude. The massive emotional baggage has remained with Kenny since Arthur was very young. Kenny would completely change his personality, and constantly yell at Arthur when he was with Kenny and Cathy. This created a vicious cycle, and had a huge impact on Kenny and his relationship with Cathy. The accumulated fatigue might then trigger Kenny and Cathy’s unhappiness, which would lead to an awful start to the week. It also left no energy to contend with stress and problems at work. Ultimately, Cathy summed up the situation:

... that’s [Kenny’s ex-partner seeking assistance] got to stop. You guys are going to have to find someone else that is going to be able to help out in these situations. The school is going to have to try harder and they need to find an after school care place that is able to look after him so that the pressure’s not on us all the time and I said when it’s our weekend, it’s our weekend. He’s constantly tired all the time and then that would make me tired and if he was unhappy, it would make me unhappy … it just feels like God when do we ever get a break, you know?

**Risk to the relationship**

It seems that Cathy was ready to cope with Arthur’s condition when she started her relationship with Kenny five years before the interview. However, the state of Arthur’s health has worsened as he has grown older. He becomes violent if he is in a bad mood. Nobody is willing to look after Arthur now, not even his grandparents. The relationship between Cathy and Kenny has deteriorated in recent years. It reached a stage last year when Cathy almost pulled out of the relationship:
It's getting too hard because no-one was helping us basically, ... so we had no-one to assist us. The school couldn’t look after him, after-school care couldn’t look after him. There was no other relatives available to look after him so it had been totally on Kenny, I and the mother.

Cathy had become frustrated as there seemed to be no solution to the problem of caring for Arthur. Nobody was prepared to help them. They were asked by the mainstream school that Arthur is attending to find another special school for him. Kenny was affected emotionally, and became depressed because of the whole situation. Cathy and Kenny have had to help out more every time Arthur’s mother cannot manage. It got to the point that everyone had absolutely had enough, and just did not know what to do next. Cathy described her feelings at that time:

… I just couldn’t deal with it anymore because he was just so out of control and I just started to think this is just getting way too hard for me because he’s not my son and when you’re not getting any answers or any assistance, you know, everyone just turns a blind eye, you think ...

Cathy started to question her ability to handle Arthur’s situation, and admitted that she underestimated the impact of caring for Arthur on her relationship with Kenny.

It was just getting to the point where I was very upset all the time and I couldn’t deal with it any longer and I just didn’t want to be at home anymore because it was just so hard to deal with, I can’t even describe it.

Cathy was weary of Kenny’s passive way of dealing with Arthur’s situation. She has been encouraging Kenny to accept the reality that he has a child with a disability, and to seek some help for Arthur before it is too late, but she was too tired to push Kenny to take action:
You’re going to have to do this, you have to do this otherwise it’s going to get worse and worse and worse, and it was, it was getting worse and worse and worse, and in the end I was basically saying, you know, how long do you want this to go on for? What has to happen? What does Arthur have to do before you wake up and realise that he is a risk to other people as well as himself when he gets in these violent ways …

Meanwhile, Kenny began to realise the enormous impact that taking care of Arthur was having on his relationship with Cathy. Kenny’s parents also came to this realisation and they became mediators between Kenny and Cathy. They could not bear the thought that Kenny might have to look after Arthur by himself, and could not risk losing Cathy.

Support

Cathy and Kenny had left the task of finding additional support beyond family for Author to Arthur’s mother. However, last year Cathy went to one of the appointments with a specialist because she was fed up with the doctors doing nothing but continuously changing medication. Cathy could not accept the doctor’s approach: ‘I mean, all they [the doctors] keep doing is going, try this medication, try that medication, they just treat him like a guinea pig basically.’

Although this appointment and a few follow-up visits helped with the diagnosis and with maintaining a regular dose of medication, Cathy realised that it was almost impossible to find the final solution in terms of caring for Arthur.

Support from society at large

Cathy was unsure about the financial support that Arthur’s mother could obtain from the government, apart from carer’s allowances. However, she did know that consultations with a private psychiatrist were not funded by the government.

Various doctors have had different opinions on Arthur’s condition. Some believe that his situation is not severe enough for him to go into formal care institutions. Cathy opposed
that view and argued that ‘it’s very easy for them to say that because they’re not dealing with him 24/7, you know … It’s just you don’t know what to do when people are giving you those sort of answers.’

Formal institutions have long waiting lists and entitlements are limited. Cathy found out that they were only entitled to a few days of formal respite care a month. She felt that this entitlement was totally inadequate:

… when it was really bad, you know, they just wanted someone to take him away because everyone was at breaking point and no-one could look after him, and that’s when they started looking at respite care … we thought that he was going to have to be looked after permanently by some form …

Cathy, Kenny and Arthur’s mother gave up the idea of using the respite service for the reasons mentioned above, and have been struggling to manage the whole situation by themselves.

Support from relatives, colleagues and friends

When Arthur was younger, his grandparents used to watch over him occasionally. However, this practice was stopped due to Arthur’s violent tendencies and his uncontrollable behaviour. No other help has been utilised by Cathy and Kenny as it is hard for Kenny to face the reality of having a child with disability, let alone accept the necessity of obtaining help from his friends. Cathy revealed during the interview that Arthur’s mother has not had a successful relationship since her break-up with Kenny. She has no choice but to look after Arthur by herself.

Although colleagues at Cathy’s workplace know that she has a stepson with autism, and are aware of her caring role, she is not willing to share details of her experiences. She believes that people could not understand the emotional strain that she faces unless they experience it themselves. Cathy remembered that she felt calmer after she had spoken to a man who had a son with autism, as she knew someone else was going through the same problem. The
man provided strong emotional support as he could relate to what Cathy was saying and experiencing. However, Cathy believes that people need to find their own ways of managing their circumstance as each autistic case is so unique; there is no conventional or universal approach.

Summary

The experience of being a full-time worker and a ‘primary’ caregiver to her autistic stepson is challenging and stressful for Cathy. Physically, she feels exhausted as a result of juggling two positions at work and spending almost all her leisure time looking after her ‘unable to amuse himself but having extremely high energy’ stepson. Despite the fact that Cathy is not the biological mother, she usually looks after her stepson on the four days a fortnight they have him because her fiancé, the child’s father, has no patience with him. Cathy and Kenny have no interest in engaging in other activities because of the accumulated fatigue. Life is so mundane and the question ‘God, when do we get a break?’ has become a common theme.

In addition to what was, in Cathy's own words, ‘their incredibly boring and sleeping all the time’ family life, Cathy is also encountering difficulties at work. Because of her qualification and her previous success in helping with a few major projects prior to her promotion, Cathy is constantly given extra work related to design, which is beyond her current official position as a showroom team leader. The huge financial burden imposed by child support and all the additional expenses related to medicine forces both Cathy and Kenny to continue working full-time.

Cathy and Kenny have no plans to start their own family. Neither of them, especially Cathy, is willing to take the risk. The fear of conceiving a child who may suffer from an affliction like that of her stepson, and her knowledge of the life that would most likely, prevent her from adventuring into this realm. In fact, Cathy is uncertain where her future lies.
4.3.3 Nina

Snapshot

Nina is in her early thirties, lives by herself, and devotes all of her time to work and to her caring role. She has been with her current organisation as a full-time ongoing employee for more than eight years. Her duties as a coordinator cover a range of areas. Her workload has increased recently as a result of restructuring within the organisation and a shortage of employees.

Two and a half years after her grandmother passed away, Nina became the primary carer for her grandfather, who turned 85 during the time of data collection. While her grandfather lives independently, Nina visits him every day after work and one day during weekends. Nina revealed that she can find the balance between the two roles of work and caring in normal circumstances. However, any incident, whether a requirement to work extra hours or the need to resolve an unexpected upset or argument related to her grandfather among other family members, can be the source of imbalance or a crisis.

The demands of work

The demands on Nina imposed by her work have been increasing dramatically in recent times as a result of a restructuring that is occurring within the organisation. The second factor contributing to the increased work pressure has been the shortage of employees; an increasing number of staff was retiring, due to the attractive new superannuation tax laws introduced at the time. In addition, the lower rates of pay offered by the organisation compared to others in the made it hard for it to retain good employees and to recruit new graduates. Further, high demands from clients, as well as the disproportion between ongoing and temporary employees, were also contributing influences. Ongoing employees
usually need to take extra workload at the time during which temporary or sessional staff members have finished their teaching role.

Work overload and burnout were issues within the entire organisation at the time of the interview. Making the situation even worse, Nina’s assistant was experiencing personal problems and depression, and was no longer reliable. Consequently, Nina had to run things by herself, and take the consequence of ‘not having the personnel’.

Shifting from full-time to part-time, or exiting the labour market, has never been on Nina’s agenda despite the pressure of meeting the high demands imposed by her work. The paid job not only offers a break from her caring duties and gives her a sense of accomplishment, but also builds a financial foundation for her future life. Nina has a well-considered general plan, and is looking forward to a prosperous life after her caring role. She articulated the reasons behind her decision to stay in the workforce:

... caring for someone, you can devote your whole life and I think that is very nice and very admirable, but that’s not me. I still want to work and I still have goals.

'... yeah, and I couldn’t afford to live basically, and it just wouldn’t be suitable anyway, I’d have to move across the other side of town and give up everything, and yeah, I couldn’t – if I had to do that, it wouldn’t be good quality care for my grandfather. Because if I wasn’t happy, then I know that he wouldn’t be happy, mainly because I would probably be an irritable person to be around, but also because I know he wouldn’t want me to do that [quit the job] anyway. I think my grandfather has realised that it’s not good to have me there all the time ...'

The demands of the caring role

*Caring for an 85-year-old grandfather*

Nina’s grandfather is Irish, and was away from his family a lot when he was young. He migrated to Australia more than 50 years ago when he was 35 years old, and married an Aboriginal woman who had totally different family values. While Nina’s grandmother
believed that all people within their cultural and linguistic region were family members, her
grandfather’s view of a family was ‘someone to write to’. Nina’s grandmother was the
person who used to take her grandfather out for social events. Since his wife’s death, life
has been very much self-contained, reserved and withdrawn for Nina’s grandfather.

Nina’s grandfather has age-related health problems including heart failure, diabetes, kidney
failure and high blood pressure. Over the last two and half years, he had undergone a
quadruple bypass and bowel repair operations, and has been very depressed. Nina recalled
the situation:

... he’s very – I would go there and he would be very down in the dumps. You could
tell he’d been crying. He wouldn’t tell you he’d been crying, but you could tell ...
You say, what’s upset you and he’d just say, oh, life. Mmm, you know, I’ve got this
disease], I’ve got that [disease] and instead of ... he’d have more poor me, feel
sorry for me days and they would go on for ages ...

However, his condition has improved after he started taking antidepressant medication:

I think he’s a lot more positive in his outlook. Now he says, oh I feel much better,
you know, I have got diabetes, I have got heart failure, but, you know, I’m still
[living] at home.

Despite the fact that his health is deteriorating, Nina’s grandfather is still fairly independent
and is living by himself. He prefers to stay at home, as it is his ‘comfort zone’ and he is
reluctant to make new friends. However, he does occasionally drive to church on Sunday,
to the local shops for groceries, and to eat out. He wants to be as independent as possible
before reaching the point where he can no longer cope.

**Current caring demands**

Nina assumed the caring role as her two aunts and her cousins were incapable of looking
after her grandfather. She was reluctant to place her grandfather in a nursing home, as she
felt that this would show a lack of respect to her grandmother. Rather than providing assistance to her grandfather with basic activities, such as eating, bathing and toileting, the main caring responsibilities encompass coordinating all of her grandfather’s care visits and doctors’ appointments, as well as managing his financial situation. Nina accompanies her grandfather to all those essential visits and is responsible for going to the bank and managing his bills.

Until recently, Nina had been visiting her grandfather every day on weekdays and one day on weekends. Currently, one of her aunts takes up the caring duties for two days a week. Nina’s grandfather lives the other side of the city, and it takes Nina half an hour to one hour to travel there, depending on the traffic. She often skips her lunch breaks and leaves the office around 4 pm to avoid peak hour traffic. Having her lunch on the way to her grandfather’s place is not uncommon for Nina. She usually gets home around 10 or 11 pm after spending an average of four to five hours with her grandfather. Nina provided the details:

… depending on what kind of mood [her grandfather], like if he’s in a very talkative mood, then I don’t like to cut that off … for example, like tonight I think there’s lots of programs on that he likes …

Nina usually keeps Saturday to herself for doing chores in her own house, but spends seven to eight hours on Sunday with her grandfather after attending a church service in the morning.

Living in one house might save some time on commuting between two sites, but it would not necessarily make the caring role easier. Nina’s perception of this issue is as follows:

In my case, I’d have to move in with him. I don’t think he would like to give up his house. His house represents freedom, independence to him; it represents a sanctuary. So if he had to live with someone, that person would have to move in,
which I think could be quite difficult because he has very fixed ideas about what he
wants. Those ideas are not my ideas’.

Similarly, Nina believes that her grandfather would prefer to live by himself. She explained
her assumption:

... Yeah, he does [like the way it’s now], and I’m thinking he likes his own space as
well, [a] very solitary person. So I think he likes his space and when he does have
time to be with others, he appreciates quality rather than quantity …

Apart from being a primary carer to her grandfather, Nina had also been a carer for her own
father at one stage when he was ill and living with her. In the meantime, she has also
provided support to one of her aunts by telephone. Nina recalled the situation:

My other aunty rings me, she rings me about every second night on the pretence, I
think of talking about my grandfather, but it just turns into her complaining, and
she complains about everything, and it can be two hours … complaining about
anything and everything, about my grandfather, about having to see my grandfather,
about the cost of living, about how she’s tired.

The recognition and the acceptance of her own limitations has been something that Nina
has learned over the last two and a half years. She eventually had to stand up for herself and
said to her aunt:

... look, you functioned for 30-odd years before I was born, you have to function on
your own, this is your life, you made the mess, you go sort it out …

At the time of the interview, Nina had successfully negotiated for one of her aunts (one of
her grandfather’s daughters) to look after her father two days a week. Although a condition
attached to this agreement is that Nina has to ‘sponsor’ her aunt financially, this
development will provide a temporary respite service for Nina.
The experience of being a caregiver

The conflict between work and caring

A sense of conflict between the responsibility towards caring and the responsibility towards employment may not be apparent when there is no irregularity in either the work or the family domain. Taking on the two roles simultaneously has become second nature for Nina. However, any emerging events, from either work or caring, could cause chaos. Nina presented following scenarios to provide further explanation of her situation:

*I only need like a relative to upset the applecart or something to happen at work … like today, I was in here at twenty to seven. I’ll leave here about six and I’ll get home about eleven and I have to be back here at six. So it’s kind of … and it suddenly, it goes wrong, the imbalance arises.*

Conflict between her paid employment and unpaid caregiving was also evident indirectly in the approaches that Nina utilise to manage the challenges she faces. Nina has reduced the amount of work that involves interstate trips in order to avoid any potential crisis that may arise when she is away:

*I used to fly interstate a lot and I’m not able to do that because of time, and also I worry about my grandfather … it seems that every time I went away, some relatives would … upset him and cause problems. Then I’d have to fix them so it got to the point where I was too tired to try and fix mistakes. So rather than fix mistakes, I prevented them by not travelling …*

However, Nina tends to work longer hours to ease the feeling of not being able to perform optimally at work. Another tactic she has used to ensure her full commitment at work and to reduce the conflict between her roles to a minimum is to program her mobile phone; she will only pick up incoming calls that she identifies as coming from her grandfather.

The impact on personal life
It seemed to Nina as though the whole family imploded after her grandmother’s death two and a half years ago. Nina became the only person who could talk to everybody. It takes a considerable amount of time to provide updates on her grandfather’s condition for other family members, and to act as a mediator between her grandfather and other relatives. Thus, Nina spends much time in these roles.

Nina realised that she had less energy than before and that she needed more caffeine to keep herself alert and to get through work meetings. The following quotes illustrate the difference between her current and previous situations:

*I used to walk 10 km a day. I can now only manage that a couple of times a week, just because I’m too tired … I couldn’t work out why I was always hyperactive and that’s because if I stopped at any point I would fall asleep because I was just so tired.*

*Yeah. I notice I drink more caffeine, more than before. I drink a lot. In fact I recognised how much coffee I drank on the weekend and I thought, I’m going to have to switch to decaf or something …*

Other ways in which Nina has dealt with her physical tiredness include keeping Saturdays to herself and regularly taking more annual leave than before:

*I have to keep Saturdays for myself, otherwise I was finding that I was getting too tired and crabby … so therefore I don’t tell people when I’m going away or when I’m having a day off because it means they won’t ask things of me. Sometimes you feel guilty about that and other times I think … yeah, I’m too tired to cope …*

Physical exhaustion and time limitations do have an impact on Nina’s personal life and other social activities:
... this [being a primary carer while working full-time] does not leave much time for a proper relationship or anything else at this stage ... In fact, I have, well, I have no time for myself really.

The impact on emotional well-being

For Nina, the emotional impact of being a carer is much more significant than the physical exhaustion. The reality of her grandfather being in and out of hospital ten times in the past six months due to chronic health problems, as well as the poor prognosis predicted by doctors, is very stressful. Nina elaborates further on the emotional effect:

... he’s got chronic heart failure, his diabetes, then he got shingles, which was a nasty case of shingles. What else? Then he had a pacing problem in his heart and they thought that he might have to have a pacemaker and then there were all the emotions around that because he didn’t want to have another operation ... also the emotional thing of doctors saying, well, it’s not looking good, that sort of stuff...

In addition to the concerns about her grandfather’s health problems, the constant worry about how he deals with visits from ‘difficult relatives’ is emotionally draining. Nina does not want to see her frail, unwell grandfather being upset deliberately, by family members. She cannot hide her frustration about her two aunts (her grandfather’s daughters):

... they have said [to Nina’s grandfather], oh you know, Nina’s only in her 30s, she shouldn’t be giving up her life for you, blah, blah, blah. So he got upset and then got really upset ... when I’m at work and she’s [a difficult aunt] visiting, I think, oh what’s she going to do now, and then I get to see him and his blood pressure’s sky high and sugar levels just sky high.

... say you’re having a long weekend and there’ll be some crisis or something that you have to – that you somehow, they try and get you involved in or they cause some argument with my grandfather and he gets upset and I have to go and sort it out.
Nina revealed that reassuring her grandfather that he was not a burden to the family was
time consuming and stressful. She needed to repeat to her grandfather that ‘I’ve never said
that [you are the burden], I don’t think that way’ until her grandfather gave up the thought
that ‘no-one wants me’.

The fact that the source of her grandfather’s stress comes from relatives, especially from
her aunts, makes things even more complicated. Nina explained further:

... if it was anyone else you could sort of say, you know, go away and don’t come
back. But family are a little difficult to say that to ...

Resolving family conflicts or disagreements that surround her grandfather’s health
problems, and have the power of attorney, further intensifies the emotional impact. Nina
confessed that dealing with all the internal issues on the periphery is emotionally draining:

... all the family stuff, one aunty saying, oh well he doesn’t need to have it [the
pacemaker operation], another aunty saying, oh he does ... other family relatives say,
oh no, he shouldn’t be driving, he shouldn’t do this, but he had the tests and he was
quite capable and he wants to and he knows his limitations. So I think, well who am
I to say, you can’t drive any more. Plus, people don’t like it when you have to put
your foot down and say, look you’re upsetting someone, you’re making it worse by
the carry on.

Nina is a perfectionist and would like to complete everything to a high standard. However,
the accumulated fatigue and the perpetual lack of time to herself sometimes make it
impossible for her to do things in an ideal way. Nina expressed her disappointment about
this during the interview:

It is a constant struggle between – I like to do everything well. Yeah, perfect, so
little things like the state of my office [papers and books were all over her desk]
which drives me crazy, but I just don’t have time to fix it ... it’s not that I’m not using time smarter, it’s just that there is so much packed into time.

Nina had anticipated that there would be a high cost once she took up the caring role, but had not expected it to be as huge as it is. She confessed that she had underestimated the psychological strains related to the caring responsibility, especially in terms of carrying the emotional burdens of other family members and of being the strong and authoritative figure in the family.

**The impact on the financial situation**

The financial impact in Nina’s case derives from paying the secondary carer, as well as the expenses directly related to looking after her grandfather, such as the cost of petrol and dining out, and parking fees in the hospitals. Attempting to give her grandfather some different interactions, as well as the chance to talk about various things, Nina has successfully negotiated with one of her aunts to provide two days of care. However, the ‘deal’ was accomplished by means of her own financial contribution. Nina provided the details of the arrangement:

> I’ll have to either go and collect her [Nina’s aunt] to help me or I’ll have to give her money or … so she gets money every week, or every couple of weeks ... the money is from me. Oh I couldn’t take it out of his [grandfather’s] money. But it’s under the proviso that she goes those two nights and that she doesn’t mention it to him.

**Family relationships**

**The relationship between carer and care recipient**

It is Nina’s belief that she has a much stronger and closer relationship with her grandfather now than she had before she assumed the caring role. There are more honest, trusting and open discussions between the two of them. Nina tries to involve her grandfather in decision-making as much as possible:
I’ll tell him if I can’t do something and he’ll say if he doesn’t like something. Like I won’t ever do anything without discussing it with him first and then I’ll show him, like, for example, the laundry needed cleaning and I said to him, this all needs cleaning and I showed him and I said, what do you think and he says, oh yeah, it does, it’s a mess. I said, fine ... we changed a few things around which was easier for him to get at and that sort of thing. So I believe in having him involved in the situation otherwise he might as well be in a nursing home if I’m just going to go up and take over everything.

Nina considers herself lucky as she gets the opportunity to know her ‘real’ grandfather. This not only adds an extra dimension to her life, but also, to some extent, influences the ways in which she views this world and her stances towards different people and issues. Nina expanded on her appreciation of her relationship with her grandfather:

*He served in the air force during the war, all of that sort of thing, he’s still got his service medal ... Yeah, very poor time [refers to his childhood] and it explains a lot of his attitudes to things around the house and to money, which other people would say, oh I don’t like his attitude of this, but I can see the wider context.*

**The relationship with other family members**

Nina is happy to be the point of contact to provide updated information to relatives (whom Nina is yet to meet) about the condition of her grandfather’s health:

*I’ve got to know his family, like they’re in Ireland, but through talking to them on the phone, like I haven’t physically met any of them because it’s so far and I haven’t been there ... But talking to them, I’ve got to know bits about him, and they know they can ring me whenever they can’t get hold of him, that sort of thing. They know that if something happens, I will ring the designated niece and give the information so that the family can be kept up to date. So it’s a lot stronger bond.*
As mentioned in various sections, Nina has to frequently solve issues derived from caring for her grandfather, in particular the disagreements or arguments with and between family members. This has greatly affected Nina’s emotional well-being in a negative way. However, the fact that she is the person who ensures that her grandfather has an independent and enjoyable life during his remaining years makes Nina proud. She remembered how upset her grandfather was when he was asked which nursing home he was in every time he was readmitted to hospital. Thus, making it unlikely that he would be placed into an aged care facility:

*I understand why some people do that [place their elderly frail family members in a nursing home] and if it got to the stage where he needed that, we’d have to look at that, but at the moment he’s fairly independent and I’m hoping that it stays that way until eventually he does die.*

**Support**

**Support from the workplace**

Nina was unclear whether there were policies, programs or initiatives implemented in her organisation to assist carers like herself to manage the challenges imposed by the combination of work and caregiving, with the exception of the carer’s leave to which every employee is entitled. However, the flexibility provided by her direct manager or supervisor, arguably the most important aspect of employment, plays a critical role in assisting Nina when she is confronted by the difficulties of balancing her caring responsibilities with the demands of her paid job. She is able to start her day earlier, skip her lunch breaks and take days off from work whenever needed. Nina expressed her gratitude:

*... yeah, my boss is very good. He’s based in another state, so there’s a lot of trust ... I’ll take my lunch hour at four and then I won’t come back, I’ll just go straight up [to her grandfather’s place] earlier … some other people don’t have a supportive work environment and that would be terrible, that would make it all harder.*
The high level of flexibility granted by her direct manager has also influenced Nina’s decision with regard to the employment arrangement with the organisation. She responded without hesitation when approached to give her perception of an ideal job:

... well this is the perfect job, for me, actually. I have a lot of flexibility, I enjoy the work that I do. It gives me a lot of personal satisfaction. It allows me to be able to leave early to see my grandfather and to take [the] time that I need to.

**Support from other sources**

As mentioned earlier, Nina assumed her caring responsibility because nobody else in the family was suitable for the role. She has one brother and two cousins who are either too young to take up the caring duties or living in another state. Nina gets little support from family members for her caring role, except the possibility of calling her own father, who was unable to care for his father, in the case of an emergency. The arrangement for Nina’s aunt to look after her grandfather one to two days a week had begun just a few weeks prior to the interview. However, Nina did not expect the current arrangement to last long, owing to her aunt’s emotional state, as well as the relationship between her grandfather and her aunt.

Most of Nina’s friends can understand her situation, as almost all of them have already established families and have their own children. A few of her friends actually visit her grandfather and play cards with him.

Nina stated in the interview that she hopes there are more associations like Carers Australia that can provide useful information to carers. While the service Nina receives is not a well-designed program or initiative, she appreciates the fact that it is accessible. Nina's comments about Carers Australia:

... just the fact that they [Carers Australia] send out this newsletter, they have people’s stories in there [Carers Australia’s website] and they often have
information, and I’ve been able to download a lot of information that I can read about where to get services for my grandfather and that sort of thing …

... Yeah, they [Carers Australia] were really good and they give you, like, a card where I can take my grandfather to the movies at certain cinemas and I only pay $1 which is really good.

Nina is yet to investigate other services available in the community, such as a respite service that could help her in her role as a working carer.

**Summary**

Being a working carer is a challenging, as well as a rewarding, experience for Nina. Physically, Nina feels exhausted as she has to visit her grandfather every day after work and stays till late in the evening (normally 10 pm) during weekdays. It is evident that Nina sees herself as dependent on caffeine to remain awake and active, otherwise she feels she will fall asleep at any moment.

The constant worry about the severity of her grandfather’s health problems, as well as his psychological status, is emotionally draining. For Nina, managing the conflicts among family members, especially resolving disagreements in terms of how her grandfather should be treated for his health problems, increases the emotional impact.

However, on the other hand, Nina is content with the fact that she is able to handle two roles effectively, to fulfil her grandmother’s wishes, and to be a bridge between her grandfather and his overseas relatives. In addition, Nina has a much stronger relationship with her grandfather than she had prior to assuming the caring role. Nina understands a lot more about her grandfather. In fact, the way her grandfather treats life somehow shapes or influences her beliefs about life in general.
While it is clear that Nina would not give up her full-time employment and has no desire to become a full-time carer, she is definitely planning to take care of her grandfather until he needs to be placed in some kind of formal care facility.
4.3.4 Dora

Snapshot

Dora is in her mid forties, and was a single parent to her three daughters from her former marriage for ten years. This was the case until she met and married Wayne the year before the interview. She has worked as an ongoing employee with her current organisation for 18 months. Dora feels obliged to work full-time as she is the breadwinner for the family, although she admitted during the interview that it is very difficult to juggle the role of worker with that of carer.

Dora is the primary carer for her daughter, Eva, who was diagnosed with Asperger’s Syndrome (AS) in 2007. Born in 1995, Eva was 13 years old at the time of interview. Eva has been seeing psychiatrists and taking medication for six years, since she turned seven, despite the diagnosis being recent. Dora is the central or single point of contact for all issues related to Eva. As a result, spending time at work resolving problems or seeking solutions has become unavoidable. Dora has been criticised at her workplace for not being able to devote herself entirely to her work.

The demands of work

Dora began part-time employment when Eva was two. She was able to juggle her work with caring for her daughters when they were young because she was a school dental nurse. She worked for the state Health department on school dental programs. The position offered her great flexibility, as the schools she was assigned to were in one district and were close to the schools that her daughters attended.
Dora stated during the interview that it was almost impossible to be a full-time worker while looking after three children by herself (prior to her second marriage to Wayne) when they were young. She switched to full-time employment nearly two years ago as the children getting older. As a full-time employee, Dora’s designated working hours are from 8.30 am to 4.30 pm, with an hour break for lunch. However, Dora reduces her lunch hour to 30 minutes so that she can drop Eva off at school at 9 am before her working day.

In the early stages of her employment with her current organisation, Dora was learning numerous new things because she had entered into office work, which was different from what she was used to. She was very happy as she felt that she was achieving something every day. The sense of success gradually faded away as work became routine and there was a lack of new challenges. Dora believes that her full capacity has not been utilised because she feels she is capable of performing much more complex tasks than administrative duties.

When asked about her daily routine in the workplace, Dora commented:

> I’ve actually learnt that I can only do what I can do … whereas probably for years I’ve stressed so much about I have to do this and I’m not doing a good enough job and I don’t give enough time and enough attention and, you know, felt stressed that I don’t contribute enough.

While Dora cannot identify the real reasons behind her feelings that her contribution to her work is deficient, she elaborated further and tried to find some explanations:

... that’s [using time at work for family issues] probably some of it. But just to try and do my best within ... I do have a tendency to have a bit of a perfectionist nature. I suppose my career has changed and diversified over the years and the nature of my work here has changed.
As mentioned earlier, Dora began her career as a dental nurse. The tasks that she was performing then were easily measurable (for example, how many patients you had assisted, and how many items you had sterilised). Now, the responsibilities of an office worker in the position she is holding are harder to quantify. Dora believes that she needs time to adapt to the new work environment. She has been making some adjustments:

... so I’ve had to teach myself in different jobs that it will be there tomorrow and it doesn’t end and as long as you’re doing the best that you can do now, then don’t stress about it ... I think it’s just one of those things, it’s a learning process and ... I keep telling myself, you know you’re doing a good job. There is no end to the job, it’s just ongoing, so you do what you do and that’s all.

Dora described her negative image by her manage and many of her colleagues in the department as a result of using company's time for family issues:

... but I still keep very closely engaged with everyone. I’ve been in trouble quite a bit at work here, because of ... you know, it’s like you’re on the phone too much; your calls are too long; Wayne will ring you too much. So it’s been brought up quite a few times ... I mean I find that ... I found that very difficult.

Dora really hopes that her colleagues can understand more about her situation, and show their compassion.

... but yeah, I don’t know, I just think that they just think that I shouldn’t be on the phone quite as much. I don’t really know. I have had some long conversations with ... Eva goes to a special Autism school once a week as well ... So I’ve had a very long conversation with her psychologist there.

**The demands of the caring Role**

*A daughter with Asperger’s syndrome (AS)*
Eva’s late diagnosis with AS was the result of an incident at school. The year before interview, Eva had retaliated physically against a child and the teacher. Dora went to a psychiatrist and obtained a formal diagnosis for Eva. Dora had told the school that certain circumstances might trigger Eva’s aggressive behaviour, but had simply ignored this warning until the incident occurred. That was also the first occasion on which Eva stated that she felt physically sick if people touched her. Her instinctive reaction is to get away in such circumstances.

Research about AS has focused mainly on boys, given that nine out of ten children with syndrome are boys. As a result, data on girls with AS are very limited. In addition, it seems perhaps ‘normal’ for a girl to obsess certain things, such as dolls and acting out parenting. Consequently, girls are often left undiagnosed for years.

According to Dora’s observation, Eva has typical signs of AS, such as an inability to deal with change. She does not like the changes that are happening to her body as she develops, and she also shows an inability to adapt to seasonal changes. Eva tends to elevate her voice when she is under stress, and to physically attack other people when she cannot get out of a situation in which she is not comfortable. Another example that illustrates Eva’s inability to deal with change is her pattern over a school week. Dora revealed that Eva hates Mondays, but tends to be happier towards the end of week because the weekend is approaching. At the start of each semester, Eva receives a lot support from the Special Education Unit, and can do really well. However, she gets tired towards the end of semester. When she is tired, she has lower levels of patience and tolerance, and is less able to handle the pressure from term-end assessments.

Dora also mentioned that Eva loves school holidays because she can stay at home, and can do her favourite things without any pressure from the external environment. For example, she can spend time with her animals, and can watch her favourite television programs. However, getting Eva back to school is always a nightmare for Dora. Another factor that contributes to Eva’s refusal to attend school might relate to school bullying. In Eva’s own words: ‘I have no friends at school, there is no-one who likes me; they tease me.’
Dora described what she explained as being three different versions of Eva. Physically, Eva is 13 years old. Intellectually, Eva could be up to 18 years old, and is extremely talented. This was evident in a reading test that Eva took part in when she was 11. The test was requested by Eva’s class teacher as she considered that Eva was falling behind. The teacher from the Special Education Unit knew how to boost Eva’s confidence, and had found a perfect time for her to perform. The results were extremely encouraging. The assessor confirmed that Eva’s reading level was equivalent to a child of 15 years old.

However, Eva can also act like a three-year-old. When she becomes very emotional, she throws tantrums. On some occasions, she cannot really do anything. Dora referred an example of such behaviour as the ‘morning horror’. Eva would just lie on the ground and do nothing, and wait for Dora to put on her clothes. However, Eva becomes active once she arrives at school.

Eva has been on medication at a fairly high dosage for almost six years. Her situation has become worse every time Dora has tried to reduce the dosage.

**Current caring demands**

Eva is an independent child when she is in a good mood. She can cook and look after herself. In a context of no external disturbance or influences, Eva is likely to be enjoying what she is doing. Dora illustrated the situation in detail:

*I probably started doing that [leaving Eva at home by herself] when she was quite young, unlike other kids, only because she was better on her own. We’ve always said she’s safer and happier on her own than if anybody else is in the house to interact with.*

*If she has an accident or breaks something or hurts something it is always when somebody else is around, it has never ever been when she’s been on her own.*
However, Eva can turn into a totally different person when she is in a poor emotional state. She behaves like a toddler. Dora illustrated this by describing an incident that happened a few weeks prior to the interview. Dora had taken Eva to school as usual. After Dora got out of the car, Eva locked herself in the car, put her arm on the lock, and tried to stop Dora getting into the car. The story continued:

*I had to say to her, look, if you don’t do this [take her arm from the lock], I’m going to have to smack you. I’m going to count to five – and there was this thong on the ground – I will pick that thong up and I will have to smack you and I started counting. So she moved her arm. So I opened the door. Then she held the seatbelt and I had to lean over and say the same the thing applies with the seatbelt. I’m going to count so you better let me get you out.*

*... So then that was fine, she let me get her out of the car. Then she held on to me and wouldn’t let me go and then she cried. That’s a classic case of when she turns into a three-year-old, she grabs hold and says Mummy don’t make me go, don’t make me ...*

*... it’s exactly like what a little person would do when they are dropped into child care, grab onto their mum, it is just like that. She is bigger and then you have to physically peel her off you and then she’s, like, crying, going don’t do it.*

Eva’s emotional state is unpredictable. Dora and Wayne are ‘on alert’ all the time. In addition, as pointed out earlier, Eva tends to be easily triggered once she is tired. Dora and Wayne acknowledged that most incidents that happen at school occur in the afternoon when Eva is exhausted. At the time of the interview, they were in the process of negotiating with the school, and waiting for an approval for Eva to go to school for half a day rather than a full day. Caregiving will become increasingly demanding next year if Eva attends school for only half a day.

