

Understanding Formal Caregivers and Work Stress

An Interpretive Description Study

Karol Czuba

A thesis submitted to Auckland University of Technology
in fulfilment of the requirements for the degree of
Master of Philosophy

2015

Contents

List of Figures	5
List of Tables.....	5
Attestation of Authorship	6
Acknowledgements	7
Definitions of terms.....	8
Abstract	9
Chapter One: Introduction.....	11
1.1 Formal caregivers and their role	11
1.2 Researcher's interest in the topic	12
1.3 Researcher's assumptions	13
1.4 Thesis structure	14
Chapter Two: Literature review	16
2.1 Challenges of future healthcare.....	16
2.2 Conceptualisation of stress.....	17
2.3 Work stress in formal caregivers.....	20
2.3.1 Inclusion and exclusion criteria	20
2.3.2 Search strategy	21
2.3.3 Quality appraisal	22
2.3.4 Data extraction and synthesis.....	22
2.3.5 Search results	23
2.3.6 Methodological quality and papers' contribution to understanding work stress in formal caregivers.....	34
2.3.7 Literature review findings	34
2.3.8 Literature review implications	38
2.4 Summary	40
Chapter Three: Methodology and Methods	41
3.1 Interpretive description: Methodological Overview and Epistemological Underpinnings	41

3.1.1 Why is interpretive description an appropriate methodology for this research?	45
3.2 Methods	47
3.2.1 Research Question	47
3.2.2 Sampling	47
3.2.3 Data collection	51
3.3 Data analysis	52
3.4 Ethical considerations	56
3.5 Credibility	58
3.6 Summary	60
Chapter Four: Findings	61
4.1 Participants	62
4.2 “What does stress mean to you?”	63
4.3 The inherent tension between the reasons to be a caregiver and burdens of caregiving	65
4.3.1 The reasons to be a caregiver	65
4.3.2 The burden of caregiving	68
4.4 Factors influencing work stress experience	72
4.4.1 Person context	72
4.4.2 Work environment	75
4.4.3 Coping strategies	83
4.5 Summary	88
Chapter Five: Discussion and Conclusion	89
5.1 The tension between the reasons to be a caregiver and the burden of caregiving	89
5.2 Factors influencing formal caregivers’ work stress experience	93
5.3 Implications for practice and policy	99
5.4 Study limitations and suggestions for future research	101
5.4.1 Future research	103

5.5 Conclusion	104
References	105
Appendix A: Participant Information Sheet.....	112
Appendix B: Consent Form	117
Appendix C: Interview guide	119
Appendix D: Ethical Approval.....	121

List of Figures

Figure 1: Search results.....	24
Figure 2: An example of the researcher's diagram.	55
Figure 3: The inherent tension of caregiving.	61

List of Tables

Table 1: Summary of papers exploring experiences of work stress in formal caregivers.	25
Table 2: Demographic characteristics.....	63

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature: 

Date: 16th September 2015

Acknowledgements

During the writing of this thesis, there were many people who supported me and I would like to sincerely thank them.

I would like to thank my supervisors Associate Professor Nicola Kayes and Professor Kathryn McPherson.

Nicola, thank you for the encouragement and mentorship along this journey. You were always available to guide and motivate me whenever I struggled. Truly, this work would not be possible without you.

Kath, thank you for inspiring me to take on this journey. You constantly challenged my thinking by sharing your expertise and knowledge. It was needed and greatly appreciated. Thank you, Kath.

To the participants, who gave their time to share their experiences with me – thank you.

I would also like to thank my family, friends and colleagues who helped along the way by offering their experience and support.

Lastly, I would like to acknowledge Auckland University of Technology Ethics committee for granting the Ethical Approval to proceed with this study on the 22nd October 2013.

Definitions of terms

Formal caregiver – within the context of this thesis, the term formal caregiver has been used to describe non health-professional paid care staff who assist people with activities of daily living.

Patient versus **client** – it is noted that differences exist between various caring professions in how they refer to their care recipients. This thesis draws on an array of health care research publications and on evidence provided by formal caregivers. Whilst the terms client and patient were used to describe recipients of care, they were used inconsistently. For consistency purpose, the term patient has been used throughout this thesis, unless the term client has been explicitly used by a participant or in a cited publication.

Abstract

Current demand for long-term care exceeds the available resources. Review of the literature suggests work stress is a common experience for non-health professionals in paid caregiving roles (formal caregivers), and the experience differs depending on the context. However, no New Zealand (NZ)-based studies were identified in the literature review, and as such, it is unclear which factors contribute to work stress for formal caregivers in the unique NZ context. Furthermore, very few studies explicitly set out to explore the *experience* of work stress for this population. To meet the increasing demand for long-term care, it is important to enhance understanding of, and address the work stress that formal caregivers' experience. The aim of this study was to explore the experiences of work stress of formal caregivers in the Auckland region.

This study used an interpretive descriptive methodology. Data from n=10 formal caregivers was collected using semi-structured in-depth face-to-face interviews. Data was analysed using thematic analysis to identify key categories and themes that captured participant reports of their experiences.

Findings suggested that formal caregivers experienced high levels of work stress, possibly leading to negative outcomes for the caregivers themselves, and their patients. Key themes were: having too much work to do, having no control over the work, feeling undervalued and under constant pressure, and not having sufficient resources to provide quality care for patients. Analysis and interpretation suggested: the caregivers' roles to be a complex and fluid experience as a result of an inherent, dynamic tension between the reasons to be a caregiver and the burden of caregiving. However, the impact that stress had on caregivers and their work appeared to depend on a range of factors that are potentially modifiable. These related to the person's context, their work environment, and their coping strategies.

Despite there being a significant body of work identifying stress as a component of caregiving roles, this appears to be the first NZ study explicitly setting out to explore work stress experiences of formal caregivers working at long-term care facilities. The findings contribute to the current knowledge about formal caregivers' work stress by identifying the challenges relating to the lack of recognition of formal caregivers', the

unintended consequences of person-centred care and particular difficulties experienced by migrant formal caregivers.

This study has increased understanding of how formal caregivers experience work stress and demonstrated the complexity of that experience. The findings of this study could be used to guide the development of interventions aiming to improve both the work environment and caregivers' ability to cope with stress.

Chapter One: Introduction

Current demand for long-term care exceeds the available resources, which could result in increased work stress for those working in the sector (Karasek, Baker, Marxer, Ahlbom, & Theorell, 1981; Weiss & Lonnquist, 2012). Formal caregivers have been called “the backbone of long-term care” (Noelker, 2001, p. 85) and are likely to be one of the most hard-hit groups in the wake of growing demand for those services. To ensure this group can deliver high quality services to care recipients it is important to address the issue of their work stress. However, to date there has been limited exploration of formal caregiver’s work stress, with no such studies conducted within the unique New Zealand (NZ) context. An improved understanding of formal caregivers’ work stress may guide the development of interventions aiming to improve both the work environment (role recognition, management support, teamwork) and the caregivers’ ability to cope with stress. Improving the understanding of work stress of formal caregivers in NZ is at the centre of this study.

This chapter describes who formal caregivers are and what their role is in the health care sector. It then describes why this topic was of interest and presents the researcher’s assumptions. The chapter concludes with an overview of the thesis’ structure.

1.1 Formal caregivers and their role

Formal caregivers provide the majority of paid care to people who have long-term care needs, including but not limited to care of people residing in nursing facilities, private hospitals, inpatient rehabilitation settings, and supported living for people with intellectual impairment. Depending on the country and setting, formal caregivers are known by a broad range of names, for example:

- paid carers;
- nursing aides;
- direct care staff;
- support workers;
- paraprofessional staff;

- health care assistants; and
- personal care assistants.

Formal caregivers' main duty is to assist people with activities of daily living (Ravenswood et al. 2014). However, the actual list of work they are expected to do is long and diverse, and can include:

- bathing, dressing, and grooming;
- transfers, fall prevention and assisting with exercising;
- medication, ostomy bag changes and skin care;
- housekeeping, laundry and cooking; and
- shopping, assisting with community outings and companionship.

Nevertheless, the essential aspect of their role is caring for another person. For many, caring is the element that makes the job attractive (Francis & Netten, 2003). Yet, by its definition, caring involves others and thus is relational – a relationship between those who care and those who are being cared for (Lloyd, 2006). The responsibility for a vulnerable person that comes with this relationship and helping to manage someone else's life make this a very challenging job, especially in light of the heavy workload that formal caregivers face (Ravenswood et al., 2014).

1.2 Researcher's interest in the topic

My interest in caregiving has been informed by both my personal and professional life experiences. My first paid job was a temporary position as a nursing assistant in a nursing home in a small town in Ireland. It was during my first summer break at the university. While I really enjoyed being in that environment, it did bother me how tired and stressed other nursing assistants appeared to be. During our lunch time conversations they would describe how much pressure they felt from their supervisors and how they had to rush through their daily routines. They also complained about the low salary. My experience with this place ended with the start of a new semester and it was not long before I stopped thinking about the difficult work reality in this Irish nursing home. However, a couple of years later, as third-year physiotherapy students, myself and other students were allocated to do a clinical placement at a nursing home in Wroclaw, Poland. The problems I observed back in Ireland were also present here.

In 2010, after graduating from a university with a Master of Physiotherapy degree I moved to NZ. Knowing that working as a physiotherapist in NZ without an appropriate registration would be impossible, I decided to look for jobs where I could use my skills and stay as close as possible to the physiotherapy environment. Within two weeks of my arrival in NZ, I was offered and happily accepted a job offer from a long-term care facility in Auckland. The work was hard, the shifts were busy and I could see that I was not the only person struggling with this reality. Yet, I did feel that I was doing something really worthwhile. Throughout my time at this facility I saw many staff members leave. While stress appeared to be a common issue, I observed that people responded differently to seemingly similar stressful situations. I started noticing some patterns and found it really interesting.

After working almost two years as a formal caregiver, I was offered a position as a Research Assistant at AUT University. With a free access to research literature from around the world, I started browsing the many databases to find out what is known about formal caregivers' work stress. I struggled to find many relevant papers. To my surprise, almost none were from NZ. Encouraged by my colleagues, I decided this was an issue worth further investigation.

1.3 Researcher's assumptions

This study used interpretive description methodology (Thorne, 2008). A detailed rationale and explanation of this methodology is in *Chapter Three: Methodology and Methods*. One of the cautions proposed by Thorne was that the researcher's knowledge and assumptions may impact on the data analysis process (Thorne et al., 1997). She argued that existing knowledge is the beginning point of any qualitative investigation. Thus, it needs to be acknowledged so that it does not over-ride the study structure.

As described in the previous section, I worked as a formal caregiver and as such had already formed some understanding and assumptions regarding the topic of this inquiry. In order to become more aware of my assumptions, I discussed my caregiving work experiences with my colleagues and supervisors and wrote some reflections (using Karin Olson's guidelines (Olson, 2011)).

Key assumptions that I held included:

- caregiving is stressful;
- stress has a negative impact on people and needs to be minimised;
- immigrating to a new country is stressful, but it is but one life stressor and was not the main reason why I felt stressed when working as a caregiver;
- stress was associated with a feeling of inadequacy, i.e. that I was unable to deliver the quality care to a level I thought was expected;
- less experienced caregivers are more affected by stressful situations than those who are more experienced.

Identifying these assumptions impacted on the design of my data collection tools and indeed were challenged throughout the process of data collection and analysis. For more details regarding managing assumptions please refer to *Chapter Three: Methodology and Methods*.

1.4 Thesis structure

Chapter Two: Literature Review, will provide an overview of literature relevant to this thesis and presents findings of a literature review exploring work stress for formal caregivers. The review is limited to papers published up to and including 2013 (the commencement year of this Master's project) given this is the evidence that informed the development of the current research. Relevant papers subsequent to this are referenced in the discussion to support interpretation of findings in the context of recent evidence. The aim of the review was to explore the experiences of work stress in formal caregivers, with a specific focus on the work stressors reported in the literature for this population. Review findings were used to identify what is currently known and what are the gaps in knowledge about formal caregivers' work stress.

Chapter Three: Methodology and Methods, will present the rationale for the methodology that underpinned this study, interpretive description. It will provide a detailed description of the methods used for recruitment, data collection and data analysis. It will also discuss the relevant ethical considerations and outline the steps taken to ensure the credibility of the study.

Chapter Four: Findings, will present the results of the data analysis. It will discuss the general definitions of stress provided by the participants and will identify the ways work

stress appeared to be experienced by the participating formal caregivers. Factors influencing the experience of work stress will be presented and discussed. The findings are presented in a narrative format and quotes from the participant interviews are included.

Finally, *Chapter Five: Discussion*, will discuss the findings in relation to the existing literature on formal caregivers' work stress. It will identify study findings' meaning for current practice, study limitations, and will provide suggestions for future research.

Together, these chapters aim to address the key aims of this thesis including to:

- 1) identify the main work stressors perceived to impact formal caregivers;
- 2) gain an in-depth understanding of the stressors impacting upon NZ formal caregivers' work stress; and
- 3) produce knowledge that could inform the development of an intervention to improve formal caregivers' ability to cope with stress.

Chapter Two: Literature review

This chapter provides a summary of literature relevant to the research topic of formal caregivers' work stress. It begins by describing the current and future challenges of healthcare systems, implications this may have for work stress and how that stress can have a negative impact on the delivery of healthcare. Some of the most influential stress models are presented to provide the theoretical basis for the current study. The chapter then provides the results of a review of studies exploring factors related to work stress of formal caregivers at the time of undertaking the study. Finally, a rationale is provided for investigating work stress experiences of formal caregivers in NZ.

2.1 Challenges of future healthcare

The number of people requiring long-term care has been growing and it is believed to be a very significant challenge of future healthcare (Academy Health, 2003; Blendon & DesRoches, 2003; Health Education England, 2015). One of the major causes of this is the aging population; a phenomenon experienced worldwide, and particularly in developed countries, such as the United States (Blendon & DesRoches, 2003), United Kingdom (UK) (Health Education England, 2015) and NZ (McGregor, 2012). Moreover, the rapid advances in medical technology have led to increasing numbers of people living with a long term condition (Health Education England, 2015). A recent report from Health Education England (2015) argues that in the UK there will be approximately a 30 % increase (to 3 million people) in the number of people living with three or more chronic conditions by 2020. Translating this projection to NZ would mean over 200,000 people with three or more chronic conditions (equivalent to current Hamilton population). Currently, provision of long term care can reach up to 70 % of all health spending in UK (Health Education England, 2015), and up to \$3 billion NZD per year in NZ (OECD, 2015). The growing number of people requiring long-term care will incur increased spending on health and this is going to be a challenge given that many countries around the world are already struggling to manage with their limited financial and workforce resources (Blendon & DesRoches, 2003).

Current demand for long-term care exceeds the supply of available healthcare workers (Academy Health, 2003) resulting in critical workforce shortages in many countries,

including NZ (McGregor, 2012). Two occupational groups particularly affected in NZ are registered nurses and paraprofessional staff (i.e. formal caregivers) (McGregor, 2012). As the population of people requiring long-term care grows, the demand is likely to increase even further. Given that funding will be limited, the increasing demand will likely need to be met within existing financial and workforce resources, which could arguably result in increased workloads for those working in the long-term care sector.

Formal caregivers provide the majority of hands-on care in long-term care settings (for example, over 60 % in UK (Health Education England, 2015)). Their performance plays a vital role in the quality of care that people in long-term care receive (McCluskey, 2000). However, the increased workload has been shown to lead to high amounts of work stress (Karasek et al., 1981; Weiss & Lonnquist, 2012), which in turn has a negative impact on the quality of care (Cohen-Mansfield, 1995; Morgan et al., 2002). Clearly the systemic issue of increased workload cannot be addressed at the individual level, however, stress itself is a highly subjective phenomenon (Lazarus, 2006).

Further research into formal caregivers' work stress appears timely. Such investigations need to be informed by a sound stress model able to capture the nuances specific to this context. Over the past decades, a number of stress models have been proposed. Some of the most frequently cited models in health research include Selye's General Adaptation Syndrome (Selye, 1976), Karasek's Demands-Control Model (Karasek et al., 1981), Siegrist's Effort-Reward Imbalance Model (Siegrist, 1996) and Lazarus and Folkman's Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). These four models are discussed in the following section.

2.2 Conceptualisation of stress

One of the most influential and commonly referenced stress models is the General Adaptation Syndrome proposed by a Hungarian endocrinologist Hans Selye (1976). It was the first ever scientific explanation of biological stress. He defined stress as "the state manifested by a specific syndrome which consists of all the non-specifically induced changes within the biological system" (Selye, 1976, p. 64). Selye postulated that an event that threatens an organism's well-being, i.e. a stressor, leads to a three-stage response:

1. Alarm – activating the organism's resources and starting the 'fight-or-flight' response;
2. Resistance – the organism returns to normal physiological levels while focusing its resources on the stressor; and
3. Exhaustion – if the stressor continues beyond the organism's capacity it leads to exhaustion of the organism's resources and makes it susceptible to disease or death.

Notwithstanding its influence on the development of the concept of stress, Selye's original model lacks focus on the role of psychological factors in this phenomenon. For example, an observation of a group of students waiting for an important examination will reveal that some of them seem nervous, while others appear relaxed – i.e. the same stressor (an examination) results in different responses (nervous versus relaxed). Many authors argued that the response to a stressful event is not determined by the stressor itself, but also by other job- and person- specific characteristics (Haley, Levine, Brown, & Bartolucci, 1987; Karasek et al., 1981; Schneider, 2008; Troup & Dewe, 2002).

The Demands-Control-Support Model (Johnson & Hall, 1988; Karasek et al., 1981) is one of the most influential models of stress in the workplace. It focuses on three job characteristics – job demands, job control and social support. The model assumed that stress is a result of an interaction between demands and control and that the interaction is buffered by social support. Karasek et al. (1981) postulated that high demands and low control would predict high strain, whereas high control would decrease the negative impact of demands on outcomes.

There is evidence for associations between health outcomes with control, demands and support (Van der Doef & Maes, 1999). However, the model focuses only on the three job characteristics (i.e. demands, control and support). As such it lacks ability to reflect the processes and interactions that occur in the modern, multi-stressor work environment. Furthermore, due to lack of focus on individual differences in perception of stress, it does not explain why the same level of demand and control in two people may lead to different outcomes.

The Effort-Reward Imbalance model (Siegrist, 1996) is another widely referred to view of stress at work. Siegrist (1996) suggested that work efforts should be compensated by suitable rewards, with a mismatch between the two leading to stressful experiences. This model has the ability to overcome the limitations of the Demands-Control model,

as it places emphasis on the subjective perception of work environment. Siegrist (1996) claimed that it is not the 'actual' mismatch between the two factors (as in the Demands-Control model), but the 'perceived' mismatch, that determines the outcome of a stressful experience. However, Mark and Smith (2008) criticised the Effort-Reward Imbalance model for not giving enough consideration to the role that individual differences play in the perception of stress.

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) addresses a number of the limitations of the abovementioned models. It has been widely adopted in many fields, including psychology, health and workplace management. Lazarus and Folkman defined stress as "a pattern of negative physiological states and psychological responses occurring in situations where individuals perceive threats to their well-being, which they may be unable to meet" (McIlveen & Gross, 1997, p. 169). Central to this model is the subjective evaluation of a stressor, namely primary and secondary appraisal. The former refers to the significance of a stressor, i.e. is the outcome of a stressful event important to the person? The latter refers to the sense of control over a stressful event, i.e. does the person have sufficient resources to deal with this event? These two processes are suggested as mediating the transaction between the person and the environment, determine which coping strategies are utilised and eventually influence the outcome of a stressful event.

Consistent with the theoretical assumptions of this model, people can be taught how to manage stress and cope with stressors through training them to evaluate a stressor from different perspectives and providing them with a range of effective coping strategies. Importantly, the Transactional Model of Stress and Coping emphasises the role of job situation, subjective perception and individual differences in how people experience stress.

Lazarus and Folkman's model (1984) has been both valued and criticised for its complexity (Mark & Smith, 2008). On one hand, this model allows consideration of the individual, the group and the workplace as an analytic unit, rather than independent variables. However, a widely criticised aspect of the Transactional Model of Stress and Coping is that, it assumes that people have an ability to report on how they engage in cognitive processes that occur outside of their awareness (Zajonc, 1980). If the cognitive appraisal processes are automatic (as postulated by Lazarus and Folkman), asking people to verbally report on them would require a conscious (not automatic)

reflection. Thus, this model's applicability may be limited in research relying on self-reports and crude quantitative data. However, it can be particularly useful in qualitative research where it is possible to explore personal perspectives regarding the experience of work stress in more depth.

The Transactional Model of Stress and Coping appeared particularly relevant given the intention of this study to explore individual characteristics as well as work context for formal caregivers to ensure an adequate understanding of work stressors and possible coping strategies that could be utilised by this occupational group.

2.3 Work stress in formal caregivers

The following section reports a review of literature aiming to explore the experiences of work stress in formal caregivers, with a specific focus on the work stressors reported in the literature for this population. The review was guided by principles of systematic literature review (Cook, Sackett, & Spitzer, 1995). Systematic review principles were used to ensure a robust approach to searching and identifying relevant existing literature on the topic. Such an approach would also help identify any existing gaps in the research focusing on formal caregivers stress.

Given this review's focus on the *subjective experience* of work stress from the perspective of formal caregivers, a decision was made to only include papers using qualitative methodology.

The methods of the review are presented below in the following order: inclusion and exclusion criteria, search strategy, quality appraisal, and data extraction and synthesis.

2.3.1 Inclusion and exclusion criteria

Peer reviewed papers were included if they reported on empirical studies using qualitative methodology and explored the experiences of formal caregivers working in long-term healthcare facilities that:

- a) sought to explore work stress; or
- b) identified work stress (or closely related concepts) as one of the main findings.

Only papers published in English and between 1995 (there was a desire to focus on more contemporary work as it is likely that organisations have changed over time, which may contribute to there being a different experience in current times compared to prior to 1995) and 2013 (the commencement year of this Master's project) were included in the review.

Papers exploring the experiences of formal caregivers in in-home care were not included. In-home care settings appear to be physically (client's own home versus a multi-bed facility), socially (client, their family and a caregiver versus a number of clients and their families, a number of caregivers, and a number of other staff) and organisationally (e.g. work planning, safety regulations, decision-making structures, management support) different from long-term care facilities.

