An Exploration of Fatigue Amongst Caregivers

An exploratory descriptive study

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Contents

List of Tables

Abstract

Working conditions of caregivers is characterised by long hours, heavy work demands and low pay. While there has been a great deal written on fatigue among nurses and doctors as a result working long and hard, little is known about other forms of fatigue, including compassion fatigue, among caregivers. A review of literature identifies that fatigue is a complex phenomenon and that it is often misdiagnosed as burnout. Compassion fatigue results from the long turn exposure to suffering of others. Although compassion fatigue is researched amongst different occupations such as nurses, police officers, veterinarians and psychologists, there is minimal research in the field of caregiving. This study, therefore, will focus on a group of caregivers and look beyond the orthodox reasons for fatigue (namely the long hours and heavy workloads), and explore other contributing factors, such as compassion fatigue.

This study was exploratory and drew on descriptive interview data from caregivers in different workplaces. The data was collected using five face-to-face semi structured interviews. The data was then analysed using thematic analysis to identify key themes and to capture the participant's experiences.

The findings suggest that not only do caregivers experience fatigue and compassion fatigue but they are unaware that they are experiencing fatigue; rather they see it as being "tired". This could be because of a lack of knowledge around fatigue. Key themes identified were caregiving is female dominated, caregivers believed they cared too much but that was part of the job. Caregivers had stable employment because most caregivers had been in their roles for extended periods of time between 5-15 years. Caregivers chose the occupation because they liked caring for people and saw themselves as caring people; they also had family members who were in need of care. Although all caregivers reported an increased workload, they found it manageable even though it had been increasing over the years. Caregivers experienced both fatigue and compassion fatigue and felt that they had a lack of managerial support, with no coping mechanisms to deal with how they were feeling. Caregivers felt they had no work life balance.

This study adds to the body of knowledge that highlights the challenges caregivers face within their job role. The findings highlight that caregivers experience fatigue regardless of what type of caregiver they are or the extent of the staff to resident ratio. Caregivers are unaware that they are experiencing fatigue because their level of fatigue is normalised. This study could be used as a baseline to further investigate fatigue

amongst caregivers in a larger scale with a wider population sample. Future research needs to look at educating caregivers and managers on fatigue and teach coping mechanisms or introduce a fatigue policy to minimise fatigue as recommended by Work Safe NZ and in line with The Health and Safety Act 2015.

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: D.

Date: 26th July 2017

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Chapter 1: Introduction

Studies have shown that working conditions of caregivers are characterised by long hours, heavy work demands and low pay (Badkar et al., 2009; Ravenswood, et al., 2014). The occupation of a caregiver involves providing day-to-day caregiving activities such as bathing, feeding and interacting with residents (Moghimi, 2007). Caregiving is seen as a low-skilled and undervalued job in which there are no formal qualifications required to work in residential care facilities (Martin, 2007). It is argued, however, that caregiving is actually a skilled occupation despite it being undervalued by society (Badkar et al., 2009). It is also an occupation that demands working long hours and in which there is anecdotal evidence to show that many of the workers suffer from fatigue.

Fatigue manifests itself in various forms and therefore is not easily identifiable by a single test or function (Satio, 1999). Fatigue is often mistaken for depression or burnout when diagnosed (Schneider, 2003). The literature identifies two forms of fatigue. Firstly, Saito (1999) and Gander et al., (2011) refer to fatigue as the inability to function at an optimum level due to long periods of excess mental and physical work. The other form of fatigue highlighted in the nursing literature is compassion fatigue. Alkema, Linton, and Davies (2008) state that compassion fatigue is the result of long-term exposure to the suffering of others and having to listen to the traumatic events experienced by others with little to no emotional support in the workplace. The literature primarily focuses on the prevalence of fatigue amongst doctors and nurses within the health sector. Very little research identifies fatigue or compassion fatigue amongst caregivers. An enhanced understanding of the role of caregivers and a better understanding of fatigue and compassion fatigue could improve caregivers’ working environment by educating caregivers and managers on how to identify fatigue, provide preventative measures and help staff build resilience.