**The experience of being a caregiver**
The impact on physical and emotional health well-being

The main impact of being a carer for a child like Eva is the emotional anxiety that occurs, although the physical tiredness is also very significant. Dora was under enormous pressure a few years ago when she was still working for her former employer. She depicted the situation this way:

... you know, it was getting to the point where it was all just far too much. It was at the end of the last position that I left, that I just couldn’t cope anymore, it was all too much. I went to the doctor and said it’s all too much, I can’t cope. She’s suggested to have some time off and see if having time off work and being away from the environment will help.

Dora resigned and stopped working for a month, in accordance with her doctor’s suggestion. However, she did not think that being away from the workforce helped to improve her emotional health. Perhaps the fact of not being able to contribute to the family financially made the situation even worse. So she went to the doctor again:

... I can’t cope anymore, my nerves are on edge. So we [doctor prescribed and Dora took] ... the antidepressants ... that’s when I took action and I think too with that feeling of the burden lifted and the drugs sort of help you work through things.

Dora has been on anti-depressants ever since. She relies on the medication, as well as strong support from her new husband, to manage the demands imposed by both work and caregiving.

The impact on career

Being criticised at work

Dora earns more than her husband Wayne, and is the main breadwinner at the moment; therefore, keeping her current job is a high priority. However, while Dora makes a big effort to keep her current employment, she realises that it is sometimes impossible not to be on the telephone. One of the main reasons for Dora’s higher than ‘average’ number of
telephone conversations and the consequent criticism and negative performance appraisal, is that Wayne is not the biological father of her three girls. Thus, although he is taking considerable responsibility for caring for Eva, and often is the person available in the case of emergency, he needs to contact Dora to keep her updated.

... but you know we do, Wayne and I, we do keep in very close contact and I suppose the other girls because Wayne is not their father, if they need something then they will contact me as well. So it just sort of all builds up [long conversation].

In addition, Dora is the contact point for all issues related to Eva. For example, the Head of the Special Education Unit, Eva’s psychiatrist and her case manager will phone Dora if anything happens to Eva.

**Relentless worry about Eva**

When Eva stays at home by herself because she refuses to go to school, or she is picked up from school earlier than normal, she often calls and begs Dora to be at home with her. Making a choice between going home and staying at work is very difficult. Dora used the following example to illustrate:

*Eva rang today, it must have been about 11.30 am, in tears on the phone, going, I need you home, come home, Mummy, come home. Just crying and crying I’m like, I can’t, I have to stay at work. She’s like, no, you have to come home. I’m like, I can’t, I just can’t come home.*

*I would probably have to work out whether he [Wayne] could get home or whether it really was a call that I had to go home ... for me that’s such a hard …*

*I really feel so guilty. I would probably tend to call Wayne and say to him, look, I really need you to go home and check on her [Eva]. Then I would be constantly worried …*
With no help from other family members apart from Wayne, and given the fact that Wayne is not Eva’s biological father, in the above scenario, Dora would phone Eva a few times during the day to make sure she was safe and happy at home ‘because I need to know what’s going on. I need to know – I want to be in control’.

**Missing promotion opportunities**

While Dora is not sure whether she is treated differently from other employees at her workplace, she confirmed that she has missed a few promotion opportunities. One of the concerns Dora has is the possibility of being unfairly judged during the selection process. However, the main reason behind her hesitancy with regard to applying for those positions is related to the feasibility assessment rather than her competence. Dora provided the following examples to further illustrate her points.

The first opportunity was a team leader position:

*I had an opportunity where there were two team leader positions available and three of us were eligible to go for it. I have been in management before, but had to sit back and think did I want the extra pressure …*

The second opportunity appeared a month ago:

… not just with that job [the team leader position], there was actually another position available only about a month ago. I went and spoke to the manager about the position and thought about it and then had to sit back and think to myself, as the next step up they’re not going to allow me to come in at 9.30 am. I am going to have to be there at 8.30 am. Eva needs me to take her to school … I need to have the flexibility to be able to do what I do with her.

Dora kept asking herself:
… can I handle it? Can she [Eva] handle it? Would I be letting my team down, because I would be a team leader? So after thinking about it really hard, I actually decided … not to go for the position.

The resentful feeling remained with Dora when she realised that the position went to a 21-year-old who ‘had no experience and no idea’, but became her direct boss as a result of a lack of competitive candidates. While Dora tried to pacify herself, she could not bear the fact that she was led by an inexperienced newcomer who is her daughter’s age. She started to look for change:

… at my husband’s institution, there is a position that is a level 6/7 and I thought I could really do that, it was very similar to the one that I was doing and I would really like to go there and I’m sure I could do a great job. But once again it comes down to [the fact that] … I would have to go into the city and I then can’t take Eva to school and I can’t be available. They’re not going to be as understanding and I can’t get home when I need to and the travel time takes more time out of our daily routine …

The caring responsibility has restricted Dora’s professional advancement, as well as her performance. Dora was not content with the fact that spending time on the telephone to accommodate the needs arising from caring responsibility was recorded in the performance review. She was disappointed:

… that [the performance review] for me it was very degrading. Like this is now on my performance review for whatever manager that ever wants to read it.

**The impact on the financial situation**

Although Dora gets some financial support from her ex-partner, she is under great pressure to keep her job due to the financial burden of being the breadwinner for the family. She goes to work with the notion that ‘I’m going to get paid and go home’. At this stage of life, she simply cannot afford to lose her job.
While Dora appreciates Wayne’s enormous support, she still wishes that she did not have to take the main financial responsibility. Dora occasionally ‘complains’ to Wayne:

… it’s your job now to be rich and famous and then I’ll only have to work part-time and I don’t have to worry [laughs]. I don’t want to work, you go off and work and earn the money, you be happy doing what you’re doing and I’ll just stay home.

Family relationships

The relationships between siblings

Eva does not get along with her older sisters Janette (21 years old) and Susan (18 years old). The older girls do not quite understand AS, and believe that ‘Eva is just a spoiled little bra’. They are jealous of the way that Eva is treated, and think that Dora ‘just gives into her and all of that’. The girls hardly played with their little sister when they were young, not merely because of the age gap, but also because they saw her as different from themselves. Janette always picked on Eva, and Eva would fight back. Ultimately it turned into a horrible war. On the other hand, Susan was often a target of Eva’s anger. Eva would yell and attack Susan when she was out of control.

Eva’s behaviour had a big impact on Susan’s daily life. Susan rarely talked to Eva when they were in their old house, which had a granny flat downstairs. In that house Susan tended to separate herself from the family as she had her own living area and bedroom, where she could entertain herself. Dora realised that Susan was more likely to spend a lot of time at her friends’ places after they moved to the new house, as Susan did not have a space of her own in this home.

The relationship between mother and daughters

Dora feels that Eva is safer when she is alone. However, she was shocked when Eva complained and expressed her loneliness. The following conversation revealed Eva’s real feelings:
… she [Eva] goes, you never spend any time with me and you never have time for me. Wayne [her stepfather] doesn’t love me like the other girls [her two sisters]. So we have this huge thing like, you’re always at work, you’re always at work, you never have time for me and we don’t ever do anything. It’s like, well, I’ve just made an effort to sit with you and watch your TV program because you wanted me to …

Meanwhile, Janette and Susan complain to Dora that they are treated differently from their younger sister. Dora acknowledged that she employs various parenting strategies with her daughters as they each have different personalities. However, the variation in approaches causes many conflicts between mother and daughters.

**Support**

**Support from society at large**

Dora is aware that the state Asperger’s club has some parent help programs. However, she finds it ‘incredibly frustrating’ that most workshops or gatherings are held during the day. Dora has to work five days per week in order for her family to survive, and does not have the luxury of being somewhere at 10 o’clock for morning tea. She needs to reserve her entitlements, such as carers leave, for urgent incidents or family crises.

Dora also knows that there are respite services, which were described by members of the state Asperger’s club as ‘rent-a-friend’, available in the community. However, she has not yet used them and explained her hesitation.

First, Eva hates to be portrayed as an ‘abnormal’ or ‘disabled’ child:

> I think a lot of my concern is that Eva … because we have so many different sides of Eva … I think that’s my fear … is that if she thought that if we got respite care that she might … she doesn’t want to be different. Most of them [children with AS] don’t want to be different. They don’t want to see that they’ve got a disability.

Second, Dora does not want to see Eva depressed:
… so I think that’s part of my fear too, because I mean we’ve had people teasing her and giving her a hard time. So then she gets really down on herself and yes, that’s when we get her becoming low …

Third, there is no need at the moment:

… so we’re lucky now that she’s getting to the age where we are happy to leave her at night. There have been three times that Wayne and I have gone out …

Support from the workplace and colleagues
Dora declared that the organisation has ‘fantastic’ policies in terms of the number of days of her entitlement, as well as the flexibility of building up the leave days in place to help carers to fulfil their caring responsibility. Dora expressed her appreciation:

… here is the only workplace that I have been able to make the time up … for instance Eva doesn’t go to school, I try and get in early and build some time up, so if I need it …

… instead of most workplaces where you only have ten sick days and if you’re sick you have to use them or if something is wrong with your child you have to use your ten. Well at [the current employer] they’ve got a policy where you have family leave as well as sick leave, and that incorporated makes up to 20 days a year … I’ve utilised a lot of that family leave.

Despite her gratitude for the company’s policy, Dora stated that there was a discrepancy between the organisation’s policy and the daily practice in the workplace. She conveyed her stress and anxiety:

…this [being frequently on the phone, and on the phone for a long time] builds up the risk of losing my job … I still find it very difficult … I find that really quite
difficult. I suppose I do try very hard to stay at work, probably because I'm always concerned that if I go [home to attend to Eva] then I'm jeopardising my job.

Dora obtained her current position through a friend, who used to work in the department Dora is in now. Although her friend was working in a different section at the time of the interview, she was still the person upon whom Dora would lean at work when encountering difficulties or challenges. They would catch up with each other at morning tea, afternoon tea or lunch breaks at work.

Apart from seeking support from her best friend, Dora has no desire to tell anyone about her situation because she strongly believes that people will not understand her circumstances. Dora has struggled for years to find the reasons behind her ‘bad luck’. The following thinking prevents her from sharing her experiences:

> It’s always been, maybe I’m just a bad person or maybe I’m a bad parent or, you know like why? Why is it me? Where did I go wrong? What have I done wrong, why have I failed and all that sort of thing … So to tell other people, for me it’s embarrassing to say that my daughter just picked a chair up and smashed it against another kids. People go, oh my God, what sort of kid is that?

Dora has assumed that she would receive a lot of support from her boss, as the boss’s son has recently been diagnosed with AS. In reality, that has not been the case. Dora explained the reasons associated with the lack of communication between her boss and herself:

> … well, she doesn’t know. Because her boy has just been diagnosed, she, I think … they’re really probably going through that denial stage. You know, she went and had a meeting with his school, but she’s very much into her own work and she is here long hours. I think that a lot of the situation maybe her husband deals with. So we don’t tend to talk, we don’t talk about it.

**Support from family members**
Dora received virtually no support from any family members in helping her to care for Eva when she was in her first marriage, and when she was single after her divorce. This is still the case. Dora’s mother works full-time, and her brother has always lived out of town. Dora’s girls have no contact with their biological father:

… No [contact], we had to go through court and have a huge court battle and stuff. The court ruled that he wasn’t fit to be part of the girls’ lives.

… I spent so much time on my own and because even when I was married the first time my husband wasn’t very supportive. He was more a hindrance than a help. Everything I did was always on my own.

I’ve never, I’ve never actually relied on anybody else. That’s always been a bit of a challenge.

Dora has had strong support from her husband, Wayne, since they married the year prior to the interview. In the case of an emergency, Wayne’s timetable is more flexible that Dora’s. She expressed her appreciation: ‘Wayne is so amazingly supportive and good and helps so much and really he’s taken a lot of the burden off.’ While Dora described her parents-in-law as lovely people, she will never leave Eva with them as they do not have the patience and the sympathy for Eva’s situation. Perhaps the fact that Eva is not their biological grandchild is one of the contributing factors.

Susan and Janette tended not to provide any help in looking after Eva when they were young. The relationship between Eva and Janette had improved the year before the interview, when Janette moved back to the state after completing her university study. She often takes Eva to her place if Dora really needs help. However, this is not the case with Susan, who still fights with Eva frequently.

Dora admitted that juggling between work and caring was demanding and challenging. The support she needs the most is flexibility. Dora revealed her thoughts on ideal employment.
The first version involves her remaining in a professional role, but with the freedom to control the time she starts and finishes work:

_I’d really like something that I had the flexibility of being able to fit my family into … I think an ideal job for me, that I would really enjoy, is being part of the International School, interacting with different people. But having the flexibility say to be on the road, so if I needed to go home or needed to take Eva …_

Dora also would like to open her own business in a field, such as dog-grooming, as long as it could provide an occupation for Eva in the future, so that ‘Eva could be at work with us and she can be with the animals [Eva’s passion].’

**Summary**

Dora had been a single mother to her three young daughters for many years prior to her second marriage a year prior to the interview. The life of being a single parent, and of being the only carer to her youngest daughter with AS, has been exceptionally challenging. Dora suffers from depression and has relied on antidepressant medication to cope with the challenge that she is confronting.

Dora does not have to provide a huge amount of physical support with caring for her daughter as Eva can take care of herself in terms of basic daily activities, such as brushing her teeth, dressing, showering and bathing herself. However, the emotional impact is detrimental to Dora. She has been criticised in the workplace for spending too much time on the telephone dealing with family matters. She has missed opportunities for promotion and career advancement due to the impact of her caring role on her work. The limited time and energy restricts her ambition to move to a more senior position, which, in turn, damages her self-esteem and confidence. Consequently, the resentment at being mother to a disabled child surfaces on occasion. As described by Dora during the interview, she often asks the questions: *Why me? Why is it me? What did I do wrong?*
Resolving conflicts among her daughters and ensuring that each of them is being treated ‘fairly’ is another aspect of the emotional impact. Dora receives frequent complaints from her older daughters about how their little sister’s access to their mother is privileged over them. They believe that their younger sister can basically get whatever she wants. This happened particularly when they were young, but the complaints continue.

The financial effect of having a child with a disability is no less than the long-lasting emotional effects. Dora has no choice but to stay in the workforce. Keeping a full-time job was vital for Dora during the years when she was a single mother, and remains so now after she remarried a year before the interview. She is the breadwinner in the family, as her husband is completing his postgraduate qualification. Dora’s future financial plan includes arrangements for herself, her disabled child and her other two daughters.
4.3.5 Haidi

Snapshot

Haidi and her husband, Paul, both in their mid fifties, are raising a family of three children: Kay is 16, Sandra 12 and Mat 10. Haidi started her family relatively late, like many career women. She is the primary carer for Kay, who was diagnosed with Velo-Cardio-Facial Syndrome (VCFS), as well as an acute anxiety disorder. In addition, Haidi has been looking after her elderly father for 12 years. He had been placed into a hostel a year prior to the interview, and Haidi’s current caring responsibilities for him are preparing food once a week, managing his financial situation and being contactable by him at all times.

Haidi has had a very comprehensive career trajectory. She worked for a giant hi-tech organisation before she had her first child. After a break from work in order to take on parental responsibilities, she re-entered the workforce part-time when Kay was four. After the completion of her qualification, Haidi established her own counselling and hypnotherapy business, and worked from home for six years until 18 months ago when she was hired by her current organisation as a full-time contract employee.

The demands of work

As a full-time employee, Haidi’s working hours are from 8 am to 4 pm. However, her day can begin as early as 4 or 5 am depending on the task she is undertaking. On the day of the interview, Haidi had started her work at 5.30 am because she needed to complete a proposal by the end of the day. Haidi is in charge of a particular project as a project manager, but also oversees a few others as part of her job. Her position requires her to take a range of responsibilities from composing a proposal, organising steering committee meetings, and managing project budgets to ensure that projects will be completed on time.
Haidi usually has to start early or stay late at work, as well as miss lunch breaks, to build up extra hours that can be used for children’s school holidays. The entitlement to annual and carer’s leave do not match the days that are needed to take care of the children when they are on a school break. She said that she becomes a ‘crazy workaholic’ when she needs additional days for other events, such as doctor’s appointments for Kay and/or her father. As Haidi must work overtime in order to generate extra leave, she regularly uses her own time to meet the demands of juggling work and caring commitments. Haidi explained:

… if I’ve got a deadline, I have to go home, deal with whatever it is and then meet the deadline. Or if Kay has schoolwork that she needs a lot of help with, you have to do that and then get back to work … So it’s quite common for me to be up at 5.30 to do work, or work on the weekend.

Haidi expects that she might not have the same energy and enthusiasm once the job becomes routine.

I wanted to get a proposal in to somebody. So much harder – I think part of it is it’s still new. I’m coming up to 18 months, so I’ve still got the energy. Ask me in a couple of years, and I think it will be harder when it’s more routine.

The demands of the caring role

A daughter with Velo-Cardio-Facial Syndrome (VCFS)

Kay, Haidi’s 16-year-old daughter, was born healthy but was diagnosed with Velo-Cardio-Facial Syndrome (VCFS) when she was 11 weeks old. VCFS is one of the most common genetic disorders in humans, and is characterised by cleft palate, heart abnormalities, learning disabilities, and other clinical findings that link to the eyes, the thorax and cardia, the ears and the brain, and vascular anomalies.

While Kay and her family were able to address the physical side of her health problems after 13 or 14 operations, she was identified as having issues with the emotional aspect of
her health when she turned eight. Kay was then formally diagnosed with an acute anxiety
disorder by a psychiatrist, and has been on medication ever since.

People with VCFS tend to have mood swings like those associated with bipolar disorders.
Kay is no exception. She is resistant to any kind of change, such as changing from her
normal uniform into a different type of clothing. She can suddenly become very anxious for
no particular reason. The following examples illustrate her anxiety:

… this morning, they’re [the children at school] having mufti [civilian clothes] at
school, so they dress up in normal clothes. It took probably an hour to get her
dressed, and convince her to dress appropriately. They’re also raising funds today
at school by selling pizza. But Kay didn’t want to buy the pizza, so I had to talk her
into it. That took probably another half hour to talk her into getting a friend to go
with her to buy the pizza to support the school. So every now and then you have to
put in a change, which unsettles her.

Another example of Kay’s opposition to change can be seen when she rejects moving from
one task to another. She will sit in front of the computer for the whole day if she is not
forced to move, and often refuses to engage in other everyday routines, such as taking a
shower, washing her face, brushing her teeth and getting herself dressed. When Kay agrees
to carry out those tasks, Haidi has to provide a lot of directions about how to perform them.

Kay’s social skills are also far behind those of a ‘normal’ child of the same chronological
age. According to Haidi, Kay is perhaps socially equivalent to an eight-year-old child. She
does not socialise well with her peers. While people at her current (secondary) school are
friendly to Kay, she has never been invited to a birthday party or any other kind of social
event.

The difficulty of finding a child psychiatrist prompted Haidi’s desire to obtain
qualifications in counselling and hypnotherapy. She has applied her knowledge and skills
not only to helping Kay, but also to running a counselling business for a few years. Kay’s
situation worsened last year when she was prescribed the wrong medication and suffered a severe reaction. She was hospitalised as a consequence of the treatment. The incident led to Haidi’s decision to try to care for Kay by herself. She worked closely with a psychiatrist to help Kay cope without medication. Consequently, Haidi’s anxiety level may increase, as most VCFS sufferers need medication to control the psychological aspect of their disorder.

A father who is 84 years old

Haidi’s father, who was 84 at the time of data collection, has lived by himself most of the time since his wife passed away ten years ago. Although Haidi has one brother and one sister, they both live in other states. As a result, Haidi is the one who provides various kinds of assistance to her father, including taking him to his doctor’s appointments.

Two years ago, Haidi’s father resided with her family for 18 months, but moved back to his own place because he could not cope with the level of noise that his grandchildren made. It was not until last year that Haidi made the decision to place her father in a hostel, where someone can keep eye on him and notify Haidi if something happens. The arrangement is the option that Haidi felt could best give her ‘peace of mind’. She explained how the situation arose:

… financially he [Haidi’s father] was stressed; he couldn’t live on the pension. So we went and sought financial advice from the people we deal with, and we’ve now set up a reverse mortgage so he’s got money to live on … all of those sort of things …

… physically, he has been sick on occasion, and [has] not known how to get help … when mum died, dad didn’t eat properly, didn’t really know how to cook that well. So he lay on the floor or in bed for two days at a time. That’s happened a couple of times. He did have a mild heart attack.

Haidi’s father still visits the family house and stays overnight one or two days a week. This places extra pressure on Haidi as she has to go back home to prepare and have lunch with
her father. Being forced to spend extra time at home during lunch breaks creates a conflict with Haidi’s desire to generate more periods of leave which she can spend with her children, or at other special events by skipping lunch breaks.

The experience of being a caregiver

Negative elements

Physical exhaustion and emotional strain

In comparison to the days when she worked from home, Haidi feels that the pace of her life has become much faster now. Having to get out of the house, get her children to school, and arrive at the office by 8 am, is really a challenge for Haidi. It is no different in the afternoon. Haidi’s post-work hours start at 4 pm, picking up the children from school, doing homework with them together, doing the washing, cooking dinner, giving or organising showers, settling the children down and putting them to bed, and so on.

While Haidi does not deny that the demands from a full-time job, as well as taking care of three children and an elderly frail father, are the causes of her physical exhaustion, she believes that she is in ‘excellent health, but high stress’. Haidi has ruled out work as the source of the stress. The following extract from the interview captures Haidi’s view about her job:

… no [stress from employment], I think if I wasn’t working that would be very hard. I get very depressed if I’m not working and just stay home. So work’s really good … that’s my time … yes, and I enjoy it and it’s something that I’m achieving, as opposed to being at home.

The emotional strains were the result of the ongoing unfair treatment of Kay, as well as the constant worry about her children’s life in the future. Tears were in Haidi’s eyes when she recalled the unfair treatment Kay had endured during her years in primary school. Haidi harked back to the old days when she had to deal with an unforgiving principal as well as other people:
… a new principal arrived in year three, and within six weeks of being there at the beginning of the year, she tried to throw Kay out. The principal had a reputation. The curriculum in year three, they go from concrete to abstract, and Kay was struggling. She also had a very sarcastic teacher. So Kay crashed and burned at the beginning of year three, and the principal’s answer was to throw her out.

Kay will soon be finishing secondary school. It is unlikely that she will gain entry to university. Haidi and Paul are willing to pay for Kay to engage in further education, but she may not gain entry even based on equity grounds given her disability. Children with a disability often get different schooling than other children of the same age. They study subjects related to life skills, which are not counted in the final year of school. Thus, the overall entry scores of children with a disability can be lower than those who study normal subjects in mainstream schools. This is what is happening to Kay at school:

… Kay got put on life skills for English and Geography this year because I think the English and Geography teacher can’t be bothered to stretch herself. So she’s now on life skills, which is dumbing her down. Every other child you try and stretch, set the bar high and go for it. Kids with disabilities are just put onto life skills and dumbed down.

… they [children with a disability] sit in the class but work differently. So it’s just like babysitting – I’m not smart enough to do what the other kids are doing. She’s got no teacher interaction; the teacher’s just there. She works from a workbook and that’s it. Occasionally she’s pulled out of class and they check her work. But it’s not that inclusive education.

Haidi expressed her view of the current education system:

… so it’s discriminatory, [as a university], it discriminates against disabled people. Kay’s smart, she’s got a good memory. But if you ask her to do abstract stuff like analyse Romeo and Juliet, no idea. So they’re not tailoring the schooling or
university entrance for kids like Kay, who’s quite bright, but more concrete than abstract. So that whole system is geared against kids with disabilities.

Another worry for Haidi is that the transition to work programs offered by the government only run for three days each week. This will put a different form of pressure on Haidi, as Kay will have to stay at home by herself for two or three days a week once she leaves high school in two years’ time. Furthermore, Haidi is also stressed with regard to Kay’s long-term future as she might never be able to live independently, obtain reasonable employment or purchase her own house. She explained the reason behind her assumption:

Now if I ask her to do something and she says no, if she does that to an employer she won’t have the job for very long. So she needs a very structured role where they cope with her disability. And that, I don’t think, is going to be easy to find. I hope it is.

The emotional strains also stem from what is going on in our community. Haidi is furious that some people in our society take advantage of vulnerable people without ever considering the impact that their actions might have on these people, as well as on those who are providing care. Haidi’s father is considered cognitively ‘frail’, and will sign documents under somebody else’s influence. This makes him vulnerable. When Haidi recounted one of the two instances when this had occurred, her annoyance was evident:

I told him [Haidi’s father] to meet me at the mobile phone shop, and by the time I got there he had signed a contract. A young, sharp fellow just sweet talked him into signing a contract, and it was the wrong one. So then I spent two hours on the phone to the mobile phone provider to try and get him out of the contract. And now we’ve got to take him back down, get rid of that contract, get another one, put an official complaint in about the person …

While Haidi understood that the above instance would not occur daily, she perceived the situation as an indication of how disadvantaged groups are treated differently or unfairly by the wider society. She could not hide her frustration during the interview about the time she
had spent to resolve those issues, as well as the uncertainty about how often the similar incident would happen.

**The impact on career**

Haidi considers herself as a career woman, and by and large, she assesses and defines her achievements and successes based on her career accomplishments. Although Haidi and Paul have made a significant commitment to stop their ‘very high flying’ jobs, it still took her years to reach the point at which she was happy to be a dedicated wife and devoted mother. Haidi has endured many adjustments in her career according to the needs of her family. While she does not resent changes, Haidi implied that she had to compromise her ambitions:

… the organisation has me on contract, a lot of our staff are on contract. So I don’t have any hopes or dreams of promotion. I mean, I’d like to, but it just has never entered my head … yeah [contractors are treated differently from permanent employees], I think so. I mean, nobody’s said that to me.

… but because of the flexibility I need, I would trade that off against a promotion. I would prefer to just do my job. If I could be promoted and be flexible, that would be good. But I’m not sure that would work … I really can’t aspire to anything. I’ve got an MBA, I’m pretty smart, but that’s not going to take me anywhere because flexibility has to be first.

**The impact on the financial situation**

As stated earlier, Haidi and her husband have made considerable adjustments to their careers in order to overcome the financial pressure of raising a young family. Having a child with a disability has a massive effect on the family’s financial situation now, as well as on their plans for the future. Haidi and Paul believe strongly that it is imperative that each of their children be treated equally. This partially explains why Haidi is still outraged about the discrimination they experienced when Kay was in primary school:
I’m still angry about that [paying $10,000 each year for most of Kay’s primary school] … because we need funds to help Kay down the track. Kay will probably never earn enough money to buy a house, so if we want her to live independently, we will have to buy that house for her … So people don’t think through the consequences of their actions on a family with a disabled person, or the carer.

Haidi does not mind working for the same company and staying in the same job for the next 10 years in order to get money so that she and her husband can purchase a house for Kay, as well as houses for Sandra and Mat.

**Positive elements**

**Involvement in VCFS campaigns and support of VCFS research**

Feelings of isolation, a sense of inequity, the desire to raise the awareness in society, as well as an aspiration to assist others in the same or similar circumstances, are the driving forces behind Haidi’s active involvement in VCFS campaigns and VCFS research.

Haidi is a member of Family Advocacy, which is part of a VCFS support group. She contributes by attending relevant conferences and by being an active advocate for the rights of sufferers of VCFS in terms of getting equal education and fair assessment. Haidi has facilitated discussion and worked in collaboration with other members to develop models that can help children with a mild intellectual and social disability, a sub-group that is neglected by the current education system but needs much support. In particular, with regard to developing and proposing programs that smooth the transition from school to work for disabled children through the provision of work experience.

Meanwhile, Haidi is a strong supporter of research in relation to VCFS. Kay is a frequent participant in related research. During the interview with Haidi, she mentioned that she planned to take Kay to another state to take part in a two-day research seminar on the neurological problems of VCFS the following week.

**Family elationships**
The relationship between husband and wife

Haidi and Paul, in her view, are soul mates. They both had very successful careers prior to starting a family. After realising that their first baby had a genetic disorder, Haidi and Paul had helped each other to survive the most challenging period of their lives together. The sacrifice they have made, especially in terms of their careers, is enormous. The sacrifices began with Haidi quitting her full-time job, obtaining qualifications in both counselling and hypnotherapy, and establishing her own business.

Once Paul identified that Haidi was sick of staying at home and was ‘depressed’ because of the loss of social contact, he decided to give up his long-term employment and work from home. Haidi and Paul take turns looking after their children. Haidi explained:

… during the school holidays I’m allowed to work from home. We [Haidi and her husband] do part-time. My husband stays at home in the morning, then I go home at lunch time and stay with the kids … he works from home; it’s his own company. So he can be flexible too.

The relationship between siblings

Kay and her young brother Mat (10 years old) fight frequently, as Mat cannot understand why Kay is getting extra attention. He ‘hates it’ that mother and father treat Kay differently. Kay normally gets what she wants, and, on most occasions Mat is the person to concede defeat. Sandra, 12 years old and the middle child in the family, usually tries to play the mediator role, but often fails. Haidi feels sorry for Sandra and insists that she should enjoy her childhood:

I said it was not up to her to do that. She’s too young and it’s too hard … that’s right. I don’t want her feeling responsible. I still want her to be a 12-year-old girl out having fun, and not taking this on board. It affects her too much anyway.

Sandra and Mat get along extremely well. Both are very bright and incredibly active. However, Kay gets agitated if she is asked to, say, go for a walk when she was doing other
things. She is ‘very stuck’, ‘very rigid’ and is never willing to compromise. This has a huge effect on the rest of the family, especially on the other two children:

… if we wanted to go on a picnic or go for a walk, we either had to leave Kay behind or put up with half an hour of screaming, and then complaining the whole time we were out ... The other two children are very active. They’re younger, and are tolerant of Kay and they love her, but it has impacted their lives big time.

The relationship with the father

Raising a young family, especially a young family with a disabled child, can be a difficult task. When that responsibility is combined with taking care of a frail elderly parent, the multiple demands often create significant stress for the carer. This is definitely the case with Haidi.

Satisfying the needs of both her children and her father was a challenging assignment for Haidi when her father stayed with her family. She had to deal with her father’s jealousy of having less attention, and postponed the dream of increasing the leisure time she spent with her children and husband. Further, she faced the issues associated with her father’s lack of cognitive capacity and his lack of tolerance with her family. Haidi expects her relationship with her father will continue to change as a result of the ongoing decline of his intellectual faculties and physical health.

Support

Support from society at large

There is no doubt that the wider society is still not sufficiently aware of the needs of those who have children with a disability. Haidi described the common feelings of people who have a child with a disability as ‘isolating’, ‘we cried a lot’. The following experiences illustrate Haidi’s frustrations:

... and dealing with Centrelink and people like that is just horrible. Kay’s just turned 16 so we’ve had to get her reassessed at Centrelink. It was just the most
shocking thing. Some people have got no heart … It’s a deficit-based model where they’ve got two different doctors who say everything that Kay can’t do. She can’t brush her own hair, she can’t tie her shoelaces, she can’t handle change. All these can’t, negative, deficit. Then we had to go for an hour interview for a job placement interview with Centrelink, and that’s the same thing. At the end of a two-month process, I still have no idea what she can do. I know as a mother, but how I’ll translate her skills into a job – and nobody helps. Nobody helps. Even the school just does a little bit …

Haidi made some suggestions about what support was needed:

… they [the government or society] should have somebody sit down with us to work on a strength-based model to say, okay well what are your child’s strengths? What can she do? How can we help her? Then she’s got a range of 20 jobs as opposed to a range of two or three low stereotype jobs such as flowers collector, garbage man. So if you want something different, you as a parent have to do all the work. And that’s where you really need support …

… and we need a different model. It needs to kick in now, in year 10, so that I can get Kay doing appropriate vocational education training in Years 11 and 12 …

While Haidi knows that respite services are available, she has yet to exploit them. There was a good reason for Haidi’s hesitation about utilising the service:

I’m not sure I’d put Kay into respite care because of the type of people that go into respite care. They’re very severely disabled, or have very bad behaviour issues where the parents can’t cope. So I’m not sure I want Kay in that environment.

**Support from the workplace and colleagues**

While Haidi expressed her gratitude to her current employer for providing flexible arrangements, such as working from home during school holidays, she noted that there was no formal program in the organisation to assist people like her to cope with the challenges
they are facing. Haidi has a total of eight weeks’ leave a year, of which four weeks are paid and four weeks are unpaid. She usually has to work overtime to fill the gap between her entitlement and the actual school holidays, approximately 10 to 12 weeks annually, and other events (such as Kay’s participation in the relevant research). Instead of taking sick leave for herself, Haidi would work at home to save her leave for when the children were unwell and in need of care. This may generate an unhealthy cycle that will exacerbate Haidi’s own physical condition.

Despite the fact that Haidi is actively involved in VCFS campaigns and research, she admitted that she has not invested enough time and energy to build up a strong network or support group among colleagues and friends. Haidi sensed the urgency of putting such a plan in place, as this special group of people is getting more and more isolated.

**Summary**

The life of being a primary carer to her three young children, one of them with a disability, as well as her frail elderly father, while working full-time, is challenging, even with the help of her husband. Haidi feels physically exhausted after being at work for eight hours, cooking dinner and washing after dinner, doing homework with her children, showering or bathing them, and sending them to bed. However, she finds the physical exhaustion much easier to overcome than the impact of emotional stress, in her view.

Resolving the conflict between caring for her young children and her elderly father, and dealing with the jealousy and intolerance from her father, is emotionally draining. Haidi’s health and well-being have been affected dramatically as a result of being an indirect victim of inequitable treatment by society. She loathes the fact that a small proportion of people within our community take advantage of a cohort that needs help the most.

Having a child with both physical and emotional health problems has a huge impact on the family’s financial situation, in both the short and the long term. Haidi and her husband have had to pay a considerable amount of money to keep their disabled child in a mainstream school. The recognition that she and her husband have to plan the future for their disabled
child, and the attempt to ensure that their other two children are being treated fairly and equally, have put a lot of financial pressure on them.

Haidi has given up on or missed opportunities for career advancement as a result of being a primary carer, simply because she does not possess the most valuable assets – the time and the energy. While the adjustment from being a high-flying career woman to a family-orientated mother was difficult, Haidi was pleased that she made the transition and that she did not have any feeling of resentment.
4.3.6 Jenny

Snapshot

Jenny gave birth to two baby boys, Calan and Jay, two years apart 19 years ago at the time of data collection. Both boys started having seizures a few months after they were brought home, and were diagnosed with the same diseases (a degenerative disease and Autism) at a very young age. Jenny was a primary carer to her two boys for almost 17 years, until two years prior to the interview when they were placed into two families through a program called ‘Out of Home Placement’. At the moment, Jenny is still very much in charge of her sons’ ongoing care.

Jenny is in her late forties, and lives with her seven-year-old daughter, Stefi. Her eldest son, Lucas (22 years old) has moved out of the house. She is in the process of filing for a divorce after two years’ separation from her husband, Nathan. Jenny was self-employed for many years prior to taking up an ongoing full-time position within her current organisation 15 months ago (at the time of interview). Her role as a state manager in fundraising and development requires a considerable amount of travelling. However, she believes that work is a ‘healthy choice’ and one of the means of reducing the high level emotional stress associated with taking care of two children with high needs.