The titles and abstracts for all papers identified in the search were screened by the main author (KC) to determine if they met the inclusion criteria. Any uncertainties were discussed between KC and the primary supervisor (NK), and resolved through that discussion. Full text copies were screened when papers appeared to possibly meet the criteria or when the title or abstract did not provide sufficient information to determine the paper's relevance.

2.3.2 Search strategy

The systematic search of literature was completed using Scopus (includes records from Embase and Pubmed) and EBSCO databases (includes records from Medline, CinahlPlus, PsychInfo and others). The search involved text-word searches and the search terms are listed below (truncation was used to improve the search strategy, e.g. nurs* assistant*).

1. Population (all terms combined with a Boolean operator "OR"):
 - paid carer; OR
 - paid caregiver; OR
 - formal carer; OR
 - formal caregiver; OR
 - nurse/nursing aides/aids; OR
 - therapy aides/aids; OR
 - care aids/aides; OR
 - nurse/nursing assistant; OR
 - therapy assistant; OR

- support worker; OR
- direct care staff; OR
- personal care assistant.

AND

2. Subject of inquiry (all terms combined with a Boolean operator “OR”):
 - stress; OR
 - distress; OR
 - burden; OR
 - dissatisfaction; OR
 - burnout.

2.3.3 Quality appraisal

Quality appraisal was used to evaluate the contribution a paper makes and not to exclude any papers. This approach was taken in order to avoid a potential risk of excluding low quality studies which could otherwise offer valuable insights into the researched phenomenon (Dixon-Woods et al., 2007).

Each article was reviewed using the relevant CASP tool (Critical Appraisal Skills Programme checklist for qualitative research: (National Health Service Public Health Resource Unit, 2006)). This tool is available for free and has been previously used in systematic reviews of qualitative research (e.g. Eades et al. 2011). The tool focuses on the following areas: clarity of the study aim and the findings; appropriateness of methodology, research design, data collection and recruitment method; ethical considerations; and data analysis rigour. It consists of ten items; each has three possible responses: ‘Yes’, ‘No’, and ‘Can’t tell’.

Please note that CASP scores should serve only as an indication of the value of contribution a paper makes. However, for the purpose of reporting in this review, each item with a response ‘Yes’ was scored one point. Any other response was scored zero points.

2.3.4 Data extraction and synthesis

Principles of thematic synthesis (Thomas & Harden, 2008) were used to guide the synthesis of the data. Each of the included papers was retrieved and read multiple times

to develop an understanding of the paper's topic. Initially, the papers were coded to help identify and extract information regarding the main findings to the data summary table (Table 1). The extracted data was then analysed with an aim to identify important or recurrent themes. Findings were summarised under thematic headings.

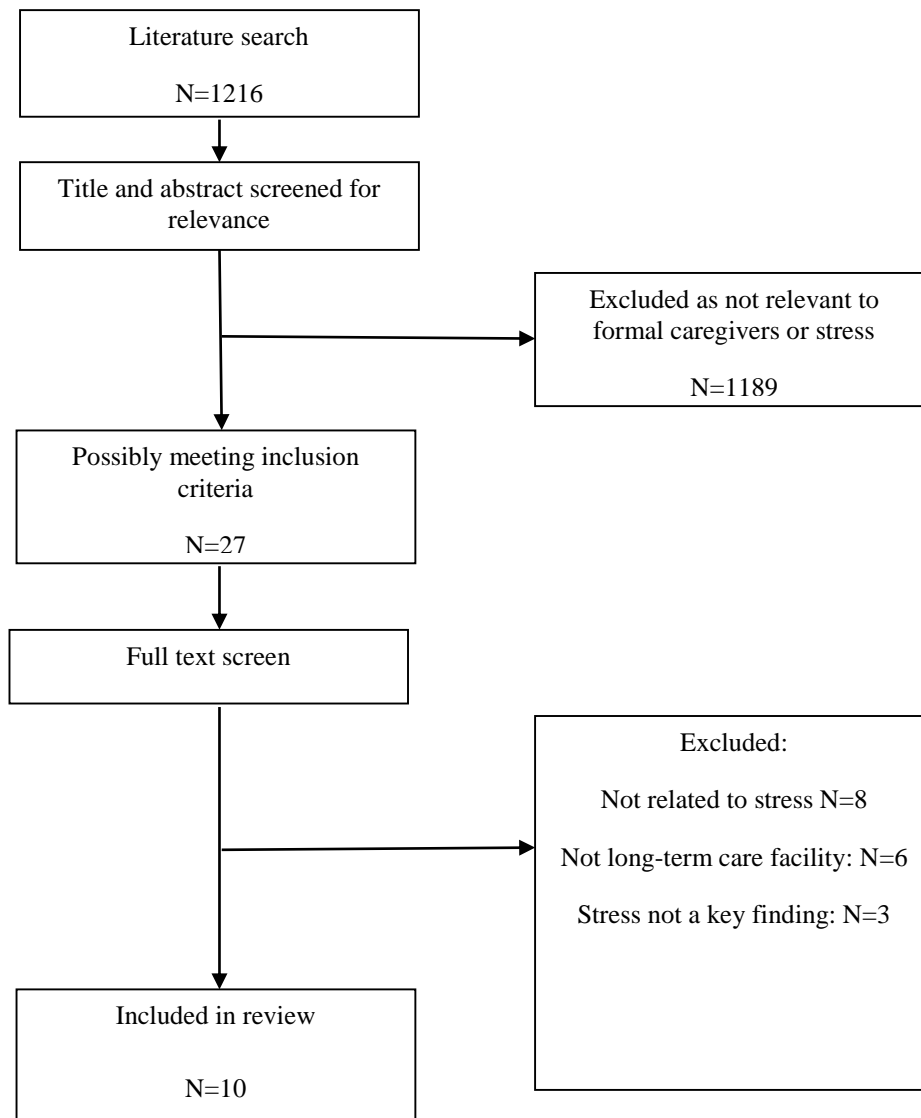
2.3.5 Search results

Figure 1 illustrates the search process and results. Initially, 1216 abstracts were identified. Following a title and abstract screen, 1189 were excluded as being not relevant to the formal caregivers' population or their experiences of work stress. All of the 27 papers that possibly met the inclusion criteria were read in full text. The review process was accompanied by an ongoing consultation with and guidance from the primary study supervisor (NK). Following full text screen, 17 papers were excluded from the review.

The reasons for exclusion included:

- a) n=8 studies focused on a concept not directly related to stress, e.g. studies on job satisfaction, self-acceptance or physical strain in transfer situations;
- b) n=6 studies not conducted in long-term care facilities, e.g. studies focusing on in-home care, emergency department care; and
- c) n=3 studies where stress was not a key finding, e.g. studies exploring health experiences of employees from a gender perspective, dealing with aggressive behaviours.

Figure 1: Search results.



Ten papers were included in the final selection for this review. Five studies were conducted in a nursing home setting (Clarke, 2001; D'Hondt, Kaasalainen, Prentice, & Schindel Martin, 2012; Gustafsson, Norberg, & Strandberg, 2008; Secrest, Iorio, & Martz, 2005; Zhang et al., 2011), four studies in a hospital setting (Hertting, Nilsson, Theorell, & Larsson, 2005; Khalaf, Berggren, & Westergren, 2009; Mininel, Baptista, & Felli, 2011; Shaha & Rabenschlag, 2007) and one in a supported community living setting (Monaghan & Cumella, 2009). In six studies all participants were formal caregivers (Clarke, 2001; D'Hondt et al., 2012; Hertting et al., 2005; Monaghan & Cumella, 2009; Secrest et al., 2005; Zhang et al., 2011), whereas in the remaining four the study sample also included registered nurses and other healthcare staff (Gustafsson et al., 2008; Khalaf et al., 2009; Mininel et al., 2011; Shaha & Rabenschlag, 2007). None of the studies were conducted in NZ.

Table 1: Summary of papers exploring experiences of work stress in formal caregivers.

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Clarke, 2001)	To explore the role conflicts and coping strategies of health care aides.	Ethnographic observational study informed by symbolic interactionism.	N=15 health care aides (HCA); nursing home.	<ol style="list-style-type: none"> 1. Conflicting expectations. 2. Role overload. 3. Lack of control. 4. Qualified but not professionally recognized. 5. Emotional involvement. 	<p>Study design appropriate for study aim; demographic characteristics of the sample not reported; valuable contribution to understanding stress in this context.</p> <p>CASP - 9/10</p>
(D'Hondt et al., 2012)	To describe and gain insight into the critical incidents depicted by personal support workers (PSW) in long-term care related to bathing residents who have dementia.	Qualitative descriptive study using Critical Incident Technique.	N=5 PSWs and N=3 HCAs; nursing homes for people with dementia.	<p>Challenges in caregiving:</p> <ol style="list-style-type: none"> 1. Managing residents' responsive/protective behaviour, including physical abuse. 2. Working with limited resources. 3. Dealing with communication difficulties (cognitive). 	<p>Study design appropriate for study aim and very well reported; valuable contribution to understanding stressful situations that occur during bathing in this context.</p> <p>CASP - 9/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Gustafsson et al., 2008)	To illuminate the meanings of becoming and being burnout for female healthcare personnel on sick leave due to burnout.	Hermeneutical phenomenology study using narrative interviews.	N=20 total sample; N=3 nurse aides; nursing homes. Other participants included: N=4 work-leaders, N=4 registered nurses (RNs), N=6 enrolled nurses (ENs), one social worker, one occupational therapist and one physiotherapist.	<p>Reasons for becoming and being burnout:</p> <ol style="list-style-type: none"> 1. Striving between what one wants to manage and what one manages. a) Falling short among all never-ending increasing demands. 2. Striving for appreciation and respect one is not receiving. 3. Being unable to change one's situation. 4. Suffering from feelings of inadequacy. 5. Suffering from troubled conscience. 6. Reaching an edge of overwhelming feebleness. 	<p>Study design appropriate for study aim and very well reported. Value of contribution limited as study sample (n=20) included only 3 formal caregivers.</p> <p>CASP – 9/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Hertting et al., 2005)	To explore hospital-based assistant nurses' experiences of psychosocial "stressors", following a period of substantial layoffs and ongoing reorganizations.	Qualitative study using guided conversational interviews.	N=11 assistant nurses; hospital.	<p>Work stressors for assistant nurses:</p> <ol style="list-style-type: none"> 1. An energy consuming adjustment period (downsizing). 2. Having a weak position (i.e. position not recognized). 3. Heavy workload (increased). 4. Shortcomings in the organization (unfinished and ineffective work impacting quality of care). 5. Frozen salary trends. 	<p>Study design appears appropriate for study aim; limited information provided regarding methodology; valuable contribution to understanding stress in this context.</p> <p>CASP – 7/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Khalaf et al., 2009)	To explore nurses' and nursing assistants' experience of and ethical reflections on nutritional care for undernourished patients.	Inductive qualitative study using semi-structured interviews.	N=13 total sample; N=8 registered nurses and N=5 nursing assistants; hospital.	<p>Experiences of stress:</p> <ol style="list-style-type: none"> 1. Organization-related stress (structure, rules and guidelines). 2. To be exposed and lonely. 3. Experience of powerlessness and helplessness. 4. Experience of being torn between demands and needs. <p>Experiences of joy:</p> <ol style="list-style-type: none"> 1. Create a trustful relationship (with patients). 2. Respect for others. 	<p>Study design appropriate for study aim and very well reported. Value of contribution limited with only 5 out of 13 participants being formal caregivers.</p> <p>CASP – 9/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Mininel et al., 2011)	To explore the work process, the psychological workloads and the strains generated in nursing workers.	Qualitative descriptive study using focus groups.	N=62 total sample including nurses, technicians and nursing auxiliaries; hospital.	Psychological workloads: <ol style="list-style-type: none"> 1. Psychological aggression. 2. Monotonous and repetitive work. 3. Constant attention. 4. Female work. 5. Lack of collective defences. 6. Abuse of alcohol and drugs. 7. Accelerated work rhythm. 8. Lack of communication. 9. Strict senior supervision. 10. Lack of autonomy. 	Study design generally appropriate for study aim; statement of findings very brief, lacks clarity and this has a negative impact on the value of the study's contribution; limited information regarding consideration of relationship between researcher and participant. Exact number of formal caregivers in the sample unknown. CASP – 7/10

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Monaghan & Cumella, 2009)	To explore a support worker's work experiences.	Participative life history study using undisclosed observation.	N=1 support worker; supported community living .	<ol style="list-style-type: none"> 1. The role appears to be frustrating, tiring and stressful, yet rewarding and fulfilling. 2. Lack of patience was observed. 3. Shift work requiring flexibility with one's time. 4. Lack of training. 5. Agency staff seems to present a problem to permanent staff (unfamiliar with environment). 6. Support workers take sick leave or quit job to cope with stress. 7. Management support seems to play an important role in relieving support workers' stress. 8. Family involvement can be problematic for support workers. 	<p>Study design generally appropriate for study aim; limited transferability of findings due to the design; study used undisclosed observation which did not seem necessary; data analysis method not reported.</p> <p>CASP – 6/9¹</p>

¹ As the author was the only study participant, the 'recruitment strategy' CASP item was considered not applicable, hence the maximum score was 9.

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Secrest et al., 2005)	To investigate the meaning of work for nursing assistant who stay in long-term care.	Existential-phenomenological study using guided in-depth interviews.	N=11 nursing assistants; nursing home.	<p>Negative experiences:</p> <ol style="list-style-type: none"> 1. Hostility (including rivalry and assaults by patients). 2. Disrespect (from co-workers and patients). 3. Lack of control (time and decision-making). <p>Positive experiences:</p> <ol style="list-style-type: none"> 1. Sense of connection with some clients. 2. Pride (doing something important). 3. Taking control. 	<p>Study design appropriate for study aims; limited information on ethical considerations and recruitment; valuable contribution to understanding work experiences of nursing assistants.</p> <p>CASP – 8/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Shaha & Rabenschlag, 2007)	To explore situations of burden from the perspective of the nursing staff.	Explorative qualitative action research study using focus groups.	N=29 total sample; N=16 registered nurses and N=13 nurse assistants; hospital.	<p>1. Working conditions were identified as major burden (lack of time, workload, and repetitive difficult situations causing lack of motivation).</p> <p>2. Complex patient situations as source of burden (patients' difficult situations, being confronted with demanding families, patients' mental health issues).</p> <p>3. Lack of training is an issue.</p> <p>5. Participants felt they were giving their best to the patients.</p> <p>6. Participants felt they could not leave their work behind when going off duty and carried their problems into private lives.</p>	<p>Study design generally appropriate for study aims; no ethical approval; lack of information regarding data analysis rigour. Limited value of contribution as only 13 out of 29 participants were formal caregivers and the findings not being reported specifically for the formal caregivers.</p> <p>CASP – 7/10</p>

Paper	Aim of study	Methodology and methods	Participants	Key findings	Comments
(Zhang et al., 2011)	To compare the perceptions between certified nursing assistants and their managers regarding their views on workplace, health and safety, work organization and psychosocial concerns.	Qualitative study using focus groups.	N=81 certified nursing assistants (CNA); nursing home.	<ol style="list-style-type: none"> 1. CNAs stated that physical abuse from patients was a common issue. 2. Double workloads, short staffing, difficult work schedules and time strain were mentioned to be an issue. 3. CNAs mentioned communication issues among staff (e.g. not getting answers from senior staff). 4. Lack of teamwork adds to job strain. 5. Stress was mentioned as a prevailing concern (e.g. not leaving work issues behind when off duty). 6. Causes of stress include: poor teamwork, lack of respect and appreciation, no control, poor communication, little involvement in care planning and risk of infectious diseases. 	<p>Study design generally appropriate for study aim; limited information regarding ethical considerations; questionable data analysis rigour. Limited value of contribution due to the above-mentioned limitations.</p> <p>CASP – 7/10</p>

2.3.6 Methodological quality and papers' contribution to understanding work stress in formal caregivers

In general, the quality of the identified papers was good. The strengths and weaknesses of the included papers are summarised in Table 1. The methodological quality varied between the studies and impacting the contribution each study makes to the understanding of work stress in formal caregivers. The findings presented below should be interpreted with this caution in mind. The main limitations of included studies include lack of reporting on data analysis method, insufficient information regarding the specific qualitative methodology used, lack of information regarding ethical considerations and lack of clarity in reporting study aims. Four studies presented data from samples consisting not only of formal caregivers, but also registered nurses and other healthcare staff, thus caution regarding the transferability of these studies' findings to formal caregivers specifically is warranted.

2.3.7 Literature review findings

The literature review identified stress as a common and complex experience influenced by a range of stressors, and related to either of the two primary concepts: stress as a result of a mismatch between demands and control (Hertting et al., 2005; Khalaf et al., 2009; Mininel et al., 2011; Secrest et al., 2005; Zhang et al., 2011), and stress as an outcome of mismatch between perceived threats and expectations with available resources (Clarke, 2001; D'Hondt et al., 2012; Gustafsson et al., 2008; Monaghan & Cumella, 2009; Shaha & Rabenschlag, 2007). The former concept is similar to the Karasek's (1981) Demands-Control-Support model; the latter resembles more the Lazarus and Folkman's (1984) Transactional Model of Stress. However, none of the included studies' designs were reported to be informed by any particular stress model.

All identified papers reported a number of factors that appeared to influence the experience of caregivers' work stress (stressors) and these are presented in the following section.

2.3.7.1 Stressors in formal caregivers work

The literature review identified a range of stressors that were perceived to impact upon formal caregivers work stress and these are synthesised into key themes:

- a) Lack of control.
- b) Conflicting expectations.

- c) Work overload.
- d) Lack of appreciation and respect.
- e) Communication and teamwork issues.
- f) Physical and psychological abuse.

Lack of control

A number of studies found that perceived lack of control was one of the major stressors for formal caregivers (Clarke, 2001; Gustafsson et al., 2008; Hertting et al., 2005; Khalaf et al., 2009; Mininel et al., 2011; Secrest et al., 2005; Zhang et al., 2011). This lack of control was experienced in decision-making situations, time management, and feelings of powerlessness and helplessness. Formal caregivers reported feeling that no one at their workplace cared about their opinion (Mininel et al., 2011) and tended to believe that they were unable to change their situation (Gustafsson et al., 2008).

As many of the authors reported, having little or no control on one's work has been frequently cited as a major source of stress in work environment (Gustafsson et al., 2008; Hertting et al., 2005; Secrest et al., 2005; Zhang et al., 2011). Of note, loss of control has been described in behavioural literature as being "one of the few forms of psychological trauma that researchers can agree is universally aversive" (Skinner, 1995, p. 3).

Conflicting expectations

Health care settings are complex work environments consisting of people with wide ranging expectations. Formal caregivers are in a difficult situation of having to meet the expectations of their supervisors (including registered nurses), their patients, as well as their co-workers. These expectations are often not possible to be met simultaneously and may lead to stress experiences for formal caregivers (Clarke, 2001; Gustafsson et al., 2008; Khalaf et al., 2009; Shaha & Rabenschlag, 2007). An example illustrating this was provided by Clarke (2001): a formal caregiver was asked by a registered nurse to allow their resident enough time "to restore her self-care deficit" (Clarke, 2001, p. 33), but at the same time the caregiver had to make sure the patient was ready to see a relative who was meeting her shortly. Importantly, some authors (Clarke 2001; Khalaf et al., 2009) reported that in such conflicting situations, the caregivers chose to satisfy the expectations of their upper management rather than those of patients.

Furthermore, Khalaf et al. (2009) found that the caregivers were also often torn between patients' wishes and relatives' expectations, e.g. when caregivers had to explain to families of undernourished patients that they could not force them to eat more. Such conflicts can create feelings of being torn between what the caregivers want to do and what they have to do, and between the needs and the demands of the people they work with on a daily basis (Gustafsson et al., 2008; Khalaf et al., 2009).

Work overload

Another common finding was that the caregivers experienced stress due to work overload, i.e. when the work demands exceed the caregivers' ability to meet them (Clarke, 2001; D'Hondt et al., 2012; Gustafsson et al., 2008; Hertting et al., 2005; Shaha & Rabenschlag, 2007; Zhang et al., 2011). Low 'caregiver to resident ratios' and working with limited resources appeared to be a common theme, and was considered to be a current and future challenge for this workforce group (Clarke, 2001). While such organisational strategies appeared to be economically viable in the short term, they may have far reaching detrimental effect on the quality of care being provided by the formal caregivers (Clarke, 2001).

Lack of appreciation and respect

A number of studies suggested that lack of appreciation and respect was an important work stressor (Clarke, 2001; Gustafsson et al., 2008; Hertting et al., 2005; Mininel et al., 2011; Secrest et al., 2005; Zhang et al., 2011). It was observed across many different levels of caregivers work relationships, including with nurses, upper management, patients and their families. The caregivers did not feel that their work was valued by other people in their organisation with some even suggesting they were treated as slaves (Zhang et al., 2011).

Although caregivers in these studies felt that they had some unique knowledge about their patients, their expertise was often not included in care planning for the patients (Zhang et al., 2011). As one of Secrest et al. (2005) study participants stated, "Everybody thinks, 'Well, they're just nursing assistants.' You know? If it wasn't for the nursing assistants, there wouldn't be any nursing homes. There wouldn't" (Secrest et al., 2005, p. 93).

The perceived lack of appreciation and respect was an important issue as it may lead to feelings of being anonymous, overlooked and forgotten (Gustafsson et al., 2008). It may

also intensify the disengagement between the caregivers and clients (Monaghan & Cumella, 2009).

Communication and teamwork issues

Lack of and issues with communication were found to be another work stress factor for formal caregivers (Hertting et al., 2005; Khalaf et al., 2009; Mininel et al., 2011; Zhang et al., 2011). The caregivers experienced issues with upward communication, i.e. with their supervisors and managers, often leaving them with unresolved queries (Zhang et al., 2011). Also poor teamwork was reported as problematic and a cause of stress (Hertting et al., 2005; Khalaf et al., 2009; Mininel et al., 2011). Khalaf et al. (2009) found that caregivers might feel lonely and abandoned due to lack of support from other colleagues, while Mininel et al. (2011) reported that workers felt that supervisors did not care about their suggestions to change their routine.