This chapter discusses the role of caregivers. It also explains the researcher’s interest in the topic and discusses any assumptions that have been made by the researcher. This is followed by an outline of the structure of this dissertation and a brief insight into what each chapter entails.

The role of caregivers

In palliative care and aged care, workers are referred to as caregivers, while in disabled adult care they are referred to as community support workers or casual support workers. While they may have different titles, they will be referred to as caregivers in this study as they all undertake the same role. According to Moghimi (2007), the occupation of a caregiver involves day-to-day caregiving activities such as bathing, feeding and interacting with the residents. However, in reality, caregivers are required to undertake more difficult tasks. Bathing also involves grooming, skin care and dressing. Feeding also includes giving out medication and preparing the food. On top of this, caregivers are responsible for housekeeping, laundry, transferring, doing exercises with the residents, shopping, going on community outings and providing company for the residents (Ravenswood, Douglas, & Teo, 2014). Overall, however, the role of a caregiver is to provide care to those who need it, that is, the residents of the organisations they work for. The benefits of being a caregiver are that the role can provide a sense of reward, satisfaction and companionship (Chen, Ngo, & Park, 2013; Ravenswood et al., 2014).

Researcher’s interest in the topic

My interest in caregiving has come about as a result of both my professional and personal life experiences. I grew up with a mother who worked as a caregiver. I observed her working very hard and always being very busy, but thoroughly enjoying her job role. I always wondered why my mother had to work three jobs at once but I never asked her. It was not until I got my first job that I realised why. I worked in a rest home with elderly people.

For me the experience was hard; I was paid $12 an hour and was always on my feet from the time I started a shift until the time it ended. I stayed in this job role throughout my high school years and left when I started university as the organisation was unable to find hours that worked around my classes. I would have stayed in this job role for longer had they been able to find suitable hours because I really enjoyed looking after the elderly residents. While the job was stressful, most times it provided me with happiness and I felt like I was doing something worthwhile.

It was not until I started university and people asked me what I did for a job that I realised the stigma attached to the role of a caregiver. I would tell them about my previous work and invariably the response would be, “I could never wipe bums” or, “That’s gross”. It was then that I realised just how overlooked caregivers are. I found the lack of recognition and respect for caregivers was widespread and disturbing. It was then I began researching and realised that while the literature has examined caregivers’ workload and pay conditions, there is little research that focuses on how caregivers feel and whether their role results in fatigue. It was at this point that I realised that this issue needed to be researched further and that people needed to be made aware of a caregiver’s experience.

Researcher’s Presumptions

As mentioned, I have previously worked as a caregiver for some time and therefore I have a good understanding of the job and the issues. Firstly, I am aware that the role of a caregiver can be very stressful and often frustrating. Secondly, I am also aware that the job can a very busy one and because of that caregivers are often very tired. Finally, I am aware that caregivers become caregivers for something other than money; they undertake the job role because they enjoy it and choose to stay in their job.

Identifying and discussing my presumptions with my supervisor helped me to design a comprehensive interview schedule that would cover the key issues. For the purpose of the interviews, (and as a requirement of the ethics application), it was decided that I would not disclose that I had previously worked as a caregiver and had knowledge about the role and issues of being a caregiver. The reason I did not disclose my experience and knowledge was to ensure reliability, remove bias and to minimise the possibility of the “Hawthorne effect” (McCambridge, Witton & Elbourne, 2014). It also meant that participants had to explain things in a more detailed way. That is, if they knew I used to be ‘one of them’, then there was the possibility that they would assume knowledge which I may or may not have had. This makes the method, therefore, more complete and repeatable, hence stronger. For more details regarding this refer to *Chapter 3: Methodology and methods.*

Dissertation structure

Chapter 2: Literature Review provides an overview of the current literature that is available and relevant to this dissertation. It examines how the current literature views fatigue and the key debates, as well as identifying the research gaps and suggesting potential consequences of these. It defines fatigue and compassion fatigue and looks at the prevalence of fatigue in different professions. It reviews fatigue in the health sector and discusses caregivers and the ‘caregiver burden’. Finally it discusses why this study is important for future research.