The demands of work

Jenny had to work in order to bear the financial burden of raising four children, particularly, given that Nathan was unemployed for the last seven years that they were together. She has been through a few different phases in her employment, starting in a self-employed role in the early days when the three boys were in school and Stefi was a baby. During the school holidays, Jenny was unable to accomplish much work during the weekdays, so she put in
more effort on weekends and nights when either Nathan or carers could look after their children.

Jenny has a Graduate Certificate in Professional Management specialising in fundraising as well as the qualification of Certified Fundraiser Executive, an internationally recognised accreditation for fundraising. She has been managing various state projects in relation to fundraising since she was employed full-time. While Jenny’s current role offers her great flexibility in the sense that she does not have to ‘clock in or clock out’, the position does demand quite a lot of intra-state or interstate travel, as well as working overtime in order to meet deadlines.

Being employed not only serves the purpose of meeting the needs of the family, but also provides an opportunity for Jenny to temporarily escape from the intense caring responsibilities and to reduce the stress involved. The following extract illustrates Jenny’s perceptions about having a paid job:

... but even if I hadn’t had to work, at the very least it would have been a better thing to do to cope because ... from my perception – once again having not one but two with high needs, it was like slap, slap, slap ... well emotionally and I suppose because [with] my children it wasn’t one it was two, they weren’t mild, they weren’t medium, they were extremely high need ...

However, Jenny realised that it was very difficult for her to go to work because it was not easy to find appropriate services and/or carers to look after her children while she was at work. This continues in her current situation, although she does not need to provide caring for Calan and Jay on a daily basis, and only has Stefi living with her. Jenny recalled the days when the boys were at home:

... I got day care to do that. Nathan wasn’t working at that stage but he couldn’t cope with her [Stefi] full-time when the boys were at school, so even though he was at home I still had to find care for her. So I think I basically still had Stefi in care
three days a week for me to go to work, and then Nathan would have her two days a week.

Two weeks after the interview, Jenny was going to be ‘madly’ busy carrying out a massive state-wide fundraising feasibility study during which she would conduct many interviews across different states. Nathan would look after Stefi while Jenny was away. However, Jenny was not concerned if Nathan could not help out:

... at this stage yes [Nathan could offer help], but otherwise I just work it out somehow you know ... No, no [not difficult to find someone to look after Stefi], because I’ve had a lot of experience at that ...

The demands of the caring role

Two children with disabilities

Calan, the second child in the family, was born with a degenerative disease. This meant that he needed surgery in order to survive. He had half of his intestines removed and was hospitalised for the first six months of his life. Unfortunately, Calan started having seizures a month after he was brought home, and was diagnosed with autism when he was two and a half years old. While Jenny was still dealing with Calan’s health situation, she gave birth to her third child, Jay, who, started having seizures seven and a half months after he was born. Calan and Jay had similar symptoms, and were diagnosed with the same disease. Both of them are still on anti-convulsants to control the symptoms.

Both boys were diagnosed with autism, although each exhibits slightly different symptoms. Calan is ‘non-verbal’, and his behaviour is more challenging than that of Jay, who demonstrates some ability to verbalise. However, Jay’s extreme and harmful outbursts mean that he is also classed as having 'high' needs. He was expelled from special school a few times as a result of his attacks on teachers. Jenny described her demanding life of having two sons with aggressive behavioural problems:
... if I went crook on Calan, Jay would start screaming, and then Nathan would say that’s enough. And then there’s another person screaming and then you know ...

Calan and Jay’s aggressive behaviours could be directed at anyone, even at their younger sister, Stefi. In addition, the disability of one would bounce off the other. If the behaviour of one of them escalated, it would be like a domino effect throughout whole family. There were many occasions when Calan and Jay threw and kicked things that could potentially hurt and harm Stefi. They would often attack Stefi. Jay actually picked up Stefi and threw her in the pool a few times. Jenny clearly remembered the following incident that triggered the process of placing her sons in the ‘Out of Home Placement’ program:

… that day, I put a video on for them, set them down nicely, and okay I’m just going to have a shower. I got into the shower, started washing my hair, had water running and three or five minutes later Stefi came running into the bathroom … the minute I walked out, the minute Jay heard the shower turned on, he must have picked her [Stefi] up, taken her into his bedroom – we had laminated windows because the boys put their head through one – he threw her into the window, according to her and as I said she was only two or three. He was throwing her about the room and she came in and she had like blood blisters on her forehead, blood blisters on her cheek, her thumb was bitten where he had bitten her. She had … no tears but she was shaking, she was in shock.

The plan to gain access for Calan and Jay into a placement program was initially suggested by one of their case managers, who believed that there was a need to take some active measures to stop Stefi being physically and emotionally hurt by her two brothers. Jenny did not want her daughter to experience the same emotional impact that her eldest son gone through.

However, due to the fact that the ‘Out of Home Placement’ program was unavailable to children under the age of 18, it did take some tenacity to achieve access as the application
had to go from department to department prior to approval being granted. Jenny recalled a process that required persistence:

... basically I had to rock up to Parliament House, you know a parliament hearing, and let them have it type of thing. So it wasn’t an easy process and it was quite degrading to do that, because it’s like you’re trying hard to get your family out of the house and it’s not what you should be ... and it’s like you shouldn’t, like emotionally that’s not the right thing to do with your family ... You had to push that, like the situation was with all the government bureaucracy and that, you really had to push for that to happen.

Jay’s aggressive behaviours were even worse than those of Calan. This had a huge impact on the relationship between Jenny and Nathan, and left Jenny no choice but to go through a similar procedure to place Jay in the same program two years later. While the process was relatively easy because of the precedent set by Calan’s case, it ‘went against the grain emotionally’.

... then about two years later like our relationship, Nathan’s and my relationship, started disintegrating, and yet Jay was aggressive so I couldn’t have coped with Jay by myself. So the only way to get rid of my husband was to get rid of Jay as well ... So basically having been through that process with Calan, the government couldn’t bluff me anymore.

Jenny hated to use the word ‘abandoned’ to describe the arrangement for her two sons. However, she commented that

When you’re at the end of your tether, you’re at the end of your tether. You know if everything else is falling apart it shouldn’t have to be like that.

At the time of the interview, both Calan and Jay were in the ‘Out of Home Placement’ program, but living with different families. While Jay was still supposed to be in special
school, Calan was already in community-based programs (once a child turns 18) for three
days a week where children with disabilities might have a music program or they might be
taken to a swimming pool or shopping.

**Current caring demands**

At the moment, while Jenny only sees her two sons once every fortnight, taking them out
for movies or other activities, she is still very much in charge of their ongoing care in terms
of medical or school appointments, or meetings with their case managers and carers. Most
importantly, she involves herself in making the key decisions.

Jenny has been keeping a good ‘professional’ relationship with the carers of both Calan and
Jay, as well as their case managers. In fact, the current carers have been caring for her sons
for more than 16 years. The service that current carers initially provided to Jenny’s two
sons was day care, which then evolved into respite care, and is now out of home placement.
Jenny always praised her sons’ carers. Her genuine feelings about those carers are evident
in the following comment:

> ... with my carers, I suppose I always admired my carers, in that I felt before I had
> my kids I was probably bigoted when it came to disabilities, ignorant [she laughs].
> So I absolutely admired these people that for very little pay step inside this world of
> yours that is just so overwhelming and so difficult that so many people do walk
> away from you. There is this handful of people who don’t walk away and they’re
> not that easy to come by.

On the other hand, Jenny had to nurture, facilitate and train most of her sons’ carers as to
how to work with her boys because the majority of them had no experience in working with
disabled children. She also helps them to obtain other sources of funding. Carers in the ‘Out
of Home Placement’ program receive funding from the government for running their
business. However, there is a limit to the amount of money that they can obtain, which, in
turn, decides the number of children they can accept as well as the number of days of care
that each child can access.
Jenny is fully aware of the difficulties involved in finding a compassionate carer. It is apparent that her children’s behaviours (especially Jay’s manners) would be too confronting for another family, even a family that deals with other disabilities. Using her strength and knowledge to fight battles for her sons’ carers in terms of acquiring enough funding, and ensuring that they are not exhausted, has become a central part of her current caring responsibility. She realises the importance of winning battles for her sons’ carers, as this is the basis upon which they can take good care of her children. Jenny illustrated her view:

... in the long term, if they [her sons’ carers] can’t cope, then I know for a fact there won’t be another family out there putting their hand up for my boys.

... if the government will look at that in the immediate instance and think, oh sorry our package is only this amount, I’ll say find another package, find another pocket of money somewhere ... if they [the government] looked big picture financially it has a future impact on the government. They’re better off looking after us, you know they’ve been thinking short term, they need to sort of think of investment. And okay, if these people doing these good jobs can’t cope, what’s the alternative?

Having regular meetings and cooperating with case managers, those who act as a bridge between government and carers or parents, and who often carry out any assessment of disability, has been another key feature of Jenny’s caring role. In the situation in which no agreement could be reached between case managers and herself, Jenny would escalate issues by referring them to local politicians.

There is no doubt that Jenny will always be there for Calan and Jay, although they are living with other families. Apart from regularly taking her sons out for activities, such as watching a movie and bowling, Jenny often offers respite service to her sons’ carers as she never wants to get to the point where ‘they [carers] cannot cope’.

**The experiences of being a caregiver**
The impact on health and well-being

Being the mother of four children, of whom two are severely disabled, has been extremely challenging. Jenny confessed that she is not coping well, either physically or emotionally, and is definitely not happy. She does not have the energy to resolve everything, nor any interest in doing so. Jenny described her life:

There was … you know he’s got this disease. Oh, he’s losing a bowel, slap. Oh, the other one has got the disease, slap. Oh they’ve got epilepsy, slap. Oh, the other one has got epilepsy.

... I suppose I started the process of thinking … I don’t know, I suppose in one way I thought, I’m not coping, although I was coping. I was coping but I suppose then you start questioning what does coping equal.

All of Jenny’s attempts to survive have been very much short-term. She takes one step at a time, and refuses to think of more than trying to get through day by day, as ‘thinking was pretty ugly’. There was a time when Jenny was reliant upon antidepressants to ease the enormous pressure of daily life. Jenny elaborated further on how difficult the situation was:

... sometimes when I was really depressed or stressed, I’d have these mind pictures snap through my head for maybe 30 seconds and they were just like someone looking through a film. That was click, click ... I’d actually start convulsing and then I’d push them away. I had a couple of incidents like that.

... it was being stiff up in the neck and the shoulders and screaming and shouting and almost spitting, you know? ... Yeah, just really ... oh ... and sort of on edge and very nervous.

Jenny thinks thought that she will always be available for Calan and Jay, and take them back home if they are forced to be institutionalised, where they would face the possibility of being mistreated. However, a recent incident has made her reassess the long-term impact
of being a carer to Calan and Jay. She wonders whether she could go though those tough days again:

Calan’s carer went over to Bali for three weeks and said do you mind having Calan? You know the first week was fine, the second week he was starting to get a bit antsy about things, by the third week I couldn’t wait for her to get back ... but after that three weeks I sort of thought oh ... I don’t know if I could do it again. I really don’t know if I could do it again ... I think I’m just totally burnt by it, just spent. Just absolutely spent by it where I couldn’t emotionally find that energy to go through all of that again.

Jenny admitted that although the need to protect Stefi had triggered the decision to place Calan and Jay into other families, she had no desire to bring them back as she was fearful of how she could cope. She commented:

So, selfishly, it’s actually got nothing to do with Stefi. So even if she was a grown up and had left home, I don’t think I could do it again full-time, no, I couldn’t. It’s too much.

The impact on the financial situation

In addition to the physical and emotional impact of caring, Jenny has also experienced financial hardship. She was forced to stay home to fulfil parenting duties while Nathan was running their family business, which brought a very low income, and the family lived on this single income for many years. In addition to having a low, single income, the family was under huge financial pressures because of the out-of-pocket expenses associated with seeing specialists and so on.

The year before the interview, the financial strain had reduced, as Calan had received a pension after turning 18. Jay will be on a pension later this year. However, Jenny is still responsible for all of the expenses related to taking them home or out for activities once every two weeks for four to five hours.
Family relationships

The reality of having two children with a disability has not only taken a heavy toll on Jenny, both physically and emotionally, it has also had a huge impact on family life. Jenny described her family as ‘a dysfunctional unit’, and this was evident in the way she talked about the relationship between her children:

... [Lucas] got on with them, but they were just never a normal sibling. You know they [Calan and Jay] didn’t have speech, they were burdensome.

... [Stefi] gets a little bit sad that we’re not all together. She’s only just kind of comprehending that disability means different. And that her brothers are different. That’s saddening her as well.

It was also apparent that the quality of family life was poor:

... that’s just 15 hours [the time spent on work and home] to get your needs met so you can still function, you know? So you can still go to work and feed the family and everything like that. So a lot of that actually took away from any respite. The rest of the family kind of gets swept aside ... there was never any time for each other.

Having two children with a disability has had a huge impact on every member in the family. Lucas was affected enormously by his two younger brothers. He had moved out of home and was currently living with his girlfriend. Lucas never really had a childhood, and was like an adult from a very early age. Jenny remembered the time before Lucas was 13 years old:

... he [Lucas] put himself in the position of being my crutch. My husband would be at work and I mean [Lucas] would come home from school and instead of going out and playing with his mates he’d hang around the house and I sort of thought, why aren’t you out of here, because if I could have been out of there, I would have been out of there.
Unfortunately, Lucas did a complete backflip and became a ‘very, very, very angry boy’, not just because of his brothers, but also because of a lot of difficulties at school where people could not comprehend his circumstances. He was constantly getting suspended and expelled from schools as a result of his angry attitude. At one stage of his life, Lucas got himself into drugs. Now, at the age of 22, he has not been able to retain a job, although he works all the time. He is angry with everyone and everything. According to Jenny, people described him as ‘having a chip on his shoulder’. Jenny described Lucas’s situation is consistent with what she has read about the impact of having disabled children in a family. Research reveals that family members primarily react in two extreme ways, either falling behind or rising above the situation.

There were many reasons that contributed to the separation of Jenny and Nathan. Nathan’s unwillingness to seek professional help and the failure of an attempt at reconciliation were two main factors related to the eventual separation. Jenny elaborated:

... we’ve been separated for two years. We got back together for three months in between that time ... to give it another go, but no ... yeah, the depression, even though we’ve been separated two years, the depression had gone on for a lot of years, and when Stefi was born – the seven year old – he [Nathan] basically couldn’t work, he had to be the other carer in the house, that impacted him even more ...

Support

Support from society at large

Jenny received little support for her caring role before Calan turned four, when she started to use the respite service. The entitlement to respite service was four hours a week in the first six years, and gradually increased to two weeks a month two years prior to the time of interview when Calan was 17 years old. Further, Jenny received respite care (one week) for Jay every month.
The respite services were provided by family-run day care centres that obtained funding from the government but received higher pay rates for looking after children with disabilities. However, such care and funding did not come from one service. Jenny remembered that at one stage she was accessing 13 to 15 services to fulfil one week’s needs. While some of those services had their own carer, others would provide funding, so it was Jenny’s responsibility to find carers for Calan and Jay.

Finding a trusted carer, in Jenny’s view, is getting increasingly difficult as there are not many carers available due to the poor wages. She suspects that this is the main reason that the majority of families’ parents are eventually forced to give up employment. The other possible reason for people being hesitant to seek support might be that they are afraid of taking support away from somebody else. Jenny credits herself with being very active and learning the support system in order to equip herself with the knowledge needed to obtain the help. She described her persistence:

… so I suppose the first thing has been being the squeaky wheel – you have to be the squeaky wheel and personality comes in to that, what kind of personality, but then there is the tenacity … also the energy too.

Jenny believes that parents should have the courage to seek assistance in order to relieve the burden imposed by caregiving, even if it sometimes means being humiliated. Jenny admitted that she had been humiliated when she had to ‘grovel’ for services, however, credited herself with being resilient:

… I think what I have been good at and what I have been successful at: first of all I’ve been successful at being the squeaky wheel. I wanted to work and I knocked on doors until I got the support I needed to be able to fix it.

… the government is trying to bluff the family carers and the people looking after the disabled person, saying the funding is not there and this and that and one thing and another. So if someone gets told the funding is not there then, you know, they
can make two decisions: well, okay, accept it and walk away, or ... say, Who is your manager?

Unlike the majority of parents in her situation, Jenny has not allowed herself to become too emotional, especially when she has not received the support that she wanted. She has never been in conflict with her sons’ case managers and carers. In contrast, she tries to work very closely and cooperatively with them in order to resolve problems and issues in relation to caring for Calan and Jay (whether to negotiate and obtain funding or finding the proper service providers). She is proud of her approach to gaining and retaining carers:

*I suppose first of all I haven’t been too choosy in what carers I got. A lot of carers I would get ... like I would advertise at my normal son’s school in his newsletter for carers or I’d just talk about the boys with people, and sometimes they’d be interested and, well, if you’d like to get into it, why don’t you ... you know I could do with some care for my boys.*

While finding appropriate services for her sons has been quite challenging, constantly retelling their story due to the turnover of staff members in the service centre has been an absolute nightmare. Jenny explained the time-consuming process of obtaining services:

*... for each of them you’d have a case manager and you’d have to go ... I’d have obviously government paperwork where if it wasn’t from the institution itself, or the service provider itself, it was from the government pushing it where they had to do this survey. So it wasn’t one survey, it was two surveys because of the two boys ... it was nothing to add another 15 hours, on top of my 40-hour week, just to coordinate all of those services, all of those carers, all of the paperwork associated with them, update their medical histories all the time. It was exhausting, it’s really exhausting.*

**Support from the workplace and colleagues**

Jenny’s current role as a manager in fundraising and development offers her great flexibility at work. She expressed her appreciation of the current organisation, and was
confident that the organisation would basically give employees that time but expect them to make up the time if it was a regular occurrence.

… being a mission-driven organisation for the common good, even if you were in one of those positions where you did have to clock in and clock out, I would think that they would be open to accommodating that, given the situation.

Jenny describes herself as a real verbaliser who needs to unload her feelings and experiences, not for counselling or advice on how to handle the situation, but to stop her ‘rolling the incident around in her head’ so she can focus on work or caring:

I need to get it out, so you’d probably overlook whether people wanted to hear or not. I’d identify colleagues who could give me half an hour in those shocking incidents such as ambulance trips without overburdening them.

Support from friends and family members

Most of Jenny’s friends have had little contact with her since the birth of Calan and Jay. The people she has befriended have basically all been carers, either the current carers of her sons or others who have come into her life as carers. In most scenarios, Jenny would have telephoned one of those carers when she was distraught about something because they were the people who could comprehend the situation. In addition, Jenny has been working in the charitable sector for years as a fundraiser, and has been fortunate to know a handful of people to whom she can talk when she needs support.

Jenny is the only child in her immediate family and gets virtually no support from other family members for her caring role. Both her parents and parents-in-law passed away long ago. Nathan’s only brother, Joe, has kept his distance from the family.

Nathan has never been a person on whom Jenny can rely for sharing the caring responsibilities. This was the case when they were together, and continue to be the case
since their separation. Jenny has to use day care services to meet the needs of her daughter in order to continue her current employment.

**Summary**

Life with two children with disabilities has been rather challenging for Jenny as it requires enormous time and energy. She has constantly been physically exhausted by being the breadwinner and carer, whether running her own business at home or employed on a full-time basis. Jenny’s husband, Nathan, stopped working when their fourth child was born, which was seven years ago prior to the interview.

Looking after two boys who can display aggressive behaviours at any moment (even to their younger sister) has been a nightmare. The constant worry about the potential harm to her daughter was really emotionally draining for Jenny, so much so that she sought help from the government in the form of placements for her two disabled children. People’s misinterpretation of Jenny’s approach with regard to putting her two disabled children into placement has had a huge negative impact on Jenny’s psychological well-being. Jenny also blames herself for her eldest son’s abnormal upbringing, and believes that he deserved much more attention than he received.

The financial impact of having two children with a disability and a husband who has contributed little in terms of finances has been extremely challenging. The family has been living in a low-income situation for many years. This situation is compounded by the additional costs incurred in obtaining specialist treatment and medication.

The family has been disrupted as the two boys have been placed into two different families, while the eldest son has moved out and is living with his girlfriend. Jenny and her husband are filing for divorce after a failed attempt at reconciliation. Jenny has lost nearly all her old friends since the birth of her two boys.
4.3.7 Marcus

Snapshot

Marcus, a 43-year-old migrant from Burma, has been living with his parents and younger brother since the whole family came to Australia 13 years ago. His focus has been on making enough money to support the whole family and looking after his elderly parents, who have long-term health problems. He has been working with the current company as an ongoing full-time employee for almost a decade. Marcus needs to devote the designated eight hours to his work during the day, with the exception of a thirty-minute lunch break.

Meanwhile, Marcus dedicates around six to seven hours a day, 30 to 35 hours a week, excluding weekends, to his caring role. He provides his parents with virtually all the basic activities that are necessary for independent living, as well as activities with aspects of cognitive and social functioning, including eating, bathing, toileting, cooking and doing housework.

The demands of work

As a full-time warehouse worker, Marcus starts his work at 7 am and finishes at 3.30 pm. Marcus’s main responsibility at work is to accept products that are shipped from other states or overseas, from countries such as Singapore and the United States. Auditing and entering the received products into the system is another aspect of Marcus’s work routine. While Marcus needs to devote the whole eight hours to his work during the day, with only half an hour lunch break, he believes that his workload is ‘just alright’.

Being at work on time is another challenge for Marcus, as he has to settle down his parents prior to leaving them with his brother during the day. Marcus’s own words were ‘I struggle a lot’. Nevertheless, he has no desire to change his working pattern as ‘it [referring to work
and caregiving] is still manageable’. On the other hand, Marcus admitted that it would be impossible for him to take on a 12-hour position if one was offered to him:

... No [changing the work arrangement] ... I would go for the eight hours job, just so, at the moment I reckon it’s a manageable thing ... if Leigh [Marcus’s direct boss] going to ask me for 12 hour shift, then I ... No, I wouldn’t take that one, definitely that’s ... can’t handle, yes, too much.

**The demands of the caring role**

**Elderly frail parents with long-term health problems**

There is a medical history of heart failure on Marcus’s father’s side. Two of his uncles passed away at ages 42 and 43, respectively, due to heart dysfunction. Marcus’s father had his first stroke in 2005 when he was 69 years old. The recent one, which happened in 2008, was much more severe than the first. He fell over and fractured multiple parts of his body. Although the fractures have been aligned after surgery, Marcus’s father has greatly reduced mobility as a result of the incident. Marcus provided the details:

_That’s [the second stroke and fall] why he break his hip and a hand. Hand as well; three or four places. All metal. So, that’s why he is having a problem with walking ... Yes, yes. Because his bottom – he can’t walk much. In fact, he was in a wheelchair after hip replacement, we have to push him around._

The doctor believed that all of the fractures had been fixed, but there was a need for Marcus’s father to do more exercise in order to gradually recover the lost mobility. He was hospitalised the week before the interview, and was to be kept in the hospital and receive more physiotherapy treatment for as long as needed.

While Marcus’s mother can carry out basic activities, such as showering herself, brushing her teeth and feeding herself, she has suffered for many years from a severe lung problem, which affects her ability to breathe. She relies on a 24-hour oxygen supply to survive.
However, there has been no formal diagnosis made because Marcus’s mother was ‘very, very weak’ so the doctors ‘can’t puncture the lungs’.

**Current caring demands**

Marcus does not need to spend time on travelling to another location to look after his parents as he is residing with them. However, the time required to provide assistance to his parents is substantial. He wakes up at 5 am every day, and spends the next one to one and a half hours looking after his parents. Then he heads off to work at 6.30 am so that he can be at his workplace on time at 7 am. Marcus described his routine in the morning:

> So, anyway, start at five o’clock. I’ve got to change my dad, because he can’t go to the toilet. Water is passed through everything, so I have to take off all the nappies, everything. I wash him and then I change his nappy and put his clothing on for him, everything, and do the bed as well, because the bed is wet as well. So, I change the bed, clothing, everything. I have to take it off, put it in the washing machine, start a wash and then that will be about, nearly about 5.15, 5.20.

> then I take both of them – I have to take sugar levels in the blood. Then measure all the blood pressure, it’s all alright or not, and then I have to put it on this record book ... Keep the record for the hospital doctors and everybody.

Marcus finishes his work at 3.30 pm and then rushes home to resume his caring duties. Then his younger brother is able to have a rest and start his part-time job. Marcus continued the description of his repetitive and hectic weekdays:

> ... then that’s when [around 4 pm every afternoon] I start again. This is changing, everything has started back from the beginning and I’ll put out the clothing, cook food, give them medication ...

Although Marcus’s mother is able to take care of herself in terms of simple daily routine, she does need a lot of assistance with regard to monitoring her blood pressure and sugar
level, taking medication and changing her breathing equipment. Marcus explained the special support his mother needs:

... yes most things [mother is able to do by herself]. We’ve got to arrange for the oxygen ordering and bringing in and replacing the filters, things like that, we’ve got to help her out ... she’s 24 hours on oxygen for her breathing problem.

The prolonged day ends around 10 pm when Marcus finally finishes his duties of working and caring for the day, and is able to ‘touch his bed’. The long day will start again at 5am next morning.

Marcus spends almost seven and a half hours every day looking after his parents during weekdays. Weekends are even more frantic for Marcus. During this period he usually has to do chores that cannot be done during the weekdays while his brother takes their parents out to do the grocery shopping:

I don’t have time [on weekends]. I don’t have much time, yes ... on the weekends, actually, this is on Saturdays, because we can’t much do all the cleaning jobs in the house, so I start cleaning all the floors and everything, all the carpets, that’s where I clean everything up. I have to clean up every room as well, because nobody would do that, can’t do that on weekdays.

The experience of being a caregiver

Conflict between work and caring

Such a hectic life of caring, work and commuting is extremely challenging, especially with little additional support. It is apparent that Marcus feels exhausted by the end of the day. However, he considers it is also a very rewarding experience, and is proud of himself for being able to fulfil the responsibilities of the roles of paid employment and unpaid caregiving. Marcus attempts to reduce the tension between work and caregiving to the minimum level by organising everything ahead with the support of his brother:
... normally, no [conflict between work and caring] ... General practitioner (GP for his parents) stays until about 5.30 in the afternoon. So, when I want an appointment with a GP, I do it after 3.30 when I finish my work ... he sits on Saturdays as well, so I could go then. But the only thing was that my mum has appointments with the specialists, so that’s where my brother comes in as well. He takes my mum away to the specialist ... Yes, I try my best to avoid everything [that causes conflict with work].

In contrast to most cases presented in this study, Marcus did not consider that he had missed any training or promotion opportunities at work as a result of his caring role.

**The impact on health and well-being**

Despite the fact that Marcus is able to manage and cope well with the challenges from work and caring, the enduring demands from both roles do take a toll on his physical well-being.

It was a contributing factor to Marcus’s heart problem which required a bypass operation.

Marcus depicted his health condition prior to the surgery:

... then I can’t walk even 100 metres. If I walk 100 metres like I’m running two or three miles or something like that, it’s just hard, you know, hard to breathe and very hard and then got a chest pain as well. So a very bad thing, it’s not muscle, pulling a muscle or something, no, very bad thing.

The situation was getting worse until one day he went to see a general practitioner. Marcus provided the details of ‘the shocked news’ he received that day:

*I stopped smoking in 2003 as I was having a problem with breathing as well ... One day, I went to see my GP, and took some ECG and came back to the doctor. The GP looked at it and said, oh, you had better go and see the specialist. So, okay, fair enough ... the GP rang up the specialist who got told about the results of the ECG. So, the specialist goes, alright, don’t do a booking to me even, ring up the man and*
tell him to go into the hospital straight away now, don’t even come to me. Tell him I send a man today.

So, I went to the emergency department in the hospital, showed the ECG. I was put on a bed straight away. Next minute the doctor from the upstairs comes down and he said, well you better stay here for a couple of days.

... actually you’ve got a heart problem, we’ve got to keep you for a couple of days. Anyway they took off all the examination and everything and they decided to do what you call angiogram, put in a camera into the heart and look into the system. The next day, Marcus was told that they [the doctors] can’t open up your heart because you’ve got three big blocked arteries, is 75 per cent block, so we can’t do the ballooning system, you’ve got to go for bypass surgery ...

... in the end, the scheduled two hours heart surgery actually went for eight hours. I had twice operation. So what actually now they do they got a vein from there and from leg, two legs and open up there, cut all the bones there and bypass, so I can feel it ... That was a pretty bad one. That was pretty bad, I was still in Intensive Care Unit for eight days ...

Marcus’s health condition has improved since the operation. However, he is still on various medications to control his high blood pressure, high cholesterol level and heart rate.

**The impact on the financial situation**

When asked whether or not he has ever considered working part-time in order to alleviate his fatigue level, Marcus answered with a firm ‘no’ without hesitation. He thought that he dealt well with the challenges of life. Further, he stated that such a change in his work arrangements would have a huge financial impact on the family.

*Oh, if I could go for part-time, that would be a big blow [financially] for me. That would be a very, very big blow. Now even when they’re having big troubles*
[referring to the cost-cutting that was happening in the company], anyway, I’m still here. I’m very, very grateful for that. But if I have to go for a part-time job, or … oh, yes. Yes, it’s going to be a big blow, yes. It is, it is …

According to Marcus, the pension that his parents receive from the government is totally inadequate. ‘The money is nothing compared to what I earn from here [the company]’.

Also, Marcus may be entitled to a partial carer’s allowance (at the moment, his brother is the one who applies for and receives the entitlement). However, the amount is too small and therefore, is ‘unhelpful’. He simply cannot afford to shift his position from full-time to part-time, or to become unemployed.

**The impact on personal life**

There is a huge cultural difference between Burma and Australia in relation to the value of marriage and the ways of raising offspring. The process of adapting to the new environment, the fear of separation or divorce after a marriage, and the new traditions have made it impossible for Marcus to embark on a stable relationship. He explained:

... yes, a bit of a difference as well. When I look around my people, they are like separated and divorced and they have got big problems with their children … The rules are not the same. So, I get very depressed by looking at them.

... no, no, no intention to even start that [a relationship] because as I said, the, what you call, the rules and regulations are changed. Because back in my country, I can check a child when they are doing something wrong. Like, you can yell at them, or you can just … check them or something. Nowadays, you do it here [in Australia], you are in big deep trouble.

There is no doubt that being a male primary carer to both his elderly frail parents for years, as well as sustaining a full-time job in order to support the whole family, are contributing factors to Marcus remaining single. He elaborated further:
... actually what happened was I did have a very, very tough life. There’s this place I was born in, I come from Burma, and then back in the country I worked for some companies as well. I didn’t have much time in the first place and then actually when I came here … actually, most of the things were like I couldn't understand, we had to settle down ... Now it’s worse, it’s gone backwards even because from two years time my dad got sick, so I’ve got no time at all.

Family relationships

Marcus has a very good relationship with his younger brother, with whom he has lived since his brother was born. Dwelling overseas for so many years does not change the inherited Asian culture. It is Marcus’s strong belief that the older son should bear much more responsibility than the younger sibling. Thus, he has made a huge effort to stay in the workforce.

Marcus’s motivation has always been to maintain the family, especially to support his younger brother in his efforts to complete his tertiary education. He was happy about his brother’s achievement:

... he [Marcus’s brother] just came out from school as well, so yeah. He’s like teaching and coaching at uni. He’s like a, what do you call, lab supervisor or something like that.

Marcus has always been the primary carer, although he and his brother share the responsibilities of caring for their elderly parents. The brothers support each other to continue their ‘not easy life’ here in Australia.

Support

Support from society at large

Marcus is fully aware that there are services available in the community to support his caring role as he was informed by nurses and social workers a few times that ‘they could
give us a carer’. However, Marcus is yet to access those services as his mother is not keen to let a stranger into their house. He explained the reason:

No [using the support services], actually, because my mum is pretty funny, so she … she doesn’t want anyone else to look after her. Yes, that’s why we didn’t have anybody coming in, and because I don’t want to let her down. Yeah, I understand that it’s good for my dad. But, the other side that I have to look at it, my mum as well, because she didn’t like it much, so I said, oh yeah, I better …

Marcus admitted during the interview that placing his father in an aged care facility is on the agenda. The plan is influenced by the doctors who believe that his father’s health is deteriorating. Here are Marcus’s interpretations of the doctors’ views:

... [the doctors] are trying to put him into a facility like that [an aged care facility], because the doctors reckon it [his father’s health] goes years, comes back, it’s going to get worse and worse. My dad is going to get worse and worse because the brain is shrinking, because they’ve got this MRI all the time in the brains, looking in the brains. The size of it is shrinking, so they reckon it’s going to get worse, so they already queue up for him for a place in aged care facility.

In the meantime, Marcus has also put his father’s name on the waiting lists of two aged care facilities in the area where they live, but it might take years as ‘it’s all backed up there’. The long waiting list means that Marcus still faces the challenges of juggling between workplace and home, and has to continue to accommodate the needs of both work and caring.

Support from the workplace and colleagues

Marcus and his brother take turns looking after their parents. They cooperate with each other’s schedules, aiming to allow Marcus to effectively manage the possible conflicts between work and caring. Marcus stressed that there was no need to investigate the programs and initiatives in the workplace that can be supportive, as he believes that he has
organised everything ‘quite well’ so far. Marcus is confident that his supervisors and colleagues will offer help if he needs it. He perceives that everyone in his section is supportive and has a strong sense of belonging to that community.

**Support from family members and friends**

Marcus has over a hundred relatives living in the same state in Australia. However, he rarely contacts any of them and has never received any assistance from other family members. One of the reasons behind this situation is that most of Marcus’s relatives came to Australia much earlier than his family. Thus, they are more successful in terms of integrating themselves into this society and accepting Western culture. Here is Marcus’s explanation:

... they’re all pretty much having a fight, big fights anyway. So yeah, we don’t ask them much. We don’t agree each other too much ... it is all sorts of troubles. They’ve got a different way of looking at things, because they’re here for 35, 40 years ago, and we just came from there [Burma], and we’ve got a different way of looking at things as well, so we clash on those grounds, yes ...

Marcus and his brother rely very much on each other in order to continue their life patterns. Marcus does not perceive any need to share his experiences or to request support from any of his small group of friends. Instead, he relies on his brother.

**Summary**

Although Marcus’s direct family (his father, mother and younger brother) have been living in Australia for approximately 13 years, the culture of his native country is still having a strong influence on his behaviour. Marcus believes strongly that the eldest son in a family should take the primary responsibility for caring for the parents and younger siblings. Marcus has tried very hard to keep his full-time employment as he understands that the family cannot survive without his income, and his younger brother needs his financial support financially to complete his university education.
Marcus has been a full-time employee as well as a primary carer to his elderly frail parents for more than a decade since the family migrated to Australia. The life of being a working carer is extremely challenging for Marcus, although he is content with what he has achieved – being the breadwinner of the family as well as the primary caregiver for his parents. The enduring exhaustion, the result of getting up at 5 am every day, has huge negative impacts on Marcus’s physical health. He has had a bypass operation and is still on medication for various chronic health problems.

The time constraint is a core contributing factor to Marcus’s single status at the age of 43 (although the cultural conflict in terms of family values and the principles of bringing up children has also contributed to this). There is no leisure time that would allow Marcus to establish a stable personal relationship and to attend other social events. His daily routine always revolves around his work and family. He rushes to his workplace after settling down his parents in the morning, and dashes back home right after he finishes his work in the afternoon.