Physical and psychological abuse

Physical abuse towards residential care patients is a major concern of today's healthcare settings with it being frequently reported by the news media (for example the footage showing elderly residents being abused at an Essex care home (The Independent, 2014)). However, this literature review found that formal caregivers often described being abused by their patients, both physically and psychologically. While such behaviours could be manifestations of patients' unmet needs (D'Hondt et al., 2012), they were reported to be difficult to deal with by caregivers and perceived as a major stress factor (D'Hondt et al., 2012; Mininel et al., 2011; Secrest et al., 2005; Zhang et al., 2011). Zhang (2011) found that in some cases the caregivers were suspended after being abused by residents. As one of Zhang et al. (2011) study participants explained: "There's no need for her to be suspended. She doesn't get paid for it until they find out it's not her fault, it's the resident's fault. She loses 3 days' pay." (Zhang et al., 2011, p.36). In another study (Mininel et al., 2011), caregivers experienced bullying from patients and other members of the team. The authors argued that in extreme cases this could lead to panic syndromes or cardiovascular disease.

Other key findings relevant to this Master's study

There were a number of other work stressors identified in the included studies. While these stressors were less commonly reported, they may be equally important in terms of the impact they have on the formal caregivers work stress.

- A. Two papers reported that caregivers considered their work to be very repetitive with recurring accidents and emergency situations (Mininel et al., 2011; Shaha & Rabenschlag, 2007). Combined with little change, these constantly occurring situations could lead to loss of motivation and increased level of stress (Shaha & Rabenschlag, 2007).
- B. Zhang et al. (2011) and Shaha and Rabenschlag (2007) found that formal caregivers struggled to leave the work issues behind when they went off duty. The issues were carried into private lives and leisure time had to be used to cope with the excessive strain their work put on them.
- C. Lack of sufficient training was found to contribute to work stress. It was associated with limited awareness of patient needs (Monaghan & Cumella, 2009) and an increased workload (Shaha & Rabenschlag, 2007). Monaghan and Cumella (2009) postulated that working as agency staff covering for vacancies in residential care facilities was particularly stressful as such staff are seen as 'outsiders' and are usually not familiar with organisational policies and procedures, nor with their residents.
- D. One study (Hertting et al., 2005) reported that formal caregivers felt underpaid, i.e. the caregivers felt they were putting in more than they were getting back in an increasingly demanding work environment.
- E. The participants of Mininel et al. study (2011) suggested that caregiving requires constant alert as a lot of things can go wrong. Specifically, the authors postulated that the constant attention could lead to stress, irritation, headaches, and even anxiety and depression.
- F. High risk of infectious disease was discussed by Zhang et al. study participants (2008) as making their work at long-term care facilities more stressful. Yet, the authors found that managers often did not acknowledge these risks.
- G. Patients' family involvement, while often useful, can be difficult and add to work stress particularly when they put their ideas forward without listening to the relatives who are in care or the caregiving staff (Monaghan & Cumella, 2009).

2.3.8 Literature review implications

While there are some differences in how the stress was conceptualised in the included papers, all studies related stress with a challenging mismatch: between threats and

resources, or between demands and control. What seems crucial in this mismatch is that it appeared to be governed by a range of stressors (as listed in the previous section).

From the formal caregivers' perspective, it appears that one of the biggest challenges they face is the increased workload (McGregor, 2012), which may lead to increased levels of work stress. The findings of this literature review confirm this suggestion. It is clear that the stress that formal caregivers experience is a result of the perceived mismatch between the increasing demands and available resources.

The findings of this literature review highlight the role that a range of stressors may play in experiencing work stress including both intrinsic (i.e. individual-specific) and extrinsic (i.e. environment-specific) characteristics. Conflicting expectations, lack of appreciation and support, and communication and teamwork issues are only a few which could be improved by organisational-level interventions. While stress is a subjective experience, the findings identify lots of key modifiable aspects of the work environment (social and cultural) that may alleviate stress.

However, before applying these findings to NZ it is important to note that the most influential stress models (Karasek et al., 1981; Lazarus & Folkman, 1984; Siegrist, 1996) emphasise the context-specific nature of stress suggesting that consideration of individuals' views and their specific social environment is required.

NZ is a bicultural country and a multicultural society. As such, the NZ long-term care context is unique and requires a specific investigation of the formal caregivers work stress experiences. Such an investigation could be particularly valuable as it may lead to interventions targeted at enhancing formal caregivers' self-esteem, ability to cope with stress, emotional well-being and physical health. Subsequently, it may have implications for the quality and sustainability of healthcare for people requiring long term residential care. As no NZ-based studies were identified in the literature review, it is unclear which of the reported and what other factors are particularly applicable to the unique NZ context. Furthermore, very few studies explicitly set out to explore the experience of work stress for this population. Therefore, it seems timely to explore the work stress experiences of NZ formal caregivers to improve our understanding of and inform potential future interventions targeted at this issue.

2.4 Summary

The healthcare organisations around the world and in NZ are facing a very significant challenge in having to provide care to a growing population of people who require long term care. Care is likely to have to be provided within the existing resources, thus making the best use of what is readily available is crucial. One resource that cannot be duplicated are the healthcare staff. The importance of staff engagement has been established in organisational and management literature (Anitha, 2014; Harvard business review analytic services, 2013) suggesting that it improves productivity and performance while reducing costs related to hiring and retention. At the same time, stress has been recognised as one of the biggest factors affecting staff retention and performance (Hastings, Horne, & Mitchell, 2004; P. C. Hsieh & Su, 2007; Innstrand, Espnes, & Mykletun, 2004; Rose, Jones, & Fletcher, 1998). Monaghan and Cumella (2005) argued that any attempts to increase staff engagement without addressing work stressors are unlikely to succeed. In order to meet the increasing demand for long-term care, it is therefore timely to focus on understanding and addressing work stress for one of the biggest healthcare organisations' assets – formal caregivers.

The findings of the literature review conducted as part of this thesis highlight the role that a range of stressors may play in experiencing work stress. However, as no NZ-based studies were identified in this review, it is unclear which of the factors are particularly applicable to the unique NZ context. Therefore, the current project sets out to enhance the understanding of work stress for formal caregivers in NZ, specifically targeting this occupational group.

The next chapter goes on to present the rationale for the methodology that underpinned this study, interpretive description.

Chapter Three: Methodology and Methods

This chapter describes the methodology that underpinned the study and the methods used to explore the experiences of formal caregivers' work stress. The first part of the chapter provides an overview of the interpretive description methodology and its philosophical foundations. The latter part describes the methods used for data collection and analysis and discusses the relevant ethical considerations.

3.1 Interpretive description: Methodological Overview and Epistemological Underpinnings

This study used an interpretive descriptive methodology (Thorne, 2008). It is a qualitative research methodology frequently used to inform nursing practice (Olmstead, Scott, Mayan, Koop, & Reid, 2014; Puplampu, Olson, Ogilvie, & Mayan, 2014; White, Pesut, & Rush, 2014). A number of authors have proposed it as a rigorous approach (Smythe, 2012; Thorne, Kirkham, & O'Flynn-Magee, 2004). Whilst some have criticised 'descriptive methodologies' as not being clear and credible (Mays & Pope, 1995; Neergaard, Olesen, Andersen, & Sondergaard, 2009), others refer to its ability to investigate previously unexplored phenomena in their natural contexts and to do work that aims to inform clinical practice (for example, improved healthcare outcomes through better understanding of work stress – the objective of this research) (Hunt, 2009; Kathleen, 2006).

Interpretive description methodology is broadly underpinned by the epistemological assumptions of naturalistic inquiry (Guba & Lincoln, 1982). Naturalistic inquiry aims to

investigate a given phenomenon in its natural setting, uses qualitative methods and the application of findings is tentative rather than absolute (Guba & Lincoln, 1982). This paradigm allows the researchers to investigate a phenomenon in great depth (Hunt, 2009). The key underpinnings of interpretive description include (Thorne, 2008):

- 1) Interpretive description acknowledges the role and value of subjective knowledge as one of the central sources of information for understanding a phenomenon. It was designed as a method for those motivated by the needs originating from their own clinical practice. Thus, when applying interpretive description, it is crucial to reflect on one's own position within the discipline, and understand one's motivations, biases and consequent way of studying a phenomenon.
- 2) There is a socially constructed element to human experience and acknowledging it is essential to understanding that experience. Consequently, the social interactions and context play an important role in conceptualising any phenomenon.
- 3) Human experience involves multiple realities that may be contradictory, i.e. people's self-identification may often not match their actual behaviour. It is vital to be aware of the existence of these contradicting realities and to withhold any premature interpretation of a phenomenon before completing the full analysis.
- 4) It focuses on an individual experience of a phenomenon as well as on shared experiences within groups of individuals. As such, both group commonalities and individual perceptions are the focus of interpretive description.
- 5) Findings emerge from the data and should be considered within the data context. While they may be relevant to a phenomenon of clinical interest more broadly, they are necessarily bound to the time and setting of a study. Interpretive

description should not be used in order to make general statements about a phenomenon, but to explore and improve our understanding of it.

The theoretical foundations of interpretive description require a researcher to take a holistic approach to the investigated phenomenon. Instead of formulating a priori hypotheses, the researcher explores real-world situations as they are revealed in an assumed web of multiple realities. Studying these realities separately would not allow us to explore how these realities interact with one another (Guba & Lincoln, 1982). Therefore, one needs to consider not only the subject and their reality, but also that the researcher and the participant influence one another through their interaction. In doing so, they create a new shared reality. The existence of that new reality may challenge the researcher's understanding of the researched phenomenon and can change multiple times as the data collection continues. Yet, in interpretive description, both the researcher and the participant should agree with the resulting interpretation of the data.

An alternate approach to this research given the focus on experience might have been phenomenology. However, in interpretive description was selected due to the focus on producing clinically relevant findings. Thorne (2008) promotes the use of existing disciplinary knowledge to provide the foundation for the work, and advocates for a pragmatic approach where methods are selected on the basis that they can produce clinically meaningful findings, rather than being informed by a specific philosophical tradition (as is the case with phenomenology). For example, some work has been informed by a van Manen's hermeneutic approach (Earl, 2008), and others take advantage of analytic procedures such as those used in grounded theory (Carbines, 2008) to enhance rigour. Despite subtle differences, all interpretive description studies seek to provide a grounded and contextualised interpretation of a clinically-relevant phenomenon (Hunt, 2009). The attention to real-world settings allows focus on a

researched phenomenon itself, but also makes the findings more understandable and relevant to the investigated population (Teale, 1982). Such findings may offer a conceptual framework to inform improvements in current practice (Mayan, 2010).

Central to designing and conducting an interpretive description study is an early focus on the credibility of such a study. Interpretive description seeks timely and contextualised results, and emphasises the expert knowledge of the researcher (Oliver, 2012). It is informed by a literature review and by the researcher's understanding of practice (Thorne, 2008). However, this brings about a risk that the researcher will seek evidence that proves his pre-understanding of a phenomenon, rather than allowing the findings to emerge from the data. This may result in a violation of the abovementioned principles of interpretive description (H. Hsieh & Shannon, 2005; Thorne, 2008). In order to enhance the study's credibility, it is of crucial importance that the researcher reflects on their experiences and assumptions prior to commencing data collection. Using explicit *analytic logic* and acknowledging the researcher's *interpretive authority* will further strengthen the study's credibility (Thorne, 2008). A more detailed description of the strategies used to enhance the rigour of the current study is presented later in this chapter.

Given the topic of this investigation, design of this study required a further consideration of other theoretical influences on this work. As noted in *Chapter Two: Literature Review*, key theoretical influences in the area of stress and coping suggest that psychological stress arises from an interaction between person and environment (Lazarus & Folkman, 1984; Selye, 1976). Central to that experience is the role of cognitive appraisal (Lazarus & Folkman, 1984). This is consistent with the epistemological assumptions of social constructivism, where meaning-making and construction of the social and psychological realities occurs through individual

cognitive processes. As such this research is also underpinned by social constructivism (Bruner, 1990; Vygotsky & Cole, 1978), since it allows the researcher to investigate how phenomena are constructed and to be responsive to their context (Young & Collin, 2004).

3.1.1 Why is interpretive description an appropriate methodology for this research?

Choosing the appropriate methodology is an important step in the research process. It depends on the research question but also on assumptions the researcher holds, and their own perspectives on knowledge. After a careful consideration of a number of approaches, interpretive description was chosen as the most appropriate methodology for this study.

This study was driven by the researcher's interest in formal carers working in the context of inpatient healthcare facilities and the challenges they face. The findings of this research needed to be easily understood by staff within those facilities and translated into practice. Interpretive description has been designed to address such practice-driven investigations and has been widely used for that purpose (Hunt, 2009; Kathleen, 2006).

Chapter Two: Literature Review identified the issue of work stress in formal caregivers has not been investigated before in NZ, making this study an exploratory one. Although, a body of knowledge about stress exists, the theories attempting to explain it [for example, Stress appraisal model (Lazarus & Folkman, 1984)] indicate that stress is a context-dependent phenomenon. Thus, investigation needs to be located in the specific context of interest. One of the main hallmarks of interpretive description is that it assumes that phenomena are socially constructed. As such, it is particularly applicable

to the current study, in which an exploration of the social context and interactions plays a crucial role in understanding the concept of work stress in formal caregivers.

The work environment of a formal caregiver consists of a number of vertical and horizontal relationships. Formal caregivers have to care for the facility patients, but also deal with their family and friends. They need to work together as a team and liaise with the facility management. Focusing the study of this phenomenon on only one of these relationship levels would limit our understanding of the complex reality of caregivers' work stress. Interpretive description assumes the existence of multiple and potentially contradictory realities. As such, it provides a useful framework for investigating the relationships and roles that the caregivers develop with different people.

In view of my interest in work stress and the process of appraisal, grounded theory (Charmaz, 2014) was considered as a potentially appropriate methodology. However, the development of a theory was beyond the primary aim of searching for timely and contextualised knowledge. The other contending methodology was qualitative description (Sandelowski, 2000). This was rejected given the researchers intention of not only describing participants' experiences but also providing a layer of interpretation. Therefore, given the primary goal of interpretive description is to develop practice insights and inform practice, it was considered the right fit for this study.

Given the above considerations, interpretive description appeared to be the most appropriate methodology to develop an understanding of work stress from formal caregivers' perspectives.

3.2 Methods

This section provides the rationale for participant selection, data collection and analysis, and ethical and rigour considerations.

3.2.1 Research Question

This study was conducted with the intention of investigating two main questions:

- a) What are formal caregivers' experiences of work stress?
- b) What do formal caregivers perceive as influencing their experience of work stress?

It was expected that exploring these questions would allow for a better understanding of caregivers' work stress, and provide an interpretation of that experience by identifying relationships, similarities and patterns (Thorne, 2008).

3.2.2 Sampling

People were eligible to take part if they were non-health professional formal caregivers (for example carers, nursing assistants, rehabilitation coaches or similar), were currently working as a formal caregiver in an inpatient healthcare facility (including but not limited to rest homes, residential rehabilitation facilities, private hospitals) and if they:

- 1) were 20 years or older;
- 2) were NZ residents or citizens;
- 3) had at least one year of documented experience in their role; and
- 4) were working more than 20 hours per week.

3.2.2.1 Rationale for inclusion criteria.

The aim was to recruit people who were 20 years or older. This criterion was used in order to recruit people of working-age, but minimise recruitment of people for whom paid work was not one of their main life activities (for example, university or high school students).

Participants needed to be NZ residents or citizens for two main reasons. NZ immigration processes can be difficult and stressful for new immigrants. While participants could have been affected by a range of life stressors that a study cannot control for, settling down in a new country puts people in a unique situation, making their lives somewhat different to people who are not going through that phase (Levitt, Lane, & Levitt, 2005). Importantly, a recent report (Ravenswood et al., 2014) estimated that over 30 % of NZ caregivers are immigrants. As this study was focused on work stress, rather than general life stress, the intention was to recruit people whose work was not affected by this potentially stressful process.

Furthermore, to become a NZ resident or citizen, a person needs to be able to communicate in English. On this basis, this criterion also increased the likelihood that potential participants could speak English and would therefore be able to take part in an interview (see exclusions below).

A further inclusion requirement was that people should have at least one year of caregiving experience and be working as a caregiver for at least 20 hours per week. The expectation was that this would ensure that people had a good understanding of the demands and challenges of caregiving and would have a wide range of experiences to reflect on during the interview. Furthermore, working as a caregiver for at least 20 hours per week, would increase the likelihood that it was the participants' main paid employment.

As data collection was based on verbal communication, participants needed to be able to communicate with the researcher. Therefore, there were two exclusion criteria: 1) communication or cognitive impairments that would preclude participation in an in-depth interview; and 2) non-English speakers.

3.2.2.2 Sampling method.

This study used purposive and theoretical sampling, consistent with interpretive description methodology (Thorne, Kirkham, & MacDonald-Emes, 1997). Initially, a subset of four formal caregivers was planned to be purposively selected for diversity in ethnicity, gender, years of work experience and level of education. As the majority of caregivers working at the study recruiting localities were women, it was difficult to find male participants who would be eligible and willing to consent to the study. After the initial four interviews and analysis of the collected data, the focus on recruiting a male participant increased. NZ European participants were also sought, as reportedly they form a large proportion of the caregiving work force (Badkar, Callister, & Didham, 2009). Early data analysis suggested that cultural and ethnic background might be an important factor in how caregivers experience work stress. Therefore, attempts were also made to recruit people from a diversity of cultures and ethnicities, including those born outside NZ. Further data analysis highlighted the role of educational attainment in how people perceive their work and work stress and this criterion guided further recruitment for the study.

Drawing on interpretive description methodology (Thorne et al., 1997) and sample sizes of similar studies (e.g.,(Murphy, 2009)) a decision was made to recruit to the point of data saturation² (Coyne, 1997) or to a maximum of 15 participants with diverse experience (due to time and resource constraints). The ongoing analysis suggested that

² Data saturation – a point in data collection when no new information or perspectives on the investigated phenomenon are offered.

the ninth and tenth interviews yielded no new categories or themes, indicating that further interviews were unlikely to have a significant impact on the findings of this study. Hence, recruitment stopped at 10 participants.

A number of attempts to recruit male participants were made. Out of six men contacted during the 8 months of recruitment, only one consented to participate in the study. Given the time constraints of this project and the number of unsuccessful efforts to recruit more male participants, further recruitment was stopped even though only one male participant was recruited.

3.2.2.3 Recruitment.

The first phase of recruitment for this study was through two local inpatient long term rehabilitation facilities. Initially, only these two facilities were chosen as it was expected that a sufficient number of participants will respond to the study invitation. A pamphlet was distributed amongst staff by a nominated representative at the recruiting locality and sign-up boxes were provided in staff rooms for staff to indicate their interest in hearing more about the study. After discussion with recruiting localities, a decision was made that either the receptionist or the health and safety representative at each locality would make the initial invitation and distribute leaflets, as participating localities identified them as the most appropriate neutral party in the organisation. This approach was used to ensure that senior staff were not involved in directly facilitating the recruitment process.

After two months of recruitment and only one consenting participant, other recruitment sources were explored including inviting participation of formal caregivers at rest homes and other residential facilities providing a hospital level of care. However, after gaining ethical approval and a number of emails, phone calls and meetings with facility managers there was no response from caregiving staff. Following this, staff unions

representing caregivers were contacted. A delegate of one of the unions suggested posting an advertisement in their monthly newsletter. This strategy proved successful and a number of people emailing to indicate their interest in the study. Many of them were not currently working as caregivers and/or did not meet other inclusion criteria (for example, they did not have one year or more work experience). However, a list of potentially eligible people was created and used later when theoretical sampling procedures were enacted.

3.2.2.4 Informed consent.

People who indicated their interest or wished to be contacted were given both a verbal explanation of the study and a study information sheet (see *Appendix A*). Potential participants were also given an opportunity to ask questions and time to consider their decision. The study information sheet and consent form (see *Appendix B*) were reviewed with each participant prior to consenting. This was an important process, which allowed for discussion of the study aims and procedures, but also helped build a relationship between the researcher and the participants.

3.2.3 Data collection

Data for this study were collected using semi-structured in-depth face-to-face interviews (see *Appendix C*). This method allows exploration of personal experiences of the investigated phenomenon (Charmaz, 2014). Observation is another method that is increasingly used in qualitative research (Kawulich, 2005). However, it was not considered desirable for the current study as the focus of this research was on the perceptions of the caregivers' experience of work stress and not on the researcher's interpretation of what constituted a stressful experience, based on observation.

Furthermore, observation was also considered not feasible as the nature of a caregiver's role, i.e. assisting people with their lives, would require obtaining consents from all the

people who they interact with during their shifts. Therefore, consistent with the aims and purpose of this study, interviewing was chosen as the data collection method.

The interviews lasted between 30 to 60 minutes. Initially, questions explored the participants' caregiving role, including sharing which parts of their work they enjoy and how they define 'stress'. Next, participants were invited to recall and describe a stressful work event experienced in the last month. This was followed by further prompts exploring perceptions of formal caregivers with respect to self and their work environment. The main prompts focused on: a) perceptions of the stressful event's severity b) what was stressful about it c) what was taken into consideration when appraising the event at the time, or after. After preliminary analysis of the first group of interviews, prompts were reviewed and refined in order to allow a deeper and more nuanced exploration of work stress experiences. Each interview was digitally recorded and transcribed verbatim.

In addition, some basic demographic information such as gender, age and ethnicity were collected.

3.3 Data analysis

Data analysis in interpretive description, like in most qualitative research methodologies, starts from analysing specific situations and moves toward broader generalisations. This process is called inductive reasoning (Thorne, 2008) and it guided the data analysis in this study. Consistent with interpretive description, data collection and data analysis occurred simultaneously, i.e. one informed the other (Thorne, 2008). Additionally, some analytical tools more commonly associated with grounded theory

(Charmaz, 2014) were used to further enhance interpretation, i.e. memoing to track the decision making process, and constant comparisons within and between categories to facilitate the thematic analysis.

Interviews were transcribed verbatim and this process itself formed part of the analysis process with each interview being transcribed as soon as possible following the interview, allowing familiarisation with the data. Transcripts were then read multiple times before structured analysis started.

The initial analysis focused on getting to know the way each participant understood their role, work environment and stress in general. Once an understanding of a participant's background was formed, an interactive process of data coding, theme identification, memoing and diagramming started (Charmaz, 2014). Throughout the process, coding remained the primary form of analysis. Details of these core analysis processes are discussed further below.

3.3.1 Coding

Initially each transcript was analysed separately using line-by-line coding (Charmaz, 2014). Throughout the process, codes were reviewed multiple times by the study's supervisors as well as by the researcher. If necessary, codes were refined with the aim of letting them remain open, short and close to the data (i.e. coding short passages of data with participant's own words; e.g. "helping people"). To avoid too much focus on the 'micro' detail in the data, the coding process was also guided by Hunt's (2009) recommendation, where line-by-line coding was conducted with some general questions in mind. This included: What is happening here? What does this mean? What am I learning here? What is this saying about work stress? The initial line-by-line coding was followed by coding larger extracts of data, which allowed further refinement of codes and helped in naming a number of code categories.