Marcus receives virtually no support from his small group of friends and relatives for his caring role, with the exception of help from his younger brother. While placing his father in a formal care facility is on the agenda following the doctors’ strong recommendations, Marcus has no intention of employing the same approach with his mother as she has rejected being looked after by people other than her sons. Thus, the incessant juggling between work and caring will continue indefinitely.
4.3.8 Darren

Snapshot

Darren is in his late forties, and is carer to his wife, Jo, who was diagnosed with breast lymphoma at an advanced stage when brain and spine metastases were detected. Being the only carer for Jo meant that Darren provided both the physical and emotional support that she needed to go through many extensive treatments before she passed away 18 months prior to the interview.

During his 20 years with the organisation in which he works as a full-time employee, Darren has been in various positions, and was promoted to his current role, inventory supervisor, at the beginning of 2008. Darren expressed his great appreciation to the company for its generosity with regard to the flexibility it offers to its employees, especially to him. It is deemed to be the key factor that enabled him to manage his roles as a full-time worker and as a carer to his sick wife and their youngest daughter (who was nine years old at the time of her mother’s death), as well as their other two grown up children.

The demands of work

Darren likes to have challenges at work and tends to ‘get bored’ after a while. Seeking opportunities to explore different sections every two to three years has been his pattern of employment. He has been in several roles including that of a system coordinator, an information technology person, an inventory controller and a salesperson over the past 18 years.

The nature of Darren’s current role as an inventory supervisor allows most of his work to be done in a flexible fashion. Darren can conduct his duties anywhere, as long as he is able to connect to the computer network and is contactable. However, his position occasionally
requires him to be present at work or to accomplish certain tasks even after normal working hours, as he works collaboratively with colleagues based in other states and countries. There is a further reason why he has been in the office after hours on occasion:

... quite often, because this is a 24-hour section now ... quite often there’s times when you have to come back at night anyway, so once [Jo] was home and asleep and everything, I quite often came back in the evening.

The hectic work schedule kept Darren incredibly busy. He had to be very alert and concentrate fully on his job. Nevertheless, going to work was deemed to be an exceptional emotional release and ‘an escape’ from the illness setting, in particular within the last difficult months of Jo’s life. Darren explained how he felt about work at the time:

... one of the things, actually, I found that work was – where I found work was really good was I’d come to work and I’d be away from the sickness environment and all that. I always felt like you’d go back into a normal world. Really, you come to work and suddenly you’d feel like you’re back into the normal world.

The demands of the caring role

Caring for a spouse with a terminal illness

As mentioned earlier, Jo was diagnosed with a primary malignant lymphoma (ML) of the breast at a highly developed stage when the ML cells had actually been identified in her spinal cord and brain. Jo received initial chemotherapy once every three weeks, and was hospitalised on a few occasions when she had a bad reaction to the high-dosage treatment. The treatment also caused all sorts of problems in other organs, including the kidneys and liver. While most of chemotherapy regimen could be carried out in the region in which they live, a few extremely strong doses needed to be done in the city as the regional hospital did not have a 24-hour support system.

Jo was in a routine of daily radiation treatment and a bone marrow transplant at the latter stage of her life. She was often in the hospital for a course of treatment one-hour in duration
and then out of the hospital afterwards. Unfortunately, the treatments did not reach her brain and spine, although they reached the rest of her body, and sadly, these did not prolong Jo’s life. Darren and their children were informed of the poor prognosis during the course of the treatment, but did not expect the last couple months of their time together to disappear so rapidly.

Caring demands

There were approximately four or five occasions on which Darren had to provide all sorts of assistance and do everything for Jo, including cooking, cleaning, washing and helping her shower. This was mainly due to Jo’s strong reactions to the treatment. Two such occasions that Darren could recall were at the time of the first course of chemotherapy, because ‘there was so much cancer there’ and the time after the bone marrow transplant.

Apart from the special circumstances mentioned above, Darren predominantly played a supporting role in which he was assisting Jo and was also trying to reduce her domestic workload. Darren recalled the agreement between Jo and himself:

... but through most of it [the course of sickness], she was – while she was very weak and that – as a rule, I didn’t have to really help her bath and that. She tried to do as much as she could; she wanted to keep doing the cooking and the washing and the ironing and the house cleaning and all that because that was important to her too, to try and not upset the whole household routine and everything ... so for the ironing, I’d do half the ironing for her and she’d do the other half so she wouldn’t get too tired from the whole lot.

Darren and Jo made the most of their time together. Enjoying the quality time together and being in each other’s company overshadowed the sadness of Jo’s declining health. Darren gave an example of how they spent time together:

... so, if she was ironing or I was ironing and we’d sit there and we’d talk and – or if she was ironing I’d be folding some clothes and vice versa. So we’d try and do
things together. If she was cooking I’d be there, peeling the vegetables and helping her prepare ... so we tried to do more and more stuff together rather than she’d do some of it and then step out and I’d do some of it.

Darren knew Jo’s personality well and was mindful of her need to feel useful. He reassured Jo that she was important and very much needed in the family, and that she was never a hindrance. According to Darren, Jo was an independent person who hated to be devalued because of her sickness. Darren elaborated further:

... she was a very strong person in that it didn’t matter how sick she was, yeah she would just push through that and do so much stuff. It was all over the house. So it wasn’t as if we had to pick her up and keep her going.

Another aspect of Darren’s supporting role was his promise to be by Jo’s side when she underwent those ‘horrible’ treatments, no matter what kind of work arrangement had to be made. In the meantime, Darren also had to look after their daughters by picking up or dropping off the younger one at school, as well as taking care of some routines that formerly been attended to by Jo, and by supporting the older one, who was 20 at the time and preparing for intensive university entrance examinations.

The experience of being a caregiver

Conflict between work and caring

Darren believed that he had no difficulty in shifting from the caring mode to the work mode, and that his caring responsibilities did not affect his performance at work. He understood how imperative it was to set a clear boundary between the work and family domains, and he made a conscious decision to keep his personal life out of work. Darren’s way of minimising potential conflicts was to talk less (or not at all) about family issues in the workplace unless it was absolute necessary. As a result, very few people in the company actually knew Darren’s circumstances:
I probably did that well that the last week when she [Jo] went into palliative care and slipped into a coma, most of the people at work, they knew I – like I had the week off and took time off with her. It was only, I think, on the Friday – she passed away on the Saturday – it was only on the Friday that most people actually found out she was on her last.

**The impact on work arrangements**

Darren considered that he managed ‘very well’ to keep his full-time position while looking after Jo and their three children, in particular their youngest daughter. However, he did have to make some special arrangements, including taking some carer’s leave and long service leave on a few occasions in order to support Jo going through the toughest time of her life. He recalled six or seven occasions on which Jo was either receiving a major treatment, such as a bone marrow transplant, or undergoing some treatments that were unable to be carried out in a regional area:

... so, I actually stayed with her in the hospital because she didn’t know anyone down there [the city] and there was no one who we knew to visit her ...

... in that 18 months that she was sick, I probably took nearly four months of annual leave ... at various times. At one stage she had a – what do they call it – bone marrow transplant. I actually took six weeks holidays with her cause I had to stay and sit with her in hospital because she got very sick during that time and didn’t know anyone down there. Apart from that there was a week or two here and there.

Darren could drive to the hospital at lunch times and in the afternoon in order to fit his work schedule when Jo had treatments in the regional hospital.

**The impact on physical health**

Sustaining a full-time position while looking after his wife and their nine-year-old daughter for 18 months was an exhausting experience for Darren, despite the fact that he had ‘good flexibility’ in terms of his hours of work. Darren’s main tactic to overcome the pressure
imposed by limited time available was to sleep less. He tended to think of himself as strong and make light of the many sleepless nights he endured during the 18 months:

... well, I probably was [very tired]. I mean, I’m one of those people who don’t sleep much at the best of times. I can survive on four or five hours. Through a lot of that time [the 18 months], I was going to one and two hours sleep ... I’d go for up to a week with only sleeping through a seven, eight hours for the whole week. I’ve found that I coped very well with that. I was thinking – there were times when I’m very tired.

The impact of the accumulated fatigue was not recognised until a few months after Jo’s death. The following was Darren’s own confession:

... but yes, I think I was [very tired] – didn’t realise until after she actually passed away just how tired I really was through that time. I – then I sat back and thought how tired I used to be and as soon as I’d sit still for more than ten minutes I’d start dozing.

Another side-effect of taking care of Jo, particularly being at Jo’s side when she was in the hospital, was that Darren put on a lot of weight. The extra kilograms were the consequence of a lack of exercise and, in turn, caused high blood pressure (HBP). The formal diagnosis of HBP was established by a doctor six months after Jo’s passing. A weight loss program tried over the following several months did not bring Darren’s blood pressure down to a desirable level, so he had to start medication in order to control it.

**The impact on emotional well-being**

The emotional impact was much greater than the physical. The constant worry about Jo’s reactions to the treatment and the concern about her prognosis were emotionally draining. Darren described his real feelings back then:

*The only other thing that I realised was that – for that 17, 18-month period, I never really relaxed at all. Like, all the time I ... her and stuff ... All those sorts of things ...*
When I was with my wife and with my family, I felt like it was artificial because I didn’t – living with someone who’s very sick and while we didn’t think she was going to die until the last couple of months. Up until then you always have that sort of thing that it’s not going well, it’s not hanging onto that plan.

Being honest with their children was very difficult. Darren knew deep down that the longer the cancer remained in Jo’s body, the worse her health situation would become. He was also clear that Jo did not react well to the treatments, and that her outcomes did not match the expectations. While Darren was well aware that all treatments were useless over the last couple months, he did not want to paint a dark picture to their children so they would have no hope that their mother would recover. He tried to keep their children optimistic:

... so, here I am trying to say to the children look it’s only ... in these last couple of little spots we’ve got to get it out. But here’s me knowing that they’re just not getting it out. It’s not happening.

The discussion between Darren and his two daughters with regard to Jo’s final moments was deemed the toughest and hardest thing during that period. Darren portrayed the picture:

... Sophia [the younger daughter] was probably easier. Well, Sophia was very close to her mother, closer. But probably at nine she – eight and nine – she didn’t have a full understanding of what dying meant, that you’re never going to see them again ...

Whereas my oldest daughter, she – and plus the fact that she was doing her entrance exam, so she was very busy throughout. That was probably the hardest thing where a number of nights when I’d sit down and she’d say is Mum going to die? Then she wanted to sit down and talk through it. They were probably the hardest thing of the whole lot.
A common theme among carers who look after people suffering from cancer is their invisible state and the loss of their own identity. This was evident in Darren’s comments about their temporarily abnormal life:

... a lot of people rang you up and they were only interested in Jo. They weren’t interested in me or the kids ... we [Darren and the children] ceased to exist and it was just how’s Jo and they’d hang up ... I suppose to some, I and the children didn’t exist. It was only Jo that existed to most other people.

**The impact on the financial situation**

In addition to the physical and emotional impact, Jo’s sickness had also created an enormous financial burden. It began with the immediate loss of an income, followed by all the extra expenses involved in purchasing medication and visiting specialists. Darren went further regarding his calculation and how the family dealt with the change:

... financially it was, well hard. There was between $1000 and $2000 a month turnaround from her dropped wage to the extra cost of the treatment. Having said that, we got through that okay. Now obviously there was a few things we had to tighten up on there with our living.

The large proportion of debt, which took Darren six or seven months to pay off, came from a sizeable chemist bill and funeral costs. Darren recalled that the total amount of money that he owed was approximately $13,000 to $15,000.

**Family relationships**

**Quality time together**

For Darren, it has always been a quality versus quantity issue when it comes to family time together. Spending quality time with each other, as well as with each of their three children, was always the focus for Darren and Jo. It became an unofficial rule that everyone in the family followed as they wanted to ‘make the most of that time [together]’.
According to Darren’s definition, spending quality time together was a 100% commitment. This meant that he would totally turn off his work mode and would not answer either mobile or home telephones when he was with the children. The children would have his full attention and vice versa. Darren used the following example to explain his approach:

... so when we had time together, like if I was spending time with Sophia playing a board game, one of the other kids answered the phone, they’d say oh no, look, Dad’s busy, can I take the message and he’ll ring you back. I think that was very important and the fact that when I gave them a half an hour or an hour it was full on that I gave them, rather than ... mucking around with everything else.

The other aspect of Darren’s definition of spending quality time together was having a regular planned chat with his children. This method applied particularly to the older ones as it made them feel important:

... with my oldest son, if he is working afternoon shift, I used to make a point at least once a week I’d go into – I used to text him at work, often around tea time and say, look, when you get home tonight, if you’re up to it, why don’t we have a chat? So it was never something that was – it was always something that was planned ... when he got home at midnight, I’d go and sit down with him and we talked for three or four hours.

... my eldest daughter doing her entrance exam, at least one night a week or one evening a week, I’d sit down and I’d just – like, I’d put Sophia to bed – I’d sit down and just dedicate some hours to her. I’d sit down and talk to her. But the only times that didn’t happen was when I was in the hospital in the city with Jo ... Then I’d try and do that on the weekend when I came home for a day on the weekend.

Darren was very conscious of the possible negative effect of Jo’s sickness on their children in terms of resentment. He tried extremely hard to ensure that they would not have a sense of being neglected, and pledged that the following scenario would never happen in their family:
... one of the things that – I read this very early on was that one of the things that does happen when one of the parents gets very sick like this, is the children actually get very bitter towards that parent because suddenly their whole life is turned upside down because they can’t do anything, they can’t spend time with their parents or anything because one of them is so sick. So they actually end up beginning to hate their parents and suddenly this sickness is covering their whole life.

Jo had done the exactly same thing as Darren. The family tradition of spending quality time with the children did not change, even during the arduous 18 months. Darren clearly remembered that Jo set times with each of their children ‘one-on-one’ in her hospital room when they visited her. Darren often took the other two wandering around the hospital and found some place to play while they were waiting for their turn. During school holidays, Darren sometimes would take only one child with him, dropping him or her off, so that each could have individual time with their mother.

When Jo realised that she had only three months left to live, she did something that would stay with her children for the rest of their lives. Darren could never forget the scene:

... in that time [the last three months] what she did, she sat down and she did up a photo album and box of all these things for each of the children. When she did that, she sat down with each of the children and did it one-on-one with them. So they will always have memories of her and a series of photos from their baby photos right up and she did that with each one of them.

In reality, the three-month farewell turned to be a five-week one. However, Jo still took time out with the children:
... even in that time where we knew it was on the countdown, that she still sat down one-on-one and said to them, now this is why I put all this stuff in this box for you. This is what happened when this – and so she gave them all these memories.

**The Children’s social life**

Another conscious decision that Darren made was to ensure that his children would attend all the social events to which they were invited, even if this meant cancelling or postponing a business trip. He could only recall one occasion that really upset his elder daughter:

... my oldest daughter was made a school captain, neither of us could be there for her presentation that she’s presented with her captain’s badge, because that was when Jo was having her bone marrow transplant. She was – I was trying to get back but then she had some pretty bad reactions that afternoon ... was really sick and so she wanted me to stay with her that night. So I didn’t get back to her [their daughter] that night. I remembered that the kids saying that they were really left behind that no-one would actually be there for them.

Darren went a long way to make amends for not being able to attend the presentation the previous year:

... Yeah. Yeah, The following year, I was supposed to be in New Zealand the following year when they had the school break-up and of course she, as school captain, to give her talk and that. I actually cancelled a – or postponed a trip to New Zealand so I could be there for that. Because I thought that would be terrible if I missed both her getting the captaincy and then her talk and her handing it on to the next person.

**Maintaining a similar home environment**

Keeping the family legacy and maintaining an environment that is as close to the one when Jo was alive continues to be the focus of Darren’s life. Darren tried extremely hard to give them a normal social life. He did not want his children to be bitter because one of their parents was no longer around.
... if the kids would have something on, so I’ll work with them – I’d stay home with them because I thought that was the only thing that would help them over that. In fact if anything, they’ve probably had more sleepovers with their friends because they did miss out on some stuff. So I’ve tried to make sure that they’re just not going to miss out on too much more now.

This helped the children to cope well. They were able to make a relatively smooth transition, and get back to their normal lives in a fairly short period:

Yeah. They’ve been through their stages. The youngest one probably took a couple of months before it really sunk in. So, probably for her it was getting on towards Christmas time when suddenly, oh Mum’s not around. It really hit hard then.

My older daughter, she fairly immediately struggled with it. But then it probably took her about, I don’t know, three weeks or a month and she started getting back on with her life.

At the time of interview, Darren and his children were settling down and living their normal life 18 months after the death of Jo. Their 22-year-old son had become engaged and was living with his fiancée. The elder daughter was working and enjoying the gap year break, and planning to start her university study two years later. Darren remained in his full-time employment and was carrying out his responsibilities related to his children, especially to his younger daughter.

Support

Support from the workplace

There were only a handful of people, including Darren’s two upper-level managers, who knew about his circumstances. The reasons behind this were twofold. First, Darren preferred to keep his work as a temporary escape from Jo and their children. Consequently, he did not intend to engage in conversation in relation to Jo’s sickness and her reactions to
the treatments while he was in the workplace. Secondly, the fear of being treated as a sick or ‘abnormal’ person (as he had already been treated within the family domain) prevented Darren from sharing his experiences with his colleagues. He hated the reality that the sickness became the centre of all conversations:

... everyone comes up to you, oh I’m so sorry. So you feel like you’re treated like a – like you’re sick yourself, type of thing. I don’t know ... I found the hardest thing for me was people either stopped talking to me or if they were talking to me they just felt sorry for me and really you don’t want that. You want to be like a normal person. You want someone to ring you up and talk about the football or cards or work or something like that. Yeah. Just have a normal chat ...

While Darren did not obtain direct support from his colleagues, he enjoyed the flexibility in the workplace for his caring responsibility. He could finish work early to pick up his daughter or visit Jo at the hospital, then go back to work afterwards in the evening or work from home. The nature of his position, in terms of working collaboratively with his colleagues in other states or other countries, enhanced that flexibility because of the time difference between various sites. Darren expressed his great appreciation during the interview:

... the company are really good because they gave me that flexibility to be able to do that. So, I could get home to care for her while I’m still working. So, it’s around that flexibility.

It is not Darren’s belief that the company has formal programs or initiatives in place to assist carers. However, he has a strong faith that the organisation takes each case on its merits and attempts to offer support in a way that suits an individual’s needs. Darren did not think that he had ever missed any opportunity for work-related training or promotion. In fact, the company offered him promotion during his time looking after Jo. Darren was so grateful to the company for their understanding and support:
... no. Not at all [missing opportunities at work]. They were amazingly good through all that. In fact the job I’d got was a promotion from where I was beforehand and I actually got that promotion about three or four months into the treatment. So they already knew then that my wife had cancer and I was going to be taking a fair bit of time off and spending with her ... So, the role evolved in such a way that I didn’t necessarily have to always be at work. I could be working from the hospital or work from home or whatever. Yeah, well, that was a huge [help]. I know they were really good. Like I said, I can’t speak highly enough of the company, how they helped me so much through that.

Support from other sources

Given the immense flexibility available at work, Darren was able to manage the roles of work and caring effectively. He was virtually the only carer for Jo in that challenging period. Some of the support that Darren received for his caring role included asking either his mother or Jo’s parents to look after their children and to keep the house running when he was with Jo in the hospital, and having hired help for approximately four weeks at the early stage of Jo’s treatment. The other aid they received was mainly for Jo’s continuous treatment after being discharged from hospital. Darren recalled:

... obviously, apart from the first – when she came home after the first chemo ... I suppose for three-quarters of the time that she was at home we would have the home nursing people coming around once a day to administer treatments and she was continually having drips and whatever.

Summary

Darren has been very successful at work. He has been working with the company for more than 20 years, during which time he has managed to advance several positions until recently being promoted to the role of inventory supervisor. Darren’s loyalty and contribution during his time with the company won him enormous trust. He is granted a great deal of flexibility in his job. Darren believes that he coped effectively in terms of meeting the demands of work and caring.
However, the emotional impact of looking after his wife, who was suffering from a primary and secondary malignant lymphoma, and their three children was enormous. Watching his wife undergo operations and experience various reactions to the treatments, as well as knowing that she had only a limited time remaining in her life, was a painful experience. Seeking an appropriate way of explaining the real situation to his children was also stressful. He wanted to be honest to their children, but, on the other hand, he had to comfort them.

Darren considers the financial impact was much less significant than the emotional one, although the family experienced the impact of losing one income during the initial period, and the extra expenses involved in seeing specialists and purchasing medical equipment followed by the costs related to the funeral.

Darren admitted in the interview that the reason he kept the situation to himself during the toughest time of his life was that he really wanted to be treated as a normal person. He considered the workplace to be a respite facility at which he could temporarily forget things that happened in the family domain, and where he could momentarily be himself. However, the long-term effect of taking care of his wife alone, especially the accumulated exhaustion and the damage to his physical health, would arguably have been less if he had sought help.
4.3.9 Amy

Snapshot

Amy is in her mid fifties, and lives with her husband, Darryl. They have three children and two grandchildren. Amy is the primary carer for her daughter Rachael, who is 33, a single mother to her two young children, Natalie, 12 and Jason, seven. Rachael had been suffering from neurofibromatosis type 2 (NF2) for 12 years at the time of data collection. Amy is also a carer for her granddaughter Natalie, who was diagnosed as having osteosarcoma in August 2008. While travelling to her daughter’s place to help her run the family has been an ongoing commitment as Rachael is unable to manage the daily routine at home by herself, Amy’s caring responsibilities have expanded to include providing indirect assistance to Natalie over the past six months since her formal diagnosis.

Amy has been working for the organisation in which she is currently employed for 15 years, and has always been a full-time shift-worker. She prefers to continue her current employment arrangement because it offers her flexibility, which enables her to carry out her carer’s roles. In addition, Amy has no plan to exit the workforce. She intends to stay at work for as long as possible in order to overcome the financial burden resulting from helping her daughter.

The demands of work

Amy has been in her current position as a full-time 12-hour shift-worker for ten years. She does two day shifts followed by two night shifts, after which she has four days off. The main responsibility as a shift supervisor includes overseeing the plants, that is, making sure that there are enough people working at four different plants. Other duties consist of
preparing the payroll and ensuring that everything is running properly and safely on the sites.

It is common for Amy to get to work 15 to 20 minutes before the start of a shift, and to stay late for the same length of time after each shift. This means that Amy basically works for 12 and ½ hours on each shift, and finishes one roster around 6.30 am on the fifth day. Amy is called in occasionally to attend some courses on her days off, in addition to the regular once-a-month supervisors meeting.

Amy’s workload has increased recently as a result of a restructuring of the organisation. The situation in which two supervisors (one shift and one regular) are on duty in each shift has been replaced by only one shift supervisor. Amy takes more responsibility and experiences less flexibility under the new structure. A senior operator can, perhaps, step up into Amy’s position and offer temporary relief in the case of emergency. However, it is Amy’s responsibility to ensure her substitute’s capability and suitability for the job. In Amy’s own words:

... so where it was before it was just hand over to someone not on an equal par but [who] was always in the loop. But now you’re handing over to someone who’s not always in the loop.

In addition to the financial security of work, the knowledge that she has four days off after each roster, which enables her to carry out her caring responsibilities, is a key factor that keeps Amy motivated and staying in the workforce. Amy is fully aware of the hardship associated with continuing as a shift-worker, especially at her age, but she does not want to switch to a regular roster as the day shift is deemed ‘not easy. Day shift’s harder.’

The demands of the caring role

_Caring for a daughter with a long-term health problem and a granddaughter suffering from terminal cancer_
Amy’s daughter, Rachael, was diagnosed with neurofibromatosis type 2, a lifelong disorder characterised by multiple brain and spinal tumours, when she was 21 years old. It commonly causes deafness, severe balance problems and decreased mobility. She has been battling with the disease for almost 12 years, during which time she has endured approximately five or six major surgical procedures. Rachael’s health has gradually declined since she was first diagnosed in 1997. Amy described Rachael’s long-term fight in this way:

... when they [operations] take place it’s full on and then it slackens off as she gets better or as she gets more of – well last time she was paralysed down one side, well that had to – she had to work to get that back.

The consequent side-effects of each ‘huge’ operation include deafness, paralysis and short-term memory loss. Rachael is totally deaf in one ear and has very limited hearing in the other. Lower leg paralysis on one side affects the way she walks. Amy described the situation:

... Rachael’s balance is terrible. Rachael falls over and walks like she’s drunk. So they’ve even had someone at the school complain to the headmaster about her coming to the school drunk. That’s just the way she walks. That’s just a balance problem.

The paralysis also makes it impossible for Rachael to carry out heavy duties, such as holding her children and hanging out clothes. Rachael needs assistance because of her inability to conduct regular tasks. Amy explained further:

... yeah. She can’t organise herself. She used to live on her own with her two young children until recently she has a new partner who is not the father of her children. She needs – if she’s got doctors’ appointments and stuff like that you’ve got to keep an eye on it so that she doesn’t forget. She will start a domestic chore and then forget and then go and do something else and then forget what she was doing.
Rachael’s short-term memory loss is also evident when it comes to looking after Natalie, who is 12 years old, and was diagnosed with bone cancer several months prior to the interview. She has to keep details of everything that is done, such as the medication she gives to Natalie, so that whoever comes to help has a physical record as a reference. Writing down upcoming activities or events and placing a note on the fridge is a way she uses to remind herself.

Natalie was taken to a doctor after she complained of some discomfort around her ankle area. Unfortunately, the doctor who first saw Natalie did not detect the symptoms of osteosarcoma and generated an inappropriate diagnosis. He put splints in Natalie’s shoes, which in fact aggravated the situation. It was too late by the time Natalie was formally diagnosed with osteosarcoma, the most common type of malignant bone cancer, in August 2008, as there were secondary cancers detected in many parts of her body. After three months of intensive chemotherapy, Natalie was bedridden and had lost her mobility.

Jason is Rachael’s second child from her second marriage. He is seven years old and is experiencing a difficult time in his life. He is adjusting to his father’s new family as well as now receiving less attention from his mother. Jason spends five days with Rachael and two days with his father. He had difficulty adapting to his new situation and became very aggressive and was out of control at one stage. The situation has worsened over the last six months, during which time his mother and grandmother have devoted most of their time accompanying his sister to the hospital. Jason is now seeing a child psychologist in order to obtain the support he needs.

**Caring demands**

Rachael encounters severe pain when conducting manual tasks because of the tumours in her arms. As a result, Amy devotes her days off to helping Rachael with household chores, such as hanging out clothes, vacuuming or sweeping floors. She has done so for the past 12 years. As Rachael has difficulty remembering things that happened only a short while
before, she needs Amy’s assistance in managing her bank account as well as paying all of her bills.

The demands of the caring role have increased dramatically since Natalie was diagnosed six months ago. Instead of only going to Rachael’s place on her days off, Amy visits her daughter and grandchildren after finishing the night shift. She has little, if any, time to recharge or relax.

She explained her current routine:

That’s only happened since Natalie’s been diagnosed. Before that I never went over there after night shift ... but now I will go there at 6.30 am so Rachael can take the little fellow [Jason] to school and then I’ll stay with Natalie. Then Rachael will come back about 8.45 am and I’ll come home and go to bed ... Then when I get up, get up about 2.30 pm, I’ll go over to Rachael’s place and hang the washing out, stay over there an hour, hour and a half ... Then go home and have a little nap before going to work at 5.30 pm [the second night shift].

Amy not only dedicates more time to Rachael and her children, but also provides much assistance to Natalie. She outlined the notable changes:

Rachael’s doing less in the house because she’s more tied up with her [Natalie]. She [Natalie] needs changing, she needs washing. Rachael does that ... at the beginning [the early stage after Natalie’s diagnosis] I used to help Rachael, but Natalie, being 12 years old, she just wants her mum to do it. Rachael is caring for Natalie and she’s also got Jason as well ... 

... now – I help with Natalie. We take her out, because she goes in a mobility bed, she can’t sit upright. It’s just to get her out of the house sort of thing. Last night we took her for a walk along the beach. That was hard. Good for her but hard for us. We walked seven kilometres.
Caring for Rachael has become second nature to Amy after 11 years of long sacrifice. Juggling between work and two families has been routine over this period. She described the context in a simple way:

... just being with her [Rachael] basically and just while you’re with her you’re doing the things ... I don’t know [whether or helping Rachael affect her life]. I just do it. Rachael is my daughter. I just do it ... you know it’s just something you do. You don’t even think about it ... it is not easy, but it’s just what we’ve done and what we do.

Rachael was living with her parents for three years when she was first diagnosed 11 or 12 years ago. She underwent a few major surgical procedures at that time, but moved out because she wanted to be more independent. Amy’s view on co-residency is different from the commonly held opinion. She perceives that carer and care recipient living in the same place makes caregiving easier, because the carer can not only save the time spent on commuting between two sites, but also avoid the double demands from two separate families:

It’s harder [not living together]. Yeah [living together is easier] because you’re there and you’re just doing everything because you’re home. Whereas I’ve got to leave. When you’re home [you’re doing what you have to do when you’re home. Whereas when you’re over there, nothing’s getting done at home. So you kind of juggle two houses. Whereas when she was home it was just juggling one household.

However, Amy did not try to persuade Rachael to live with her and Darryl, as she knows how Rachael loves her independence. Amy and Darryl want Rachael to be as happy as possible for the remainder of her life.

The experience of being a caregiver

The impact on work arrangements
It seems that Amy is able to meet the demands of both work and caring in normal circumstances, as she has ‘more days off as a shift-worker’ as well as high energy levels. She is able to organise a senior person or her manager to temporarily fulfil her duties when she is going to be absent for a short period. On occasion, Amy has needed consecutive periods of leave from work. For example, when her granddaughter needed chemotherapy treatment, Amy took three months’ leave in order to stay with Rachael and Natalie in the hospital.

Amy wants to continue her current work arrangement with her employer for as long as her current carer role continues. In fact, Amy rejected an offer from the company that would have allowed her to change to the day shift. She explained the benefit of being a shift-worker in the context of her situation:

*I’m only missing from home for two days. Whereas if you work day shift then you’re missing for five. They [the company] saw that and I explained. Plus I couldn’t get into – I’m used to the shift work and that’s what I – your life revolves around the shift work. If it went to five days I just …*

**The impact on physical health**

Looking after Rachael has become second nature to Amy, and has not seemed to have had a noticeable impact on her physical health until recently. However, the additional demands imposed by caring for Natalie over the past couple of months have evidently affected Amy’s health. She often feels exhausted due to the lack of recovery time between two night shifts, as well as between two rosters.

As Amy has trouble sleeping, she has consulted her doctor and has been on prescribed medication for her accumulated exhaustion, chronic insomnia and the extra stress derived from the excess caring responsibilities. Amy’s understanding of the medication was ‘*the stuff she [the doctor] gave me as a sleep formula is also helps with my depression.*’
The emotional impact of having two family members from two generations having terminal diseases is obvious. Tears were in Amy’s eyes on a few occasions as she spoke during the interview.

**The impact on emotional well-being**

‘Going through’ each surgical operation, major or minor, and experiencing the subsequent side-effects with Rachael was painful for Amy. Witnessing her daughter face a variety of complications of different levels of severity was emotionally upsetting and a great hardship.

In addition to the stress derived from observing the decline in Rachael’s health, seeing her daughter trying to raise two young children on her own after two marriage breakdowns was difficult. Amy views her daughter as a person who loves to be independent:

> ... when she lost her driver’s licence she was more dependent on Darryl and I then. But now she’s got her licence back she can at least go where she wants to within reason. Out and about anyhow. She doesn’t drive really far out of town. But it gives her the freedom and independence which she likes.

While Amy and Darryl support Rachael’s desire to live with her children on her own, and attempt to help Rachael as much as possible at the moment, they are also ready to ‘jump the fence when it happens’ and welcome her family into their home at any time.

Natalie’s diagnosis has intensified Rachael’s complex life, which, in turn, has placed additional pressure on Amy both emotionally and financially. Amy is fully aware of Natalie’s diminished life expectancy, and finds the thought that each new day might be the last day of her granddaughter’s life very distressing. Amy admitted that her own stress levels ‘have gone higher’, and she elucidated her feelings:

> ... we brought her [Natalie] out of hospital on the 18th of December 08 [after several courses of treatment] and didn’t think we’d see her birthday on the 25th of January
09. She’s still alive ... yeah. We’ve been through lots. Yeah we just try and make every day count for us.

Jason’s aggressive behaviour due to his inability to adapt to a new life is another constant worry for Amy. She hopes that Natalie’s diagnosis, and Jason’s father’s new family, will not have a long-term impact on Jason’s emotional health. She worries that Jason might fall behind without help from professional and family members.

**The impact on the financial situation**

The family has organised a significant fundraiser for Natalie. The funds received from donations are sufficient to cover the out-of-pocket medical expenses and the cost of special equipment that supports Natalie’s daily life. It is impossible for Rachael to be in paid employment because of her health problems; she has always lived on a pension. The out-of-pocket expenses related to her illness, as well as the extra living costs involved in raising her two young children, are simply too much for Rachael. Amy and Darryl have provided enormous financial support to Rachael over the years, especially when she was a single parent. Amy explained the financial pressure encountered in supporting Rachael in her efforts to raise her two young children:

... Rachael’s financial problems have always been our problems. We put a lot of money to make up for – mainly just for the kids. They needed shoes or clothes, we would pick up the bill.

In the meantime, Amy and Darryl have to be mindful of the possible ‘unfair’ treatment his imposes on their other two children, an elder daughter and a younger son, and they do not want to incur any resentment. Amy expressed her concerns:

... We don’t start doing things that – we said to ourselves that Rachael was getting quite a lot financially. So you try and do your best to balance so that the other two children don’t get angry.
Rachael’s poor prognosis and the uncertainty about her future have had a considerable impact on Amy and Darryl’s own plans for the future, in particular the decisions relating to whether or not to stay in the workforce. They had a thorough discussion and a genuine assessment of their financial situation, and reached a temporary consensus. Amy and Darryl are ready to quit their jobs and become full-time carers at some stage of their lives. Here is their evaluation. They decided that, in the first instance, Darryl’s situation might change:

... well, we thought that [leaving the workforce] would be for Rachael for the future. We thought that would come about in time with Rachael ... Because my job pays better than what Darryl’s job does it was always going to [be] Darryl leave work. We don’t know. But if it happens it happens. But we sort of discussed it.

Family relationships
Rachael has good relationships with her parents and siblings. She has relied upon her immediate family enormously, especially during the times of her marriage breakdowns and as she was often raising her two young children by herself. Rachael’s younger brother was living at home when she was first diagnosed as having neurofibromatosis type 2, but moved out a few years later. He was shocked by Natalie’s diagnosis and decided to be by his sister’s side. Amy depicted the close-knit family:

... Yeah she’s [Rachael is] very reliant on myself and Darryl and her eldest sister and her youngest brother. She’s very, very close to her younger brother. He was over in there [Rachael’s house], living over there, and when Natalie was diagnosed he came home.

Support
Support from the workplace
Like other caregivers in this study, Amy is unaware of any existing formal program or initiative within her place of employment that aims to support carers who are looking after a spouse with long-term health problems, a child with a disability or a frail elderly
individual. However, she has been grateful for the company’s support in her caring role. Amy expressed her appreciation:

Yeah, well when we put Natalie in hospital the company was very good. They paid me more than 10 days’ carers leave and because you work in blocks of four with four off, you’re only using them up – if you go a month, then you’re only using eight days up. So the company just covered everything for me. They’ve been good.

The support comprised the use of her entitlements, such as carers leave, sick leave, annual leave and long service leave. However, Amy believes that the company would offer a different kind of help if she had no leave left. Her perception of the company’s flexible policy is as follows:

I think if I hadn’t had any leave I think I could have applied for leave without pay. I think they would have. It’s not something they give out lightly, but in this case I think they would help.

It is Amy’s belief that every individual carer faces his or her own challenges in dealing with multiple roles. Thus, it is hard for an organisation to implement programs or initiatives that suit all carers. She is convinced that she would get the support she needed, and deems the support from the company to be ‘excellent’.

**Support from other sources**

While Amy is a primary carer to her daughter and granddaughter, she receives a reasonable level of support from other family members for her caring role, in particular, during her two day shifts. Amy provided the details of the arrangement:

Darryl’s been able to leave – he’s been working in town and he was able to leave and go and help her [Rachael]. Or my daughter could go and help her. My eldest daughter’s only been working 12 months so she was a stay-at-home Mum until then. So there was always someone we could call.
During the interview, Amy also stressed her gratitude to the community, especially to Ronald McDonald House Charities, an independent, non-profit organisation that strives to help seriously ill children and their families. Amy and Rachael had stayed at Ronald McDonald House, which was near the hospital where Natalie was being treated. Not having to pay the accommodation themselves, and the fact that most of the extra costs were covered by the substantial amount of money raised during the big campaign for Natalie, eased the financial pressure on Amy and Darryl enormously. Amy could not hide her gratitude to all of those generous people.

Amy has never thought about using the respite service for Rachael, as she believes that ‘Rachael wasn’t at a stage where you needed respite for her situation’, nor has she considered using the respite service for Natalie, because ‘her life expectancy is very low’. The family would prefer to spend as much time as possible with Natalie.

Although Amy has very little time to recover after spending almost all her days off work with Rachael and Natalie, there is no regret or resentment in assuming her caring role. Amy put it simply: ‘Rachael is my daughter ... I just do it’. In fact, she is quite content that she can offer strong support to her daughter. Amy could not anticipate where Rachael’s and Natalie’s lives would head, but she was well prepared to accept the worst scenario.

**Summary**

Being the primary carer to her daughter, and helping to look after her granddaughter, are deemed to be part of her normal life by Amy as ‘they are my kids’. Her dedication is ongoing. She prefers to remain in her current employment arrangement with the organisation as a shift-worker, because the position allows her to have more days off in between two rosters. Further, she visits her daughter’s place virtually every day, with the exception of two day shifts. She even took her long service leave to be at her granddaughter’s side during her intensive treatment in the hospital.
The life of being a primary carer to her own daughter and a helper to her daughter’s young family while working full-time as a shift-worker is exceptionally complicated and challenging. Physically, Amy feels exhausted as she gets virtually no break in between two rosters, especially since her granddaughter’s diagnosis. She relies on sleeping pills to get enough sleep to recover.

Emotionally, Amy needs to be very strong in order to go through all of the challenges at hand. Being a witness to the deterioration of her daughter’s health is hard. Being informed of her granddaughter’s diagnosis was difficult, and knowing her granddaughter’s short life expectancy is devastating.

While Amy is willing to help Rachael financially, including buying clothes for her grandchildren, she has to be mindful of her other two children’s reactions. In fact, ensuring that each of her own three children is getting their equal share and being treated ‘fairly’ is not always an easy task. Amy expects that in the near future, she and her husband will have to take Rachael home to live with them. This apparently has had an impact on Amy’s retirement plan. She is likely to be forced to stay in the workforce longer because of the potential financial pressures.

### 4.4 Summary of Case Studies

The nine unique cases reported in this chapter provide detailed and unique information in relation to individuals’ perceptions of the experience of being working caregivers. These cases also form the basis for themes presented in findings chapter.

Individuals assume their caregiving roles for a variety of reasons. Some were forced into the position, as nobody else in the family was available or suitable for the role. Others automatically became caregivers as they were parents of one or more children with a disability. It is apparent that being a working caregiver is a challenging experience, no matter how ready people claimed to be. As the nine cases show, simultaneously fulfilling the responsibilities imposed by work and caregiving is extremely demanding and challenging, and has a huge impact on caregivers, as well as on other members of the
family. However, it is also worthwhile to note that the impacts vary from one context to another.

The experience of being working caregivers, the support that working caregivers need to meet the responsibilities imposed by work and caregiving roles, the methods that working caregivers employed to cope with their challenging lives and the effects of being working caregivers will be discussed further and in greater detail in the following chapter.
CHAPTER 5 – BALANCING THE ROLES OF PAID EMPLOYMENT AND UNPAID CAREGIVING: THE MAIN FINDINGS

5.1 Introduction

The case studies presented in the previous chapter provide evidence that the task of balancing the roles of paid employment and unpaid caregiving is a complex one. Being a primary caregiver to a family member (or members) while retaining a full-time job is a challenging task. The perceptions of the experience of being a working caregiver vary, depending on a range of factors, as was made evident in the previous chapter. However, some common themes have emerged from the data analysis. This chapter examines emerging patterns and findings from both the nine case studies displayed in the preceding chapter and the other eight interviews conducted during data collection. Pseudonyms are used for all interviewees (see table 5.1).

Table 5.1: Research interview participants

<table>
<thead>
<tr>
<th>Case Study (pseudonym)</th>
<th>Other Interviews (pseudonym)</th>
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</thead>
<tbody>
<tr>
<td>1. Terri</td>
<td>10. Lisa</td>
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<tr>
<td>2. Cathy</td>
<td>11. Carey</td>
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<tr>
<td>4. Dora</td>
<td>13. Mary</td>
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<tr>
<td>6. Jenny</td>
<td>15. Joe</td>
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<td>7. Marcus</td>
<td>16. Francis</td>
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<tr>
<td>8. Darren</td>
<td>17. Mark</td>
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<tr>
<td>9. Amy</td>
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5.2 Analysis and the Development of Themes

Chapter 2 has provided detailed information in relation to data analysis and theme identification, which was carried out both manually and using NVivo (an application that is used for qualitative analysis). As discussed in that chapter, the first step in data analysis was to develop text-based categories. The process consisted of selecting and coding segments of text that were seen relevant to the main foci of the study. A list of main themes...
or categories was developed in a similar manner. The procedure did not develop in a linear fashion but rather emerged from repeated reading and analysis of the transcripts. Using an iterative process, a range of key themes emerged from the data analysis. For example, the analysis of data, such as ‘just do it’, ‘no one was available’, ‘it’s my time to look after them (parents)’ were categorised under the following broad grouping: the reasons for taking up the caregiving role. Further analysis of this category, along with other data, led to the emergence of the theme: ethical obligation (the decision to engage in the caregiving role). Similar procedures and analytical strategies were utilised for identifying initial main themes emerged from the transcriptions of semi-structured interviews and the review of literature.

Sub-themes were then developed in an attempt to inform the research questions and capture various factors that contribute to (The perceptions of being of working caregiver – main theme 1); different strategies employed by working caregivers to deal with challenges arising from juggling work and family responsibilities (Coping strategies – main theme 2); Effects of carrying out multiple roles on the lives of working caregivers (Consequences of being a working caregiver – main theme 3).

The initial themes and sub-themes were regrouped, and new themes were added during the course of analysis. The final themes and sub-themes were built progressively through numerous careful revisits and constant comparison to transcriptions, and discussion with my supervisors. The final themes are listed below:

Main theme 1: The perceptions of the experience of being a working caregiver.

This theme includes statements that describe the factors, within both work and family domains, that influence the perceptions of the experience of being a working caregiver. These consist of the demands related directly to the provision of assistance to the care recipients, the health and prognosis of the care recipients, the future arrangements for the care recipients, as well as how the care recipients are treated by the wider society. Further, the issue as to whether or not caregivers receive support from their immediate family members and other relatives for their caregiving role also had an influence on the
experience of being a working caregiver. Along with the factors emanating from within the family domain, the demands imposed by work, such as excessive workload due to low staff level, the pressure of retaining a paid job, and whether or not working caregivers have the autonomy to their work arrangements exerts an influence on the lives of working caregivers.

Main theme 2: Coping strategies

This theme includes the statements that describe the approaches adopted by working caregivers in order to deal with the challenges arising from fulfilling multiple responsibilities in the absence of lacking of willingness to seek and utilise support. While the majority of working caregivers were able to embrace the reality of life with a positive manner, a few of them were reliant upon antidepressants as a survival tactic to cope with the difficult life. Social detachment was employed as a strategy to overcome the challenging life.

Main theme 3: Consequences of being a working caregiver

This theme includes the statements that describe the effects of carrying out multiple roles to the lives of working caregiver and their family members. While the task of balancing multiple roles was deemed to be manageable by the majority of the participants of the current study, there were associated costs. In addition to accumulated fatigue and psychological impact, working caregivers had to make substantial sacrifices in various aspects of their lives, including personal life, career promotion and advancement and financial security.

The themes and sub-themes will be discussed and presented in detail below with evidence in the form of quotes from the participants.

Prior to presentation of the themes, the reasons participants of this study took up their caregiving roles are discussed in this section as they influence the perceptions of the experience of being a working caregiver. As indicated in chapter 3, the majority of
participants (15 of 17) involved in the current study had a full-time paid job, and occupied a primary caregiving role for a family member (or members) at the time of the interviews.

Data analysis in the current study shows that the reasons caregivers take on their role are based on various aspects of ethical obligation. These may be derived from an implicit sense of obligation to a loved one, a belief that no-one else is available, cultural expectations within the community, or an explicit commitment to reciprocity for support given by current care recipients in the past.

For the majority of the participants in this study, the reason behind their decision to assume the caregiving role was fairly straightforward. For instance, ‘she is my daughter, I just do it’. (Amy). Darren, for example, became the caregiver to his unwell wife when she was diagnosed with a life-threatening disease and continued in this role for the last 18 months of her life. Assuming the caregiving role also resulted from a situation in which no other family members were available or suitable for the caregiving role. Haidi was caring for her elderly father while nurturing her three young children, simply because ‘my brother is in Brisbane, and sister is in Melbourne – not where my father resides’. A similar situation existed in Nina’s case: ‘I do [have a brother], but he’s in the armed forces and he’s not here in Victoria … I have three cousins, they are either too young, too busy or couldn’t cope.’

Cultural influence could be seen as an ethical obligation. Culture played a role in the expression of caregiving and how familial obligations or societal expectations were met. Two of the participants in the study, Nina and Marcus, felt bound by their traditional culture (Indigenous and Asian respectively). Nina was proud of herself for being the person who ensured that her grandfather had a relatively independent and happy life during his final years. Thus, she was hoping that ‘he can stay this way [living in his own house] until eventually he does die’. Marcus’s desire to provide assistance to his elderly parents, both physically and financially, was influenced by Asian culture. It was Marcus’s belief that children, especially an older son, co-reside with their elderly parents. ‘We [Marcus’s dad, mum, brother and he] migrated to Australia 13 years ago and have been living together since then.’ Consequently, looking after his parents when they were getting older had
become a natural step for him and his brother. The decision to keep elderly care recipients at home and enable them to live independently for as long as possible is associated with the notion of integrity. Nina and Marcus felt that their cultures would not sanction placement in an aged care facility. Thus, placement would not likely be on the agenda unless deemed mandatory for the benefit of improving the care recipient’s health.

The group of caregivers who had been providing assistance to their elderly parents or grandparents for years viewed their caregiving as reciprocity, that is, a way of giving something back to their parents. Participants such as Terri, Lisa and Jane seemed to cope well and felt that caregiving was not burdensome. Caregivers also felt intrinsically rewarded for their effort.

Lisa grew up in an extremely close-knit family and had always been her mother’s ‘little sweetheart’. It was her belief that providing care to her mother was one way of repaying her parents as she felt she was loved deeply by her mother as a child. ‘I have been always close to my mother. It is my belief that providing care to my mother is one way of repaying my parents. I was a child whom my mother loved deeply’.

Similarly, Terri perceived providing care to her parents to be a great privilege and a means of paying something back to her parents. The loving commitment was evident in her willingness to offer help to her parents at any time and under any circumstances. ‘My parents have looked after me for so long … I will do whatever it takes to help them, to support them … to try and help them as much as I could’.

While perceptions of the experience of being a working caregiver are influenced by demands emanating from both the family and work domains, they are also affected by the amount of support that caregivers receive. Although caregivers have their own unique ways of coping with demanding responsibilities, the impact on caregivers themselves and significant others within a family of caring for a person with a disability, a chronic health problem or a terminal illness, or a frail elderly person is substantial.
This chapter begins with the findings pertaining to the perceptions of the experience of being a working caregiver, followed by an exploration of strategies employed by working caregivers to overcome challenges they are facing. The impact of balancing the roles of paid employment and unpaid caregiving on working caregivers and other family members is examined later in this chapter.

### 5.3 The Perceptions of the Experience of Being a Working Caregiver

This section covers the first of the three primary themes that emerged from the data analysis. The perceptions of the experience of being a working caregiver are examined in the light of a range of influential factors within the work and family domains.

#### 5.3.1 Influences within the family domain

The perceptions of the experience of being a working caregiver in the family context are influenced by multiple factors, including the context of caregiving, caregivers’ emotional responses to the care recipients’ situation and the impact of family dynamics and support.

##### 5.3.1.1 The context of caregiving

Demands related to caregiving generally refer to assistance that caregivers provide to a family member, whether it is help for activities of daily living (ADL), including eating, bathing and toileting, or for instrumental activities of daily living with aspects of cognitive and social functioning (IADL), including shopping, cooking, doing housework, managing money and using the telephone. However, the current study shows that there are several demands associated with caregiving, which vary with context. The extent and nature of the demands related to variation in the context include the kinds of caregiving and the time required for the role, the dynamic of caregiving demands, and the number of care recipients being looked after.

The kinds of caregiving activities required were primarily determined by the form and severity of the illness or disability of the care recipient. The assistance required by those who were relatively independent usually consisted of help with organising medical appointments, managing money and finances, doing grocery shopping, cooking meals,
changing bedding and clothes, and administering medication and the like. For example, Nina’s main caregiving responsibility to her relatively independent grandfather was to coordinate ‘all his care visits and doctors’ appointments as well as going to the bank and paying his bills’. Terri was taking responsibility for ‘having the house clean, cleaning clothes and things being ironed, and buying groceries’ as ‘nothing gets done when they [parents] both had a bad day and were sick …’ Marcus had to ‘take sugar levels in the blood … measure all the blood pressure … keep the record for the hospital doctors’.

For those who were either at the stage of undergoing extensive treatment for their newly diagnosed disease or were extremely fragile, caregivers usually had to offer physical assistance. Such care recipients required extensive care due to their limited mobility. This included assistance in bathing, toileting and feeding. Darren, for example, had to provide physical assistance. He was by his wife’s side when she received intensive treatments for the newly diagnosed but advanced cancer, because ‘she needed my support to go through treatments, but also the actual physical help after treatment’. Marcus was in a similar situation. Due to physical limitations as a result of multiple fractures, Marcus’s father was unable to walk alone. Thus, Marcus would have to give his father a shower before changing all his clothing, nappies and bedding, as well as washing all the dirty clothes afterwards as ‘they were all wet, and my dad can’t go to the toilet’.

The kinds of caregiving activities required were also dependent on the nature of the care recipient’s situation. While most children with a disability in the current study did not require physical assistance in their daily lives, caregivers were on ‘alert’ constantly as one of the common symptoms among those children was emotional reactions to stress or to a change of routine. Haidi provided an anecdote about her daughter: ‘She [the child with a disability] doesn’t like change, not very flexible. In fact, she’s really resistant to change, very stuck and very rigid’. Dora’s description of her daughter was as follows:

She [the child with a disability] has tantrums a lot. When she is really stressed she actually falls into a slump, where if she is really bad at some stages she really can’t
do anything. Or when she gets too activated or stressed she is a bit like a frightened animal. She can’t get out of the situation then she will retaliate and respond.

In addition, the current study reveals that the range of caregiving activities has expanded beyond the conventional categories defined by WHO (providing care recipients with help for activities of daily life or instrumental activities of daily life. The process involved in obtaining an accurate diagnosis for a child or children with a disability was deemed by several participants as a substantial type of caregiving activity. Most parents in the study recognised their children’s symptoms, such as aggressive behaviours and delayed intellectual development in their early lives, but were annoyed when they could not gain a formal diagnosis. The parents felt that some doctors viewed them as being invasive and lacking knowledge with regard to obtaining a diagnosis. Consequently, the doctors attempted to convince parents not to label their children. Responses from health professionals were often the source of parental anger.

The process of gaining a formal diagnosis was seen not only as a type of caregiving activity, but also as a cause for stress. The importance of having a formal diagnosis and the frustration expressed by several participants were apparent in the following examples:

*It is out of control, the school is even talking about getting the police involved ... I need a diagnosis or something ... we’ve been trying for years to get answers and, you know, we can’t do that.* (Dora)

*Kay [Haidi’s 16-year-old daughter] was on medication for severe anxiety since she was little ... we tried to find a child psychiatrist when Kay was four, five, six, and we couldn’t find one. So that’s when I retrained as a counsellor.* (Haidi)

*Unfortunately he [Cathy’s 10-year-old stepson Arthur] was only diagnosed last year although they [Arthur’s parents] always knew something was wrong from a very young age ... He went under a lot of testing for a long time but always came back inconclusive ... they [doctors] were very late.* (Cathy)
As noted in chapter 4, most participants’ children with special needs went to mainstream schools. Participants reported that their children were consequently expected to display conventional conduct, or, in other words, behave in the same manner as a child without a disability. Thus, children’s mood swings and aggressive behaviours were deemed to be a result of a lack of discipline. It was participants’ belief that a professional diagnosis meant a child with a disability would be better understood and treated appropriately, thereafter leading to fewer incidences of unmanageable behaviour.

While the reasons behind a long wait for a formal diagnosis might be of interest for further investigation, and have implications on how professionals could offer support, demands associated with obtaining a proper diagnosis and the frustration arising from the process of obtaining one certainly influenced the experience of being a working caregiver. For example, Cathy was annoyed by the situation regarding her stepson: ‘the amount of times he’s seen different doctors and just not getting anywhere’.

The time aspects of the caregiving demands, whether they were the time spent on caregiving activities or the level and timing availability required from a caregiver when not directly active, undoubtedly influenced the experience of being a working caregiver. The time required for the caregiving role included the time needed for travelling between two sites if caregivers and their care recipients were not living in the same household. Nina commented, ‘Depending on traffic, it can take me up to an hour to get there [her grandfather’s place] if I leave at peak hour or something’. Both Nina and Cathy experienced issues with the time spent on caregiving, such as providing long hours of supervision to a child with a disability or long hours of accompanying to the care recipient. Nina said, ‘I’ll watch with him [her grandfather] for nearly all the programs he likes and then I might say, okay, well I’m going to go home now. Just depends on what needs doing’. (Nina). Cathy described her stepson as ‘a child who needed to be engaged and switched on all the time as he cannot amuse himself … his health state has worsened as he grows older, and his obsessive behaviour went to an advanced stage … he completely dominates our
life ... stopping him from doing things he shouldn’t do just wears us down as we have to forever repeat ourselves.’

Most caregivers were required to be available, or at least to be contactable, at any time during the day in case urgent matter arose, and in some situations were compelled to use their company’s time for family matters, in particular, those issues related to caregiving. Scarcity of time was a dominant contributing factor to conflict and stress. Working caregivers respond differently to cross-role pressure, which, in turn, affects the outcome of performance. For some working caregivers, cross-role pressure could enhance productivity due to the completion of tasks in shorter periods. However, for most caregivers, the outcomes of performance are likely to be negative as the result of difficulty with time management, distraction at work and low energy levels.

The nature and scale of caregiving demands change over the course of caregiving. In most cases, demands increased as a result of a decline in the health of a care recipient. As the respective disease or disability advanced, some care recipients were confined to a wheelchair or lost the ability to take care of themselves due to cognitive deterioration. Others showed behavioural changes and became more violent as they grew older. The caregiving experience was affected substantially by the increasing demands of caregiving.

Lisa’s case was a typical example that illustrated the dynamic nature of the demands of caregiving, as well as the effects of increased demands within caregiving experience: ‘The deterioration just went down and down. First of all she stopped being able to do things, like, she couldn’t send Christmas cards …’, while six months later ‘she was forgetting how to cook. She was cooking vegetables in a pot with a teabag in a pot because she thought the teabag would give it flavour or colour … I’d feed her, cook dinner for her …’ and eventually, ‘she wasn’t showering any more …’

However, the caregiving demands could also be reduced due to health improvement or arrangements organised for care recipients, such as placement. For example, the main assistance that Terri provided to her parents at the time of the interview was ‘organising
and taking my parents to doctors’ appointments once every two to three months’, as her parents had been treatment-free for approximately 12 months. The demands of caregiving had changed noticeably for Lisa since her mother has been placed into a hostel six months prior to the interview.

Caregiving demands increase as a result of growth in the number of people who need help in a family. Most participants in the current study provided care to more than one family member with special needs. This could be providing assistance to both parents (either elderly or with long-term health problems), to a child with a disability and a frail elderly parent, to two children with disabilities, to a daughter and a granddaughter, and to a frail grandfather, and to a father and aunt. It was revealed by participants that caregiving for more than one care recipient is challenging and stressful, and serves to compound the effect on the caregiving role.

Haidi, a career-focused woman prior to establishing her own family, was now a primary caregiver to her oldest daughter who had a disability, as well as to her 84-year-old father. While organising and taking her father to doctors’ appointments was considered routine and could be included in arrangements of daily life, being obliged to prepare and eat lunch with him during his visits was deemed to be a substantial increase in the time demands already imposed by caregiving. It was ‘difficult because it takes away time from the children’.

By the same token, Jenny admitted that looking after two sons ‘with high needs, very high needs, with challenging behaviours’ was demanding. One child’s disruptive activities would trigger those of the other. On many occasions, it became ‘a domino effect throughout the whole family’. She expressed the pressure under which she lived during the interview: ‘in the end, I was the one for the family. I did everything’.

In Terri’s case, the demands imposed by caregiving were substantial, not only because she was the only person responsible for providing assistance to both her parents (as she was the only child in the family), but also due to her parents having cancers of different types and their strong but diverse reactions to the post-surgery chemotherapy. Hence, demands
imposed by caregiving expanded to include the need to create an environment that was nearly contamination-free, in order to accommodate various restrictions on her parents’ lives. ‘I have to change everything in the house, and getting rid of products with alcohol, changing your mouthwash, everything …’

Amy was certainly a primary caregiver to two generations. She was caught between balancing the needs of her own daughter, who has had a disability, for more than twenty years, and her granddaughter, who has a newly detected cancer at an advanced stage. Life had been much more challenging for Amy since her granddaughter’s diagnosis, simply because of additional caregiving demands as ‘she’s picking up the slack as Rachael [her daughter] had to spend more time with Natalie [her granddaughter] … it’s just the extra …’

At one stage of her life, Nina had been a primary caregiver to her elderly and frail grandfather, her unwell father, and her aunt with a mental health problem. The excessive caregiving demands and apparent negative impact on her physical and psychological health had led to her decision to seek alternatives for her caregiving role, as ‘it’s been all too much, I am not a superwoman and can’t be a family social worker’.

5.3.1.2 Caregivers’ emotional responses to care recipients’ situations

Perceptions of the experience of being a working caregiver are influenced by caregivers’ emotional responses to care recipients’ situations, more specifically, the declining health of care recipients, as well as the ways care recipients are treated by society.

The continuing decline of the health condition of care recipients, whether it is due to normal ageing processes or resulting from chronic disease, influences perceptions of the experience of being a working caregiver. The gradual deterioration in health means that care recipients became more dependent. It is very disconcerting for caregivers to witness poor prognosis.

Nina constantly worried about her grandfather’s health condition – ‘his blood pressure’s sky high and sugar levels … he’s got depression …’ – not only because it was linked to his
independence, but also because it could be the source of disagreement with regard to the caregiving. For example, Nina supported her grandfather’s intention to be independent, but other family relatives believed that ‘he [her grandfather] shouldn’t be driving, he shouldn’t do this although he had the tests and he was quite capable and he wants to and he knows his limitations’. Lisa expressed her anxiety as her mother simply had lost her ability to look after herself:

   Mum had a couple of falls … she thought that she was looking after herself, but … I mean with mum I would worry about her all day long … All day long I’d worry. I hope she’s okay and is she alright … I found it so emotionally draining to be with her and realise that she didn’t know what she was doing … She didn’t look like my mother any more, she didn’t smell like my mother any more.

Having caregiving responsibilities thrust upon them at fairly short notice was challenging for those who were caring for their loved ones with newly detected cancers, as there was a very heavy demand imposed in terms of physical assistance and emotional support during the period of extensive treatment. Witnessing care recipients’ negative responses to the treatments, and knowing the poor prognosis, was heartbreaking. For instance, Terri had numerous sleepless nights when her father underwent post-surgery chemotherapy treatment, due to, ‘the way he responded to the therapy he received … It was a very big thing for him when he lost all his hair, and when he was very sick.’ The experience of being a working caregiver is also affected by elderly care recipients’ reluctance to seek help when it was needed. Haidi was restless because her elderly father ‘hasn’t known to get help … didn’t eat properly … and lay on the floor or in bed’.

The ways in which care recipients are treated in society has influences on the experiences of being a working caregiver. This can be discussed from the interactions among care recipients and their siblings and their friends, as well as the treatment care recipients receive from institutions such as schools or community organisations.
Comments during interviews indicated that children with a disability were often different from other children in terms of their interests and their social skills, were perceived by their siblings and friends as ‘abnormal’, and were usually not welcomed at social events, such as birthday parties. While on some occasions the children with a disability expressed no interest in participating in the activities organised by their parents or by their school, the psychological impact of social exclusion on children with a disability and their caregivers was enormous. Some children eventually refused to attend school and had unpleasant feelings about life in general because they were ‘a target or a victim of bullying all the time’ (Dora), and had experiences of being ‘bullied very very badly in the school’ (Haidi).

It was revealed by the participants of this study that most of their children with a disability were placed in a special education unit within the mainstream school, and were offered or taught subjects that were not counted among the subjects required for entry into university. The outcome of this arrangement was viewed by some participants as inappropriate treatment because their children were unlikely to obtain a tertiary education after Year 12. ‘It’s discrimination … children [with disability] were dumped down …’ (Haidi).

Most participants also expressed their concerns in relation to the future life of their care recipients in terms of time and financial arrangements (this point will be discussed in the section – financial impact). With regard to time arrangements, attending a mainstream school means that children are normally at school during the day, with the exception of special events. However, programs available to children with a disability after ‘graduation’ from high school are run by either the government or the community for a maximum of two to three days every week. This imposes increased pressure on caregivers as they have to alter their schedule to cover the resultant gap.

While the issue of unfair treatment seemed most apparent among working caregivers who had caregiving responsibilities to a child with a disability, it was also relevant to those who were looking after an elderly frail person. For example, Haidi expressed her angers during the interview about how her father, and more broadly vulnerable people, was treated by the wider community: ‘Somebody for the gas [company] knocked on his door, and he thought
It was also revealed that responding to other family members’ emotional responses could have an impact on the experience of being a working caregiver. The most difficult thing for Darren, for instance, was the effort associated with finding an appropriate way to remain optimistic when confronting his children: ‘I understand deep down that the longer it [cancer] remained there, the worse it looked … however, you didn’t want to paint a dark picture and – so they’d have no hope.’ It was tough for Darren not to disclose details to his children while knowing his wife’s ultimate fate.

5.3.1.3 **Impact of family support and dynamics**

Support in the family domain is undoubtedly crucial for caregivers in managing the remarkable stress inherent in what they do, and influences the perceptions of the experience of being a working caregiver. It was revealed by most participants that they received limited support from their children in caregiving and minimal support from extended family. Participants who had a partner confirmed that spousal support had an influence on the experience of being a working caregiver. Family relationship was also considered as a related factor.

Noticeable conflict between siblings in a family (for example, the disabled child and other children) is one of the findings that emerged from the current study. This was described by caregivers as mainly due to a feeling of jealousy and a lack of understanding of the situation. Examples provided by some participants clearly indicated that their children without a disability were often puzzled about their siblings’ responses to family events, and their siblings’ privileged status in the family. They often asked questions such as ‘Why does Eva get what she wants all the time?’ (Dora), and ‘Why doesn’t Kay join us for a walk?’ (Haidi).

The confusion and increasing tension between siblings reduced the possibility of getting support in the caregiving responsibility from the children without a disability. Another
explanation for receiving limited support from children might be associated with caregivers’ unwillingness to involve their dependent children in caregiving. Jenny, for example, could not endure the thought of her oldest son giving up his childhood in order to help her. Haidi considered her two younger children to be too immature to take on even partial responsibility for caregiving.

Receiving limited support from children in caregiving was related not only to participants who had a child with a disability, but also to participants who were caring for frail elderly individuals. This situation was due to the adult children either no longer living in the same household or being focused on pursuing their own interests. Darren’s daughter was entirely occupied with preparing for her university entrance examination, and his son was living elsewhere with his girlfriend and was extremely busy in his part-time employment. Lisa’s daughter was living in Italy at the time of the interview, and her son was always engaged in his own pursuits and most of the time was unavailable to offer help.

With regard to support from relatives, Mark was an exceptional case, and the only case in which support from extended families was available and accessible at any time as both sides of his family, and that of his wife, lived close by. Jenny, Dora and Terri, as only children, had no siblings who could offer help when it was needed. As a migrant, Carey had her parents and her brothers and sisters living in her home country. To make things worse for them, Carey, Jenny and Dora received no support from their husband’s side of the family for their respective caregiving roles.

This research also shows that whether or not caregivers received support from their partners was crucial for their caregiving experience, as they were usually offered limited or no help from their adult children. The more assistance that primary caregivers could obtain from their supportive partners, if they had one, the better they managed the pressure.

Haidi, for example, was a primary caregiver to her three young children, including one with a disability. Her husband had quit his long-term employment and become self-employed in order to get the flexibility needed to share the responsibility for caregiving. Amy’s case
also illustrates how the experience of caregiving is influenced by partner support. Although Amy was the primary caregiver to her long-ailing daughter, as well as to her newly diagnosed granddaughter, her husband would take up the caregiving responsibility whenever she was unavailable due to her work commitments. Amy expressed her appreciation of her husband’s contribution: ‘He usually goes over to my daughter’s place on my two day shifts and he was also a regular of taking our granddaughter for a walk or a play.’

On the other hand, a lack of support from partners could be a source of resentment, ill-feeling and annoyance. Carey knew too well the difficulty of raising two children (one of them with a disability) virtually by herself because her husband travelled considerably for work. Carey described the lack of support: ‘He was away all the time … his family, no help. No help … and my family’s so far away – all relatives from my side are living in Spain … his family doesn’t care … my family can’t help.’

A similar situation could be seen in Jenny’s case. The stressful nature of the caregiving experience was evident during the interview, when Jenny expressed her resentment at being the only person in the family who took responsibility for resolving all of the issues related to her two disabled children. Jenny commented on her situation:

*He [Jenny’s husband] was overwhelmed by the situation of having two children with a disability and aggressive behavior … he used to worry and worry and worry about the boys and their epilepsy when he was away, but couldn’t cope when he was home … organising, coordinating, facilitating, training – all that was all me.*

In addition to the level of familial support, the perceptions of the experience of being a working caregiver, in the context of family domain, are also influenced by the relationship between caregiver and care recipient, as well as the relationship between primary caregiver and other family members. Nina revealed during the interview that her relationship with her grandfather ‘is so much stronger’. She elaborated further:
The relationship is more open to discussion – well, I think I’m lucky because I get the stories and I get the close relationship and I think he gives my life an added dimension … I think my job and caring for my grandfather is okay together … yeah, I think for me I can get a balance.

Conflicts and tensions between children with a disability and their siblings not only meant caregivers received limited support from their children in caregiving, but also put extra pressure on caregivers, and consequently on the caregiving experience. On the other hand, caregivers experienced fewer difficulties if they were in a close-knit family. This was seen in the cases of Amy, Marcus, Terri, Darren, Mary and Jane, where the relationship was based on trust, reliance and faith. The healthy relationships were reflected in the caregivers’ stance on being working caregivers:

We are private people, and we keep things in the family, and we rely on one another … I’m happy with how I’m feeling with things at the moment, and still feel capable of going on with life, of having a happy life, of achieving things. (Terri)

Spending quality time with our children is a family tradition. So, even if it might be while we were cooking tea, I’d include Sophia in helping me cook tea. Yeah. So what I was doing, she could do to help … It [the caring responsibility] didn’t … it didn’t affect my work. I’ve held a full-time position right through the whole thing. (Darren)

5.3.2 Influences within the work domain

The perceptions of the experience of being a working caregiver in the workplace are influenced by excessive workload and pace, financial pressure to stay in paid employment, the perceived importance of employment tenure, the desire to appear normal, and the support that caregivers receive from their employers, managers and colleagues (more specifically, the informally granted flexibility at work).


5.3.2.1 Excessive workload and pace

Demands imposed by work can be assessed through an analysis of key elements, including workload (number of tasks assigned) and pace (the timeframe given to complete assigned tasks). Work demands are, in a broad sense, dependent on the nature of the occupation and the position that an individual holds.

As noted in chapter 3, as a result of restructuring and cost-cutting program, several participants were experiencing excessive demands from work due to lower staffing levels. It was common for employees to sacrifice their rest time in order to catch up on their heavy workload, or work full-time to meet part-time work commitments. For example, it was usual for Haidi to ‘wake up at 4 or 5 am even on weekends to capture the quiet time’. Carey, as a part-time librarian, felt regularly that she was ‘behind [in] her work’. Amy believed that it was getting much more difficult than before in terms of finding a substitute in her absence, as the number of employees in her section had been reduced by 50% after amalgamation. A similar situation happened in Marcus’s section, where he was required to perform tasks assigned from different divisions as a result of merger and restructuring.

While participants understood that the situation might be provisional, they also confirmed that excessive work demands were stressful and unpredictable, as nobody knew when the restructuring would be finished, and whether or not any new staff would join the company. Low staffing levels could also become a permanent situation. The additional work demands made life more challenging for working caregivers.

Cathy was an extreme case that illustrated the effect of excessive workload on the experience of being a working caregiver. At the time of interview, she was officially the leader of a team that was functioning lower than her own standard as a result of a scarcity of time and poor management. She mentioned during the interview that she was required to carry out a huge number of tasks from both her current and previous positions, the latter related to interior design. Cathy felt under enormous pressure from the increased work-related demands, the reduced amount of time that she was given to complete tasks from both her official and unofficial roles, and the frenetic work schedule. She was depressed
about her underperformance in both roles. The massive workload was one of the sources of her unhappiness and depression. Cathy described her situation: ‘they [the organisation] have given me an awful lot of additional work and it has affected my ability of performing the team leader role, but at the end of the day, I feel like they haven’t been that loyal to me …’

The phenomenon of excessive workload and pace was evident in the study, as the majority of participants experienced one or more of the following:

- the feeling of being behind in their work;
- the pressure of keeping up with the pace that the job demanded;
- the need to work longer hours or give up their relaxation time;
- the lack of control in the workplace and, in particular, relating to the number of tasks assigned;
- the requirement to complete an excessive workload within a stretched timeframe, and to shuffle priorities regularly.