Following coding each participant's transcript, analysis moved to comparing codes and categories across the data from all participants. This was an iterative process and was continued throughout the data analysis as each new data set was collected. This is considered fundamental to interpretive description studies (Hunt, 2009).

3.3.2 Theme development

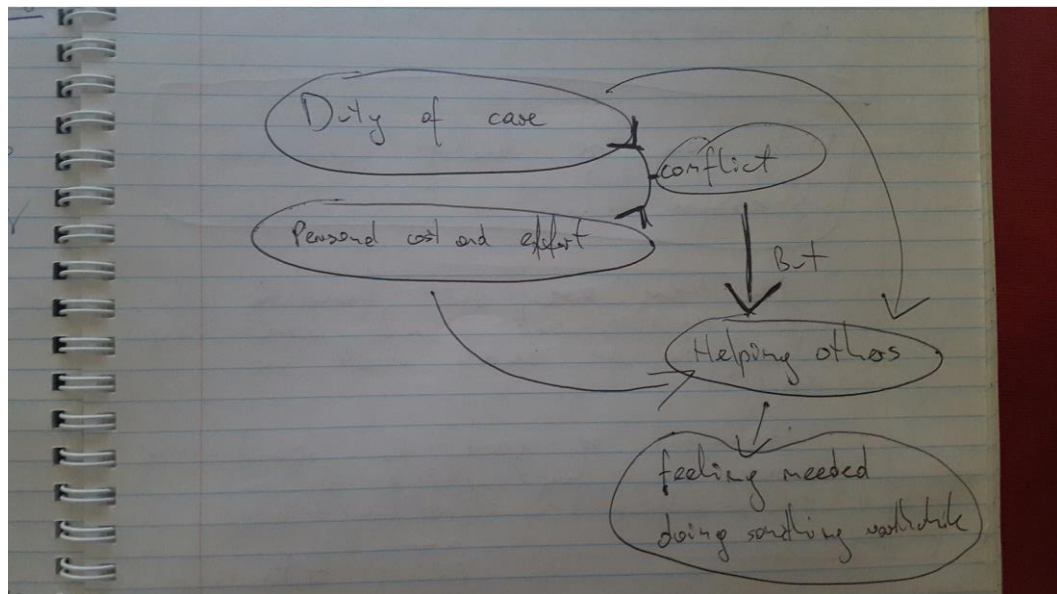
The coding was followed by the process of theme development used for identifying, analysing and interpreting themes within data. Themes can represent a pattern or meaning within the data set.

The codes and categories that were identified during coding were organised into potential themes along with relevant data extracts. All identified patterns and relationships were challenged with two main questions in mind: "What am I seeing here?" and "Why am I seeing that?" (Thorne, 2008). The themes were reviewed and related back to the data to challenge initial ideas and see whether proposed patterns were in fact present in the data. During that process, themes were clearly defined and named. Themes identified in thematic analysis guided the write-up of study results. Using thematic analysis and constantly going back to the transcripts helped verify the results and ensured that the resulting interpretation was grounded in the data.

3.3.3 Diagramming

Diagramming was used to supplement the analysis (Figure 2). It helped to visualise the patterns appearing in the data across codes and categories. This method allowed a more structured approach to analysis and helped to identify inconsistencies and gaps within it.

Figure 2: An example of the researcher's diagram.



3.3.4 Memoing

After the completion of each interview, time was spent reflecting on what was said, creating memos (Charmaz, 2014) and noting emerging ideas about the experience of caregivers' work stress. Ideas that emerged during transcription, coding, thematic analysis and diagramming were also memoed. Writing memos facilitated the process of familiarisation with the data, capturing and challenging the researcher's early thinking about it, and informing the data analysis.

3.3.5 Managing assumptions

This study was motivated by the researcher's personal interest and experiences of caregiving and work stress. Hence, a number of assumptions (as detailed *Chapter One: Introduction*) had to be identified and challenged throughout the data analysis.

The most important formal mechanism that helped to uncover the researcher's assumptions were meetings with the study supervisors throughout the data analysis process. The discussions held at those meetings highlighted other possible interpretations of the data. Consequently, this helped to refine the analysis. One example of such an assumption was when a participant described the relationship with

their patient. At first, it appeared that the experience of stress was caused by a cultural difference between their country and NZ, i.e. that in their country of birth, as a healthcare provider, they were used to being treated with respect and given absolute authority in such relationships. However, the interpretation that this stress was caused by a cultural difference was challenged by the supervisors and the data was re-analysed. It led to concluding that the *nature of the relationship* was crucial to the experience of stress, and not the cultural difference itself.

Other mechanisms that helped manage the researcher's assumptions were: memoing and conversations with fellow researchers and others who worked or used to work as caregivers.

3.3.6 Checking interpretation

The study supervisors were closely involved in the study and their involvement was crucial in checking the data interpretation. They were involved in reviewing the interview transcripts, and discussing the codes, themes and diagrams. Regular supervisory meetings guided the researcher throughout data analysis and helped to interpret the data and refine ideas and conclusions. As previously mentioned, their involvement was very important in managing the researcher's assumptions.

3.4 Ethical considerations

This study received approval from the AUT Ethics Committee (see *Appendix C*). Any amendments to the study design (e.g. recruitment, as previously described) were approved by AUT Ethics Committee prior to their implementation.

3.4.1 Participant distress

Recalling stressful events can sometimes be distressing. All participants were advised about available counselling organisations through the information sheet. Efforts were made to have a short debrief conversation after the interview to help the participant deal with any distress and to remind them about the counselling opportunities.

3.4.2 Voluntary participation

Participation in the study was voluntary. Initially, potential participants were identified by their employers (i.e., all employed caregiving staff deemed potentially eligible) and were sent a study invitation. They were instructed to contact the study researcher if they wanted to hear more about the study.

During recruitment, some of the consenting participants discussed the study with their co-workers and if interested, they provided them with my contact details. On a few occasions, potential participants contacted the study researcher directly to indicate their interest having heard about the study via a colleague.

All participants were informed a number of times of their right to withdraw from the study at any time. As previously mentioned, efforts were made to minimise the involvement of management staff in the recruitment, i.e. the invitation letters were sent by Health and Safety Representatives at recruiting localities given their neutral relationship to caregiving staff.

All participants reported being grateful for the opportunity to provide data to the study, with a number of them seeing the chance to reflect on their work stress experiences as a form of therapy.

3.4.3 Confidentiality

Participation in this study was confidential. In order to maintain participants' confidentiality:

- 1) The data was transcribed by the study researcher;
- 2) Participants' names were replaced by initials (transcripts, recording files' names) and pseudonyms (thesis, reports, dissemination);
- 3) Identifiable information was edited out from the data (e.g., partner's name, home address);
- 4) The consent forms were stored in a locked filing cabinet in a secure area at AUT University; and
- 5) Digital information was stored on password protected computer domains.

3.5 Credibility

Thorne (2008) recommends four key principles that should be applied to studies across the qualitative methodology spectrum in order to ensure high scientific rigour: epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 2008).

Epistemological integrity requires consistency between the study design and the epistemological assumptions (Thorne, 2008). As explained in this chapter, the study design was guided by the key principles of interpretive description. Such an approach ensured the sound epistemological integrity of this study.

Representative credibility refers to the consistency between the study findings and the sampling and data collection methods used, i.e., a study investigating a phenomenon

within one group of health care workers should not make claims about that phenomenon being common across all worker groups. As described above, a purposive sampling approach was used in this study with a key aim being to seek diversity in key characteristics, consistent with the principle of maximum variation (Glaser & Strauss, 1999). Furthermore, data analysis was strengthened by using a combination of different analysis methods, i.e. coding, thematic analysis, diagramming and memoing. Additionally, the *Chapter Four: Findings* includes a significant amount of raw data, enabling the reader to evaluate the credibility of interpretation themselves.

Finally, an interpretive descriptive study should reflect *analytic logic* and *interpretive authority*. The analytic logic refers to the researcher's reasoning being explicit, whilst the interpretive authority ensures that the interpretation is trustworthy (Thorne, 2008). In this study, it was important to reflect on the researcher's pre-existing assumptions about caregivers and their work stress due to the fact that the researcher had worked as a caregiver himself. These assumptions were detailed in *Chapter One: Introduction*. In order to reflect interpretive authority, it is important to interpret the findings in light of the specific study context. To help ensure that, data about participants is provided in Table 2. Furthermore, in line with Thorne's guidelines for interpretive description (2008), no a priori codes were used. Regular supervision meetings, records of analysis decisions and a detailed account of the analysis process (as outlined in the 'Data analysis' section) further strengthened the interpretive reasoning.

Although qualitative studies have been sometimes criticised for lack of clarity and rigour (Mays & Pope, 1995; Neergaard et al., 2009), application of the abovementioned criteria helps address these allegations and enhance the academic credibility of this study.

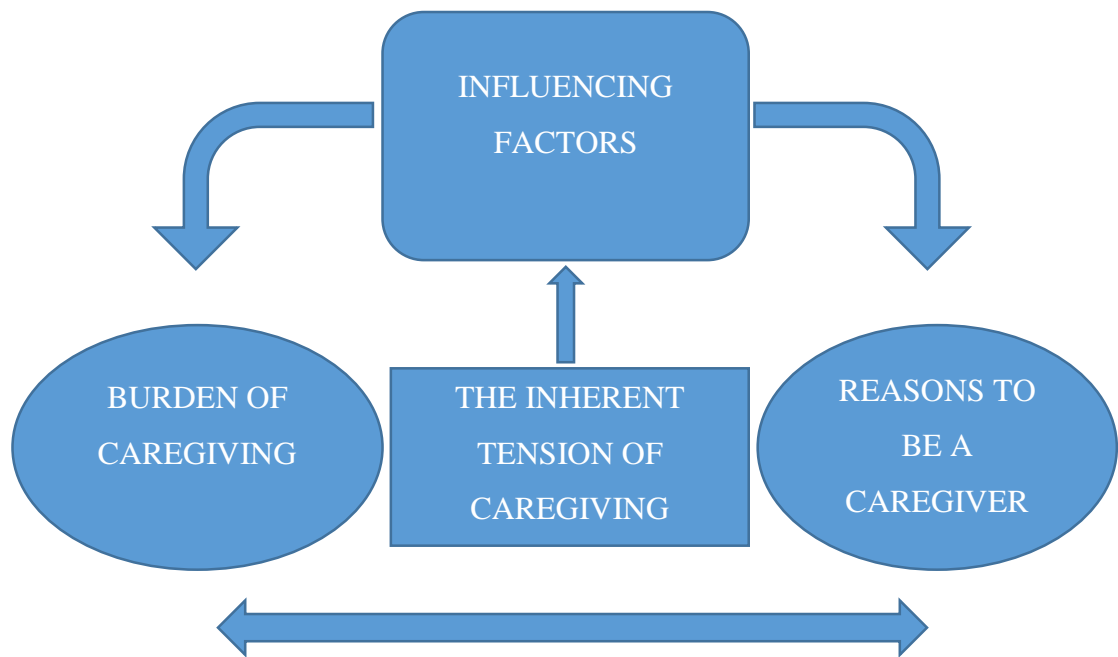
3.6 Summary

This chapter has described what interpretive description is, and why it was appropriate for this research. The strategies that were used to recruit the participants, and collect and analyse the data have been presented. The next chapter will report the findings of this study – experiences of caregivers' work stress and their perceptions of what influences that experience.

Chapter Four: Findings

Work stress for the participants of this study appeared to be an everyday experience of having too much to deal with and feeling under constant pressure. At the same time, it seemed to be a complex and fluid experience representing an inherent, dynamic tension between *reasons to be a caregiver* and the *burden of caregiving* (Figure 3). Outcomes of those stressful experiences seemed to be governed by a range of influencing factors.

Figure 3: The inherent tension of caregiving.



This chapter will first describe the study participants. Next, it will discuss the definitions of stress provided by the participants, followed by the presentation of key themes regarding the nature of work stress with particular focus on the *reasons to be a caregiver* and the *burden of caregiving*. Finally, the factors influencing the experience of work stress, namely person context, work environment and coping strategies will be discussed.

4.1 Participants

In total, 34 caregivers were approached in person by the researcher, 15 of which met eligibility criteria and were invited to participate in the study. Of these, four indicated they were too busy. One person who initially agreed, eventually decided that they “did not feel comfortable” taking part due to concerns that their private views might not remain confidential.

Table 2 presents the demographic characteristics of the consenting participants. The study sample includes participants from a diversity of age groups (median age=41 years), ethnicities and years of experience (median experience=4 years). As such, the sample allowed exploration of a breadth of experience. It is worth noting that six participants were NZ immigrants and five of them completed a post-secondary qualification.

Table 2: Demographic characteristics.

Pseudonym	Gender	Age range ³	Country/region of origin ⁴	Years of experience	Educational attainment
Helen	F	50-59	Pacific Islands	4	Tertiary school
Valerie	F	30-39	Asia	2	Tertiary school
Patricia	F	30-39	North America	7	Tertiary school
Jim	M	50-59	NZ	6	Secondary school
Amanda	F	50-59	Pacific Islands	16	Secondary school
Rosie	F	60-69	NZ	16	Tertiary school
Stacey	F	30-39	NZ	2	Secondary school
Olivia	F	20-29	Asia	1	Tertiary school
Diane	F	40-49	NZ	4	Secondary school
Lana	F	30-39	South America	2	Tertiary school

4.2 “What does stress mean to you?”

One of the initial questions asked of the participants was “What does stress mean to you?” Every participant had their own definition and opinion on what stress was. For Stacey, a “certain amount of stress is good because it puts pressure on you, you make sure that you are doing everything the right way.” Olivia also felt that stress “at times (makes her) get things done faster”. However, as she reflected, only a “certain amount of stress” can be good and only “at times”.

³ Age range rather than specific age is reported in order to protect participants’ identity.

⁴ For people not born in NZ, region of origin is reported rather than specific ethnicity, in order to protect their anonymity.

For most of the participants, stress was perceived to be negative as well as having the potential to impact on the quality of care they provide. When Olivia was asked what stress meant to her, she explained:

“Like you sort of... your mind is in too many things at the time. You are sweating, rushing ... because of the rushing you are not able to give quality of work in those tasks. You are multitasking and you are not able to give quality to each one.” (Olivia, 1 year of experience)

Experiencing stress often appeared to be associated with “pressure”. For some, this pressure was about not being able to do things on time or “not being able to make decisions straight away”. Lana reported there was a “terrible pressure” from management and no one cared if she was tired or “had stress”. Valerie noted stress could on one hand be a result of the person’s actions, “an outcome of my own mistakes”. On the other hand, stress could be “coming from outside”, i.e. caused by situations that had “nothing to do with her”. Valerie believed this type of stress was more difficult to deal with for her as she could not control it; it “just comes”.

Stress was also perceived to be a physical experience. These experiences included shaking, headaches, sweating. When discussing stress in general, Amanda retorted:

“I, a few years ago, totally body just shut down. I worked in one house and it was physically demanding, and mentally demanding. And then you had your managers on top of you and just the whole organisation. And I think I overdid it. I think I just wanted to do too much. And just physically ... just sort of collapsed. (...) Physically just exhausted, totally stressed and the body just stopped working.” (Amanda, 16 years of experience)

In general, stress appeared to be both a mental and a physical experience. In some cases, it seemed to help people “get things done faster”, but most of the participants reported that work stress was a problem, and had a negative impact on them and their ability to provide quality care.

4.3 The inherent tension between the reasons to be a caregiver and burdens of caregiving

The stories described by the participants appeared to revolve around the reasons to care and the burden of care. The coexistence of these two aspects represented the tension inherent in caregiving. Arising from that tension were the participants' work stress experiences.

4.3.1 The reasons to be a caregiver

During interviews, caregivers described a number of reasons why they wanted, or had, to do this job. There appeared to be two main categories:

- Commitment to care;
- Making ends meet.

4.3.1.1 Commitment to care

For a number of participants, caregiving appeared to be about helping vulnerable people. Helen, who had originally left her "office job to care for both her parents" did not want to go back to the corporate world and "wanted to do something that [she] felt would be more in the way of helping others." The participants often compared caring for their patient to caring for their relatives. Lana felt that caring is like "looking after your mother and father" and that one would not "put his family in a place where they cannot look after people well". When asked about the reason to become a caregiver, Diane answered:

"I have a nephew who is severely intellectually disabled. Who lives in Brisbane. And yeah, I know how I would like my nephew to be looked after, so it's just a follow on from that." (Diane, 4 years of experience)

Rosie enjoyed helping her patients as it made her see that she "made a better difference in their lives". She also wondered whether it could be a "big ego trip" – thinking that the patients' lives "are better for you having been there". Although it was "nice" for her to see she "is making a difference", Rosie appeared to genuinely care for her patients and wanted them to "blossom and become more independent".

Importantly, helping others or simply "making somebody else's life really happy", as Amanda put it, did not seem to be stressful in itself. The caregivers in this study

appeared authentically concerned about helping their patients “achieve personal goals, dreams and aspirations”. When discussing caregiving in general, Helen reflected:

“I imagine if that was my son or that was my mother or father. What sort of person would I want working with them when I am not around, and it wouldn’t be a lazy worker, or a worker that didn’t care, you know what I’m saying.”

(Helen, 4 years of experience)

When talking about their work, many participants appeared to be really passionate about what they do. For Stacey, caregiving was “kinda the best job”, where she got to see “people go from being very vulnerable (...) to walking out the door and going home”. She found it very rewarding. It was similar for Helen, who began her interview saying:

“I just want to say, no matter what I say about my stress, I love what I do, I am really passionate about the people I care for and I work with my heart.” (Helen, 4 years of experience)

Another aspect of the commitment to care which a number of participants described was a sense of responsibility for their patients. Although many participants felt accountable for what they are expected to do by management, their sense of responsibility appeared to go beyond that. Valerie felt that if any emergency situation happened it would be “completely her responsibility” to deal with it. Helen also felt responsible for anything that might happen to her patients. Moreover, she felt responsible for every patient that was in the facility she was working in. Helen reflected:

“So in my head, constantly, I just... If I am working with this client, in my head I am thinking: I need to go and see what so and so is doing to make sure they are OK.” (Helen, 4 years of experience)

Some participants felt responsible not only for the people they directly worked with, but for all patients within their facility. On one occasion, when she was driving to have a lunch with her friend, Diane saw one of her service users standing at the intersection and looking lost. She decided to “abandon what she was doing” and approached that person. She found out that the patient decided to leave the facility without telling anyone. When Diane took him back to the facility, staff who were on duty, told her that they “did not want him there. He was performing.” She concluded her story:

“Here I am on a day off, going completely and utterly out of my way to make sure that this person I don’t even work with, I don’t even support him in his facility, but here I am with that stress of making sure he gets home.” (Diane, 4 years of experience)

The sense of responsibility for patients appeared to be an important aspect of caregiving. However, it appeared to drive some participants to feel responsible and accountable for *every* client at *all* times. Helen felt that this might have been one of the reasons for her fatigue:

“I give so much myself, that there’s not much left of me when I finish my shift at the end of the day. I don’t know if I have to give that much of me, but I do. Like I said, I feel responsible and accountable.” (Helen, 4 years of experience)

Interestingly, for many study participants their identification with work was so complete that a patient’s success often felt like their own. Some of the participants stated they were “achieving goals for people”, rather than just helping them in those achievements. To that extent, being able to help other people provided a feeling of satisfaction and personal success as a caregiver.

The participants of this study seemed to have a huge sense of empathy and wanted to see their patients happy. Driven by the commitment to care, they often did “their utmost best plus more” to help their patients live the best life possible. For many, the commitment to care was the main reason to keep doing what they do.

4.3.1.2 Making ends meet

Some participants simply reported needing a job to be able to pay their bills and provide for their families. For both Lana and Valerie, who were new immigrants, caregiving was their first job in NZ. They “really needed a job” and “had no other choice” but to become caregivers. When discussing difficult times at work, Lana reflected:

“And I don’t want go to job. I go, but I am not happy. Cause I need the money. (sic)” (Lana, 2 years of experience)

Caregiving was also an important source of income for Helen and Amanda. Even though she was already experiencing a range of health issues caused by working long hours, Helen felt she still needed to sacrifice her health “to make ends meet” and kept asking for extra work hours. On the other hand, Amanda explained that she was not

worried about her own financial situation as much as for her colleagues. As she had “heaps of leave”, she would often take a day off just so someone else could work her shift and earn the money they needed to support their families.

One of the views which appeared to be common for many participants was that they did not want to lose their caregiving job. Diane felt that she needed to perform her duties well as her job might be at stake. She explained:

“At the end of the day, when things go wrong, it’s my neck on the block. All it takes is one service user to make an allegation that I can’t defend and could be my job gone!” (Diane, 4 years of experience)

Olivia and Valerie, both NZ immigrants, had a health-related tertiary qualification from their home country and getting a job in the NZ health sector was important to them. They were unable to get NZ registration to work in their professions and thought that caregiving “would be a good experience to start as [a healthcare professional]”. They would be able to “learn something about the medical sector in NZ”, “some clinical procedures” and “visit hospital with clients”.

In summary, participants identified a range of reasons to be a caregiver, including both altruistic and pragmatic. These reasons appeared to sit in contrast to the burden of caregiving discussed in the next section.

4.3.2 The burden of caregiving

As well as identifying reasons to be a caregiver, all participants described experiences that reflected the burden of caregiving. Participants referred to a range of complex and interconnected experiences which appeared to represent a conflict between the reasons to be a caregiver (as described above) and their work reality.

Most of the caregivers appeared to put their patients at the centre of their work, thus making the patients’ well-being a work priority. Examples included not going for their break, accidentally injuring themselves and continuing to work, or taking on other people’s roles. By doing so, many caregivers “went above and beyond” what was expected of them by their job description. ‘Going above and beyond’ was a theme underpinning most of the experiences relating to the burden of caregiving.

The participants of this study took their jobs very seriously and appeared to do whatever it takes to “give their clients a quality of life”, as described by Patricia. During the

discussion, she highlighted the fact that caregiving “is not an easy job”, particularly because it involved working “with people who have behaviours, people who have high and complex needs”. Patricia appeared to think that what she was actually doing as part of her caregiving role was more than her job description suggests. She stated:

“It’s a huge amount of work for people to turn around and say: that’s actually your job... which I know is my role, but most of the time we go over to what’s on the piece of paper.” (Patricia, 7 years of experience)

The “fast-paced” caregiving environment required the caregivers to constantly adjust to changing situations. However, Helen felt that caregiving staff worked “their guts out and did their very best and still things weren’t really running smoothly”. Often, the caregivers would give up their break because the procedures they have to do for the patients were taking more time than planned. Valerie described an experience with one of her patients, who is totally dependent on staff:

“When we are doing the procedure, and he is receiving a phone call we have to stop the procedure and leave his room. And we don’t know for how long we are leaving the room. For one hour, for half an hour, for one and a half hour. This is everything... probably he has a right to do what he is doing now... but what about the staff? “ (Valerie, 2 years of experience)

Lana, for whom caregiving was almost “like looking after your father or mother”, also discussed losing her breaks. Even though her contract allowed her to have a 10-minute break, she often did not have one. She thought that it could have been because of the number of things staff had to do every day. Lana sounded very frustrated when she reflected on what was happening at her work:

“We don’t have breaks, sometimes we don’t have breaks. We don’t have lunch time, we lost everything!” (Lana, 2 years of experience)

Although being able to have a break is clearly a worker’s right, some participants felt that this and some other rights were not always acknowledged, including by patients. Valerie felt that one of her patients “did not accept the staff as human beings” and treated them as “piece of routine in their life”. She reflected:

“It’s stressful how he is treating us as very low qualified staff and that we don’t have any rights”. (Valerie, 2 years of experience)

By “not having any rights”, she was referring to the fact that the patient had “all the authority” and had “all the right to decide by himself”. Olivia described a similar situation; however, in her case it was her manager who did not let her explain what happened between her and a patient. She felt that when a patient complained, she had to do whatever the patient wanted:

“[The managers] will always come and say: ok, this person said that and now we are going to do as they want. If they want to sleep in, ok sleep in. There will be no rules for them. There will be then rules for [staff].” (Olivia, 1 year of experience)

Many participants discussed how trying to do their work the best they could resulted in them being very tired and dealing with fatigue in their lives. During the interview, Stacey explained that, although caregiving was a very rewarding job, it did make her very tired, and had consequences for her personal and family life. Often, she did not “want to cook dinner or do anything” and would just “collapse” after a shift. Helen also felt “useless” after her shifts. Just a couple of months before the interview she had a month off work due to burnout and fatigue. When asked about the reasons for her burnout, she explained that she worked “graveyard shifts” (12-13 hours night shifts) consistently for a long period of time. Her eating pattern had changed and she could not fall asleep although she felt tired all the time. Amanda who at one stage was also off work due to fatigue described her situation similarly to Helen’s.

It was quite apparent that the majority of participants struggled to keep boundaries around their work and it often affected their personal lives. Lana stated that she “had no life”.

“I was working during the week, weekends. Swap sometimes for night time. Sometimes I was working 3pm to 11pm, and the next day you had to start 7am. Do till 3pm. And come back again. All like that. Weekends... I had time for nothing, to have an ice cream, go out with my daughter, or with my family...”
(Lana, 2 years of experience)

For Jim, it was especially important to have a “happy house” and keep every patient happy. However, he felt that he often “spends too much time in trying to keep [patients] amused and occupied”.

Participants also described how their work could affect their mood and their mental health. Olivia admitted that she often found herself being grumpy after work. Helen, Lana and Diane were diagnosed with depression and felt that their work could have played a role in their condition. Lana described caregiving as “very, very depressive, and sad, very emotional”. She observed how throughout the years she became numb to her patients dying. In the beginning, when someone died she was very sad and could not believe that person was not there anymore. But it changed:

“Now, if someone dies, it’s whatever for me. Because it’s every day... the same thing.” (Lana, 2 years of experience)

It seemed that she almost stopped seeing a human in another person. Later in the interview Lana explained how counselling played an important role in dealing with loss. The role of counselling will be further described later in this chapter.

The caregivers felt responsible for their patients and saw their patients’ well-being as a priority. However, even though they went “above and beyond” to meet their patients’ needs, they reported being blamed for any shortfalls in the delivery of care. Valerie stated that as caregivers they “have no other choice” but to do what a patient wants. If anything went wrong, “only staff will be guilty”. At the same time, the caregivers “put themselves out there, sometimes for what?” as commented by Diane. She felt “vulnerable with what she had to do” as a caregiver, because caregivers can be involved in a range of emotional and exposing situations:

“You don’t want people to see you crying or losing it. You don’t want people to think that you don’t know how to control yourself in a situation where you are working under pressure. It feels embarrassing. Like not knowing what to do.”
(Diane, 4 years of experience)

The caregivers expected themselves to go above and beyond and be able to give their patients the best lives possible. As reported above, helping others “blossom and become independent” was not stressful in itself. On the other hand, in their work reality, there appeared to be a number of costs and consequences for caregiving that they had to consider. It was that conflict between the reasons to be a caregiver and the burdens of caregiving that created a significant challenge for them and appeared to lead to experiences of work stress.

While work stress seemed evident and inevitable in the participants' stories, no single pattern of getting through a stressful work situation was identified, with the participants finding their own ways of working through these events. The data analysis suggested that a range of factors may influence the experience of work stress. These factors are presented in the following sections along with an explanation of how they appeared to impact on the experience of work stress.

4.4 Factors influencing work stress experience

There appeared to be an inherent tension between the reasons to be a caregiver and the burden of caregiving. However, the experience of work stress was not static; it seemed to be in constant flux. The analysis highlighted a range of factors which may account for that fluidity. Three main categories of these influencing factors included:

- Person context;
- Work environment; and
- Coping strategies.

The following sections describe these influencing factors and explain their apparent role in caregivers' work stress experiences.

4.4.1 Person context

This theme relates to a range of person characteristics which participants identified as influencing their personal experience of work stress, including personal skills, gender, cultural background and personality traits. These characteristics appeared to influence how the caregivers perceived their everyday work, the way they interacted with their work environment and the strategies they used to cope with work stress.

Participants reported there were a number of personal skills which were important. For example, Jim suggested that one of the crucial skills a caregiver needed to have was to be able to listen and "pick out the real problems instead [of] all the one's that are running through [patients'] heads". As Jim reflected, being able to understand what was really bothering his patients helped him identify the triggers for their behaviours. This in turn could facilitate patient management and help avoid unnecessary stressful situations.

Another “skill” that was important for a caregiver was “patience and heart to look after another human being”, as suggested by Patricia. She told a story of a caregiver she knew who worked in Christchurch when the earthquakes happened:

“She left her family. To be there with the guys. So it’s like, that’s fine. I will worry about my family later, this is my job, I am here to look after them, this is my responsibility.” (Patricia, 7 years of experience)

The skills mentioned above did not appear to be trainable and as Lana suggested – “not everybody can work as a caregiver”. However, participants talked also about the importance of practical skills which one can be trained in. Valerie reflected:

“If you don’t know even simple principles of physiology... they don’t even understand what is going on with a client, like our specific client, or we have a lot of clients with diabetes. Or they should be trained maybe...if they don’t have medical background.” (Valerie, 2 years of experience)

Another aspect that seemed to play an important role in influencing the work stress experience was English as a second language. It appeared stressful for both caregivers for whom English was as second language and for other caregivers who had to communicate with them. When she first started working as a caregiver, Lana’s command of English was very poor. She struggled to understand what was being said at handovers and what she read in medical notes:

“I look at the person, what he has, and then this is for me like Japanese, because I understand nothing”. (Lana, 2 years of experience)

Although she wanted to help and wanted the job, the language barrier made her “want to cry” and was “hard and stressful”. Not knowing the language and being new in the country appeared to make her feel lost and vulnerable. “It’s like you are born again”, she added.

On the other hand, born in NZ Jim, described how frustrating working with people “who can’t speak clear English” could be.

“I will sit there and explain what I want, like could be asking for a car, and they are; ok, ok. And then you go down there and they are: oh, did you need it now? and then I go: yeah. And they say: oh but we need it till the afternoon or

something. So I go: never mind. I wish I knew that earlier, when I first phoned you, you know..." (Jim, 6 years of experience)

Cultural background appeared to play an important role in how caregivers perceived their relationship with the patients. Olivia, who was born and raised in India, observed that the relationship between a health care professional and a patient was "very different". She was used to a more authoritative carer-patient relationship and she felt that her patients did not have respect for her.

"Here the doctor has to ask: can I give this or can I do that? It's very different in India. The doctor would just say: have this or I am going to give you an injection. You know, the authority thing (...). There is no respect, there is no sense of authority." (Olivia, 1 year of experience)

Some participants discussed the issue of caregiver's gender. One aspect of it was "a stigma of being a male", as reported by Jim.

"In those days I used to hear things about women trying to get into men's environment, and I kind of got it same way with a man trying to get into women's environment (...). I still think it's there with how males act in the law... like caregiver, support worker, child caregiver or even a nurse aid. There seems to be a stigma about males..." (Jim, 6 years of experience)

Jim explained that, for years, it was difficult for him to find a job as a caregiver. However, now he has a "good team" and being a male does not seem to affect his work.

Helen reported that some patients preferred to be cared for by same-gender caregivers:

"It's very stressful for me if I need a man to put a client to bed and there's not one available. Or I might need another female to help me and there's no one available." (Helen, 4 years of experience)

This could lead to tensions between caregivers and patients and their families. As Helen explained, a patient could feel that his dignity was not protected. Furthermore, delays could occur when no staff were available to shower a patient who was supposed to be showered by male staff only. These tensions could lead to more stressful situations.

4.4.2 Work environment

This theme relates to a range of work environment features including patients and their families, teamwork and communication, recognition and resources. While these features were extrinsic to the participants, they appeared to be interconnected with the person context factors described in the previous section.

4.4.2.1 Patients

As described in the reasons to be a caregiver section, the majority of study participants saw their patients' well-being as a work priority. Thus, not surprisingly, patient characteristics appeared to play a major role in caregiving and potentially stressful situations.

Participants cared for a range of patients including elderly people, people with neurological conditions, people with behavioural problems, and many others. Caring for all these groups of patients might present different challenges. The caregiver-patient relationship appeared to provide an important foundation for managing these challenges and therefore reducing the likelihood of a stressful situation arising. Rosie reported that a good relationship with a patient could help facilitate the management of patients with behavioural problems:

“The unpredictability of self-harming, harming others... you know what's in place and you follow it... but there also comes a point when you've been doing it for a long time that if you know the person very well and have... when everything is smooth, you have a reasonable relationship with them as such, or report, they trust you, like you or respect you... that seems to have more weight sometimes.” (Rosie, 16 years of experience)

“Building a rapport with clients” was also important for Stacey and Lana. Having a good relationship with patients made Lana feel “not stressed about [working with] residents at all”. Stacey believed that it can really help to know her patient and build mutual trust. She reflected on her relationship with patients:

“When they are having behavioural issues, or when they are getting angry, I can calm them down quicker than other people who they don't trust or know. So that's my way of building a rapport with my clients, so when they do get angry, you know, you can kind of get them to calm down a little bit I suppose.”
(Stacey, 2 years of experience)

Some participants felt that their relationship with patients grew beyond their work life. Amanda invited her patients to her husband's funeral as she felt they were "a part of [her] life". Lana considered some of her patients to be her "friends". In their stories, getting close to a patient appeared inevitable. However, it could lead to an increased workload and add to the caregivers' work challenges. When asked about the meaning of getting too involved with the patients, Rosie responded:

"When you are doing residential, it's harder to keep a distance. When you are doing residential. I found it that way. You become involved in their lives. Because you are sleeping in their home, you are helping them with their cares, you are taking them out. You are eating your meals with them. Giving them chores, and you get involved in their lives. It's very difficult not to. You have a lot more to do with their families. It is very hard to sort of keep your pace back."
(Rosie, 16 years of experience)

However, sometimes even a good relationship did not seem to help in dealing with difficult patients. Stacey found that with some patients, particularly those who can go "AWOL⁵" or are angry, there was not much she could do to calm them down. It was very difficult for her to deal with such patients, as on one hand they could harm her, and on the other hand she was not allowed to restrain her patients at all. Such situations "bring [her] the most stress and are the one thing that [she] hates most about this job".

One of the patient characteristics which appeared to cause stress to many participants was the presence of a mental or psychological issue. Valerie observed that many patients "need not only clinical treatments and care" and that they needed "psychological help" as well, which she found stressful.

Another aspect of working with patients who are "mentally affected" which could influence work stress experience was that these patients could sometimes lie about what happened between them and a caregiver. Diane found it stressful, as she reported feeling that a patient would always be believed over staff. She recalled a situation when a patient told what she believed to be a lie to their parent, which Diane could not defend. As a result she had to be redeployed to another facility.

"It came down to the fact, that if I stay there, as good as I am at my job, if I was to stay there, this parent could possibly make allegations against me that I would

⁵ AWOL – (military) Absent Without Official Leave.

not be able to defend. And that would cost me my job.” (Diane, 4 years of experience)

Similarly to Diane, other participants also reported that patients’ families played a significant role in work stress experience. The parents of one of Olivia’s patients appeared to constantly make new complaints and “never giving up”. Olivia felt that family members were often trying to “overrule the things” at the facility, which could be “annoying”. However, her strategy was to not discuss any complaints with patients’ families. Amanda described a patient whose family not only made staff’s work more stressful, but also had a negative impact on other patients.

“We thought [this patient] was going to be a problem, he was very demanding, very... big and could be violent, outburst, but his family were worse. It was like, just the stress in this house was unbelievable. It was horrible. They would walk in here unannounced, they would lie... (...). We couldn’t do anything.”

(Amanda, 16 years of experience)

Overall, patients and their families’ characteristics seemed to influence the experience of caregivers’ stress in different ways. It appeared that the patients could act as a source of support but also as a source of conflict and challenge. Regardless, patient’s and their families appeared to be a salient component of the work environment.

4.4.2.2 Teamwork

Interactions with other team members appeared to affect the work stress experience. As caregiving teams could include a number of people, lack of communication with co-workers could result in misunderstandings and patient complaints. Patricia recalled a situation when a new staff member who she was training did not inform her about a patient developing pressure sores. When the patient was sent home, the family found the problem and complained. As she felt responsible for the patient, she found this situation “annoying” and stressful, because “no one said anything”.

Many participants discussed the role of team dynamics in their work. Olivia felt that she worked in a “big team” and that they had “a good social thing” where staff could talk to each other if they got stressed. Socialising with her co-workers was also valued by Stacey. It allowed her to “destressify” with people who know her and her patients and understand the reality of her work.

On the other hand, some participants reported that they felt isolated in the team, particularly when they were new and not well trained. It was only when she had enough experience to work independently, that other staff wanted to work with Lana. Valerie noted that it was stressful to work with staff who are not trained.

“Sometimes it’s stressful, because a lot of staff they are not working anymore, especially good staff, who had training with that particular client. They left, they just... and when you work with a team, you have to rely on each other. And now all people are new, and if emergency situation happens, sometime you don’t know, can you rely on other person or you should do it by yourself, or you should ask for help, or... this is a problem.” (Valerie, 2 years of experience)

Another aspect which appeared to influence stress experiences when working in a team was gossiping amongst staff. Diane believed that gossiping can disturb good teamwork and can be “annoying”. Patricia suggested that while “you need to get [stress] out” by talking with others, it was important to talk to people who could be trusted and not to those who were “well known for gossiping”.

There appeared to be some tension between the caregivers and registered healthcare professionals (for example registered nurses or physiotherapists). One participant, Lana, felt that the nurse seemed to “just do the meds and that’s it, finished”. Also Stacey thought that there was some disconnection between her and a physiotherapist with whom she attended an in-service.

“The therapist said: look, if you feel like anything needs to be changed, you are welcome to come to us. And I am like: yeah, but I have asked for things to be changed before and it’s taken 6 weeks for something to be done. When I am asking you for getting a new bed because a client is rolling around and he is in pain every night, when I am on a night shift for 5 hours, just going: urghh, urghh! It shouldn’t take you 6 weeks to get this done. It should just be done.” (Stacey, 2 years of experience)

4.4.2.3 Recognition

It appeared that rewarding caregivers for their efforts could have a positive impact on their work and attitude. Being rewarded for her hard work appeared very important to Lana:

“Then I got one certificate, “caregiver of the month”. And so: I did it!” (Lana, 2 years of experience)

It gave Lana motivation to work and enhanced her confidence. However, many caregivers did not feel valued by facility management and by the patients and their families. As caregivers are the people who probably spend much more time with the patients than any other residential care team member, it seemed reasonable to include their views and opinions about a patient in the care planning process. However, for the participants of this study the reality was different. It was very frustrating for Stacey that her opinion did not count:

“Everyone’s here, like therapists, will go, and the key worker. We are never invited to any of that stuff, we don’t have a say. And how the clients rehab is going, so for us. They see them for maximum 5 hours in a week. We see them a minimum 40 hours in a week. Minimum 40 hours. And it can be really frustrating that our opinions don’t count.” (Stacey, 2 years of experience)

The caregivers often felt that they went above and beyond their job description. Some of the participants did that because they had high expectations towards themselves. When talking about her work, Patricia commented:

“It’s not an easy job, especially with people who have behaviours, people who have very high and complex needs. Which are people that people believe they are not capable of doing anything, or doing little.” (Patricia, 7 years of experience)

Patricia saw herself as the person responsible for enhancing her patient’s quality of life and felt she was doing her best to achieve that, even though it was more than her job description would suggest. She sometimes felt her ‘extra’ efforts were not acknowledged by anyone.

On another occasion, when one of the registered nurses did not come to work, Stacey was asked by the shift manager to cover for her. At the same time, due to being short of staff, she also had to cover for another person and perform some tasks that she had not been trained for. She took that responsibility on and tried her best to do what she was asked to do. However, despite her effort, her hard work was not acknowledged.

“I felt pissed off, that it was put on to me, that I am expected to do three people’s roles. It’s frustrating that... the most frustrating thing for me is that you never get thanked for the hard work that you put in.” (Stacey, 2 years of experience)

Many participants thought that they were not being paid enough for what they did. Diane was considering moving overseas due to her low wages.

“I’m seriously at the moment looking at moving to Australia, and doing the same job over there. Simply because they get paid more (...).When I started I was on 14.20 an hour. As a level 1. Now as a level 3 I am on 18.43 an hour. That’s not enough for what I do, what I have to do. For the responsibilities I take on every time I walk in the door at work. It’s not enough. It really isn’t.” (Diane, 4 years of experience)

The low wages seemed to make the caregivers feel unimportant and undervalued. They did not seem to be in a position to negotiate them because they could be easily replaced by someone else “who really needs the job”.

“And the management of the facility doesn’t care if you tired, if you have stress. Because if you don’t want to work, they say if you don’t want to stay here then leave. We will take another one, who really need the job. And it never ends. Because it’s always inside, people inside are leaving because it’s too stressful.” (Lana, 2 years of experience))

The participants did not feel their efforts were recognised and valued by the people they worked with. This feeling, which co-existed with a sense of ‘commitment’ could often create an emotional conflict, where on one hand they felt they were giving ‘their best’ to the patients and on the other hand they did not feel rewarded for their efforts.

4.4.2.4 Resources

Another factor which appeared to influence caregivers work stress experience was the lack of personal and material resources. Most participants reported that they often had to deal with lack of staff during their shifts. It meant, as Patricia suggested, that “all the work is on [one caregiver’s shoulders]”. If another staff member “comes down sick” it often required a caregiver to replace that person. When Valerie had to cover for a sick co-worker, she found herself lost and stressed:

“I don’t know the client. I talk to the client and I ask him what he or she wants me to do, what has to be done and just please tell me if I am doing something wrong. But it shouldn’t be like that. I should know the client. I should know his medical cares and any recommendations for him.” (Valerie, 2 years of experience)

Some participants felt that it was problematic when a new staff member was coming on board. The training period seemed too short and new staff did not appear ready to work independently. This put extra pressure on the experienced staff but also put the patients at risk, as they were supported by people who were not yet ready to work without supervision. Lana identified herself as an example of such unprepared staff:

“One time was, because when I was transferring with the hoist I hurt somebody else in the hand. Then when I did that: oh my god! And I saw blood. I do that, do that, and there’s only one week they train you, people do things for you. And after that they say, whatever, you can do it by yourself now.” (Lana, 2 years of experience)

Sometimes, the facilities would call for agency relief staff. Relieving staff could make work “comfortable”, when used “to help during the busy hours”, as observed by Olivia. However, Patricia felt that being dependent on agency staff can be problematic.

“Not having permanent staff, like if it was staff that normally works in that house in that place, I know they know what to do. So I wouldn’t have to explain them the things they know, like if we don’t do this, this gonna happen, having new relievers, because that means I have to keep training them all the time.” (Olivia, 1 year of experience)

It appeared that as a consequence of staffing difficulties many participants were asked to perform additional roles for which they were not trained or asked to “do job that is not their job”. Participants felt stressed about this as they did not feel that they were competent enough to, for example, give out medication or be responsible for the management of diabetic patient insulin injections. At the same time, they were also asked to “clean the rubbish” or help in the kitchen, which they did not feel was part of their jobs.

Participants also had to deal with a lack of their facilities material and financial resources. Jim found it difficult to plan the activities for his patients as the car he was using was shared with other facilities.

“You phone the house with the car and you go round, and then they might need it. And then you might have to come all the way back again, so... it’s usually if it’s something urgent or... you’ve got to plan and do everything to make sure you have got a car for the day for that person, but it’s quite hard sometimes. Because you are actually taking... going to another house to take a car, you are actually taking away from them.” (Jim, 6 years of experience)

Lana appeared frustrated about the fact that every time she needed to change a patient’s diaper, she had to find the nurse and ask for it. She thought it would be better to have spare diapers in the patient’s room. However, in this facility there was supposed to be “just one [diaper] each” and that was “the rule of the facility”.

4.4.2.5 “Stressed every day”

Participants described a range of characteristics which they believed were specific to caregiving. Many caregivers reported that stress is constant in their work. For example, Valerie “felt stressed every day”. Helen felt that giving care to people with brain injuries was just “challenging”. She reflected:

“If you are not prepared to have those things on your shift, you’re in the wrong industry, basically.” (Helen, 4 years of experience)

A number of caregivers highlighted the fact that the caregiving environment was “fast-paced” and “demanding”. Stacey, who worked as a chef prior to becoming a caregiver, felt that stress levels in caregiving were high, but somewhat different to what she had experienced before.