5.3.2.2 Financial pressure to stay in paid employment

The decision on whether or not to remain in paid employment has an impact on the perceptions of the experience of being a working caregiver. The wish to stay in the workforce was a theme across all interviews. The motivation for staying in the workforce, while varied, related mainly to the given financial situation, whether it was assessed based on an individual or a household situation. For single caregivers, like Terri and Nina, the desire to work full-time was associated with financial security, but in a more implicit way. They had a clear vision of their future lives. The financial concern did not derive from the burden of caregiving, as they were fortunate in that their respective care recipients were financially independent. Rather, paid employment enabled them to gradually build up a financial base that served as the foundation for their future lives. For caregivers like Amy and Lisa, who were approaching, but still had not reached their retirement age, the key concern was the fear associated with giving up employment and then having to face the difficulties of re-entering the labour market.
The major concern for caregivers who had children with and without a disability was to keep their young family running. It is clear from the interviews that being a caregiver can be quite expensive, due to the out-of-pocket costs and/or the possible reduction in family income. Paid employment, for most participants, provided the essential income that kept the family running, and built the financial base for the future. For example, Jenny was forced to resume her career as a qualified fundraiser when her husband was unable to continue operating their family fishing business. The family simply needed income to cover the cost of their daily lives and the additional sums expended on their two children with disabilities. For Marcus, the wish to stay with his current employer was directly related to his financial commitments. He needed to be able to support his younger brother’s tertiary education, and his elderly parents, who had limited financial support from the government. Cathy was under enormous financial pressure to continue what she was doing despite her eagerness to work less. Cathy and her fiancé found it impossible to ‘live where we are without my income because he’s got more financial strain on him to support his previous family, which is ridiculous’. In a similar situation, Haidi was willing to sacrifice everything, such as opportunities for promotion, as long as she was employed. The family needed the combined income to pay a $10,000 per annum tuition fee, in addition to medical expenditure, in order for their daughter to be kept in her mainstream primary school.

In a household context, the decision to carry on in paid employment was also influenced by who the breadwinner was in the family. In Dora’s case, her new husband was undertaking postgraduate study at the time of the interview, so there was virtually no income from his side apart from a scholarship. Dora had no alternative but to keep her current job despite the fact that she was constantly criticised by her direct boss and colleagues, and was not content with her performance review. She would have been ‘happy staying at home’ if her new husband had been able to become the breadwinner for the family after the completion of his doctoral degree. There was no shortage of discussion about the plan for the future in Amy’s family, in particular, the organisation of life for their disabled child once she needs a full-time caregiver. Amy’s husband will likely be the person who ‘will give up his job as
my jobs pay better’, although at the time of the interview, Amy was the primary caregiver to her daughter as well as to her granddaughter.

For participants who were caring for a child with a disability, financial pressure derived also from their wishes not to penalise other family members, in particular, the siblings of the child with a disability. Caregivers wanted to stay in the workforce in order to provide their children with the same or similar upbringing. For example, Haidi’s willingness to stay in the workforce for as long as she could was influenced by her desire ‘to buy houses for her [the child with a disability] and buy one for the others … just to be fair’. Amy had exactly the same concern with regard to the fairness of the treatment that all her children might receive: ‘We have to be very careful because we gave so much financially to Rachael [the child with a disability], we have to be careful that the other ones don’t miss out’.

5.3.2.3 Importance of employment tenure

The experience of being a working caregiver within the work domain is also shaped by how caregivers perceive their employment. One of the emergent themes in the study, which has rarely been reported in previous research, is the caregivers’ propensity not only to stay in the workforce, but also to retain their employment status. Most participants were content with their long tenure with their employers, and at the stage where they could just manage the challenge of being a working caregiver after many years of adjustment.

Amy, for example, wanted to remain as a shift-worker because it gave her more days off, which was what she needed in order to take care of her daughter and granddaughter. While Marcus admitted that while he could not afford to lose his job, he was unable to take the option of becoming a shift-worker, although it would certainly provide him with more income. Assisting his elderly frail parents was a daily routine job. The subtle balance between caregiving and work could easily be destroyed by any change made either in the workplace or the family domain.

5.3.2.4 Desire to appear normal: Self-imposed silence

Along with excessive workload and pace, financial pressure and the perceived importance of employment tenure, this research reveals that the desire of working caregivers to appear
normal influences the experience of being a working caregiver. This phenomenon is depicted in this section as self-imposed silence, a theme across many cases in this research. While self-imposed silence could be due to the reality that most caregivers do not have many confidants in their workplaces and in the wider society (as described by Dora: ‘I don’t actually have any people that I can talk to about it … I don’t actually disclose to people, at all’), it is motivated mainly by the following factors.

First, the desire to stay in paid employment not only influences the perceptions of the experience of being a working caregiver, but also contributes to the unwillingness to disclose personal information. Caregivers are concerned that they might be treated differently once the company or colleagues know about their caregiving role. For instance, Terri’s hesitation to make her caregiving role public was influenced by her assumption that she might be criticised by colleagues and managers for her mood swings, and for using family issues as ‘a crutch for your behaviours and bad performance’. Being treated as an unreliable person was another concern for Terri. Some caregivers even believed that revealing their caregiving responsibility in depth would only make things worse. Dora’s reluctance to share her caregiving experience with others was the result of her problematic relationship with her direct boss, the disapproval from her boss about caregiving impacting on work, and her unpleasant treatment at work.

Second, the long-lasting self-imposed silence in the workplace may link to caregivers’ wishes to be treated continuously as an ordinary person. The personal and family lives of many caregivers had changed dramatically after they had assumed their caregiving role. Darren and Terri revealed during the interviews that their unwell loved ones usually became the centre of the family as well the principal topic of conversation among caregivers and their limited circle of friends or colleagues. ‘They’d [people] ring up and, how’s Jo [Darren’s wife], how’s this, how’s that … Then they’d hang up … when somebody becomes the sick person, he or she the only one that really exists.’ The conversation, by and large, revolved around the ‘state of the care recipients’ health including diagnosis, treatment and prognosis’ (Terri). How caregivers coped with the challenges was rarely the subject of discussion.
The majority of the participants in the current study were reluctant to share their caregiving experience, and to seek support for their caregiving role. One of the consequences of prolonged self-imposed silence was the lack of awareness of any available formal initiative within the organisations in which the participants worked: ‘I’m not really sure, I haven’t investigated it’ (Terri). ‘I don’t know of any program or initiative’ (Nina). Most participants claimed that there was ‘no formal program’ (Haidi, Lisa and Carey) or ‘policy or procedure’ (Darren) in their company which would help them to meet the challenges of being a working caregiver.

The only policy that the majority of working caregivers knew of and utilised was the ‘carer’s leave’ entitlement. Such leave, as reported by most participants, was not sufficient to meet the demands imposed by both work and caregiving responsibilities. It is inevitable, then, that working caregivers search for their own ways to organise workload in order to meet the demands of work and caregiving.

5.3.2.5 Informally granted flexibility

The phenomenon of self-imposed silence and consequential unawareness of formal existing programs led to the working caregivers seeking accommodations in the workplace that would enable them to meet the challenges of their multiple roles. A range of strategies, mainly in the form of enhancing informal flexibility, were implemented by working caregivers.

Nearly all of the participants were in managerial positions or had a long tenure with their current employers. Being in a senior position allowed working caregivers to ‘organise a person to fulfil my duties when I am going to be absent for a short period of time’ (Amy). As a leader in her section, Nina was able to decide when and where she took her lunch break. If there was no meeting scheduled, she would have her lunch break late in the afternoon and then immediately head to her grandfather’s place. Haidi and Darren were another two examples that illustrated the relationship between the position held by an individual and the informal flexibility of their employment arrangements. In addition to
using the same tactic by skipping lunch breaks, Haidi took advantage of living closer to her workplace, which allowed her to go home in the case of an emergency and return to work afterwards. Darren’s current position did not require him to be present on the company premises all the time. He was able to work from home or any other location to carry out part of his workload while looking after his wife at home, and to complete his work in the evening.

While self-imposed silence is a main theme across many interviews, those, such as Amy and Nina whose caregiving role had been revealed to their direct boss, credited their ability to manage simultaneously the roles of full-time worker and caregiver to their managers’ acceptance of the need for flexibility and willingness to offer it. Nina described her manager as a ‘great boss – he knows that I work hard but he also knows that sometimes I need flexible hours’. Amy was grateful to her manager for approving her leave request without considering the categorisation of the leave – she was able to use all her entitlement for caregiving purposes. It was also Amy’s belief that her upper level manager would grant her the needed flexibility, such as allowing her to switch from being a shift-worker to being an employee with a normal work schedule, and permitting her to take leave without pay: ‘They [her managers] were very supportive.’

The overwhelming majority of participants of the current study benefited from the informal flexibility in the workplace and considered that the responsibilities imposed by work and caregiving were manageable. Accomplishing the tasks of paid employment and unpaid caregiving was deemed to be routine for these caregivers. One participant, Dora, experienced the adverse effect of inflexibility in the workplace on the perceptions of being a working caregiver. Although she had successfully negotiated with the company to start her day half an hour late so she was able to take her daughter to school, the arrangement was made on the condition that she had to make up the time by regularly missing her lunch breaks or working late.
The discussion above emphasises the significance of flexibility in managing multiple roles. A flexible arrangement about work time and location had an impact on the perception of the experience of being a working caregiver.

While the perceptions of the experiences of being a working caregiver have been discussed and presented from within the family and work domains separately, the reality that an individual has to combine the roles of paid employment and unpaid caregiving makes the whole situation more complicated and challenging. Caregivers have to dedicate a substantial amount of time to their caregiving role. For some, caregiving become a permanent, full-time but unpaid job in addition to their paid employment. It is the totality of the responsibilities that makes the life more demanding. In addition, working caregivers have to constantly, but not necessarily in sequence order, assess and resolve the issues arising from both work and family domains.

5.4 Ways of Coping with Multiple Roles

All but one of the working caregivers in this study sought help from a support group or could envisage the benefits of joining such a group. This leads to the discussion of the next key finding in the current study: the personalised ways of tackling issues and problems arising from combining work and caregiving. The purpose of this section is to examine various techniques that working caregivers implemented in order to fulfil their multiple responsibilities. While this section focuses mainly on an individual’s coping strategies, it also covers the support used from the broader society. Support from working caregivers’ immediate and extended family members, as well as from their workplaces, have been discussed already in the sub-themes of ‘influences within the family domain’ and ‘influences within the work domain’, respectively.

5.4.1 Constructive approaches

Through the narratives conveyed by the participants, it is clear that those who embraced the caregiving role and its corresponding responsibilities with a positive manner were able to face the reality and employ effective coping approaches.
Tactics utilised by individual working caregivers to manage the responsibilities imposed by work and caregiving are, to some extent, driven by individuals’ characteristics often developed from childhood and through family relationships. These include a concern to help those in need and a commitment to being positive about life, whatever the circumstance.

While all of the participants in the current study commented on the complexities involved in carrying out the responsibilities imposed by both the work and family domains, those who described themselves as having grown up in a close-knit family environment or having a close family relationship believed that they were able to manage the challenges imposed by combining the roles of caregiving and employment.

Terri disclosed during the interview that her parents were strongly reliant on each other’s support to go through the difficult times, even though life seemed unfair to them. Terri believed that the mutual caring, compassion and recognition of one another as individuals were the keys for the family to overcome the hardship of life. She credited her ability to view her dual roles, or life in general, through a relatively positive lens to the close relationship with her parents, and her upbringing. As a result, the experience of combining work and caregiving was deemed to be ‘an intricate, but more rewarding journey’ (Terri). Terri emphasised her keenness to become a competent caregiver – she had obtained medical knowledge and improved the skills that were required to provide safe and effective care to her parents.

Darren’s case was another example that illustrated the connection between the individual’s characteristics and the strategies they employed as working caregivers. The unexpected and dramatic life changes in terms of finance and responsibilities since his wife had been diagnosed with an incurable illness had not caused disruption within the family. Rather, Darren and his wife had been able to face her approaching death openly and had discussed mortality between themselves and with their children. In an effort to normalise the situation as much as possible, Darren had continued his job without a break, except for the occasions on which he had had to accompany his wife for special treatment sessions. It was Darren’s
belief that ‘abandoning his paid employment would only bring the enormity and sadness’ of what was happening to the surface.

In the same vein, Amy expressed her unconditional commitment in terms of providing assistance to her daughter and granddaughter, as well as her satisfaction with being able to manage well the combined roles of caregiver and employee. Amy perceived that the stable caregiving environment she and her husband had created and the close-knit family unit were the basis for viewing life in a more positive way.

Being actively involved in the relevant research and advocacy activities was a constructive approach employed by some working caregivers. This approach helped them to alleviate the burden of being the primary caregiver and reduced the feelings of social isolation. It also enabled them to develop a new set of connections. Haidi, for example, believed that supporting the research related to her daughter’s disease (in the form of giving consent for her daughter to be a voluntary participant), and being an advocate, would help ‘to raise awareness in society with regard to the unfair treatment that disabled children and their families receive’. As a key member of the Family Advocacy Association, Haidi was a regular attendee for many years at the ‘Family Advocacy’ conference on making the transition from school to work for disabled children. At the time of the interview, she also described her plan to facilitate and work in partnership with other advocacy bodies in developing the new models that could suit people with disadvantage. It was described by Jenny that her functional coping strategies, that is, establishing a trust relationship between the caregivers of her two disabled children and herself, as well as patiently seeking relevant information from government bodies, enabled her to cope with the challenges imposed by work and caregiving. Jenny expressed her desire and plan to help people in a similar situation by using the experience and expertise she had gained from caregiving.

Being able to set boundaries between work and family domains was another constructive approach utilised by working caregivers to cope with multiple responsibilities. Family and work were the two main domains within the life of the caregivers in this study. The findings suggest that participants who were able to set a clear boundary between the work
and family domains, whether actively or passively, tended to expose themselves less to the negative outcome of spillover. Consequently, they coped better than those who suffered the adverse effects of bi-directional spillover, as the result of the blurring boundaries between the two domains.

The workplace is not merely a place from which people generate their income. For some caregivers, it was also seen as a temporary ‘getaway’ destination, where they were able to enjoy a break from the worries and physical challenges related to caregiving, and where they could be themselves for a short period. This was particularly true in the situation in which their caregiving status was not disclosed.

Terri believed that she benefited from a total attachment to work while in the workplace. Her full concentration and dedication allowed her to change focus temporarily from the personal and family situation to the work situation. Darren’s tactic for minimising the conflict between work and family was to avoid talking about family issues in the workplace. Darren credited his excellent skills in managing his multiple roles and extremely demanding life to his willingness and ability to separate family from work: ‘So I actually did keep work and home very separate.’

Jenny considered being employed to be a healthy choice as she believed that being in the workplace initiated the process of getting herself recharged, refreshed, and ready for a totally different set of responsibilities. Jenny admitted that she probably would not have been the same person had she not had a paid job, and it was impossible for her to manage the family and its well-being without the much-needed respite that she gained in the workplace.

While treating the workplace as a getaway destination can be viewed as a proactive approach of caregivers in terms of compartmentalising, some working caregivers were forced to disengage themselves from caregiving responsibilities while at work. This was mainly due to the nature of their job. For example, it was impossible for Marcus, a full-time warehouse worker who had limited access to a dedicated telephone or computer, to check
the status of his frail elderly parents during the time he was at work. Carey described her frantic work schedule as a part-time librarian as ‘crazy and unmanageable’, and was ‘forced to do nothing but work-related tasks’. Whether caregivers actively or passively set a clear boundary between work and family domains, they benefited from employing this approach as it enhanced their performance at both roles.

5.4.2 Survival orientation

For those who had underestimated the complexity inherent in caregiving and the adjustment needed in their lives, life was challenging. As a result, this group of people perceived caregiving as a burden. The overwhelming physical and emotional fatigue that accumulated as a consequence of the caregiving role being combined with an excessive workload had an adverse effect on caregivers’ daily lives.

Cathy was puzzled about her decision to thrust herself into a complicated situation, and kept asking herself when the cheerless life would end. Likewise, ‘why me?’ and ‘what I have done wrong?’ were recurring questions for Dora.

Dora’s case exemplified the detrimental effects of not being able to set the distinction between work and family domains. She suffered the consequences of utilising too much of the company’s time to deal with family issues. The resultant poor performance review was recorded in her portfolio and became an apparent hindrance to her career promotion and advancement. At the time of the interview, her enthusiasm and motivation to learn new things waned, compared to the early stage of her employment in her current company, and had been replaced by stress, anxiety, resentment and a keenness to seek a new position.

Several of working caregivers relied upon antidepressants to get through their daily lives and copy with the challenges they were facing. This theme was particularly evident in the case of young families consisting of children without a disability and a child or children with a disability. The reality of caring for a child with a disability – an unpaid position with a huge responsibility, in most cases, shouldering the caregiving role on their own while allocating ‘equal’ time to other children in the family – left working caregivers with only a
limited number of alternatives in managing their lives. Some working caregivers saw antidepressants as allowing them to carry on with the realities of their life, and it was not uncommon that both partners relied on prescribed medication to continue fulfilling their roles.

Dora believed antidepressant medication to be useful, as it ‘helped [her] to see things a bit clearer’. Having been a single parent to her three daughters for a considerably long period, Dora relied on antidepressants to cope with the tremendous difficulties arising from domestic issues. Dora revealed that she also used antidepressants to ease unpleasant feelings, for example, in the situation where she received criticism in the workplace. She employed this coping strategy after the failure of temporarily departing from the workforce, which had neither alleviated Dora’s nervous tension nor improved her psychological health and well-being. Dora’s ongoing depression had led to her doctor’s decision to prescribe antidepressant medication.

Amy appreciated a prescribed ‘sleeping formula’ she used, which ‘could overcome the symptoms of chronic insomnia’. She confirmed that the medication enabled her to gain sufficient sleep so that she was able to cope with the roles of caregiver and shift-worker. In addition to getting adequate sleep, Amy admitted that the prescribed medication was helpful in controlling her mood swings and depression. She relied upon medication to reduce the grief that had followed the receipt of devastating news (her granddaughter’s diagnosis with a life-threatening disease), to conquer the sleepless nights, and to be ready for the non-stop cycle of working and caregiving.

Jenny disclosed that she had been on antidepressants for many years, as had her husband. She described the hardship of raising a young family of four children, two of them with a disability, as unmanageable at one stage of their life. Antidepressant medication was one of the coping strategies that Jenny and her husband relied on to deal with the difficult situation.

A similar situation had developed for Cathy and her fiancé, both of whom had been on antidepressants for years, though for different reasons. According to Cathy, it was
extremely challenging to perform to a high level at work during the day and have sufficient energy for caregiving duties after work. While Cathy described that the initial cause of her need for antidepressants was related to the stress of her work, she admitted that antidepressants helped to ease the accumulated stress resulting from work overload, as well as from looking after an overactive disabled child. The reason for her partner using medication was associated with the guilt and the pressure of having a son with a disability. Despite the reasons of reliant on antidepressants might vary for Cathy and her partner, the medication was believed of helpful in terms of relieving the pressure associated with their tough life and to save their relationship.

5.4.3 Social isolation as an approach

Isolation from the wider community is one of the common feelings among caregivers. While social isolation might be due to scarcity of time, it was seen by the majority of participants as an approach to copy with the overwhelmingly responsibilities of both work and caregiving.

Most participants in the current study reported that friendship between them (and their family) and old friends faded away. This was due to either caregivers’ lack of time to attend social events or former friends’ decisions to keep their distance from caregivers. The consequence of having a limited network and prolonged silence was that most working caregivers in the current study received virtually no support from their friends and colleagues at work and beyond.

The paucity of time was a reason for not seeking supportive information. The time required to meet the frantic work schedule and the everlasting caregiving demands prevented caregivers from conducting or participating in other activities, including reaching out for resources in a proactive manner.

While participants in this study agreed that cultivating a supportive network might be an effective way of learning and sharing ways of coping, and a means of reducing the feeling
of loneliness in the caregiving process, most of them confirmed that they had yet to reach the point at which they desperately wanted aid from the surrounding society.

Working caregivers provided a range of explanations about why they were unwilling to seek support from the wider community for their multiple roles. The section below elaborates further on the reluctance of working caregivers to search out and use available services.

The first prominent reason was outlined by participants who were able to manage their multiple roles effectively. People in this group, such as Terri, Marcus and Darren, were extremely confident about their competence and their ability to manage the demands imposed by both work and family domains. They were content with the ways in which they controlled the situation and dealt with the challenges, both emotionally and physically. For some working caregivers, the reluctance to seek support was also perhaps about keeping the situation private.

The second reason for rejecting the idea of obtaining aid from the wider population was related to the trust that caregivers had in public services. There is no shortage of reports and news regarding the poor treatment an elderly frail person has received in formal caregiving institutions. As a result of hearing such stories in the media, participants with elderly family members to support were hesitant to utilise the short-term respite and/or long-term placement arrangements. Terri, for example, insisted that she ‘wouldn’t want to be in that situation [placing her parents in a nursing home] if she didn’t have to’ as ‘you hear such horror stories on the news about people being abused in situations’. The possibility that their loved ones might experience such a situation reinforced the decision of caregivers to keep care recipients at home for as long as possible, although it was believed by some participants that ‘it [the stories reported by the media] definitely doesn’t reflect the whole industry, but the stories that are in the media are the worst stories imaginable’ (Terri).

Most participants in this study had reservations with regard to long-term institutional caregiving. In addition to the reason mentioned above, the desire to maintain the integrity
of the care recipients was another contributing factor. It was the caregivers’ belief that they should be the key agent in the provision and mobilisation of care, and they could not bear the possibility of their loved ones, particularly elderly care recipients or care recipients with a terminal illness, spending the last days of their life somewhere other than in their own home.

Terri, for example, knew only too well what her parents liked and how they could support each other. The positive relationship that Terri had with her parents gave her full confidence that she was the person who could best provide her parents with the support they need. This was how she felt: ‘It would break my heart. I would be so damaged afterwards if their [her parents’] last day was spent in some sort of home or respite care.’

The following extract from Nina illustrated the same belief:

*I saw it [looking after grandfather and keeping him at home] as that one last mark of respect with my grandmother. We want the last years of his life were as comfortable and as independent and as enjoyable as possible, instead of just shoving him in a nursing home and leaving him to vegetate.*

Unwillingness to seek and use public services was further influenced by working caregivers’ belief that it was extremely difficult or impossible for people to sympathise entirely with their situation. In other words, people who were not living in similar circumstances would not comprehend the difficulty of their lives in terms of combining the roles of paid employment and unpaid caregiving. Thus, for Terri, Jenny, Dora and Cathy, it was not worthwhile making their situations public. Jenny felt that people did not really understand her situation unless they had been in a similar predicament. She summarised based on previous experiences: ‘well, you do learn either some people don’t give a rat’s and don’t want to know or they can’t relate …’ Comments made by Terri illustrated this finding:

*I never told one of my jobs that I did have a caring role. People don’t understand that it [some days are good days, some days are incredibly bad] fluctuates so much.*
It's very emotional, day to day. So I didn't know how to share that with people’.
(Terri)

The feeling of social exclusion, the limited time and energy, a lack of faith in public services, the wish to retain the care recipient’s integrity, and the working caregivers’ belief that nobody could comprehend their situation potentially make caregivers shut off particular avenues of social support, both physically and emotionally. This leads on to the discussion in the next section on the effects of simultaneously carrying out a paid job and unpaid caregiving on caregivers themselves and other family members, or the family as a whole.

5.5 Impact on Working Caregivers and Significant Others

As mentioned in chapter 1, the care recipients’ experiences of illness are not the focus of the current study. Thus, the study is less concerned with the specific conditions of recipients, which are only briefly outlined in chapter 4. Rather, one of the key objectives of this research, in addition to examining the perceptions of the experience of being a working caregiver and coping strategies, is to explore the impact of combining work and caregiving commitments on caregivers and their families. The impact is examined from a number of aspects, including physical health, emotional well-being and caregivers’ sacrifices, including social contacts, personal relationships, career advancement and financial security. While it is largely understood that the strain and burden imposed by caregiving are significant and can take a huge toll on caregivers, the effect on the family as a whole of having a family member who needs intense care cannot be ignored.

5.5.1 Physical health: Exhaustion and health deterioration

The consequences for physical health of juggling work and family commitments are considered in relation to three areas, namely, physical exhaustion, chronic health problems and health promotion activities. Physical exhaustion is one of the main negative outcomes of being a working caregiver. The fatigue that accumulated from work and caregiving was enormous for nearly all of the participants in this study, while it was particularly evident in
cases in which caregivers were full-time workers and/or bearing the caregiving responsibilities by themselves.

The accumulated fatigue was reported to be the result of the following: ‘countless sleepless nights and working on weekends from time to time in order to accumulate leave entitlement’ (Terri); ‘sleeping only seven – eight hours a week’ (Darren); ‘spending twe hours before and six hours after work to showing and toileting my parents every day’ (Marcus). Cathy stated: ‘It's so draining as you’re forever having to repeat yourself because of his [her stepson’s] obsessive behaviours, at the same time taking official and unofficial roles simultaneously.’

The signs of physical tiredness found in participants’ accounts include reliance on caffeine to prevent falling asleep during the day; the need for more rest during the weekends to overcome mood swings and grumpiness; an inability to engage in exercise; and a lack of desire to participate in other social activities.

Exhaustion had led to other health problems for some caregivers, as they believed that their physical health was poorer than it had been before they took on the caregiving role. For example, Lisa believed her ‘worse than average health condition’ was the result of long-lasting demands emanating from combining work and caregiving over the past decade. According to Lisa, the excessive workload and caregiving responsibilities exacerbated the state of her physical health beyond the normal ageing process. Others, such as Marcus and Darren, reported that they had been diagnosed with, and prescribed with medication for controlling, high blood pressure and high cholesterol levels. While ongoing fatigue and tiredness might make caregivers more likely to fall ill than they otherwise would, there is no clinical evidence from this study to support the causal link between combining work and caregiving, and physical illness.

Several participants mentioned during the interviews that they participated less in regular physical activities due to having limited time and energy, and took meals irregularly or skipped meals on a regular basis with the intention of building up leave entitlement or
catching up on their workload. However, there was no report by participants in relation to unhealthy behaviours such as problem drinking or tobacco use.

5.5.2 Emotional well-being: Strain, stress and depression

The effect of combining the roles of paid employment and unpaid caregiving on emotional well-being, such as strain, depression, anxiety and life stress, are the result of concerns originating from both work and caregiving roles. This has been discussed in the theme of ‘the perceptions of the experience of being a working caregiver’. The desire to be competent in the caregiving role could also have an impact on caregivers’ psychological well-being. Caregivers constantly seek information with the aim of enhancing their medical knowledge and caregiving skills. Furthermore, the sudden change in life, in terms of being thrust into the caregiving situation and the long and seemingly endless caregiving duties, could be a contributing factor to the effect on emotional well-being. The extract below highlighted the feelings of one of the interviewees:

It was such a shock to me. I was so upset. That when people say they’re paralysed by fear and emotion … Yes, and just being in that environment, where whoever you’re caring for is unwell, and then hospitals where everybody is unwell … I was not as outgoing as I used to be, and not as cheerful and upbeat as I had been previously. (Terri)

Caregivers’ emotional well-being is also impacted by work-related factors. Individuals have their own standards, and are willing to perform at a level in accordance with their responsibilities in the workplace. It was revealed by several interviewees that disappointment associated with ‘lower than desired standard’ (Cathy) work performance and disappointment over not being able to ‘commit fully to their work’ (Nina) were sources of anxiety and stress. The psychological impact, in turn, contributed to the consequent outcomes of a loss of enthusiasm and a willingness to learn new work-related skills.

The impact of having multiple roles on caregivers’ psychological well-being was deemed by some participants as ‘greater than the effect on their physical health’ (Darren). This was
made evident by the fact that several participants were heavily reliant upon antidepressants (as noted in the theme of ‘ways of coping with multiple roles’) which they said they took taken to overcome their emotional ups and downs (which usually followed the changes in mood of their care recipients) and their frustration and anger (as a result of the unfair treatment that the care recipients received from the wider community) Antidepressants were also reported to be used to ease the overwhelmed sense of responsibility, the devaluation of self (the caregiving role was a central commitment), and the constant worry about the care recipients.

5.5.3 Caregivers’ sacrifices: Social contacts and personal relationships

While one participant (Terri) commented on the positive effects of combining the roles of paid employment and unpaid caregiving, the overwhelming majority of participants reported the sacrifices they had to make, in terms of social contacts, personal relationships, career advancement and financial security, in order to carry out multiple responsibilities.

The positive outcome was referred by Terri as being able to view life in a positive lens, through the process of re-evaluating and reassessing life, and the desire to search for meaning in caregiving, and personal growth. For Terri, along with the experience of being a caregiver to her parents came the realisation of how much she meant to her parents and the depth of her commitment to help them. Not only had she been embracing life with a more positive attitude; her parents had also been reassessing what was vital and valuable in their lives. Terri had a totally new insight to life and believed that she ‘made the best of a bad situation. It [caring for her parents] changed my life very positively, and gave me new meaning to life and to the importance of being positive and making the most out of life’. Nina had similar feeling about her relationship with her grandfather: ‘I understand a lot of things that I didn’t understand when I was a child.’

Another reported positive aspect was the enhanced performance in both roles. It was Terri’s belief that her role as a primary caregiver enhanced her work role, as she ‘was far more compassionate for other people’s hidden situation and need, and to work well in a crisis, to act and react at a moment’s notice’. By the same token, she believed her experience at
work as a professional librarian enabled her to search for and locate the relevant medical information, and to be more competent in her caregiving role.

The impact of combining work and caregiving on an individual’s life is dynamic. Working caregivers regularly experience the impact of having limited time and energy, and have to make sacrifices. The majority of participants reported that the immediate consequence of becoming a working caregiver was the scarcity of time, as for some working caregivers, ‘spare time’ was dedicated to either the caregiving role or carrying out necessary domestic tasks. For others, leisure time was occupied by doing things that were unpleasant, such as catching up on the unfinished chores, or doing virtually nothing but acquiring much-needed sleep in order to revitalise themselves for the week ahead. Going out with friends or attending social activities was seen as a luxury that was out of reach partly due to caregivers’ strong commitment to their caregiving role. Below are some of the comments made by interviewees:

    Coming home tired and not even – just coming home feeling numb because I’m that tired ... it [having no time and being tired] does make it difficult to catch up with my friends. I’ve really missed that … (Nina)

    They [parents] always come first, because I don’t know how many more chances I have with them. Every moment is the last moment. (Terri)

    … I felt that all I did was work and look after my mum and there was nothing ... It’d be that I was going from work to my mother. There wasn’t a lot of opportunity for hobbies or leisure. (Lisa)

    We were so exhausted that we didn’t have the energy to want to go and do anything. So we didn’t see our friends, we didn’t go out. We had no time for ourselves to do something nice. (Cathy)
Life after assuming a caregiving role was seen as extremely mundane and ‘*incredibly boring and not living anymore*’ (Cathy). Having less and less ‘free’ time was a common complaint voiced by interviewees in this study.

In addition to the perceived monotony of life, combining caregiving and work also has an adverse impact on the establishment or maintenance of a healthy personal relationship. This could be the result of ‘*not having any time for each other*’ (Jenny) and there being ‘*hardly any conversation between us, our relationship goes on hold because caring takes all of our attention and emotion …*’ (Cathy). The difficulties involved in maintaining a healthy personal relationship could also be the outcome of being unable to manage the pressure arising from the endless responsibilities imposed by the combination of work and caregiving. The demands of caregiving were seen by participants as one of the causes of constant argument, dispute and tension between partners. Cathy, for example, said that she was very much in love with her partner, but the reality of having a stepson with a disability and other consequences originating in the situation ‘*were causing so much strain on our relationship*’. Cathy believed that the stress could overtake the compassion and become the grounds for the termination of their relationship as at one stage she ‘*nearly decides to walk out of the relationship*’.

Some participants believed that unresolved confrontation and issues between couples could take the imperilled relationship to the next level of marriage breakdown. Both Jenny and Dora disclosed during the interviews that the decision that each of them took to terminate a marriage was a consequence of being unable to reach an agreement or consensus, whether it was one party’s disengagement from daily activities, or the lack of enthusiasm and energy for life in general.

Taking up the caregiving role also changed the nature of the relationship between caregivers and other family members. Caregivers and their siblings could disagree with each other with regard to who should be the primary caregiver to their elderly parents or what kinds of treatment were best for the care recipients. There was tension between caregivers and their children due to perceived mistreatment and the feeling of being
underprivileged. For example, the strained relationship between Dora and her two older daughters was the product of their strong view that their younger sister was enjoying all the privileges they had never experienced. A similar situation developed in Haidi’s family. Her two younger children could never really understand why they were treated differently from their older sister.

The dynamics of relationships among family members has an impact not only on individual caregivers, but also on other family members or the family as a whole. This is particularly evident in families comprising children with and without a disability.

Many participants reported that their family had gradually grown apart as a result of enduring tension and misunderstanding between siblings. Children without a disability could not comprehend the reasons behind the rejection or unwillingness expressed by the child with a disability when asked to join family events. This was also a source of quarrels among siblings. For example, Dora’s two older daughters had never got along with their younger sister, and tried to avoid her if possible. Haidi’s two younger children were always puzzled about their older sister’s strong mood swings and her resistance to change. The family, as described by Jenny, gradually became a ‘dysfunctional unit’.

It could be argued that leaving home and living independently when a child reaches a certain age is a normal process of growing up; however, participants in this study confirmed that the tension between family members could be the cause for the premature departure from home. Dora mentioned that her two daughters without a disability chose to spend time in their friends’ house, and her oldest daughter had selected an interstate institution for her tertiary education. This could be seen as signs of her older daughters’ unhappiness and willingness to keep distance from their mother and her sister with a disability. At the time of the interview, Jenny’s older son had moved out of the family home and was living with his girlfriend.

It was also revealed that children without a disability were, to some extent, given less time and attention due to the limited time and energy that working caregivers had. In Jenny’s
view, her oldest son was a typical example that demonstrated the negative impact on other family members of having children with a disability. Jenny’s older son had witnessed all of the changes within the family throughout his upbringing. Jenny was devoting most of her time looking after her two sons with high needs and her emotionally ‘frail’ husband. As a result of a lack of attention, her oldest son was transformed from ‘a little sweetheart who was so keen to help his mother to a teenager who hated nearly everyone and everything around him’.

The uncertainty of working caregivers’ lives makes it difficult for them to establish healthy personal relationships. A number of participants put the potential for relationships or the intention to form them on hold as a result of the unpredictable nature of their lives and their strong commitment to their caregiving role. Terri’s fear of embarking on a new relationship was partly a long-term effect of her previous experience, as well as the conflict between her belief and the reality. Terri believed that honesty should be one of the basic principles for a long-standing relationship; however, she had yet to comfortably disclose her life situation to anyone. The uncertainty associated with caregiving, more specifically, the state of her parents’ health, and the willingness to perform caregiving duties unconditionally, prevented her from establishing a stable relationship.