“This is just a different of stress. It can fluctuate from; oh man it’s been such a crazy day, to oh my god, when am I going home?!” (Stacey, 2 years of experience)

Another aspect of caregiving which added to the difficulty was unpredictability. Many participants talked about the unpredictability of their patients in terms of not knowing what to expect from them but also not being able to plan ahead. Rosie talked about a patient she knew who had attacked her one day without warning. Since then she always

had been concerned about what he might do next. Olivia, who liked to prepare herself and plan her day, reported feeling stressed when work “did not happen the way it should have”.

Participants appeared to be trying to do “their best” for the patients. However, a work principle that appeared to stand out was to keep their patients safe at all times. As mentioned previously, Diane was concerned about her patients even on her days off and believed that she needed to “make sure they are safe”. As a new staff member, Olivia injured herself when trying to get another staff member to help her safely transfer a patient. For her, a patient’s safety appeared to be of the highest importance. Olivia recalled the situation when she fell and injured her leg:

“I went into clients room and I saw that he was safe and then I just relaxed in that room because my knee was really hurting [laughter]. So I had to drink a glass of water and calm down. And then start with the cares. I ignored that pain till all was done”. (Olivia, 1 year of experience)

The stories presented in this section highlight the strong sense of responsibility that caregivers felt for their patients. They showed that work stress experiences in caregiving were complex and dynamic. The next section discusses the coping strategies participants described in managing their work stress.

4.4.3 Coping strategies

Participants in this study reported using a range of coping strategies. Some of the strategies appeared to be proactive, for example, resting before the shift or planning the work. However, the majority of the strategies were used in response to a particular stressful situation.

Some caregivers appeared to be proactive with regard to their work stress and described how they prepared themselves for work and stressful situations. When asked whether she prepared herself for work stress, Helen retorted:

“Yeah. I guess that’s why I go to work early, so I don’t have to walk in the door and walk straight into starting work. I can ease slowly into it (...). And I try to have some downtime at home before I go to work. I don’t wanna be busying myself right up to the minute I leave home.” (Helen, 4 years of experience)

Olivia and Valerie also believed that adequate rest is important, especially if “the next day was going to be stressful”. Moreover, they also suggested that a proper diet was important for work stress management. Valerie reflected:

“I am trying to at least in the morning to have breakfast, because sometimes I cannot have my break and if I don’t eat like from 7am until 1pm it makes me more stressful.” (Valerie, 2 years of experience)

Most of the reported coping strategies appeared to be adopted in response to a stressful situation. A number of participants found that smoking was something they associated with stress. Jim would usually realise that he was stressed when he wanted to smoke more.

“Well, I can go without smokes for hours, I know when I am stressed because I will start smoking one after the other. I know I am stressed because of the way I smoke.” (Jim, 6 years of experience)

Smoking during work breaks became a habit for Stacey and Helen. Although she was aware of the risks of smoking and had recently quit, Helen felt that it really helped her release the accumulated stress.

“When I finish work, it’s like uff... all my stress comes out with blowing that cigarette out of my mouth. That’s kind of my release. Blowing that, taking that cigarette in, but it’s more the blowing it out, that’s kind of my stress release.” (Helen, 4 years of experience)

Another caregiver, Diane, explained that one of her coping strategies was smoking cannabis. She appeared a little ashamed to admit:

“Well... don’t ask. At work I just distance myself from that service user. And I actually became really hard on her. But away from work, what I was doing was smoking a lot of drugs. I mean... in my downtime I smoke cannabis, and I was ... I’d be at home and I’d be smoking, just trying to relax.” (Diane, 4 years of experience)

A number of participants reported that when dealing with a stressful situation at work they would simply shut out and not engage with their patients. Patricia believed that a caregiver needed to be able to draw a line between themselves and their patient:

“If you keep engaging with the person it’s gonna hurt you more. It’s like putting a line, drawing a line, that’s ok. And then you become kind of cool.” (Patricia, 7 years of experience)

It appeared that having some boundaries and not getting too engaged could act as a shield that protected her from the harmful effects of stressful situations. Stacey described a similar mechanism which she and her workmates used when they got stressed. She called it “robot mode”.

“Yeah, they get stressed, they get really stressed. And pissed off and angry. They kind of shut down, you know, like you just go through the motions of, making sure everything is done, but you are not engaging with people, especially with clients, like you just don’t engage with them. You just kind of go into “robot mode”. (Stacey, 2 years of experience)

For Valerie, who had a health professional degree, not engaging with a patient seemed to not only be a coping strategy, but also something which she believed was a part of being a professional. She consciously avoided engaging with her patients as people, not going beyond the requirements of the ‘task’ at hand because it helped her deal with work stress.

“We just do our work and we are checking ourselves that our work is done properly. That we are doing the right things for him. Without any emotions. Just dealing as professionals.” (Valerie, 2 years of experience)

Although it seemed to help caregivers alleviate the impact of stress, not engaging with the patients and denying any emotions did not seem to facilitate the delivery of good quality care.

Another approach which appeared to help participants cope with work stress was to do what had to be done and worry about the rest later. Olivia explained:

“I told myself: ok, 10am, I am going to be free and I will relax and have a break. That’s what I told myself, just keep going till 10 and then everything is almost over, the work would be over, so I would have a good break and then relax.” (Olivia, 1 year of experience)

Rosie wondered whether this approach could be associated with “the age group, the era we grew through”. It appeared to her that when she was growing up they had never heard the word “stress”. She was taught to get on with things:

“That’s life, get on with it.” (Rosie, 16 years of experience)

However, according to Diane, avoiding stress was not the solution, and one had to acknowledge the difficulty and deal with a situation in a conscious way. She explained that this was particularly important in caregiving where one did not have “the luxury” to ignore a patient who needs help but causes stress. Diane believed that she had to deal with the stress and find a way of resolving it. One of Diane’s and Rosie’s effective coping strategies was prioritisation of work tasks which also helped to put things into perspective. Furthermore, Rosie noted that it was necessary to recognise whether one had any control over the situation or not:

“Once I’ve acknowledged it, I work out (...) why do I think it is, and then what can I do (...) am I the cause of the stress? (...) If it’s something that I can fix, I do, I try to. If it’s just something of everyone being human and having bad days... then... basically if I can do something about it, I will. If I can’t, that’s where the laid back bit comes in I think. Just: well, I can’t do anything about that, and just go on and see what’s gonna happen.” (Rosie, 16 years of experience)

Some caregivers found their religious faith to be helpful in dealing with stressful situations. Amanda, who was raised in a Catholic family, explained that her faith helped her to accept her work reality. For Rosie, her religion was something that gave her a set of rules and kept her “grounded”.

“It’s just, perhaps, I’ve got a foundation, that isn’t gonna move, and... that’s a security and assurance that I have... and that keeps me grounded.” (Rosie, 16 years of experience)

As noted above, caregiving appeared to be a fast-paced environment and this was something that Olivia struggled with when she first started. She tried to keep up the pace but it led to more stress and even resulted in her injuring herself. Interestingly, it was one of her patients who told her to slow down and not rush things. Olivia admitted that “rushing things” did seem the right solution at the beginning. After some time she

realised that the best coping strategy was actually to slow down and relax. She also added:

“Ask for help, ask, say that you can’t do it. I need help. Demand. Because if you don’t request then nobody comes to help you. You have to demand: ‘ok, I am not going to do this alone, I need somebody to help me’. And just ask somebody to help you.” (Olivia, 1 year of experience)

Another coping strategy was “switching off” at the end of the shift. Nearly every participant reported that spending time on their hobbies helped them stop thinking about work. Their hobbies included going out with people, art and music, sport and others. Patricia, who did volunteer work in her free time, explained that to be able to “switch off” she needed to do something she liked. However, not everybody was able to “switch off”. For Helen this strategy was not working anymore:

“I just used to leave home at home and work at work. And there was a very distinct line between the two. But now, when you have a one of those stressful shifts, when you come home, you’re throwing yourself on the couch and you might just have your eyes closed resting, but your brain is still thinking about all those incidents that went on, yeah.” (Helen, 4 years of experience)

Importantly, all participants who had tried counselling were very satisfied, saying it was a great experience and a really effective way of dealing with their work stress. It was a tipping point for Lana, who at the time was also dealing with a difficult personal life situation.

“All the guys there, some of them didn’t want to talk about their lives. But I didn’t want to, but I was in such a situation and I had to sit down cry and say my story. I said please help, what do I do? I have to look after my daughter, what do I want for her? How do I go out of the grief? They said: this is natural. You are sad, you will feel better with time. Every week she was talking about different topics and it helped me.” (Lana, 2 years of experience)

Participants described a range of coping strategies which could be utilised but not all of them seemed to work for every caregiver. Often, the most helpful coping strategies seemed to be associated with more experience and improved understanding of the work reality (for example, putting things into perspective or slowing down). Some of the strategies, like not engaging with patients, risked there being some unintended

consequences, such as the potential to hinder quality care. Nevertheless, many of the reported coping strategies could be taught to and adopted by this workforce.

4.5 Summary

On first reading, the experiences of caregivers' work stress appeared to be about having too much to do and being under constant pressure. However, the iterative analysis of participants' stories showed that their experiences may be much more complex. First, it appeared that their experience is dynamic and represents a constant tension between the reasons to care and the burden of caregiving. Second, a range of 'person context' and 'work environment factors' may account for the fluidity of their experience. While the participants' jobs and the situations they encountered were in principle very similar, their perceptions differed. This highlights the subjectivity of work stress. *Chapter Five: Discussion* will position these findings in the context of relevant literature and discuss their implications.

Chapter Five: Discussion and Conclusion

The aim of this study was to explore how formal caregivers experience work stress, and to identify factors they perceive as influencing that experience. The study highlighted that the experience of stress was for many, both fluid and complex. The core theme that emerged from the findings was *the tension between the reasons to be a caregiver and the burden of caregiving*. Findings suggest that caregivers may be torn between the reasons to be a caregiver and the burden of caregiving, with this in turn contributing to experiences of work stress. Importantly, the level of impact of stress on the caregiver and their work appeared to depend on a range of potentially modifiable factors: *person context factors, work environment factors and coping strategies*.

This chapter will consider the findings in relation to recent literature. Limitations of the study will be reviewed. The chapter concludes with discussing implications of the study and recommendations for future research.

5.1 The tension between the reasons to be a caregiver and the burden of caregiving

Formal caregivers' experience of work stress represented an uneasy *tension* that varied and was complex by nature. Two key themes were identified that underpinned or contributed to their experience of work stress: *the reasons to be a caregiver* and *the burden of caregiving*. The following sections will discuss these findings in the context of other research.

The reasons to be a caregiver highlighted in this research related to either needing a job or a commitment to care. A number of study participants reported that they needed a job to help them "make ends meet". This notion is perhaps unsurprising and evident in other research. As suggested by Sung et al. (2005) in their study involving nurses' aides, monetary needs are an important reason for continuing to work as a formal caregiver. Clarke (2001), in her Canada-based study, noted that the formal caregiver workforce included highly qualified immigrants from the Philippines and Eastern-block countries, and that many of them did this job simply to meet their economical obligations. Similarly, a number of the current study's participants were new NZ immigrants (see

Table 2), and even though they had bachelors or higher degrees, they felt they “had no other choice” but to become caregivers in order to generate an income.

However, many studies reported that formal caregivers are not satisfied with their income (Häggström, Skovdahl, Fläckman, Kihlgren, & Kihlgren, 2004; Ravenswood, Douglas, & Teo, 2014; Sung et al., 2005) which is indeed low in most countries (Kaine & Ravenswood, 2014). For example, the hourly rate in NZ ranges between the legal minimum wage (\$14.75) and \$19 (Ravenswood et al., 2014). This indicates that the monetary needs, while important, may not be the sole reason to be a caregiver.

For many participants in the current study, even those for whom the practical necessity of needing a job existed, being a formal caregiver also meant doing something worthwhile. They described their belief that they were helping vulnerable people and were making a positive change in their patients’ lives. It appeared truly important to many participants to be helping their patients “achieve their goals, dreams and aspirations”. Most participants talked about their job and patients with passion, and considered their work very rewarding. This is consistent with the current literature. Häggstrom et al. (2004) and Ravenswood et al. (2014) found that many formal caregivers reported “love” for their job and felt that they got a lot back from their work. Other studies found that the caregivers felt “needed” by the patients (McCluskey, 2000; Sung et al., 2005) and that they did “something worthwhile” (Atchison, 1998).

Participants in the current study articulated feeling a sense of responsibility for their patients and their lives. Many participants developed strong relationships with patients, sometimes comparing caring for them to caring for their own parents. As suggested by Sung et al. (2005) and McCluskey et al. (2000), formal caregivers often develop a sense of compassion and become emotionally attached to their patients. In the current study the participants would celebrate their patients’ achievements; however, they would also blame themselves for their patients’ failures. They considered themselves to be responsible and accountable for delivering the best possible care to their patients. This is consistent with Windley & Chapman (2010), who found that the support workers considered maximising the patients’ quality of life as their key role.

In this context, it is evident that the *commitment to care* was about both doing something worthwhile in the formal caregivers’ own lives and being responsible for the lives of their patients. For many participants the commitment to care and needing a job appeared to be equally important reasons to be a caregiver.

The burden of caregiving appeared to be a consequence of a clash between the commitment to care and the caregivers' work reality. The findings suggest that for many participants the patients' well-being was the highest priority. They would go above and beyond what was expected of them by their job description, e.g. not go for their breaks or take on other people's roles. Many participants reported constantly feeling responsible for their patients, and in some cases even for all patients at their facility regardless of whether they were at work or not. As discussed by Häggström et al. (2004), a perceived sense of absolute responsibility can be a source of 'irritation', and become a major burden for the caregivers. With caregivers aiming to maximise their patients' quality of life, such a sense of responsibility may lead to feelings of dissatisfaction and of failing their patients (Häggström et al., 2004).

The perceived and assumed responsibility in formal caregiving has been highlighted as an important issue in the recent literature (Ahlström & Wadensten, 2012; Elwér, Aléx, & Hammarström, 2010; Gustafsson et al., 2008; Häggström et al., 2004). Elwér et al. (2010) argued that caregiving is historically associated with responsibility. However, given that the pressure on resources is increasing (Blendon & DesRoches, 2003) while the demand for and on healthcare is growing, the strong sense of responsibility for meeting the caregiving demands has become problematic, and is potentially likely to become even more so. Carer attempts to meet these increasing demands may lead to increased levels of work stress (as hypothesised by Karasek's model of stress (1981); see *Chapter Two: Literature Review*). This may in turn have a negative impact on the quality of care (Cohen-Mansfield, 1995; Morgan et al., 2002).

As observed in the current study and consistent with the recent research (Ahlström & Wadensten, 2012; Elwér et al., 2010), caregivers appeared to have a strong desire to meet their patients' expectations and demands. At the same time, many participants in this study reported they were constantly dealing with a lack of staff and other resources required to deliver the care as planned. This notion is evident in recent literature, with studies reporting that caregivers often have heavy workloads (Clarke, 2001; Hertting et al., 2005; P. C. Hsieh & Su, 2007; Lapane & Hughes, 2007; Ravenswood et al., 2014). Clarke (2001) found that in some nursing homes the caregiver to patient ratio can be up to 1:16. Given the limited resources, meeting most or all of the patients' demands and expectations is likely to be unrealistic. The inability to fulfil their assumed responsibility appeared to contribute to *the burden for caregiving*.

Nevertheless, assuming responsibility for improving patients' well-being may be beneficial for the patients' outcomes and health-related costs (Health Education England, 2015). A recent report by Health Education England (2015) suggests that formalised training for care assistants has led to them assuming more responsibility within a UK accepted/standardised competency framework. This allowed nursing time to be released, and gave nurses more confidence to delegate and to engage meaningfully with patients.

The consequences of *burden* on formal caregivers warrant further consideration. Participants in the current study commonly reported feeling mentally and physically tired. The participants felt "useless" after their shifts and that feeling accumulated over time. They observed changes in their sleeping and eating patterns (or lack thereof). Some reported being off work for weeks due to burnout, with others taking sick leave days to deal with their fatigue. Fatigue and burnout have been reported to be a common problem in formal caregiving (Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Kennedy, 2005; Santana et al., 2013; Shinan-Altman & Cohen, 2009). This may negatively affect caregivers' well-being (Häggström et al., 2004) and has been found to be associated with other issues such as patient abuse (Cohen & Shinan-Altman, 2011; Shinan-Altman & Cohen, 2009).

A specific term for fatigue, compassion fatigue (Hooper et al., 2010; Joinson, 1992) has been proposed and used in nursing research. Compassion fatigue has been described as a natural and treatable consequence of working with suffering people (Hooper et al., 2010). It has been associated with changes in job performance, personality changes, health declines and staff turnover. As such, the *caregivers' burden* affects not only the caregivers, but may also have a negative impact on the care they provide to their patients.

In light of the above, it may be timely and justified to develop an accepted NZ competency framework and offer training for formal caregivers in association with that. Such a framework could help ensure that caregivers are better equipped for the roles and responsibilities they are inevitably required to take on. In turn, this may lead to a more formal acknowledgement of the range of activities caregivers perform. On the other hand, recognising their increased responsibility may have to be reflected through better pay. It remains unknown whether or not offering more training and increasing caregivers' remuneration is cost-beneficial for the healthcare system. Therefore, it also

appears crucial to evaluate the association between the burden of caregiving and the quality of care provided by caregivers. Such developments should be an aim of future research, and may hold potential for decreasing *the inherent tension in caregiving* and for improving the quality of care caregivers provide, which could potentially benefit care recipients.

The theme *burden of caregiving* represents the difficulties experienced by caregivers, and together with *reasons to be a caregiver*, contributed to creating the core concept: *the inherent tension in caregiving*. To an extent, this interpretation resembles Siegrist's Effort-Reward Imbalance model (Siegrist, 1996), i.e. work stress being caused by a perceived mismatch between the two factors. However, the analysis of the participants' stories suggested that individual and contextual differences appeared to play an important role in the perception of stress. These differences do not receive sufficient consideration in the Siegrist's model (Mark & Smith, 2008). The next section will discuss these factors in more detail.

5.2 Factors influencing formal caregivers' work stress experience

The participants' experiences of work stress appeared complex and fluid. The analysis highlighted a range of potentially modifiable factors which may account for that, including: person context, work environment and coping strategies. These factors appeared to influence the experience of work stress that could arise from the *tension* between *the reasons to be a caregiver* and *the burden of caregiving*. This section will focus on a selection of key findings that have the potential to advance research and practice in this field: lack of recognition, unintended consequences of person-centred care and specific caregiving challenges within the NZ social context.

5.2.1 Lack of recognition

One of the key findings of this study was that there appeared to be lack of recognition of what caregivers do in their role and of what they could be contributing as part of the health care team. The first notion ('role recognition') refers to the fact that caregivers have an extreme sense of emotional connection to their caring role and frequently go above and beyond their formal job expectations. The latter (expertise recognition)

relates to caregivers' feelings of not being heard, and that despite having important expertise to offer the healthcare team, their knowledge is not respected.

Lack of 'role recognition' appeared to be one of the biggest issues affecting caregivers, with regard to their work stress. Caregivers provide the majority of paid care to the most vulnerable people in society (Noelker, 2001). Their duties range from providing personal and intimate care, to providing and managing medication and organising their patients' community lives. They take on a huge responsibility of trying to let their patients live the best lives possible. As presented in *Chapter Four: Findings* and discussed in this chapter, this often came at a significant personal cost. As one of the study participants stated: "I give so much of myself, that there is not much left when I finish my shift at the end of the day". Yet the participants of this study did not feel their contributions were recognised and acknowledged by the people they worked with. It is particularly worrying, given that job performance recognition is central to nursing staff morale and that it is considered primarily the manager's responsibility (Cronin & Becherer, 1999).

The other aspect of the lack of recognition is the reported absence of the caregivers' expertise acknowledgement. Participants of this study found it very frustrating that their opinion and knowledge about patients was not valued and not included in the care planning process. As formal caregivers provide the majority of hands-on care in long-term facilities (Health Education England, 2015), not utilising their first-hand knowledge appears to be a missed opportunity to inform the planning and delivery of care. Moreover, in NZ, a high proportion of formal caregivers are overseas registered health professionals (Ravenswood et al., 2014). Their roles here are limited by a caregiving scope of work. Yet, theoretically, they do have the ability to provide clinically relevant information based on their daily work with the patients. Again, this appears to be another missed opportunity for the health care team. Importantly, this study participants' report of feeling not valued are consistent with the current research (Zhang et al., 2011). A recent survey by American Psychological Association (APA) (2011) showed that workers who do not feel valued by their employers, are more likely to report high levels of work stress. It was also argued that feeling valued appears to be a key indicator of job performance (American Psychological Association, 2011).

Lack of recognition has been identified as an important work stressor for formal caregivers previously (Clarke, 2001; Gustafsson et al., 2008; Häggström et al., 2004;

Hertting et al., 2005; Ravenswood et al., 2014; Secrest et al., 2005). It refers to recognition of the caregivers' skills, capabilities and knowledge; of the quality of care they provide and the relationships they develop with their patients; and of the overall role they play in the health care system. It is evident, that the caregivers want to be recognised and valued (Sung et al., 2005). Furthermore, a recent survey of NZ employees conducted by SHL Talent Measurement (reported online by J. Keown (2011)) showed that lack of recognition was the most frequently (59 % of respondents) reported factor affecting the level of effort employees put in at work. It is therefore crucial for future research to address this issue.

One way of providing recognition would be by increasing remuneration and this is a widely debated topic around the world (Health Education England, 2015; Parsons, Simmons, Penn, & Furlough, 2003; Ravenswood et al., 2014). Cronin and Becherer (1999) found that monetary recognition received the top ranking in their survey of nursing staff's meaningful types of recognition. However, remuneration is clearly not the only option (Cronin & Becherer, 1999; Naeem & Zaman, 2013). In the current study, it was noteworthy that recognition would come (or would be noted as absent) in many forms – particularly in how the knowledge or perspective of the carer was considered (or ignored) by qualified health professionals. Strategies to increase caregivers' recognition will be proposed later in this chapter (see *Implications for policy and practice*).

Regardless of the outcome of funding debates, a careful consideration of the role of caregivers in the healthcare system is required. The demand for their services is going to increase due to the ageing population (McGregor, 2012), and given the high numbers of people living with disabling and long term conditions (Health Education England, 2015). The potential impact of the care they provide on the quality of life of many people requiring long-term care is therefore significant and growing. Caregivers appear to have much to offer with regard to improving long-term care, given their first-hand knowledge about their patients and the direct daily contact with them. They could potentially be very effective mediators in the process of long-term care. However, first they will have to be recognised as legitimate members of the health and social care team.