Jane was another example illustrating that the uncertainty of life and the dedication to caregiving were some of the main reasons behind a caregiver’s decision to postpone the pursuit of a steady relationship. At the age of 56, Jane had never had a serious personal relationship due to her strong commitment to the long-distance caregiving responsibility. Jane’s mother was 92 years old at the time of the interview, and had been living with her younger sister in an Asian country for most of her life. Although Jane was not involved in daily caregiving activities, she tried to make herself available at any time her mother needed her. Thus, travelling to another part of the world a few times a year was not uncommon for Jane.

Several participants admitted during the interviews that they had entered the caregiving role with no sense of what it would really involve, and overestimated their ability to handle the
demands. Caregivers also gradually realised that the role of caregiving was a long-term commitment. The question ‘when will this end?’ was raised by some of the participants on several occasions. The nature of uncertainty also required working caregivers to make a long-term amendment to their life plans.

Using Jane’s case as an example again, she had no plan to purchase a house or apartment in Australia because of the uncertainty of her finances and the time required for caregiving. She could not predict the time when she would need to go back to her country of origin to look after her mother. Most of her savings over the years had gone to cover the cost of frequent travelling, and other caregiving-related expenditure.

The same scenario was seen in Marcus’s case. While there were other reasons behind Marcus’s single status at the age of 43, he saw the caregiving role to be the main contributory factor. Marcus was not convinced that someone other than himself and his brother would have given the same level of attentiveness to his parents, and was not willing to take the risk of moving into a more complicated life situation.

5.5.4 Caregivers’ sacrifices: Career advancement and financial security

Amendment to an individual’s career goals can be considered broadly as one type of caregivers’ sacrifice. While most participants in this study were holding a full-time position at the time of interview, it was revealed by caregivers with a child with a disability that they had been caught up in the dilemma of whether to pursue a career or stay at home looking after their children.

Career interruption – entering, exiting and re-entering the workforce – is another dimension of the adverse impact on career advancement. While changing career trajectory and acquiring special qualifications were not unusual among participants, the perception that an individual caregiver had, with respect to the process of entering and leaving the workforce varied. For some, this practice enhanced an individual’s adaptation to the environment and built their resilience as well. Those who preferred not to disclose their private life in the
workplace believed that the process of starting a new job actually provided an opportunity for a new start, which was needed in the context of combining work and caregiving.

For others, their multiple roles constituted a perceived impediment to re-entering the workforce, whether it was the possibility of being thrown into a position that did not match one’s skill and knowledge, or at the more general level of finding it difficult to get into the workforce. In the short-term, caregivers could not rely on a carer’s allowance to cover their living expenses as ‘they [the government] are cutting back on the pay for care’ (Lisa). In the long run, working caregivers had concerns about their career prospects as ‘it’s very difficult to go back to the workforce’ (Lisa), especially ‘with the current climate [economic crisis], the company might tap me on the shoulder tomorrow’ (Amy). Age could be an influence on the contrasting insights regarding the outcomes of career interruption. The perception of the difficulty associated with re-entering the workforce after finishing the caregiving role was a concern mainly for middle-aged caregivers.

Furthermore, career advancement for working caregivers is the tendency to forgo the pursuit of promotion opportunities. This is usually a decision made after a thorough assessment of the feasibility of engaging in another position that carries more responsibility and requires more time and effort. The decision to give up opportunities for promotion is an indication of self-denial, as all of the attention is on the care recipient. In addition, declining a promotion opportunity highlights the importance of stability. Most caregivers really wished to maintain the established subtle balance between the roles of caregiving and paid employment.

Dora allowed two promotion opportunities to slip away, although she believed on both occasions that she was a more competent and competitive candidate than those who eventually got the positions. While the resentment or regret arising from not being able to apply for the positions was temporary, the ‘dreadful’ feeling and experience of working under the leadership of a person who was much younger and had less experience was a cause of ongoing suffering.
Obtaining a senior position in the hierarchy was, for Haidi, no longer an ambition despite her various qualifications and her work experience. She was fully aware of the difficulty involved in raising a young family with the additional caregiving responsibilities for one child with a disability, and for her frail elderly father when needed. The caregiving role was a central commitment at the current stage of her life, and likely to be a life-long sacrifice. She was grateful for the flexibility that her current position offered, and was keen to remain in that position for as long as possible.

While none of the participants stated that they were struggling to cope financially at the time of interview, a few of them did express their concerns regarding the costs associated with caregiving. These included transportation costs or parking fees for the visits to doctors and hospitals, frequent dining out due to the irregular schedule, and the out-of-pocket expenditure for medical procedures and medical equipment. According to Terri, ‘additional expenses for special foods and daily products in order to accommodate the need for the chemotherapy treatment were the huge and unpredictable’. Jenny stated that ‘financially it has an impact because we’re trying to find a proper diagnosis … This is where I had to get out to work financially’.

In addition to the regular and frequent caregiving-related expenses, the financial impact in the long-term was linked to the desire of caregivers (mainly those who were looking after a child or children with a disability) to offer financial support to the care recipients, and not to penalise other children. Caregivers realised that their children with a disability would be unlikely to obtain and sustain paid employment due to their social immaturity, and their poorly developed personal and organisational skills. Their poor employment prospect meant that the care recipients could encounter difficulties in living independently. Thus, building a strong financial foundation that could provide financial assistance to all their children turned out to be a long-term financial burden for many caregivers. This was evident in caregivers’ statements: ‘If she [the child with a disability] needed something, we picked up the living costs. She just couldn’t do it on her own.’ (Amy); ‘She may never be employed …’ (Haidi); ‘They are too severe to be in a job, too severely disabled to ever … obtain … employment …’ (Jenny).
This financial impact was also perceived and addressed from other perspectives. While using a respite service or purchasing a service from private providers seemed irrelevant to caregivers in the current study, Nina’s effort to provide her grandfather with various interactions with other family members was costly: ‘I had to compensate my aunty to visit. I give her money every week towards her petrol etc. ... yeah, it was the only way I could get her there ... yeah, I pay her.’ For Darren, the financial deficit could be due to the lump sum expenditure related to his wife’s funeral. The extra financial pressure for Haidi and her family was largely due to the annual tuition fee they had to pay in order to keep the child with a disability in a mainstream school.

5.6 Summary

This chapter presented the main themes that have emerged from the current study. The experience of being a working caregiver has been examined in the contexts of both the work and family domains, and has been detailed in the first main theme. The strategies employed by working caregivers to cope with the challenges of combining work and caregiving have been explored in the second main theme. Issues of support have also been covered throughout this chapter.

A thorough discussion with regard to the impact of combining paid employment and unpaid caregiving on caregivers and their families has been provided in the third main theme. While the impact of combining work and caregiving on caregivers’ physical health is recognisable, and may vary depending on the actual assistance each individual provides to a care recipient, the effect of carrying out two roles simultaneously on caregivers’ psychological well-being is apparent. In addition to the physical and psychological impact, caregivers’ personal lives are also affected. Life becomes mundane as a result of caregivers’ commitments to work and caregiving and their limited leisure time. Furthermore, the impact on the financial situation of the family and family as a whole of having a member who needs special care, whether with a disability, long-term health problems or a terminal illness, cannot be disregarded.
The following and final chapter presents the conclusions of the study and recommendations, as well as raising opportunities for future research.
CHAPTER 6 – CONCLUSIONS AND DISCUSSION

6.1 Introduction

The outcomes of the fieldwork were presented in chapters 4 and 5 as case studies and themes arising from the data, respectively. The contribution of this chapter is to map the factors that impact on perceptions of the experience of managing multiple roles as a working caregiver. As discussed in chapter 3, this chapter is written from a phenomenological perspective. Thus, the various figures and explanations, while triggered by the data collected in the current study, however, only used as a catalyst for the purpose of description, interpretation and the researcher’s self-reflection (Van Manen 1990).

6.2 Conclusions and Discussion

There are four figures. The first (figure 6.1 below) provides a summary of the main factors impacting on working caregivers’ perceptions of the experience of their roles. The three major factors, each of which will be mapped later in this chapter to provide more detail, are:

- work situations;
- the context of caregiving;
- family, work and community support.
Figure 6.1: Factors impacting on working caregivers’ perceptions of their experience of multiple roles

The context of caregiving

Health & emotional well-being

Family, work & community support

Time & energy

Finance

Work situations

Factors impacting on perceptions of experience of multiple roles
The first two are indisputable factors as they address both aspects of the term ‘working caregiver’. The third factor represents external aspects of the life of the working caregiver and has been shown, in the findings of the current study and in the literature, to also influence perceptions of the experience of the multiple roles involved.

As is true of any mapping process, this figure could have been drawn differently. The three major, different, factors influencing the working caregiver’s perceptions depicted in figure 6.1 are not independent from each other, and their relationships are complex. Figure 6.1 acknowledges this complexity, and that the various factors interact with each other and through other aspects that are common to the three key factors. Hence, these other aspects, such as time and energy, finance, and health and emotional well-being, are represented in figure 6.1 as circular ribbons running across the three key factors. For instance, the nature and level of caregiving demands affect whether and to what extent a caregiver experiences extra financial obligations. In turn, a caregiver’s financial status and aspirations affect decisions about continuing, changing or terminating paid employment in the context of the competing demands of paid employment and unpaid caregiving.

In the next three sections, each of the three factors depicted in figure 6.1 will be elucidated in turn from that phenomenological perspective aiming the essence of shared experience (Patton 2002).

**6.2.1 Work situations**

The first set of factors to be considered comprises those that arise from the work situation. Figure 6.2 summarises the most significant aspects in four pairs focusing on:

- work demands;
- interaction between work and other roles;
- financial matters;
- career and life aspirations.
Figure 6.2: Work situations

- **Work-related factors**
  - Effects on available time
  - Effects on energy & focus
  - Work flexibility: time and location
  - Relation between work and home life
  - Employment income
  - Caregiver’s financial status
  - Career aspirations and expectations
  - Life-long goals of self and family members

- **WORK DEMANDS**
- **INTERACTION BETWEEN WORK AND OTHER ROLES**
- **FINANCIAL MATTERS**
- **CAREER AND LIFE ASPIRATIONS**
Work demands

There are two main aspects with respect to work demands. The first relates simply to the time that is required for working caregivers to spend doing the work that they are employed to do, and the second pertains to their capacity to apply energy and focus to their various roles in turn.

It is perhaps self-evident that the more time required to be spent at work, the less time there is available to undertake caregiving responsibilities and to attend to other aspects of family and community life. Many of the participants in the current study experienced real and perceived excessive work demands due to low staffing levels resulting from restructuring and cost-cutting in their organisations. Stress in the workplace, work demands and work demand overload have all been found to be positively associated with caregiving strain and conflict between work and family responsibilities (Burke 1986; Fredriksen & Scharlach 1997; Fredriksen & Scharlach 2006; Pocock, Skinner & Williams 2008).

A desire to negotiate and deal with conflicting demands from multiple responsibilities can lead to caregivers to choose between reducing the level of hours of paid employment, terminating employment and dealing with the conflict without a change in the employment. There are many examples in the literature reporting a reduction in working hours (Robison, Moen & Dempster-McClain 1995; Spiess & Schneider 2003) or a complete exit from the workforce (Henz 2004; Pavalko & Henderson 2006). Both of these decisions relate to whether or not income from paid employment can compensate for the cost of caregiving (Taskforce on Care Costs 2006), with one study showing that caregivers in low-income employment without career-related benefits, are more likely to exit the workforce (Henz 2004). None of the participants in the current study reduced or terminated their paid employment. Almost without exception, paid employment was perceived as being imperative. This is a significant finding, which is largely absent from the literature, and some of the reasons for such decisions are explored in other sections that follow. All of the participants indicated that one important factor was the need to maintain their income level, despite the level of remuneration varying considerably across the group of participants. The relation between the income levels of paid employment and the value of carers’ pensions
and other entitlements could be a factor, among others, that explains the variation between the findings of the current research and some reports in the literature. The findings of the current study suggest that this could be a useful focus for future research.

The second aspect of work demands relates to caregivers’ capacity to apply energy and focus at appropriate times to their multiple roles. One of the common findings of the current study is that effort was required to focus on caregiving when necessary and to shift away from that focus when the caregiver was in the workplace. Indeed, as will be detailed in the next section, the opportunity to focus on work activities can provide a means for reviving energy and relieving stress associated with multiple roles.

**Interaction between work and other roles**

The relationship between work and home activities has two key aspects. One is the extent to which the two domains interact and the positive or negative effects that are produced. The second is the extent to which, even if the activities in the two domains are kept separate, the time and geographical constraints can be more or less flexible, with consequential impact on the working caregiver’s capacity to attend appropriately to their multiple roles.

What these two aspects produce when combined is a complex mix of domains, at times interacting and at other times being kept strictly separate. Nippert-Eng (1996) argues that individuals create boundaries around their work and personal life in a deliberate fashion, and other reports suggest that strong boundaries are constructed in order to maintain work and family as separate domains, whereas weak boundaries are constructed to facilitate ease of interaction between domains (Ashforth, Kreiner & Fugate 2000; Clark 2002). While work–family role blurring or integration has become an increasingly relevant work–family phenomenon (Desrochers, Hilton & Larwood 2005), a number of participants in the current study spoke of the value of maintaining strong boundaries. They referred to the value of being able to immerse themselves in work activities and to put aside for that period of time the tensions and concerns associated with caregiving, a case of reviving energy and relieving stress.
In contrast, while it is not a dominant theme of this research, one participant in the current study spoke positively of the value of their activities in each domain on activities in the other. Aspects of tolerance, perspective, resilience, compassion and competence were traits that she felt overlapped the domains. The development of aspects in one domain spilled over to activities in the other domain and was valued highly. The positive aspect of this impact is in line with the notion of an expansion approach (Marks 1977), and role enhancement or role enrichment (Carlson et al. 2006; Frone 2003), and supports the call that the study of work–family interface should take a more positive approach rather than focusing only on the negative elements of impacts (Greenhaus & Powell 2006).

One consensus in the extant literature and from the current study is that flexibility in the workplace is critical in managing multiple responsibilities. Flexibility is the extent to which work duties can be performed outside the usual spatial and temporal parameters of work (Glavin & Schieman 2012). More flexibility is seen as related to more enhancement, less flexibility to more interference (Bulger, Matthews & Hoffman 2007). One aspect of caregiving is the difficulty of confining it to a particular time and space. Care recipients have a range of physical, intellectual and emotional needs that emerge from time to time in a relatively random way. Medical appointments, school meetings, emotional trauma and inter-city travel in emergencies are all examples of a wide range of caregiving needs that do not occur according to a controlled timetable. On the other hand, most paid employment has a set of conditions attached that at least to some extent requires attendance at particular locations and at particular times. In order to attend to these caregiving responsibilities, many of the participants in the current study attempted to rearrange work times, take special leave, work through lunch breaks or work longer hours, among a range of measures to fulfil employment responsibilities while remaining flexible enough to cope with seemingly random caregiving needs. While it was unveiled by participants of this research that flexibility in the workplace was the key for their success in fulfilling multiple responsibilities, this flexibility was granted informally. The informal flexibility is usually ‘granted’, for the majority of participants, usually in relation to their long tenure with their employers and, logically, in spite of the phenomenon of self-imposed silence. This need for reliance on flexibility uncovered during this study signifies the important role that
employers could play in helping working caregivers to overcome their challenging lives. This will be discussed in the recommendation section.

The effects of role-blurring (Desrochers, Hilton & Larwood, 2005; Glavin & Schieman, 2012) can be seen as positive in terms of managing competing role demands in such cases (Gajendran & Harrison 2007). They can be seen as negative, however, for those who see work as a ‘getaway destination’, as it increases role conflict (Olson-Buchanan & Boswell 2006; Voydanoff 2005). While the majority of participants in the current study had high degree of flexibility in the workplace, they managed to deliberately differentiate identities and activities between work and family domains, and benefited from devoting their attention to work and avoiding the negative impact associated with boundary integration.

**Financial matters**

The third set of factors, financial matters, is fairly self-evident. There are ongoing expenses involved in meeting the special needs of care recipients (Taskforce on Care Costs 2006). The financial status of working caregivers is relevant, as is the level of income from their paid employment. Any reduction in income levels and increases in costs associated with caregiving would reduce the financial position of the relevant caregiver.

Working caregivers who are wealthy or whose employment income is in excess of requirements for daily living have a significant capacity to use their wealth or additional income to reduce the stress associated with multiple roles by paying for services they do not wish to or cannot provide themselves. This has a linkage to decisions about reducing or terminating employment, with the logical conclusion that those on a high income might be less likely to make such decisions because of the negative financial impact that would have. Again logically, those who are wealthy without paid employment may find it more beneficial to reduce work, depending on other issues discussed later in this chapter. While the current study points to such possibilities, further research would be necessary.

For those who are not wealthy or who do not have additional income, any decisions to reduce employment levels also have financial implications. These caregivers tend to work
unsatisfactory hours and even change their job in order to maintain paid employment (George et al. 2008), as income from a paid job may be crucial for financial security (Couch, Daly & Wolf 1999). Whereas short-term economic disadvantages such as lost wages are visible, the long-term economic impact should not be overlooked. Caregivers are likely to receive little or no superannuation because they are on low incomes (Corti, Laurie & Dex 1994), in part-time jobs (Evandrou & Winter 1992) or on government pensions. This could present a significant problem when it comes to funding caregivers’ own retirement or future care needs.

There is a possibility that those in very low paid employment and with no flexibility in their work activities might find it beneficial to move to caregivers’ pensions with less significant reductions in income and substantially increased time availability for caregiving. This could be an area for further research in the future.

**Career and life aspirations**

Many of the participants in the current study, as well as in other reports (Carmichael et al. 2008; Leiter et al. 2004; Vickers 2005), made considerable career sacrifices as a consequence of the limitations imposed by their caregiving role. This was in the form of changing career trajectory and interrupting career continuity, accepting a position that mismatched an individual’s qualification, skills and knowledge in order to obtain a level of flexibility (as reported by Taskforce on Care Costs 2007), deliberately declining opportunities to be promoted to a higher level position or a higher hierarchy within an organisation, and being hesitant to take up future career endeavours by moving elsewhere (as reported by participants in the current study). Some participants in the current study had direct managers who lacked empathy for their complex life situation. The combination of self-imposed silence in the workplace and frequent absences on caregiving duties produced inferior work performance appraisals. Dealing with family issues in the workplace was unacceptable, and individual working caregivers were expected to replicate their manager’s attitude towards a paid job.
This is a conflict. Many caregivers in the current study expressed a desire to provide equal or similar financial support to all their children when one was disabled. While limiting their career advancement was a consequence of their wish to meet their caregiving responsibilities, it ran counter to their life aspirations for themselves and their families.

### 6.2.2 The context of caregiving

The second set of factors to be considered comprises those related to the context of caregiving. Figure 6.3 summarises the important aspects in three pairs:

- caregiving demands;
- interaction between caregiving and other activities/goals;
- financial pressure.

**Caregiving demands**

There are two facets with regard to caregiving demands. The first relates to the time and energy required for working caregivers to carry out their unpaid caregiving responsibilities and the second relates to their health and emotional well-being after assuming the caregiving role.

Providing assistance to a family member in need, whether it is physical assistance due to the care recipient’s functional limitations or instrumental assistance due to cognitive limitations, requires substantial time and energy. The amount of time and energy needed for the caregiving role is associated with the severity of health impairment of care recipients. The more dependent care recipients are, the more time and energy must be spent on caregiving. As evidenced in the current study, more time and energy are also required for caregiving to multiple care recipients, as well as when a person is a primary rather than a secondary caregiver. Being a primary care provider increases the likelihood that caregivers will miss days from work due to the hours of assistance given (Fredriksen-Goldsen & Scharlach 2006). This, in turn, impacts on working caregivers’ time availability for other daily activities and goals in life (which will be further detailed in later sections).
Figure 6.3: The context of caregiving
The time and energy required to carry out caregiving responsibilities leads to a situation where working caregivers have to make choices and decisions in order to manage multiple roles. These could be:

- changing their employment arrangements and career ambitions;
- making other sacrifices, including giving up personal hobbies and postponing the process of starting a stable personal relationship or a family;
- doing the caregiving role less well by attending less to it.

While there is no significant evidence in the literature or the current study for the third ‘under-performing’ caregiving choice, there are, as noted in the section of ‘work situations’, many examples reported by previous researchers to illustrate the impact of caregiving on employment arrangements due to the caregiver’s need to devote hours and energy to caring. Also stated in the previous section was the fact that nearly all of the participants in the current study preferred to maintain their employment arrangements as far as possible – one of the significant findings from this research. Thus, the scarcity in terms of time and energy can be exacerbated. The consequences of time and energy demands associated with one role restrict the amount of time and energy that can be devoted to other roles (Greenhaus & Beutell 1985).

The second facet of the caregiving demands relates to their effect on working caregivers’ health and emotional well-being. The impact of caregiving demands on working caregivers’ physical health has been reported in the extant literature (Brumett et al. 2006; Scott, Hwang & Rogers 2006; Pavalko & Henderson 2006). These include fatigue and exhaustion, reported by the participants of the current study as a dominant impact on physical health. Unhealthy behaviours, including problem drinking (Grzywacz & Marks 2000) and tobacco use (Ng & Jeffery 2003), are not found in the current study. Other outcomes, such as physical illness and weight change, while discussed by three participants, are less verifiable.

Although the impacts on both physical health and emotional well-being were acknowledged by many participants of the current study, the latter was stated by them as
being greater. Their comments, consistent with the extant literature, confirm that working caregivers constantly experienced higher rates of depression than control populations (Amirkhanyan & Wolf 2003; Edwards et al. 2002; Spector & Tampi 2005), and being a caregiver of a child with a disability significantly increased the levels of stress and depression (Einam & Cuskelly 2002; Ong, Bergeman & Bisconti 2005). Also revealed by the current study is the iterated relationship between working caregivers’ health and emotional well-being and their caregiver role. Several participants were forced to consider the options of placement for their care recipients due to their own health deterioration. Further revealed by the current study is that carrying out multiple responsibilities has an adverse impact, not only on working caregivers, but also on other family members and the family as a whole. Disagreements between partners and tension between children with and without a disability were perceived by some participants as triggers for marriage break-up and/or family breakdown, or the root of a family’s becoming a dysfunctional unit.

There is no shortage of reports from previous research on work–family interface with respect to the direct linkage between the stress level of working caregivers and the role conflict (Allen et al. 2000; Bellavia & Frone 2005; Eby et al. 2005; Frone 2003 Pocock, Skinner & Williams 2008; Skinner & Pocock 2008). Role interference (Noor 2004) has emerged as the principal contributor to emotional strain and stress. However, it is revealed by participants of the current study that, in fact, the caregiving demands, indeed, were the foremost causes linked to the negative emotional well-being – one of the contributions that the current study made to the knowledge in the research field of work family interface by adding different dimension to the existing literature.

Further exploring the caregiving demands, the current study supports such a view that the severity of the illness of the care recipient is positively associated with the level of the caregiver’s stress (Fredriksen-Goldsen & Scharlach 2006). Parents who care for children with a disability experience greater emotional and psychological distress than parents of healthy children (Isaacs & Sewell 2003), and the stressors involved in caring for a child with a disability are exacerbated for those parents who are also working (Einam & Cuskelly 2002), probably due to the longevity of caring for a child with a disability. Nevertheless, in
the current study there were also nominally secondary caregivers who experienced high level of stress from providing more caregiving than the nominal primary caregivers, or from the uncertainty allied to the time and financial support needed in a long-distance caregiving responsibility. This raises a question about both the definitions used in the literature and the relative stress impact, which calls for further research in the future.

Further, and worthy of particular note, is that the most confronting challenges, or, in other words, the primary causes of emotional stress disclosed by participants of the current study, are issues related to the broader concept of caregiving demands. These include the prevailing stereotype attached to a person with a disability and their family, the real and perceived discrimination and ‘unfair’ treatment by society, the difficulty associated with seeking help from professionals (for example, obtaining a proper diagnosis), the pervasive feeling of social isolation and the long-term financial pressure. These findings are beyond the span of stressors commonly reported by previous research, such as the resentment towards the care recipient (Williamson et al. 2005), the feeling of guilt attached to the placement (Ryan & Scullion 2000), and locating appropriate and affordable child care (George et al. 2008).

Variations with respect to the origins of the emotional impact on caregivers suggest that caregivers to different care recipients and at different stages of caregiving may face unique sets of challenges. Caregiving is context-specific; therefore, experiences are unique. Hence, caregiving should be viewed as a dynamic process, and the knowledge and acceptance of difference is of primary importance. While caregiving demands, such as the time devoted to the caregiving role, the assistance provided and the number of care recipients being cared for, influence the ways of managing multiple roles, the caregivers’ emotional well-being is impacted, to a great extent, by the context of caregiving. In other words, the totality of caregiving demands rather than a narrow concept of caregiving demand is of most importance when considering the adverse impacts of caregiving on the emotional well-being of caregivers.

**Interaction between caregiving and other activities/goals**
The relationship between caregiving and other activities and goals in life has two aspects. One is the extent to which the caregiving responsibility restrains the ability of caregivers to carry out other activities in their daily lives. The second is focused more on the extent to which working caregivers are forced to reassess their life goals due to their caregiving responsibilities.

Time and energy constraints resulting from fulfilling seemingly endless caregiving duties combined with accumulated fatigue could lead to various consequences. Caregivers could devote less time to interaction with other family members. They could also spend little or no time on personal interests and hobbies or attending other social events. Some caregivers could even sacrifice the time they should dedicate to their own health, including the time for exercise or for their own doctors’ appointments. As argued by Roxburgh (2004), as well as illustrated by several participants of the current study, deficits in time and energy can be blamed for the incredibly boring and mundane life people experience after taking up the caregiving role. The daily lives of many working caregivers in the current study, after fulfilling their work and caregiving responsibilities, revolve around catching up with accumulated domestic chores and securing much-needed sleep. The consequential pervasive feeling of being socially unacceptable was shared by the majority of participants in the current study, as well as the care recipients, as revealed by participants. The feeling was compounded when friends of caregivers deliberately kept a distance from them and their families. Caregivers perceived that the exclusion was due to perceptions of ‘abnormality’, such as the impaired intellectual and social skills of care recipients. In other words, the exclusion was perceived, to some extent, to be the result of discrimination existing within the wider society.

In addition to the interference caregiving on working caregivers’ daily lives, the extent to which this role impedes the life goals and plans of working caregivers cannot be ignored. The challenging life of combining paid employment and unpaid caregiving, especially the uncertainty in terms of the duration and intensity of the caregiving role, leads not only to adjustments to day-to-day lives, but also to reassessment and amendments to life at a general level. Suspending and postponing the process of embarking on a stable relationship.
and establishing a family, and deferring a plan for retirement, are examples that show the impact of being a working caregiver.

**Financial matters**

The financial status of working caregivers is relevant and dynamic, and is determined by such factors as working caregivers’ employment income and wealth level, household income, and expenses required for daily living, including the costs of caregiving. The financial status of working caregivers – in other words, the balance between earning and expenditure – has, in turn, an impact on the strategies that they employ to manage their financial situation. The effects of the financial status on decisions about paid employment – that is, the relationship between financial status and income from employment – have been detailed in the section of ‘work situations’. Here the focus will be on another element, namely, the financial pressure related to caregiving, an issue often considered to be a significant problem for many families.

The ongoing costs of caregiving can be considered from two aspects: the short-term caregiving-related expenditures and the long-term caregiving-related financial concerns. The former usually refers to expenditure on medical equipment and supplies, co-payments, pharmaceuticals, home modifications, food and household groceries to cater for the special needs of care recipients, transportation costs, and additional and frequent dining out. The long-term caregiving-related financial concerns could be seen among caregivers to children with a disability, and derive mainly from caregivers’ long-term financial commitment to their disabled children.

While many participants in the current study, as well as in other reports (Evercare & National Alliance for Caregiving 2007), did experience the short-term costs of caregiving mentioned above, the majority of them, with one exception, were not struggling with their financial situation. Only one participant emphasised short-term financial pressures at the time of interview, as the family faced costs equivalent to private school tuition fees in order to keep their child with a disability in a mainstream school. One of the explanations provided by several participants was that their care recipients had a fairly healthy financial
status. This might also be due to the fact that working caregivers in the current study did not spend money in the areas commonly reported in previous research, such as on respite, counselling, care management and assisted living facilities (Evercare & National Alliance for Caregiving 2007). The insignificant short-term financial impact could be further explained by the reality that working caregivers spent very little on recreation and other social events.

Working caregivers face long-term financial concerns. Those who care for disabled children who are unemployable have to plan for their financial future. Many are concerned to give equal support to their other able children, and this carries a further burden. There are, in addition, the caregivers’ concerns to establish a solid financial base for their own future. All of these, evident in the current study, are in conflict with the costs of caregiving and the impacts on work and career of giving time and energy to caregiving. The long-term financial concerns could be the cause not only of the conflict between career advancement and life aspirations, as noted earlier, but also of the adverse impact on working caregivers’ emotional well-being. This finding from the current study has implications to how society could offer help to children with a disability. This could, eventually, reduce the burden imposed by combining paid employment and unpaid.

6.2.3 Family, work and community support

The last set of factors relates to the existence of a supportive network, which has been stated as one of the most significant ways of coping with caregiving activities (Kramer & Kipnis 1995; Parks & Pilisuk 1991). The most important aspects of supportive networks are summarised in figure 6.4 – will be detailed under three categories:

- family dynamic and familial support;
- support at the workplace;
- services and support in the wider community.
Figure 6.4: Family, work and community support
**Family dynamic and familial support**

The terms family dynamic and familial support, sometimes are referred to as support from informal sources (Chun-Chung Chow et al. 2010), and are fairly self-explanatory. The healthier the relationships among family members are, the better working caregivers cope with the challenging tasks. In a similar vein, multiple responsibilities are more manageable if the demands from caregiving can be shared by immediate family members or other relatives. In other words, the pressure and stress associated with the caregiving role can be alleviated by the presence of more than one informal caregiver. Also noted is the inverse association between the availability of familial support and the use of formal support in the wider community, which will be detailed in a later section.

The relationship between perceptions of experience of being a working caregiver and the family dynamic is evident in the current study. Caregivers who perceived themselves as having a healthy relationship with their care recipients and other family members were able to embrace and have a natural and bonded reaction to the complicated life circumstance, and consequently maintain a subtle balance between work and caregiving. However, the tension or incongruity between family members, whether between working caregivers and their immediate or their extended family members, has been revealed as having a considerable adverse impact on the emotional well-being of working caregivers.

Also of importance to the ability of working caregivers to cope with their demanding life is the support of other family members. However, the level of familial support is, to some extent, out of the working caregiver’s control, and could also be a reflection of cultural preferences (Clark & Huttlinger 1998). Many of the participants in the current study carried out multiple roles with little or no support from their adult children and extended family members. The almost non-existent support from other family members could be due to either the working caregiver being the only child in the family and there being a lack of connection with the in-law family, or other family members being unwilling or unavailable to offer assistance to care recipients. Cultural belief systems may influence the availability of familial support, as reported by Wallace and Lew-Ting (1992), who assert that Latino cultural values regarding the centrality of family create an expectation that extended family...
members will assist with the care of older relatives. Similar situation can be seen in families from Asian backgrounds (Sung 1998).

It should be noted that the perceptions of the impact of family dynamics on working caregivers’ ability to manage multiple roles and their emotional well-being was illustrated solely by working caregivers. The perceptions from care recipients would provide a more holistic view. This will be covered in the section – signposts for future research.

**Workplace support**

Along with familial support, receiving support in the workplace is the key for working caregivers to cope with multiple responsibilities and to manage the work–life balance. Support at the workplace includes informal social support and/or understanding from colleagues and supervisors, as well as formal policies and programs implemented within an organisation. Employers’ attitudes towards work–life balance and their perceptions of the benefits of implementing flexible working practices are essential in helping working caregivers carry out their multiple roles.

Whether or not people in the workplace know that someone has a caregiving role depends on the caregiver’s intention to disclose their status. Co-workers’ responses to a person who has a caregiving role could be supportive and helpful or they may treat their caregiver colleagues differently. It is quite obvious that colleagues can neither help nor harm under the circumstance of concealment. An in-between state is when only key managers know, and they may either facilitate multiple roles or be unsympathetic and demanding. How this pans out in any one case depends on decisions taken by the working caregiver, and there are positive and negative examples of various choices presented in the literature and the current study.

The level of understanding from an individual’s manager or supervisor and support from one’s co-workers has been found to be associated with lower levels of conflict and stress in meeting multiple family and work responsibilities. This finding was reported by Karasek (1989), Fredriksen and Scharlach (1997), and Skinner and Pocock (2010), as well as by
several participants in the current study. In some cases in the current study, a trust
relationship between supportive supervisors and participants allowed working caregivers to
get permission from time to time to vary work activities in the context of caregiving
demands. The time missed from work was not even considered as time lost. In contrast, it
was commented by two participants that the demands placed on them as a result of their
caregiving role were often or sometimes not well understood by their work colleagues.
Thus, the majority of participants in this research had great reservation about telling their
work acquaintances about the details of their situation, and mentioned their policy of not
divulging their caregiving status (referred to earlier in the thesis as ‘self-imposed silence’).
The reasons they gave related to a need to feel ‘normal’ while at work and their wish to
prevent their colleagues from treating them as someone different from themselves.

While the ‘self-imposed silence’ can be seen as a means of obtaining informal flexibility in
the workplace, there are other consequences attached to this phenomenon. Not revealing
caregiving status makes accessing workplace formal support difficult. So these choices and
decisions form a complex and potentially dynamic matrix of interdependent aspects. There
are many ways to address this issue but no single way is without complication or side-
effects. ‘Family friendly’ policies are often advanced as helpful in alleviating caregiving
strain and stress (Scharlach, Sobel & Roberts 1991; Singleton 2000; Skinner & Pocock
(2011). Greater workplace flexibility, including working more flexible hours and working
from home, was considered by Taskforce on Care Costs as one of the priority strategies in
their report in 2007. Providing employee-centred flexibility was identified as one of the
seven factors that can help to improve work–life interaction (Skinner & Pocock 2010).
Taken in the context of the interview as a whole, one of the dominant themes across
interviews of the current study is the revelation that informal flexibility in the workplace
plays a pivotal role in fulfilling multiple responsibilities. However, the offshoot of this
informal flexibility is that the working caregivers, almost without exception, were unaware
of the existence of formal policies and programs in the workplace.

Services and support in the wider community
The decision pertaining to the use of community services and support is influenced by such factors as the working caregivers’ financial situation, the costs of the services, accessibility and quality of services, and whether or not caregivers receive support from informal sources. Working caregivers’ differential utilisation of the various types of services is further associated with caregiving demands, working caregivers’ health and emotional well-being and possible cultural preferences (Chun-Chung Chow et al. 2010).

The relationship between the working caregivers’ financial status, including income and wealth level, and the decision on employment arrangements has been discussed in earlier sections. Financial status has also been linked to working caregivers’ ability to use services and support. Any given support comes with some financial cost. Whether it is cheaper for a person to do the caring themselves by reducing the hours of employment depends on the person’s income. For someone who is lowly paid it might be so; for someone with a high income, continuing to work at the same level and paying for services may be more productive. Further, doing it yourself requires time and energy (discussed in the previous section), and whether or not to outsource activities is related to the caregiver’s level of comfort with their capacity to manage by themselves. As reported by Taskforce on Care Costs (2007), a quarter of carers were forced to reduce their hours of work as the cost of services was too high and financial support from the government was insufficient.

Seeking and utilising support and services is further related to the difficulty that working caregivers faced in understanding how to access information and assistance. The task of knowing what assistance might be available appeared to have been made particularly complex by various divisions and agencies (Taskforce on Care Costs 2007), which to some extent explains the underutilisation of services and support. Compounded by the reality of limited time and energy, obtaining information and accessing services becomes even more difficult. Indeed, this was one of the main reasons revealed by most participants in the current study for not using services.

With the limited support from informal sources (family members and friends), it could be envisaged that working caregivers in this research were likely to seek and use formal
community-based care support for their multiple responsibilities. Surprisingly only one person (out of 17) actively sought support. The vast majority of participants reported that they had no intention of sharing their stories and experiences with other people, of obtaining supportive information and exploiting the services that were available. The relationship between the use of formal support and informal support has been reported by previous research. For example, a lack of informal support is positively linked to the use of formal support (Strain & Blandford 2002), and the availability of informal support decreases the likelihood of using formal support (Kosloski, Montgomery & Youngbauer 2001; Strain & Blandford 2002). However, this was not evident in the current study.

Working caregivers in the current study believed that the daily challenges of their lives were difficult to understand for those who were not afflicted. The desire to keep the caregiving matter private, in other words, retaining the care recipient’s integrity, and a lack of faith in public services, were also associated with the limited enthusiasm in accessing formal support for the majority of participants of the current study. The reported advantages of being in a supportive network, including making new friends, having others to chat with on a regular basis, identifying with others in a similar situation and normalising the caregiving process (Koeske, Kirk & Koeske 1993; Latack, Kinicki & Prussia 1995; Wanberg 1997) were not seen by the participants in the current study.

While recognising and acknowledging the challenges of combining the roles of paid employee and unpaid caregiver, many participants in the current study did not show feelings of self-doubt or worthlessness, and were determined not to allow grief and depression to become a central focus of their lives; rather, they chose to embrace their complicated life circumstances. Working caregivers were, to some extent, content with their ability to maintain the subtle balance between work and caregiving. Multiple roles were deemed as manageable by participants of the current study. These findings suggest that the perception on whether or not multiple roles are manageable might be crucial in terms of exploring the sources of support, and have implications for changes to assist working caregivers to manage their multiple responsibilities.
Another aspect of services and support in the wider community is related to the types of service and support working caregivers choose to use. The decision by working caregivers to choose different types of services and support is influenced by the demands of caregiving and by their own health and emotional well-being. It has been reported that caregivers who provide ADLs are found to be significantly more likely to use respite service (Toseland et al. 2002; Kosloski, Montgomery & Youngbauer 2001), a service designed to ease the physical and temporal demands of caregiving (Dal Santo et al. 2007). Counselling services, in contrast, have been reported to be accessed more by caregivers who experience high levels of emotional distress, for example, as a result of caring for a person with behavioural problems (Toseland et al. 2002).

Findings from the current study suggest that in addition to the conventional approaches (for example, seeking formal support), caregivers explore other pathways to cope with their demanding and complicated lives and to fulfil multiple responsibilities, including both constructive and passive approaches. Getting involved in research on respective diseases and advocating rights for care recipients and caregivers are other strategies employed by participants in the current study to cope with the demanding lives. Several working caregivers relied on antidepressants – a survival orientation to take them through their daily lives. The use of antidepressants medicine, whether prescribed by the doctor or requested by the patient, helped working caregivers to relieve the stress and pressure associated with the combination of work and caregiving. These findings also highlight the importance of understanding that individuals differ in their preferred strategies for coping with the strains associated with the performance of multiple roles (Jex et al. 2001). One of the main explanations for the discrepancy between the findings of the current study and reports from previous research is the reality that most previous studies conducted surveys among people who had been using or interested in accessing formal services.

6.3 Summary

This chapter presented the factors that impact on perceptions of the experience of managing multiple roles as a working caregiver. The dissemination has been strengthened by encompassing the current study and other studies reported in the literature, and by
exploring the full potential meaning of the phenomenon through reflective phenomenological way. In addition to demonstrate the factors impacting on the phenomenon being explored, the figures highlight aspects that need further research.

The conclusions and discussion provided in this chapter has implications with regard to areas of improvement to enable better outcomes for working caregivers and employers, as well as exploration for future research. This leads to the presentation of next chapter, which is comprised of the contributions of the current study, the implication and recommendations that are pertinent to employing organisations about how to help working caregivers alleviate the burden of multiple responsibilities and raising opportunities for future research.
CHAPTER 7 – IMPLICATIONS AND RECOMMENDATIONS

7.1 Introduction

The provision of the conclusions and discussion from the previous chapter set the foundation for the production of this chapter. This chapter begins with the summary of the contributions of the current study, followed by the implications and recommendations from the doctoral research. While noting the boundaries of the current research, the final chapter also provides suggestions for future research.

7.2 Contributions of the Current Study

The contributions of the current study to the body of research and knowledge in relation to informal caregiving and paid employment, multiple roles, the interface between work and family domains or the interaction between work and life, role interference and work–family or work–life conflict, role enhancement and work–family or work–life enrichment have been discussed and addressed throughout this chapter. They can be summarised as follows.

First, most previous studies focused mainly on activities of daily living and/or instrumental activities of daily living when assessing the caregiving demands, and emphasised the difference between primary and secondary caregivers. This research provides a more complete picture of the caregiving context and argues that the concept of caregiving demand should expand to include other aspects of caregiving, such as the process of seeking help from professionals (for example, obtaining a proper diagnosis), as it is strongly linked to working caregivers’ emotional well-being. The revelation of the totality of work and caregiving demands, especially the caregiving demands rather than the widely reported work–family or work–life interference, as the main determinant of negative emotional impact, offers insight on how the government and the wider community could offer help to alleviate the difficulties working caregivers encounter. The finding of less than apparent difference between nominally primary and secondary caregivers (including long-distance caregiving responsibility) with regard to the level of stress experienced raises the question about both the definitions used in the literature and the relative stress impact. It
also has implications for organisational practice and caregivers’ entitlement, and warrants further research.

Second, reports from previous research on preference of work arrangements due to time strain, whether for the general working population or working caregivers, are similar – reduce work hours or exit from the workforce even taking into account the effect on income. The significant finding that none of the participants in the current study reduced or terminated their paid employment complements the extant literature. This finding not only provides an explanation for the phenomenon of prolonged self-imposed silence, but also discloses that long-term financial concerns rather than short-term caregiving-related expenditure is the key contributor to the adverse effect on emotional well-being, and the creation of conflict between life aspiration and career advancement. It further highlights the importance of developing and implementing employee-centred multifaceted policies and programs that could be tailored to an individual’s needs.

Third, the current study suggests that there are other mechanisms through which demanding life can be managed and strain can be reduced, including both constructive and passive approaches. This finding underlines the primary importance of the knowledge and acceptance of individual’s differences and preferences. In addition, the finding of the iterated relationship between working caregivers’ health and emotional well-being and their caregiving role implies that support from the government, employers and society is imperative despite the fact that multiple roles are manageable at certain stages of their life.

Fourth, this research shows that flexibility in the workplace is crucial in managing multiple roles, especially under the circumstance of receiving limited support from family members and minimal use of public services. However, flexibility was ‘granted’ as a result of concealment of working caregiver status or long tenure with the organisations. This finding provides an extra piece of evidence to support the recommendation that the enactment of ‘right to request’ flexible working arrangements should extend to employees who are caring for older Australians and those caring for a person with a serious long-term illness or disability.
7.3 Implications and Recommendations of the Current Study

With the main objective of providing a comprehensive understanding of the perceptions of the experiences of being a working caregiver, this research employed the case study methodological approach using primarily a semi-structured, face-to-face interviewing method for data collection. This approach provided an opportunity for participants to describe and share their stories in their own words. Thus, attention is paid in this research to an individual’s perceptions and insights. In addition, in achieving the main objective, this research studies a group of people with diverse caregiving responsibilities rather than focusing on caregivers who provide care to people within a specific group, such as the frail elderly (Beitman et al. 2004), individuals with dementia (Savundranayagam & Montgomery 2010), or the specifics of the illness or disability of the person for which care was provided. The perceptions of the experience of 17 people who were in paid employment at the time of interview while simultaneously acting as informal caregivers to family members with a disability, chronic health problems, a terminal illness, or a frail elderly person are examined.

The findings from this research contribute to the body of research and knowledge in relation to multiple roles, informal caregiving and paid employment, interface between work and family domains, role interference and work–family conflict, role enhancement and work–family enrichment, as detailed in the conclusion and discussion section above, and also have implications for employers, policy-makers within organisations, health professionals and society. The researcher of the current study understands that the development of policy cannot rely upon one single study because of concerns with regard to its generalisability. However, the findings from this research shed some light on how the issues of combining paid employment and unpaid caregiving might be addressed.

The revelation that multiple roles are manageable largely by means of exploiting informally granted flexibility, due to the participants’ long tenure with the organisations and concealment of the caregiving status, is important given the widely accepted notions that caregivers usually have weak attachment with the labour market and are often employed as
part-time or casual employees (Henz 2004). Thus, caregivers in general would probably not have the luxury of informal flexibility that the group in this research enjoyed. The emerged theme of enduring self-imposed silence in the workplace may provide the benefit of allowing most participants to be more in control with regard the time and location for work. The downside of this phenomenon is the participants’ lack of awareness of the possible existence of policies and programs that are designed to help working caregivers to manage multiple responsibilities, as well as the possibility of obtaining support from colleagues and friends. Choosing not to divulge the caregiving status could probably also link to the stigma attached to caregivers, as participants of the current study expressed their wish to avoid undesirable attributes, such as being viewed as an unreliable employee.

The reality that the majority of participants of this research were exceptionally keen to maintain their full-time employment status for as long as possible rather than seeking alternative work arrangements further highlights the significance of having in place policies that aim to assist and meet individuals’ needs and, more importantly, encouraging the use of formal workplace programs or initiatives. Thus, both employers and employees can benefit from greater job satisfaction and organisational commitment (Anderson, Coffey & Byerly 2002; Wayne, Randel & Stevens 2006).

Employers should, first, realise their imperative role in establishing an encouraging and friendly environment, in other words, a family-support culture within an organisation that allows employees to freely disclose their caregiving status. Also of importance is the recognition of the importance of providing education to the colleagues of persons who are in caregiving roles. Employers should put effort in making information about programs and initiatives more transparent and more accessible to working caregivers.

Second, once they have succeeded in encouraging employees to reveal their issues and difficulties, employers, when designing and implementing interventions, should aim to enhance potentially rewarding aspects of work and caregiving activities. These include mutual role enhancement and opportunities for individualised adaptive strategies, especially taking into consideration the totality of responsibilities, for example, the tremendous
responsibilities of caring for more than one family member with special needs, in addition to mainstream parenting, as it is a common scenario, at least for the group of working caregivers in the current study. Programs and initiatives should aim to achieve creative solutions (for example, crisis leave) to accommodate the needs of working caregivers. It is likely that programs that fail to consider the potential rewards of caregiving, and that are potentially incompatible with the preferences and needs of working caregivers, may result in an outcome of low utilisation (Scharlach, Sobel, & Roberts 1991).

Employers could also be more constructive when designing and implementing employee assistance programs and initiatives by linking those programs to support services and groups in the community. Thus, employers could provide counselling and facilitate the process of gaining social support from society to prevent caregivers from falling out of the loop due to a lack of communication within social services and across agencies. Working caregivers could be referred to someone who may be knowledgeable about available services or encourage the use of services in the community. Informal caregiving, per se, is a complex, evolutionary and intersubjective life experience. Managing the roles of paid employee and unpaid informal caregiver is even more challenging.

Nonetheless, employers should take a holistic approach when devising and inventing programs, and have some concern for other employees, given that teamwork has become a trend in contemporary organisations. Desired programs and initiatives should also include plans for staff education and management, with the aim of raising awareness of the difficulties that working caregivers encounter and the support that colleagues could offer. An individual’s management of the interface between work and family to meet their own needs and preferences may affect other members in the work domain (the supervisor, peers and subordinates) and the family domain (the partner, children and extended family members). Well-designed programs should endeavour not only to enable one team member to respond to family needs, decrease their perceived stress, burden, anxiety and somatic complaints, and lead to greater work–family enrichment but also to improve morale and teamwork spirit.
The frustration associated with obtaining a formal diagnosis for a child with a disability was deemed as an overwhelming type of caregiving ‘demand’ for several participants, in addition to the uniformly accepted demands imposed by the caregiving role, such as providing assistance to someone with activities of daily living and instrumental activities of daily living. This is also one of the main causes, along with concerns about ‘unfair’ or ‘discriminative’ care recipients are treated by society and other institution, such as school, for the negative impact on working caregivers’ emotional well-being. These findings indicate the importance of creating an inclusive and harmonious community. Schools, especially mainstream schools, should focus on educating staff and students on the needs of a child with a disability. Thus, prejudice and mistreatment of a child with a disability can be overcome through empathy and awareness. Special programs in mainstream schools and within the community should be designed with long-term objectives to enhance the independence and employability of a child with a disability. Furthermore, doctors and other experts could offer support to both care recipients and caregivers, especially in terms of providing updated knowledge and rationalised explanation, as well as a professional diagnosis, in order to minimise the trepidation that many working caregivers in the current study had experienced.

The key to encouraging the use of support and services remains in the affordability, accessibility, and quality of service provided given the reality that working caregivers are usually in the lowest income quintiles of income ranges (Taskforce on Care Costs 2007), experience deficits in time and energy, and lack trust in public services. While getting people into a supportive network earlier rather than later is important in order to avoid some of the crisis points, the improvement in the areas mentioned above is essential.

7.4 Signposts for Future Research

A number of interesting avenues for future research arise from the study presented in this dissertation. These areas deserve further investigation as unresolved issues in relation to combining the roles of paid employment and unpaid caregiving are likely to become even more prevalent in the future as a result of greater life expectancy and the increasing number of people being diagnosed with a disability.
This research has found that perceptions of the experience of being a working caregiver are influenced by factors within both the work and family domains. Work and family are the two principal domains within which all participants live and work. It is a dynamic environment which requires constant assessment in relation to the work–family linkage. Thus, in order to gain a better understanding of this linkage, it would be ideal to collect and analyse multiple data collected at different stages of caregiving, career and family situation, using different methods (Bianchi & Milkie 2010); thereby, other aspects of perceptions, especially changes over time, can be explored. For example, the foremost trepidation for working caregivers to a child with a disability might be the shift from caring to the worry of who will replace them and take over the caregiving responsibility when they themselves are getting older. The dilemma working caregivers to a frail elderly person face could be the decision between continuing the enduring caregiving responsibility and choosing a venue for the care recipient’s placement. It would be informative to interview the same group of people several years later to find out whether working caregivers face a different set of challenges, and employ coordinating strategies.

Scarcity in time and energy and the resulting feeling of social isolation, and the phenomenon of self-imposed silence in the workplace, are two of the main themes. Despite the fact that self-imposed silence has been used as a coping strategy to fulfil responsibilities, further study is warranted on the issues of whether or not the decrease in social interaction and the reluctance to disclose private life are causes of negative impact on working caregivers’ emotional well-being. It would also be interesting to know whether involvement in voluntary activities is a way of alleviating the isolation experienced. While self-imposed silence in the workplace may bring temporary benefits to working caregivers, it would be interesting to find out whether the advantage of ‘keeping it to myself’ outweighs the benefit working caregivers might have gained from getting the support they needed. Studying and comparing the experiences of being a working caregiver among two groups, one with and one without support would offer more insights.
Research in relation to the impact of combining employment and caregiving often focuses on caregivers themselves. A study that attempts to have care recipients interviewed would enable a more holistic understanding of the phenomenon of being a working caregiver. The perceptions of care recipients, in particular their views on the relationship they have with their caregivers, will add a further dimension to the understanding among researchers and the general population of the challenges working caregivers face, as well as the support they need to cope with their demanding lives.

While the participants in this research had diverse caregiving responsibilities, all except two were in full-time employment and had long tenure with their companies. Thus, the consequent informally granted flexibility was the key to the theme ‘multiple roles are manageable’. The informal flexibility also partially explained the reasons most participants in this study were not keen to seek support and assistance for their multiple roles. People in part-time or casual employment may not be granted such flexibility as there are no leave entitlements and there may be no ability to choose the time of work. A study that explores the difference between full-time and part-time working caregivers, long and short tenure with organisations and other employment condition variables, in terms of their desire to search for and utilise support services would be useful.

The current study design did not focus on or allow gender or age comparisons. A study centred around a gender-balanced and wide age span sample would allow researchers to examine these areas, that is, whether female and male working caregivers encounter different sets of challenges and have unique needs for support in order to cope with the demanding life, or the variation in perceptions and complexity of being a working caregiver among people in various age groups. Furthermore, a lack of awareness of the existence of formal programs and initiatives within an organisation, which is one of the main themes of the current study, is not equivalent to the non-existence of such programs. Thus, it is worthwhile for future researchers to allocate time with both participants and organisations to explore working caregivers’ eagerness to use support programs and the frequency of their use, whether these programs are offered by government or employers. Along with a holistic understanding of the needs of an individual, researchers will be able to provide
constructive suggestions and recommendations to employers or the government with regard to the design and implementation of programs that tailor to individuals’ needs and aim to help working caregivers for their multiple responsibilities.

7.5 Summary

This dissertation provides a close examination of perceptions of the experience of being an informal caregiver to one or more family members while simultaneously holding a paid job by studying a group of people with diverse caregiving responsibilities and a full-time paid job (15 out of 17 participants were full-time employee at the time of interview). The current study also explores strategies that working caregivers employed to manage the roles of paid employment and unpaid caregiving. This research further investigates the impact of having one or more family members with special needs on working caregivers and their families.

A case study methodological approach using semi-structured, face-to-face interviewing as a primary method of data collection was employed for this research. Outcomes from the fieldwork are presented through nine data-rich case studies in chapter 4, themes that emerged from both the nine cases and other interviews are presented in chapter 5. Meta-analysis guided by phenomenography in chapter 6 strengthens the dissertation by exploring the full potential meaning of perception of the experience of being a working caregiver through a reflective way. The contributions, implications and recommendations from the doctoral research, and the direction and venues for future research are highlighted in chapter 7.

The findings from this study demonstrate that there are various interpretations and perceptions with regard to the experience of being a working caregiver, the preferred coping strategies and the importance of having a supportive network. These have implications for employers, other professionals such as doctors and educators, and the community at large.
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APPENDICES

Appendix 3.1 – Information Statement

INFORMATION STATEMENT

Balancing the Roles of Paid Employment and Unpaid Caregiving

Joyce Jiang is a PhD candidate at Swinburne University of Technology carrying out research which is funded by Australian Research Council and supported by a number of industry partners: RACV, Qantas, Australian Catholic University and Laminex. Other industry partners include the national rehabilitation body, CRS Australia and the South Australia and Queensland OHS authorities. Her research is about people who are both in paid employment and who are carers. For a variety of reasons, more and more people combine roles of caregiving and paid work.

This research is an additional component to the “Redesigning Work for an Ageing Society” project. While the central aim of the project is to identify and respond to challenges to the health and well-being of workers as they age and to develop an Australian framework and guidance materials for the promotion of work ability, the main objective of this part of the research is to better understand the experiences of employed carers, and their perceptions of family-work balance. In conjunction with the project, the findings from the PhD study will throw some light on how issues arising from combining roles of caregiving and paid work can be tackled more effectively. It will assist government and others to design more appropriate support.

Information for this study will be collected by Joyce through face-to-face interviews with carers. The interview will last about 45 minutes to an hour and will likely be conducted outside of the participant’s work hours and at a location convenient to participant. Involvement in this study is entirely voluntary. The participant may refuse to participate or withdraw at any time by informing Joyce.

All information provided during the interviews will be kept confidential and only used by Joyce Jiang under the supervision of Professor Pam Green. This information will be stored for five years in accordance with the University rules. It will be used as part of preparing the dissertation for Joyce Jiang’s PhD and the report for the “Redesigning Work for an Ageing Society” project. But, at all stages, information will be aggregated and de-identified. This means anyone reading the final document will not be able to identify the individual participant. Participants’ confidentiality and privacy will be maintained throughout the entire study. Access to any identifying and coding information will be limited to the PhD student and the academic supervisors.

This research study will be published as a PhD dissertation as part of ARC funded project “Redesigning Work for an Ageing Society” conducted by the research team at Business, Work and Ageing Centre for Research at Swinburne University of Technology. Any
questions that have not been adequately answered by Joyce Jiang can be directed to Professor Pam Green at 03 9214 5224, or email her at pamgreen@swin.edu.au

If you have any concerns or complaints about the conduct of this project you can contact:
Research Ethics Officer, Office of Research & Graduate Studies
H68, Swinburne University of Technology
P O Box 218, HAWTHORN VIC 3122

Tel (03) 9214 5218 (or +61 3 9214 5218)  
or email to resethics@swin.edu.au
Appendix 3.2 – Study Flyer

Carers Wanted for Research Study

Caregiving can be both a challenging and a rewarding experience. Demands from roles such as work and caregiving can make it difficult to do your job well and sustain your physical and emotional health and well-being. In recent times, more people than ever before are combining caring and working responsibilities. A research study is underway to explore the experiences of employed carers. It aims to identify the support that carers need to help them cope with potentially competing demands.

You are invited to participate in a PhD research project entitled “Balancing the Roles of Paid Employment and Unpaid Caregiving”, which is funded by the Australian Research Council.

Inclusion Criteria:
- Employed by the Australian Catholic University/Laminex (e.g. full-time, part-time, causal, permanent/fixed term contract).
- A major carer for a family member or an adult dependent (this means providing informal assistance, in terms of help or supervision, to a person with a disability or long-term health problem, or a person who is elderly) for at least six months, either in the same or in different household.

Length of Participation Session:
- The participation session will last between 45 minutes and one hour.

Share your story and help increase understanding of employed carers’ experiences. To show our appreciation of the time you spend on this study, you will be rewarded with a $20 voucher at the end of interview.

If you are interested in participating in this research study, or you would like further information about participation, please contact:
Joyce Jiang
Telephone: (03) 9214 4693
Mobile: 0418 168 989
Facsimile: (03) 9214 5040
Email: jjiang@swin.edu.au

Thank you for your time and interest
Appendix 3.3 – Participant Recruitment Letter

PARTICIPANT RECRUITMENT LETTER

Balancing the Roles of Paid Employment and Unpaid Caregiving

Date: ____________

Dear Sir/Madam

You are invited to take part in a study of carers, which is a part of the Redesigning Work for an Ageing Society project. The research will look at how people carry out both caring and work roles. It is funded by the Australian Research Council and supported by a number of industry partners. The following are answers to some questions that people frequently ask (FAQs) about this research

FAQ Why is this study needed?

The study has two objectives. The first is to better understand the experiences of employed carers. The second is to find out what information and support would make caring easier.

FAQ Why should I take part?

Your contributions could help community organizations and government to do their job better. Information you provide will also help to increase knowledge in the areas of work-family conflict and work-life balance.

FAQ What will I have to do and how long will this study take?

You will be contacted or asked to contact me, Joyce Jiang, to arrange a meeting for a semi-structured interview. The interview will likely take place outside your work hours, at a place and time convenient to you, and will take approximately 45 minutes to an hour. During the interview, you will be asked questions about what it is like caring for a family member(s) with chronic disease(s), a frail elderly relative, or a child with disability, while you are working full-time or part-time.

FAQ Can the researcher guarantee my privacy?

Everything you tell the researcher will be held in the strictest confidence. All information will be stored securely to prevent unauthorized access. Information you provide will not be disclosed to third party including your organization by any means. Any information that could identify you in the data will be removed, and you will not be identifiable in any report and publication. Your privacy and confidentiality will always be strictly maintained.
If you are interested in taking part in the study, or you would like further information, please contact Joyce at (03) 9214 4693 or 0418 168 989. Or email her at jjiang@swin.edu.au.

Your participation is needed to make sure this study represents the views of as many employed caregivers as possible.

In order to thank you for taking part I would like to give you a $20 supermarket voucher. You will receive this at the end of our interview.

Thank you for reading this letter. I hope you will be able to take part in the study.

Joyce Jiang
PhD Candidate and Researcher (ARC Grant Project)
Business Work & Ageing Centre for Research
Swinburne University of Technology

Telephone: (03) 9214 4693
Mobile: 0418 168 989
Facsimile: (03) 9214 5040
Email: jjiang@swin.edu.au
Appendix 3.4 – Informed Consent Agreement for Participation in Research

INFORMED CONSENT TO PARTICIPATE IN RESEARCH
Swinburne University of Technology
Business, Work & Ageing Centre for Research

Balancing the Roles of Paid Employment and Unpaid Caregiving

I agree to participate in Joyce Jiang’s PhD research, ‘Balancing the Roles of Paid Employment and Unpaid Intensive Caregiving’. I understand that my participation is voluntary and that I may refuse to participate or withdraw at any time without consequence.

My signature below indicates that I have read and understood the information provided and any questions I have asked have been answered to my satisfaction.

I hereby give my consent to participate in this study and for what I say to be recorded on the condition that it will only be used in conjunction with this study to enhance the accuracy of the information obtained. I understand that this materials will be treated as confidential, being used solely for the purpose of the PhD study.

I agree that information collected during my discussion with Joyce will be used in the preparation of her PhD dissertation on the condition that my anonymity is preserved.

Name of Participant: __________________________________________
(Please Print)

Participant Signature: _________________________________________

Date: _________________________________________________________

Researcher Signature: _________________________________________

Date: _________________________________________________________
Appendix 3.5 – Semi-structured Interview Schedule

SEMI-STRUCTURED INTERVIEW QUESTIONS

Balancing the Roles of Paid Employment and Unpaid Caregiving

Current work

- What’s your current employment arrangement? How many hours, on average, do you work per week on your current job including overtime?
- What do you do in a typical day at work?
- How do you think the demands from your current work in terms of work load and pace?
- How do you feel at the end of your working day, physically and emotionally?

Current caregiving role

- How did you come to be a carer and how long ago did this occur?
- The table below are questions related to care recipients

<table>
<thead>
<tr>
<th>Their health condition</th>
<th>Why do they need assistance</th>
<th>Where do they live</th>
<th>Comments on not living together</th>
</tr>
</thead>
</table>

- What kind of caring activities do you provide in general?
- In terms of the assistances you provide, have they changed over time? How?
- On average, how many hours do you spend on this caring role on weekdays? What about weekends?
- What have been the rewards or benefits, if any, for you from caregiving?
- Or the difficulties, if any, associated with caregiving?

Relationship between carer and care recipient

- How do you describe the relationship you are having now with the person you are caring for compared with the relationship that you had with him/her before caregiving began?
• If relationship does change in the course of caring, do these changes affect the caregiving experience? How?

**Impact of caring responsibility**

• What is the most important experience/the biggest impact you have had as a carer?

• How do you rate your own health? Do you think your health condition is getting worse compared to the state you were before taking on caring role? If yes, what could be the causes?

• How do you think your/your family’s current income, are they enough?

• How do you think the effect of devoting time to caring affects your personal and family life?

• What is your view on opportunities of personal development for a carer compared with a non-carer?

• In what ways do you think that you are different from people without any caring responsibilities?

• If you could design the perfect job for yourself, at this stage in your life, what would it be?

**Interactions between roles**

• How does your work fit in with your life at the moment? Specifically, the caring responsibilities you have?

• In what way, do your current job responsibilities affect your caregiving?

• Similarly, could you describe any positive or negative ways in which caregiving affects your work?

• In your experience, what kind of conflicts or situations are the ones most difficult to handle?

**Coping strategies and social support**

• Could you please give me some examples of how you manage any conflict from arising from your job and your caring responsibility?
• Who can you call on if you are feeling stressed, or if you need help with managing your caring responsibility? Is it sufficient for your needs?

• Have you ever used any formal support services (e.g., institutional service, respite service) available in your community in the case you need help for your caring role?
  o If yes, what’s your experience of using these support services? Please elaborate the things are helpful to you as a carer.
  o If no, why not? Under what circumstances would you consider utilizing these support services?

• Could you please give me some examples of programs or initiatives offered to you by your employer?

• In your opinion, how effective are those programs and initiatives compared to general child care services?

• Are there any other strategies you adapted and believed are more effective in terms of helping you to manage the paid employment and unpaid caregiving? To what extent? Could you please give me some examples?

**Final question**

That covers the things I wanted to ask. Is there anything else you think would be important for me and other researchers to know about your experiences as a carer?
Appendix 3.6 – Samples of Invitation Letter (via email)

Dear Colleagues,

Carers Wanted for Research Study

Caregiving can be a challenging and rewarding experience. More people than ever before are combining caring and working responsibilities. However the demands from the roles of work and caregiving can make it hard for people to do their job well and also look after their physical and emotional health and well-being. A groundbreaking study is underway to explore the experiences of employed carers. ACU National is supportive of the aims of this study, which include identifying the supports that carers need to adapt to the potentially competing demands.

Ms Joyce Jiang is a PhD student who is located with the Business, Work and Ageing Centre for Research at the Swinburne University of Technology. Joyce is seeking to contact volunteers who would like to be interviewed for the Australian Research Council funded study, "Balancing the Roles of Paid Employment and Unpaid Caregiving".

The study is seeking volunteers who are a major carer for a family member or an adult (which is defined as providing assistance in terms of help or supervision, to a child or adult with a disability, and or a long term/chronic condition, or an elderly person) for at least 6 months, either in the same or in a different household.

Participation is voluntary and confidentiality and anonymity are assured and there will be no report back to ACU National. Participants will also receive a $20 voucher as token of appreciation for their willingness to participate in the proposed interview. The interviews will normally take between 45 and 60 minutes.

If you wish to participate in this study or would like further information, please contact Joyce Jiang directly. If you do not personally meet the criteria but you are aware of a friend, co-worker or neighbour who is an employed major carer, would you please advise that person of this study and ask her or him to contact Joyce directly. Joyce's contact details are as follows:

Ms Joyce Jiang
Business, Work & Ageing Centre for Research
Swinburne University of Technology
Ph: (03) 9214 4693
Mobile: 0418 168 989
Fax: (03) 9214 5040
Email: jjiang@swin.edu.au

Thank you for your assistance with this important research project.

Yours sincerely

Ms Joyce Jiang
Business, Work & Ageing Centre for Research
Swinburne University of Technology
Ph: (03) 9214 4693
Mobile: 0418 168 989
Fax: (03) 9214 5040
Email: jjiang@swin.edu.au

Thank you for your assistance with this important research project.

Yours sincerely
## Appendix 3.7 – People Who Have Been Interviewed

<table>
<thead>
<tr>
<th>Interview Number</th>
<th>Participant Name (pseudonym)</th>
<th>Gender</th>
<th>Age/Age Group</th>
<th>Caring for a child/ren with disability</th>
<th>Caring for elderly/older person</th>
<th>Caring for people with terminal illness</th>
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</thead>
<tbody>
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<tr>
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<tr>
<td>3</td>
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<tr>
<td>4</td>
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<tr>
<td>5</td>
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<td>√</td>
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</tr>
<tr>
<td>6</td>
<td>Jenny</td>
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<td>45-50</td>
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</tr>
<tr>
<td>7</td>
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<td></td>
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</tr>
<tr>
<td>8</td>
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<td></td>
<td>√</td>
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<tr>
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<td>Amy</td>
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<tr>
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Note: pseudonyms are used to maintain the confidentiality and anonymity
## Appendix 3.8 – Final Sample for Case Study

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<th>Case Number</th>
<th>Participant Name (pseudonym)</th>
<th>Gender</th>
<th>Age/Age Group</th>
<th>Caregiving Role</th>
<th>Employment status</th>
<th>Co-residence with care recipient</th>
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<td>Terminal illness</td>
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<td>√</td>
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<tr>
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<tr>
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<tr>
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<tr>
<td>6</td>
<td>Jenny</td>
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<td>√</td>
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<tr>
<td>7</td>
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<tr>
<td>9</td>
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</table>

3 Amy is a full-time shift worker
Appendix 3.9 – Ethics Clearance

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<th>Recipient</th>
<th>Action</th>
<th>Date &amp; Time</th>
<th>Comment</th>
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<td>To: Joyce Jiang (JJiang)</td>
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<td></td>
<td></td>
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<tr>
<td>To: Patricia Healy (PaHealy)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To: Philip Taylor (PTaylor)</td>
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</tr>
</tbody>
</table>

To: Prof Philip Taylor/Ms Joyce Jiang/Ms Patricia Healy, BWA, FBE

Dear Philip, Joyce and Pat

**SUHREC Project 0607/121 Balancing the Roles of Paid Employment and Unpaid Intensive Caregiving**
Prof P Taylor BWA, FBE, Ms Joyce Jiang
Approved Duration: 01/03/2007 To 30/11/2008

I refer to your response (emailed 15 February 2007 with revised recruitment/consent instruments attached) to the ethical review of the above project undertaken by Swinburne’s Human Research Ethics Committee (SUHREC). The response was put to the Chair for consideration and, I am pleased to advise, approved. But please note that full clearance is dependent (as applicable) on clearance of the quantitative survey instrument being developed for related SUHREC Project 05/39 Redesigning Work for an Ageing Society. Parts of SUHREC Project 0607/121 not related to the quantitative survey can therefore proceed.

The standard conditions for on-going ethics clearance are as follows.

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the current *National Statement on Ethical Conduct in Research Involving Humans* and with respect to secure data use, retention and disposal.

- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/ clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact me if you have any queries about on-going ethics clearance. The SUHREC project number should be quoted in communication.

Best wishes for the project.
Yours sincerely

Keith Wilkins
Secretary, SUHREC

*****************************************************************************
Keith Wilkins
Research Ethics Officer
Office of Research and Graduate Studies (Mail H68)
Swinburne University of Technology
P O Box 218
HAWTHORN VIC 3122
Tel: 9214 5218
Appendix 3.10 – Ethics Clearance for Modified Protocol/Extended Project

To: Assoc Prof Pam Green/Ms Joyce Jiang, Swinburne Research & BWA, FBE
c Assoc Prof Elizabeth Brooke, BWA, FBE

Dear Pam and Joyce

**SUHREC Project 0607/121 Balancing the Roles of Paid Employment and Unpaid Intensive Caregiving**
Assoc Prof P Green, Swinburne Research & Assoc Prof Elizabeth Brooke, BWA, FBE, Ms Joyce Jiang
Approved Duration Extended To 30/04/2009 [Project Modified/New Supervisors October 2008]

I refer to your request, as emailed on 8 October 2008 with attachments, to modify the above project protocol and to extend the project duration. The request was put to a delegate of SUHREC for consideration and, I am pleased to advise, approved in line with standard on-ethics clearance conditions previously communicated and reprinted below.

Please contact me if you have any queries about on-going ethics clearance. The SUHREC project number should be quoted in communication.

Best wishes for the continuing project.

Yours sincerely

Keith Wilkins
Secretary, SUHREC