5.2.2 Unintended consequences of patient-centred care

The concept of patient-centred care was first introduced in the 1960s (Balint, Ball, & Hare, 1969). Since then it has been increasingly used in health care practice, including long-term care (Schuldheis, 2007; Tanenbaum, 2015). Central to this concept is well-being and quality of life as defined by the patient (Schuldheis, 2007). It has become so synonymous with high quality care, that not using it may be seen by some as indefensible or ‘politically incorrect’ (Brooker, 2003). However, as with many popular concepts, different people use different definitions to explain what person-centred care means (Brooker, 2003). The findings of the current study highlight there may be some unintended consequences of patient-centred care affecting formal caregivers.

As reported in *Chapter Four: Findings*, the participants of this study appeared to have a huge sense of empathy and driven by the *commitment to care*, they strived to help their patients live the best life possible. Undoubtedly, patients’ well-being and quality of life was the participants’ priority. However, the focus on patient-centred practice and the “patient is always right” culture seemed to have a potentially disempowering impact on the caregiver. The caregivers reported not going for their breaks, injuring themselves while trying to help a patient, continuing to work after their shift had finished, or taking on other people’s roles. It appeared that going out of one’s way to accommodate a patient’s needs may inadvertently impact on carers’ working conditions in a potentially negative way.

As noted by (Brooker, 2003), the confusion around what patient-centred care means might be one of the reasons for the abovementioned unintended consequences. A simplistic understanding of patient-centred care is that it is about seeing the patients as experts and putting them at the centre of decisions (McCance, McCormack, & Dewing, 2011). Such an approach may potentially lead to further marginalisation of formal caregivers who are already low in the health care hierarchy. Indeed, such was the experience of some of this study’s participants. They reported feeling that a patient or his family would be always believed over a caregiver. However, Brooker (2003) argues that truly patient-centred care values both the patients and the people who care for them. Thus, in person-centred care, formal caregivers who do provide the majority of care to patients in long-term care facilities (Health Education England, 2015) should be considered as ‘people’ and arguably valued more than they currently appear to be.

Participants in this study identified some potentially maladaptive coping strategies. For example, some participants reported that to cope with the work stress, they would often not engage with their patients and simply complete tasks for them in a routinised manner to avoid any delays and manage workload. Similar findings were reported by Clarke (2001). Such practices may be caused by the mismatch between the work demands and resources, and be used to limit the experienced emotional labour (Bailey, Scales, Lloyd, Schneider, & Jones, 2015). However, such approaches strip the recipients of care of their status as thinking and feeling individuals (Milligan, 2012). Furthermore, as Bailey et al. (2015) postulate, engagement is seen as a positive ideal for caregiving staff. Therefore, such an approach (not engaging with patients) should be taken seriously as a care issue and actively managed in training and support.

The unintended consequences discussed in this section may be related to health care staff (including formal caregivers) and organisations potential misconceptions of what constitutes person-centred care. Person-centred care appears to be the appropriate and civilised way to respond to people requiring long-term care (Brooker, 2003). Given the discussed disempowering impact on formal caregivers, in order to achieve all the benefits person-centred care offers, it should be implemented in a well-planned and coordinated way (Pelzang, 2010).

5.2.3 Specific caregiving challenges within NZ social context

The existing research suggests that people's perceptions of work stress may vary widely across the spectrum of characteristics such as gender, age, years of work experience, education, cultural background and others (Aranda, 1997; Folkman, Lazarus, Pimley, & Novacek, 1987; Matud, 2004). However, two characteristics identified in this study appeared particularly important within the NZ social context, namely using English as a second language and the cultural background of the caregiver.

In NZ, there is a growing number of migrant caregivers (Ravenswood et al., 2014) for whom English is a second language (ESL). The findings of the current study highlighted that ESL may play an important role in work stress experience and act as a stressor itself. Being unable to communicate efficiently was problematic for both sides – those for whom English was their mother tongue as well as for those who struggled with it. The significance of the impact of using a second language on stress has been long recognised in psychology (Peck Jr, 1974). In the current study, English was not a mother tongue for half of the participants. The recent NZ Census data (Statistics New

Zealand, 2013), suggests that English may be a second language for at least 10% of NZ's total population. At the same time, no caregiving-related studies investigating this important issue have been identified. Such studies would be particularly beneficial in the NZ context, where many caregivers as well as the patients do not communicate primarily in English.

The second characteristic requiring specific attention, given the NZ demographic structure, was the cultural background of the caregiver. One aspect, highlighted by the study's findings, is that relationships between people are often not governed by the same rules in different cultures. For example - one participant in this study expected an authoritative staff-patient relationship - a situation that existed in their country of birth. They felt disrespected when their patient did not treat them as a superior (as would be expected within the participant's cultural background). The significance of delivering culturally appropriate care is receiving growing attention around the world, as highlighted by a recent review by Williamson & Harrison (2010). Williamson and Harrison (2010) have suggested that more research is required in this area, specifically about the incorporation of such approaches into practice. The findings of the current study indicate that cultural appropriateness should also be considered in the context of the caregivers' cultural needs. Thus, further research investigating strategies facilitating adjustment of caregivers of different cultural backgrounds is recommended.

5.2.4 Summary

The findings of this study suggest that formal caregivers in NZ experienced high levels of work stress and that for many, the level of stress resulted in a range negative impacts. These appeared to be a result of an imbalance between the *reasons to be a caregiver*, and the *burden of caregiving*. A range of influencing factors were identified and found to be consistent with the current literature. Furthermore, many individual differences seemed to exist with regard to how work stress is perceived and dealt with.

This study enhances the understanding of formal caregivers by highlighting the challenges relating to the lack of formal caregivers' recognition, the unintended consequences of person-centred care and the difficulties experienced by migrant formal caregivers. These findings, in the context of increasing pressures within the health care system, indicate work stress in formal caregivers warrants further attention in research and practice. As well as producing new knowledge of importance, this may be crucial

to inform developments in training and support mechanisms for a sustainable care system in the future.

5.3 Implications for practice and policy

There are a number of implications for practice and policy arising from this research. This section discusses three areas which, arguably, require the most attention from healthcare organisations and policymakers: caregiver support, recognition of contribution and training.

Most participants reported that they experienced stress at work every day. As has been highlighted in recent research, prolonged exposure to stress has proven to have many adverse effects on people's health (DeLongis, Folkman, & Lazarus, 1988; Koch, Sepa, & Ludvigsson, 2008; Pittenger & Duman, 2008), and also on work organisations as a whole (Laranjeira, 2012). It has been associated with job absenteeism (Davey, Cummings, Newburn-Cook, & Lo, 2009), reduced productivity (Anderzén & Arnetz, 2005) and job satisfaction (Zangaro & Soeken, 2007); and has been recognised as an important issue in formal caregiving (Ravenswood et al., 2014; Windley & Chapman, 2010). The current study has enhanced our understanding of formal caregivers' work stress by identifying a number of potentially modifiable factors that appear to contribute to and govern *the inherent tension in caregiving*. Thus, the findings of this study should be of interest to health care providers and policy makers who recognise the increasing challenges facing the health care system in NZ.

As reported in *Chapter Four: Findings*, most participants appeared to value counselling and management support, yet reported a limited availability or lack thereof.

Counselling, particularly, provided them with an opportunity to discuss their work issues with someone who understood their work reality and gave them a sense of having someone who cared about their work struggles. This is consistent with the existing literature and the use of counselling for formal caregivers has been recommended (Nakahira, Moyle, Creedy, & Hitomi, 2009; Rosa, Massaia, & Zanetti, 2013).

Interestingly, this study's participants reported how therapeutic it was for them to reflect on their work stress through the interview process. This may be an encouraging finding,

especially given that the anecdotal evidence suggests that counselling support has been withdrawn at many facilities around NZ.

These findings suggest that it may be beneficial for healthcare organisations to consider and incorporate effective ways of supporting their caregiving staff. One way of doing this could be to allocate time during the daily handovers for staff to discuss the difficulties they had encountered during the shift. However, the findings suggest that some caregivers preferred more private settings so that they could feel comfortable and safe to discuss their work stress. Thus, group discussion may not be appropriate for everyone. Employee Assistance Programs (EAPs) could provide a more individualised and confidential opportunity for staff to discuss their issues. Importantly, a recent Australian study (Compton & McManus, 2015) found that EAPs can attend to a range of psychological issues and are perceived as beneficial to organisations that use them.

As discussed in this chapter, this study found that there appears to be lack of recognition of formal caregivers' role in the health care system. Participants of this study suggested that one way of increasing the recognition of their role that would also potentially enhance team building, would be for management staff to occasionally (e.g. once per year) buddy-up with the caregivers for some time and accompany them throughout the shift. Such a strategy could expose the managerial staff to the challenges formal caregivers face on a daily basis. In turn, it may validate the formal caregivers' feelings of struggle and potentially help them deal with the difficulties they experience. Cronin and Becherer (1999) found that another low-cost strategy valued by nursing staff was providing private verbal feedback. It can be easily implemented and may facilitate the provision of high quality care (Cronin & Becherer, 1999; Kimmerle & Wilson, 1994). Other strategies that could increase the recognition of formal caregivers' role in the health care system include: written acknowledgement (Cronin & Becherer, 1999), awards (Frey & Gallus, 2014) and provision of training and upskilling opportunities (Voegtlin, Boehm, & Bruch, 2015).

The findings also suggest that there are a number of potentially modifiable and trainable factors which appear to influence work stress. Some participants reported struggling with their general work for weeks when they first started, as they had not received any formal induction training. Establishing a standard induction training for formal caregivers at a health care facility appears to be the first important step.

To become a good caregiver may take a lot of practice and experience. However, many skills can be taught (Health Education England, 2015) and knowledge can be provided during an initial staff training. Participants of the current study suggested such knowledge might include: basic principles of physiology and anatomy, basic understanding of the patients' conditions, health and safety rules, patient handling and others. Moreover, many participants reported issues with regard to communication within the team. All these skills are difficult to acquire within one training session, but it seems worth considering strategies that may facilitate development of these skills as part of on-going training. While such initiatives may require increased spending in the initial stages, they may be cost-effective over time and also enhance the quality of care (Health Education England, 2015).

In addition to the above, with the challenges and context of the NZ health care system, it appears crucial to continue working on an accepted NZ competency framework and to train formal caregivers adequately. Such developments could be guided by the work currently being done overseas, for example in the United Kingdom (Health Education England, 2015).

Finally, participants of this study reported that their knowledge about the patient was often not recognised or utilised by the care team. However, the amount of time formal caregivers spend with their patients enables them to get to know each other very well. Moreover, as highlighted by recent research (Clarke, 2001; Ravenswood et al., 2014), among migrant formal caregivers (estimated to be over 30% of the caregiving workforce in NZ (Ravenswood et al., 2014)) many have health-related qualifications and are likely to have an advanced clinical knowledge. Thus, formal caregivers may well be able to provide very valuable information about their patients. Such knowledge should not be overlooked and it is recommended that caregivers be included in the patient progress meetings and contribute to related reports.

5.4 Study limitations and suggestions for future research

This study provides valuable insights into the experience of formal caregivers' work stress. However, there were some limitations to the study which need to be acknowledged.

This study used a qualitative research methodology (i.e. interpretive description (Thorne, 2008)). The chosen methodology enabled the recruitment of much smaller samples than would be expected in a study using quantitative methodology (Trotter, 2012). Whilst being appropriate for the methodology and very cost-effective, it does have some downsides. Findings from a qualitative study should not be used to make generalisations about the investigated phenomenon. Importantly, the study sample was purposefully selected (Thorne et al., 1997) and this is recognised as a robust approach (Hunt, 2009; Kathleen, 2006) allowing a diversity of work stress experiences to be explored. Therefore, whilst not producing generalisable results, these findings provide a deep understanding of formal caregivers' work stress, guide further decision making, and have generated ideas for future quantitative research (see *Future research* below).

The design of the study, particularly the recruitment and data collection processes, may have had an impact on the findings. Firstly, the recruitment was conducted in Auckland, the most populated and ethnically diverse city in NZ. Auckland represents almost 40 % of the total NZ population and as such it seemed reasonable (and within the limits of a postgraduate research study) to start the investigation of NZ formal caregivers work stress there. As it is possible that the experiences of caregivers are different in smaller communities, it may be useful for future studies to explore formal caregivers' work stress further in such contexts.

Secondly, the data was collected and analysed by one researcher who is a NZ immigrant and not a native English speaker. It may have affected which people responded to the study invitation (e.g., matching ethnicity), how and what questions were asked during the interviews (the researcher could have used an incorrect word and confused a participant, shifting his focus to potentially unrelated issues), and what findings emerged from the data (possible language-related misinterpretation of data). However, as can be seen in Table 2, the study included people from a range of ethnicities and age groups. The study researcher conducted practice interviews with other more experienced researchers and did not experience any difficulties in that process. Also, data analysis and interpretation was conducted in close collaboration with the study supervisors to ensure the study's credibility and strengthen interpretive reasoning.

Thirdly, an additional limitations of this study relates to the exclusion of people who were recent immigrants (as explained in *Chapter Three: Methodology and Methods*). Such an approach might have had reduced the transferability of the findings. However,

settling down in a new country puts people in a unique situation, making their lives somewhat different to people who are not going through that phase (Levitt, Lane, & Levitt, 2005). Therefore it was deemed necessary, to not include people who had not been NZ residents or citizens.

Lastly, despite of the researcher's efforts, only one male participant consented to take part in this study. While this proportion is representative of the NZ caregiving workforce (Ravenswood et al., 2014), the lack of men recruited to the study should be considered as a potential limitation of this work.

In spite of all the above limitations, this study enhances the understanding of formal caregivers' experiences of work stress in NZ. As work stress has not been explored in this population before, this study is a valuable addition to the body of knowledge about work stress in formal caregiving.

5.4.1 Future research

As discussed in this chapter, further investigation into formal caregivers work stress and their work in general is timely.

Firstly, future research could focus on the development of a training programme for formal caregivers. As discussed previously, this could be guided by the findings of this study and include training of skills listed above. An important component of such research projects would be to investigate the impact of the training on both formal caregivers' stress and on the quality of care they provide to patients.

Secondly, there appears to be a lack of a tool to measure work stress in formal caregivers. Such a tool could be developed based on existing work stress measurement tools, input from an expert panel, and possibly guided by the findings of this research. Given the importance of context and perception in the experience of stress (Lazarus & Folkman, 1984; Mark & Smith, 2008; Siegrist, 1996), it appears important for such a tool to be specific to formal caregiving. The tool could be used for benchmarking in any interventions targeting stress in formal caregivers and to quantify any consequent changes. It may also be of value as a discussion guide to facilitate caregivers' annual appraisal meetings or discussions held as part of Employee Assistance Programs. Additionally, such a tool would allow further exploration of correlates of work stress that could be a target for future intervention.

Lastly, there is a need to increase the recognition of the formal caregivers' role. Future research could focus on developing a national competency framework, increasing social awareness of the caregivers' role, and the development of strategies to empower formal caregivers.

5.5 Conclusion

This study offers new and valuable insights into formal caregivers' experiences of work stress. It was the first NZ based investigation of this phenomenon. The findings highlight that this group reports high levels of work stress, potentially leading to negative outcomes for caregivers and their patients. However, the level of impact of stress on the caregivers and their work appeared dependent on a range of potentially modifiable factors.

This study enhances understanding of formal caregivers' work stress by highlighting the challenges relating to the lack of recognition of formal caregivers' role and expertise, the unintended consequences of person-centred care and the difficulties experienced by migrant formal caregivers. The findings highlight the experience of formal caregivers' work stress to be both complex and fluid.

These findings, within the context of increasing pressures within the health care system, indicate work stress in formal caregivers warrants further attention in research and practice. The findings could be used to guide the development of interventions aiming to improve both the work environment (role recognition, management support, teamwork) and the caregivers' ability to cope with stress.

References

- Academy Health. (2003). *Long-Term Care: Confronting Today's Challenges*. Washington, USA.
- Ahlström, G., & Wadensten, B. (2012). Enjoying Work or Burdened by it? How Personal Assistants Experience and Handle Stress at Work. *Journal of Social Work in Disability and Rehabilitation*, 11(2), 112-127.
- American Psychological Association. (2011). *Stress in the Workplace. Survey Summary*. Washington D.C.: American Psychological Association.
- Anderzén, I., & Arnetz, B. B. (2005). The impact of a prospective survey-based workplace intervention program on employee health, biologic stress markers, and organizational productivity. *Journal of Occupational and Environmental Medicine*, 47(7), 671-682.
- Anitha, J. (2014). Determinants of employee engagement and their impact on employee performance. *International Journal of Productivity and Performance Management*, 63(3), 308-323.
- Aranda, M. P. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *Gerontologist*, 37(3), 342-354.
- Atchison, J. H. (1998). Perceived job satisfaction factors of nursing assistants employed in Midwest nursing homes. *Geriatric Nursing*, 19(3), 135-138.
- Badkar, J., Callister, P., & Didham, R. (2009). *Ageing New Zealand: The growing reliance on migrant caregivers*. Wellington, NZ: Institute of Policy Studies, Victoria University.
- Bailey, S., Scales, K., Lloyd, J., Schneider, J., & Jones, R. (2015). The emotional labour of health-care assistants in inpatient dementia care. *Ageing and Society*, 35(02), 246-269.
- Balint, M., Ball, D. H., & Hare, M. L. (1969). Training medical students in patient-centered medicine. *Comprehensive Psychiatry*, 10(4), 249-258.
- Blendon, R. J., & DesRoches, C. (2003). Future health care challenges. *Issues in Science and Technology*, 19(4), 32.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(03), 215-222.
- Bruner, J. S. (1990). *Acts of meaning*. Cambridge, Mass: Harvard University Press.
- Carbines, M. (2008). Being together and separate: a grounded theory study of the experience of first-time fathers during childbirth (Master thesis). Retrieved from: <http://aut.researchgateway.ac.nz/handle/10292/281>.
- Charmaz, K. (2014). *Constructing grounded theory*. Los Angeles: SAGE.
- Clarke, E. (2001). Role conflicts & coping strategies in caregiving: a symbolic interactionist view. *Journal of Psychosocial Nursing & Mental Health Services*, 39(1), 28.
- Cohen, M., & Shinan-Altman, S. (2011). A cross-cultural study of nursing aides' attitudes to elder abuse in nursing homes. *International psychogeriatrics*, 23(8), 1213-1221.
- Cohen-Mansfield, J. (1995). Stress in nursing home staff: A review and a theoretical model. *Journal of Applied Gerontology*, 14(4), 444-466.

- Compton, R. L., & McManus, J. G. (2015). Employee Assistance Programs in Australia: Evaluating Success. *Journal of Workplace Behavioral Health*, 30(1-2), 32-45.
- Cook, D. J., Sackett, D. L., & Spitzer, W. O. (1995). Methodologic guidelines for systematic reviews of randomized control trials in health care from the potsdam consultation on meta-analysis. *Journal of Clinical Epidemiology*, 48(1), 167-171.
- Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, 26(3), 623-630.
- Cronin, S. N., & Becherer, D. (1999). Recognition of staff nurse job performance and achievements: Staff and manager perceptions. *Journal of Nursing Administration*, 29(1), 26-31.
- D'Hondt, A., Kaasalainen, S., Prentice, D., & Schindel Martin, L. (2012). Bathing residents with dementia in long-term care: Critical incidents described by personal support workers. *International Journal of Older People Nursing*, 7(4), 253-263.
- Davey, M. M., Cummings, G., Newburn-Cook, C. V., & Lo, E. A. (2009). Predictors of nurse absenteeism in hospitals: a systematic review. *Journal of nursing management*, 17(3), 312.
- DeLongis, A., Folkman, S., & Lazarus, R. S. (1988). The Impact of Daily Stress on Health and Mood: Psychological and Social Resources as Mediators. *Journal of Personality and Social Psychology*, 54(3), 486-495.
- Dixon-Woods, M., Booth, A., & Sutton, A. J. (2007). Synthesizing qualitative research: a review of published reports. *Qualitative Research*, 7(3), 375-422.
- Eades, C. E., Ferguson, J. S., & O'Carroll, R. E. (2011). Public health in community pharmacy: a systematic review of pharmacist and consumer views. *BMC Public Health*, 11(1), 582-582.
- Earl, D. J. (2008). Keeping birth normal: midwives experiences in a secondary care setting: a qualitative study (Master thesis). Retrieved from: <http://aut.researchgateway.ac.nz/handle/10292/267>.
- Elwér, S., Aléx, L., & Hammarström, A. (2010). Health against the odds: experiences of employees in elder care from a gender perspective. *Qualitative Health Research*, 20(9), 1202-1212.
- Folkman, S., Lazarus, R. S., Pimley, S., & Novacek, J. (1987). Age differences in stress and coping processes. *Psychology and Aging*, 2(2), 171-184.
- Francis, J., & Netten, A. (2003). *Home care workers: careers, commitments and motivations*: Personal Social Services Research Unit, University of Kent at Canterbury, Kent, UK.
- Frey, B. S., & Gallus, J. (2014). The power of awards. *Economists' Voice*, 11(1), 1-5.
- Glaser, B. G., & Strauss, A. L. (1999). *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine de Gruyter.
- Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and Methodological Bases of Naturalistic Inquiry. *Educational Communication and Technology*, 30(4), 233-252.
- Gustafsson, G., Norberg, A., & Strandberg, G. (2008). Meanings of becoming and being burnout -phenomenological-hermeneutic interpretation of female healthcare personnel's narratives. *Scandinavian Journal of Caring Sciences*, 22(4), 520-528.
- Häggström, E., Skovdahl, K., Fläckman, B., Kihlgren, A. L., & Kihlgren, M. (2004). To feel betrayed and to feel that you are betraying the older residents: caregivers'

- experiences at a newly opened nursing home. *Journal of Clinical Nursing*, 13(6), 687-696.
- Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and aging*, 2(4), 323-330.
- Harvard business review analytic services. (2013). The Impact of Employee Engagement on Performance. Retrieved from: https://hbr.org/resources/pdfs/comm/achievers/hbr_achievers_report_sep13.pdf.
- Hastings, R., Horne, S., & Mitchell, G. (2004). Brief report Burnout in direct care staff in intellectual disability services: a factor analytic study of the Maslach Burnout Inventory. *Journal of Intellectual Disability Research*, 48(3), 268-273.
- Health Education England. (2015). Raising the Bar. Shape of Caring: A Review of the Future Education and Training of Registered Nurses and Care Assistants. England. Retrieved from: <http://hee.nhs.uk/wp-content/blogs.dir/321/files/2015/03/2348-Shape-of-caring-review-FINAL.pdf>.
- Hertting, A., Nilsson, K., Theorell, T., & Larsson, U. S. (2005). Assistant nurses in the Swedish healthcare sector during the 1990s: A hard-hit occupational group with a tough job. *Scandinavian Journal of Public Health*, 33(2), 107-113.
- Hooper, C., Craig, J., Janvrin, D. R., Wetsel, M. A., & Reimels, E. (2010). Compassion Satisfaction, Burnout, and Compassion Fatigue Among Emergency Nurses Compared With Nurses in Other Selected Inpatient Specialties. *Journal of Emergency Nursing*, 36(5), 420-427.
- Hsieh, H., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Hsieh, P. C., & Su, H. F. (2007). Retention and attrition of certified care assistants in the long-term care industry from the Taipei area: An interview survey. *International journal of nursing studies*, 44(1), 93-104.
- Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19(9), 1284-1292.
- Innstrand, S. T., Espnes, G. A., & Mykletun, R. (2004). Job stress, burnout and job satisfaction: an intervention study for staff working with people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(2), 119-126.
- Johnson, J. V., & Hall, E. M. (1988). Job strain, work place social support, and cardiovascular disease: a cross-sectional study of a random sample of the Swedish working population. *American Journal of Public Health*, 78(10), 1336-1342.
- Joinson, C. (1992). Coping with compassion fatigue. *Nursing*, 22(4), 116-120.
- Kaine, S., & Ravenswood, K. (2014). Working in residential aged care: A Trans-Tasman comparison. *New Zealand Journal of Employment Relations*, 38(2), 33-46.
- Karasek, R., Baker, D., Marxer, F., Ahlbom, A., & Theorell, T. (1981). Job decision latitude, job demands, and cardiovascular disease: A prospective study of Swedish men. *American Journal of Public Health*, 71(7), 694-705.
- Kathleen, H. (2006). Exploratory Studies. In (pp. 187). New York: Springer Publishing Company.
- Kawulich, B. B. (2005). Participant observation as a data collection method. *Forum Qualitative Sozialforschung*, 6(2).
- Kennedy, B. R. (2005). Stress and burnout of nursing staff working with geriatric clients in long-term care. *Journal of Nursing Scholarship*, 37(4), 381-382.

- Keown, J. (2011). Recognition workers' top concern Business Day. Retrieved from: <http://www.stuff.co.nz/business/small-business/4957813/Recognition-workers-top-concern>.
- Khalaf, A., Berggren, V., & Westergren, A. (2009). Caring for undernourished patients in an orthopaedic setting. *Nursing Ethics*, 16(1), 5-18.
- Kimmerle, E., & Wilson, J. F. (1994). Motivating the nursing staff. *Journal of Nursing Administration*, 24(6), 5-6.
- Koch, F. S., Sepa, A., & Ludvigsson, J. (2008). Psychological Stress and Obesity. *Journal of Pediatrics*, 153(6), 839-844.
- Lapane, K. L., & Hughes, C. M. (2007). Considering the Employee Point of View: Perceptions of Job Satisfaction and Stress Among Nursing Staff in Nursing Homes. *Journal of the American Medical Directors Association*, 8(1), 8-13.
- Laranjeira, C. A. (2012). The effects of perceived stress and ways of coping in a sample of Portuguese health workers. *Journal of Clinical Nursing*, 21(11-12), 1755-1762.
- Lazarus, R. S. (2006). *Stress and emotion: A new synthesis*. New York: Springer Publishing Company.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.
- Levitt, M. J., Lane, J. D., & Levitt, J. (2005). Immigration Stress, Social Support, and Adjustment in the First Postmigration Year: An Intergenerational Analysis. *Research in Human Development*, 2(4), 159-177.
- Lloyd, L. (2006). Call us carers: limitations and risks in campaigning for recognition and exclusivity. *Critical Social Policy*, 26(4), 945-960.
- Mark, G. M., & Smith, A. P. (2008). Stress models: A review and suggested new direction. *Occupational health psychology*, 3, 111-144.
- Matud, M. P. (2004). Gender differences in stress and coping styles. *Personality and Individual Differences*, 37(7), 1401-1415.
- Mayan, M. (2010). Commentary 3: The Disciplinary Divide. *Qualitative Health Research*, 20(11), 1467-1468.
- Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ (Clinical research ed.)*, 311(6997), 109-112.
- McCance, T., McCormack, B., & Dewing, J. (2011). An exploration of person-centredness in practice. *The Online Journal of Issues in Nursing*, 21(4), 417-446.
- McCluskey, A. (2000). Paid attendant carers hold important and unexpected roles which contribute to the lives of people with brain injury. *Brain Injury*, 14(11), 943-957.
- McGregor, J. (2012). *Caring Counts*. Wellington: Human Rights Commission.
- McIlveen, R., & Gross, R. (1997). Biopsychology. *Education Section Review British Psychological Society*, 21, 39-39.
- Milligan, C. (2012). *There's no place like home: Place and care in an ageing society*. Farnham, UK: Ashgate Publishing, Ltd.
- Mininel, V., Baptista, P. C. P., & Felli, V. E. A. (2011). Psychic Workloads and Strain Processes in Nursing Workers of Brazilian University Hospitals (Report No. 1518-8345, Vol. 19). Retrieved from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2011252886&site=ehost-live&scope=site>.
- Monaghan, V., & Cumella, S. (2009). Support workers and people with learning disabilities: Participative and life history research. *Housing, Care and Support*, 12(3), 28-36.
- Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Job strain among staff of rural nursing homes: A comparison of nurses, aides, and activity workers. *Journal of Nursing Administration*, 32(3), 152-161.

- Murphy, J. (2009). Strategies older New Zealanders use to participate in day-to-day occupations (Master thesis). Retrieved from: <http://aut.researchgateway.ac.nz/handle/10292/684>.
- Naeem, S., & Zaman, A. (2013). For love or money? Motivating workers. *PIDE Working Papers*(90), 1-22.
- Nakahira, M., Moyle, W., Creedy, D., & Hitomi, H. (2009). Attitudes toward dementia-related aggression among staff in Japanese aged care settings. *Journal of Clinical Nursing*, 18(6), 807-816.
- National Health Service Public Health Resource Unit. (2006). Critical appraisal skills programme: qualitative research appraisal tool. Retrieved from: www.phru.nhs.uk/Doc Links/Qualitative%20Appraisal%20Tool.pdf.
- Neergaard, M., Olesen, F., Andersen, R., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology*, 9(1), 52.
- Noelker, L. S. (2001). The backbone of the long-term-care workforce. *Generations*, 25(1), 85-91.
- OECD. (2015). *Health spending (indicator)*. Retrieved 24/5/2015, from: <https://data.oecd.org/healthres/health-spending.htm>
- Oliver, C. (2012). The relationship between symbolic interactionism and interpretive description. *Qualitative Health Research*, 22(3), 409-415.
- Olmstead, D. L., Scott, S. D., Mayan, M., Koop, P. M., & Reid, K. (2014). Influences shaping nurses' use of distraction for children's procedural pain. *Journal for Specialists in Pediatric Nursing*, 19(2), 162-171.
- Olson, K. (2011). *Essentials of qualitative interviewing*. Walnut Creek, CA: Left Coast Press
- Parsons, S. K., Simmons, W. P., Penn, K., & Furlough, M. (2003). Determinants of satisfaction and turnover among nursing assistants. The results of a statewide survey. *Journal of Gerontological Nursing*, 29(3), 51-58.
- Peck Jr, E. C. (1974). The relationship of disease and other stress to second language. *International Journal of Social Psychiatry*, 20(1-2), 128-133.
- Pelzang, R. (2010). Time to learn: understanding patient-centred care. *British journal of nursing*, 19(14), 912.
- Pittenger, C., & Duman, R. S. (2008). Stress, depression, and neuroplasticity: A convergence of mechanisms. *Neuropsychopharmacology*, 33(1), 88-109.
- Puplampu, G. L., Olson, K., Ogilvie, L., & Mayan, M. (2014). Attracting and retaining nurses in HIV care. *Journal of the Association of Nurses in AIDS Care*, 25(3), 253-261.
- Ravenswood, K., Douglas, J., & Teo, S. (2014). *The New Zealand age care workforce survey 2014*. Auckland, NZ: New Zealand Work Research Institute.
- Rosa, E., Massaia, M., & Zanetti, O. (2013). Burden-of-care determinants in immigrant paid caregivers who care for patients with dementia. *Giornale di Gerontologia*, 61(2), 103-106.
- Rose, J., Jones, F., & Fletcher, B. (1998). Investigating the relationship between stress and worker behaviour. *Journal of Intellectual Disability Research*, 42(2), 163-172.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340.
- Santana, L. d. L., Miranda, F. M. D. A., Karino, M. E., Baptista, P. C. P., Felli, V. E. A., & Sarquis, L. M. M. (2013). Description of workloads and fatigue experienced among health workers in a teaching hospital [Portuguese]. *Revista Gaucha de Enfermagem*, 34(1), 64-70.

- Schneider, T. R. (2008). Evaluations of stressful transactions: What's in an appraisal? *Stress and Health*, 24(2), 151-158.
- Schuldheis, S. (2007). Initiating person-centered care practices in long-term care facilities. *Journal of Gerontological Nursing*, 33(11), 47.
- Secrest, J., Iorio, D. H., & Martz, W. (2005). The meaning of work for nursing assistants who stay in long-term care. *Journal of Clinical Nursing*, 14(8b), 90-97.
- Selye, H. (1976). *The stress of life*. New York: McGraw-Hill.
- Shaha, M., & Rabenschlag, F. (2007). Burdensome situations in everyday nursing: an explorative qualitative action research on a medical ward. *Nursing Administration Quarterly*, 31(2), 134-145.
- Shinan-Altman, S., & Cohen, M. (2009). Nursing aides' attitudes to elder abuse in nursing homes: The effect of work stressors and burnout. *Gerontologist*, 49(5), 674-684.
- Siegrist, J. (1996). Adverse Health Effects of High-Effort/Low-Reward Conditions. *Journal of Occupational Health Psychology*, 1(1), 27-41.
- Skinner, E. A. (1995). *Perceived control, motivation, & coping* (Vol. 8): Sage Publications.
- Smythe, L. (2012). Discerning which qualitative approach fits best. *New Zealand College of Midwives Journal*(46), 5-12.
- Statistics New Zealand. (2013). *2013 Census*: Statistics New Zealand.
- Sung, H. c., Chang, S. m., & Tsai, C. s. (2005). Working in long-term care settings for older people with dementia: nurses' aides. *Journal of Clinical Nursing*, 14(5), 587-593.
- Tanenbaum, S. (2015). What is Patient-Centered Care? A Typology of Models and Missions. *Health Care Analysis*, 23(3), 272-287.
- Teale, W. H. (1982). Naturalistic inquiry, literacy and education. *Australian Journal of Reading*, 5(3), 107-109.
- The Independent. (2014). Elderly care home abuse: Shocking footage shows elderly residents being taunted and assaulted at Essex care home Retrieved from: <http://www.independent.co.uk/news/uk/home-news/shocking-footage-shows-elderly-residents-being-taunted-and-abused-at-essex-care-home-9303888.html>.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45.
- Thorne, S. E. (2008). *Interpretive description* (Vol. 2). Walnut Creek, CA: Left Coast Press.
- Thorne, S. E., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169-177.
- Thorne, S. E., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International journal of qualitative methods*, 3(1), 1-11.
- Trotter, R. T. (2012). Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives. *Preventive Medicine*, 55(5), 398-400.
- Troup, C., & Dewe, P. (2002). Exploring the nature of control and its role in the appraisal of workplace stress. *Work and Stress*, 16(4), 335-355.
- Van der Doef, M., & Maes, S. (1999). The Job Demand-Control (-Support) Model and psychological well-being: A review of 20 years of empirical research. *Work & Stress*, 13(2), 87-114.
- Voegtlin, C., Boehm, S. A., & Bruch, H. (2015). How to empower employees: Using training to enhance work units' collective empowerment. *International Journal of Manpower*, 36(3), 354-373.

- Vygotsky, L. S., & Cole, M. (1978). *Mind in society: the development of higher psychological processes*. Cambridge: Harvard University Press.
- Weiss, G. L., & Lonnquist, L. E. (2012). *The sociology of health, healing, and illness*. Boston: Prentice Hall.
- White, C., Pesut, B., & Rush, K. L. (2014). Intensive care unit patients in the postanesthesia care unit: A case study exploring nurses' experiences. *Journal of Perianesthesia Nursing*, 29(2), 129-137.
- Williamson, M., & Harrison, L. (2010). Providing culturally appropriate care: A literature review. *International journal of nursing studies*, 47(6), 761-769.
- Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, 38(4), 310-318.
- Young, R. A., & Collin, A. (2004). Introduction: Constructivism and social constructionism in the career field. *Journal of Vocational Behavior*, 64(3), 373-388.
- Zangaro, G. A., & Soeken, K. L. (2007). A meta-analysis of studies of nurses' job satisfaction. *Research in Nursing & Health*, 30(4), 445-458.
- Zajonc, R. B. (1980). Feeling and thinking: Preferences need no inferences. *American Psychologist*, 35(2), 151-175.
- Zhang, Y., Flum, M., Nobrega, S., Blais, L., Qamili, S., & Punnett, L. (2011). Work organization and health issues in long-term care centers: Comparison of perceptions between caregivers and management. *Journal of Gerontological Nursing*, 37(5), 32-40.

Appendix A: Participant Information Sheet



Participant Information Sheet



Understanding formal caregivers and work stress

Invitation

Hello. We would like to invite you to take part in a research project which aims to improve understanding of work stress in formal caregivers. This information sheet will explain the study. We really appreciate your time spent reading this information.

Taking part in this study is voluntary. It is your choice. You do not have to take part in this study. Whether you take part or not, it will not result in any disadvantage to you. Even if you do agree to take part, you can withdraw at any time without having to give a reason. We are very happy to answer any questions about the study or to explain anything that is not clear. Please do feel free to contact us.

Who is organising this study?

This study is carried out by Karol Czuba, a postgraduate student at AUT University and ex-caregiver. Karol is supervised by Dr Nicola Kayes and Prof. Kathryn McPherson from the Person Centred Research Centre at AUT University.

What is the purpose of this study?

We know that giving care to people in residential care facilities is a very demanding job and can cause a lot of stress. This affects you as a formal caregiver. It also affects your colleagues and clients. It is known that each person experiences stress differently. What is stressful for me, does not have to be stressful for you. How you see yourself in the situation may also influence whether it will cause you stress.

In this study we aim to explore your experiences of work stress. We would like to get to understand your view on this. What makes you feel stressed? What do you do to deal with work stress? We hope this will help us to understand formal caregivers work stress better.

How was I identified and why am I being invited to participate in this study?

You have been invited to take part in this study because you are currently working as a formal caregiver in a residential care in Auckland. The facility you work in provides care to people with neurological disorders (e.g. Alzheimer's, Huntington's, dementia, acquired brain injury). You may be eligible to take part if:

- You are 20 years or older.

AND

- You are a NZ resident or citizen.

AND

- You have at least one year of experience in your formal caregiving role.

AND

- You work at least 20 hours per week in this role.

What will happen in this study?

This study involves one face to face interview. If you agree to take part we will arrange the interview at a time and place that is good for you. This could be at your workplace during your worktime, at AUT University or at your home. The choice is yours.

The interview questions will focus on your experiences of work stress and what you think makes it stressful or not. We will ask for your consent to audiotape and transcribe the interview. The interview will take up to one hour. A member of your family/whānau or another support person is welcome to be present at the interview.

Please be aware that if during the interview you provide us with information that indicates you or someone else may be at serious risk of harm, the New Zealand Privacy Act means that we have to report that to relevant parties. Where possible we will speak with you about this before contacting relevant parties.

What are the discomforts and risks?

There should not be any discomforts or risks to you from this study. The researcher will make every effort to ensure you feel respected during the interview.

We do understand that you might find talking about stress difficult at times. If during the interview you find a question upsetting, you do not have to answer. You can also choose to stop the interview at any time. If any distressing issues arise during the interview and you would like to discuss them with someone, please do let us know. We can help you with finding some suitable support. You may wish to talk to someone at your workplace or use other local services. You are also welcome to attend one of the free counselling sessions available at AUT University, if you experience distress resulting from taking part in this study.

What are the benefits?

This study will help us better understand formal caregivers work stress. You will have the chance to reflect on your work stress experiences which you may find helpful.

This study is conducted as a part of Master of Philosophy programme and will contribute towards completion of that qualification.

It is also likely that this study will lead to a further project aiming to develop and test the effectiveness of a stress management intervention for formal caregivers. When completing the consent form, you will be able to indicate whether you are happy for us to keep your contact details for future use, so we can let you know about any related future projects.

How will my privacy be protected?

We will remove all personally identifiable information from the transcripts and study findings. There will be no identifying features included in any data extracts from this project. We will keep all gathered information in secure filing cabinets. This data will only be accessible to the researcher and study supervisors.

What are the costs of participating in this study?

The only cost to you is your time – approximately one to one and a half hours. We will offer you a small gift to acknowledge your contribution.

If you will have to do additional travel to the interview location you will be also given a petrol voucher to cover travel expenses incurred.

What opportunity do I have to consider this invitation?

It is important that you take time to consider this invitation. Please do take this information sheet with you and take the opportunity to seek advice from family and friends regarding your potential involvement. Please contact the research team if you would like to ask any further questions or if you would like to take part. If we do not hear from you within three weeks we will follow up with you.

How do I agree to participate in this study?

Once you decide to participate, you will be asked to sign an informed consent. This is an official document. It is required by AUT Ethics Committee and it shows your willingness to participate in this study.

Will I receive feedback on the results of this study?

If you would like to receive a copy of study report or summary of findings, please indicate that on the consent form. Please note, however, that these documents may not be available until at least 6 months after you take part.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Study Supervisor, Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext 7309.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Karol Czuba, kczuba@aut.ac.nz, 09 921 9999 ext 7768.

Project Supervisor Contact Details:

Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext 7309.

**Approved by the Auckland University of Technology Ethics Committee on 22
*October 2013, AUTEK Reference number 13/251.***

Appendix B: Consent Form



Consent Form



Understanding formal caregivers and work stress

Project supervisors:	Dr Nicola Kayes	Phone: 921 9999 ext. 7309 nkayes@aut.ac.nz
	Prof. Kathryn McPherson	Phone: 921 9999 ext. 7110 katmcphe@aut.ac.nz
Researcher:	Karol Czuba	Phone: 921 9999 ext. 7768 kczuba@aut.ac.nz

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 16th October 2013.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one):
Yes ☐ No ☐
- ☐ I would like a copy of my interview transcript (please tick one):
Yes ☐ No ☐
- ☐ I would be willing to be contacted about future related projects (please tick one):
Yes ☐ No ☐

Participant's signature:

.....
.....

Participant's name:

.....
.....

Participant's Contact Details (if appropriate):

.....
.....

Date:

***Approved by the Auckland University of Technology Ethics Committee on 22 October
2013 AUTEK Reference number 13/251.***

Note: The Participant should retain a copy of this form.

Appendix C: Interview guide

This interview schedule provides examples of the type of questions or prompts that will be used. Interviews will take the form of a 'guided conversation' with a focus on following up points raised by participants.

Introduction:

Thanks for agreeing to take part in this research. It would be helpful for me to understand a bit about you and the work you do so can you tell me a bit about:

1. What are the main things you do in your role here (in this company)?
2. What was the reason that you wanted to work as a formal caregiver (rehabilitation coach, rehabilitation assistant)?

Primary aim:

The main focus of this research is on stress at work for people working as carers – ways it is stressful and ways people manage that stress. So to start off - :

1. Can you tell me a bit about the parts of your job you enjoy most?
2. Can you tell me what does 'stress' mean to you? What's your definition of stress?
3. Can you tell me a bit about the parts of your job you find the most stressful or worrying?
4. Can you tell me about a specific situation you experienced in your work role in the past month where you felt stressed?

NB: depending on the individual interviewee – some of the following prompts will be used to explore a stressful work situation or event

- a) Tell me a bit more about what happened?
- b) Can you tell me what was stressful about it? Why was it stressful? What caused your stress? Could you tell me more about that?
- c) I'm interested in how you reacted when that happened? Do you know why you reacted this way?
- d) Did you notice how other people reacted when that happened? What do you think about their reaction? Was it helpful/unhelpful?
- e) Do you remember what were you thinking when this happened? What were you worried about?
- f) Were there some risks that you had to think about in managing this situation – for you, for the patient/client? Why did you consider them? What is important about them?

- g) How does this situation compare to the worst work stress you have ever experienced? What was worse/better?
- h) Would you feel stressed if this happened again? Why would you? Does it still cause stress? What did you try to do to deal with this stress?

5. Thinking generally about work stress – I'm interested to know how it impacts on you a bit more so can you tell me a little about...

NB: depending on the individual interviewee – some of the following prompts will be used to explore impact of stress

- a) How work stress impacts on you at work? How does it impact on your life? How does it impact on your patients/clients?
- b) Do you think you perceive stress differently to how most of your colleagues do? What is different?
- c) Do you think there are harmful effects of stress for you?
- d) Do you think work stress ever has some benefits?
- e) Do you think your work causes you more stress than other parts of your life (like family, home etc)?

6. The last area I'd like to talk with you about are the ways you deal with your stress?

NB: depending on the individual interviewee – some of the following prompts will be used to explore the ways of dealing with stress

- a) What are the things you do to help deal with your work stress? Are there any people/resources? Which of these are the most helpful in dealing with work stress? What else could be helpful?
- b) Sometimes people talk about preparing themselves for stressful situations. Is this something you do as well? Can you think of any possible ways to prepare yourself for stress?
- c) What could your employer/manager do to decrease your work stress levels? What could be done to help you manage your stress?

Appendix D: Ethical Approval



A U T E C
S E C R E T A R I A T

22 October 2013

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **13/251 Understanding formal caregivers and work stress.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 21 October 2016.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 21 October 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 21 October 2016 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

A handwritten signature in black ink, appearing to read 'K O'Connor', written in a cursive style.

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Karol Czuba kczuba@aut.ac.nz