Chapter 3: Methodology and methods discusses and justifies the methodology chosen for this study. It discusses why the chosen methods were used to recruit participants and describes the data collection methods and the data analysis choices. It presents the time frame for this study and discusses ethical considerations. It also discusses the importance of bias, reliability and protocols.

Chapter 4: Findings presents the results of the data analysis. It discusses the findings based on interviews with five participants and uses the participants’ own words to describe how they are feeling.

Chapter 5: Discussion discusses the findings in relation to the literature on fatigue and caregivers. It highlights key themes identified in the findings and how they relate to the current literature on caregivers. It discusses implications and areas for future research.

Chapter 6: Conclusion and implications discusses the implications that were identified in the study. It discusses the limitations of the research and discusses future research, followed by a conclusion of the study that highlights the findings and main points of the study.

The following chapter’s purpose is to address the aim of this dissertation, which is to identify varying forms of fatigue, such as compassion fatigue, experienced by caregivers. It also aims to identify the key factors that contribute to fatigue amongst caregivers and how workplaces deal with this fatigue.

Chapter 2: Literature Review

Introduction

Fatigue is the inability to function at the desired level (Gander et al., 2011). Given that this study is located in New Zealand, it is important to first outline the New Zealand legal definition of fatigue. Work Safe New Zealand (previously known as the Department of Labour) defines fatigue as, *"The temporary inability or decrease in ability, or strong disinclination to respond to a situation, because of previous over-activity, either mental, emotional or physical."* (Department of Labour, 2003, p. 6). Under previous New Zealand legislation, fatigue was specifically treated as harm. Under section 6 of the Health and Safety in Employment Act 1992, 'harm' is defined as "illness or injury or both" and employers are required to take all practicable steps to prevent harm in the workplace (Department of Labour, 2003, p. 12).

Notwithstanding the legal definition, fatigue is ubiquitous and often difficult to define (Chalder et al., 1993). It affects everyone differently. Saito (1999) and Gander et al. (2011) refer to fatigue as the inability to function at an optimum level due to long periods of excess mental and physical work. The intensity of work affects the level of fatigue and because fatigue is a complex phenomenon that results from various factors and can manifest itself in various forms, it is difficult to measure (Saito, 1999). Vila, Morrison, and Kenney (2002) argue that the negative impacts from fatigue tend to spill over into family and social life, compounding the effects. For the purposes of this study the author also assumes that the reverse can be true – and that fatigue reported in a work context may unavoidably be the cumulative product of caring and other roles both at work and at home.

The purpose of this chapter is to examine how the current literature views fatigue and the key debates, as well as to identify the gaps in the research. The chapter looks at the prevalence of fatigue and compassion fatigue in different professions, in particular doctors, nurses, caregivers, police officers, veterinarians, counsellors and psychologists. For the definition of 'compassion fatigue' this research draws primarily on the nursing literature. Compassion fatigue was initially identified in this discourse and then later mentioned in the psychology literature. This is followed by a review of the literature on fatigue in the health sector, in particular, fatigue among caregivers, as well as a discussion on the consequences of fatigue. Included in this review is a discussion of the term 'caregiver burden' in relation to how it affects caregiving and caregivers. The terms 'resilience' and 'compassion satisfaction' are also discussed and more specifically the link each has in relation to compassion fatigue and burnout. The chapter concludes with a summary of gaps that have been identified in the process of undertaking this research and why this study is important for future literature.

Prevalence of fatigue

Fatigue is a perennial issue in a number of occupations. For example, there is evidence to show that fatigue is a widespread problem in the police force (Vila et al., 2002; Vila, 2006). Police officers experience fatigue and burnout from their job roles, which include exposure to death, disaster, having to deal with victims of sexual crimes and routine work factors (Martinussen, Richardsen, & Burke 2007). The negative impact of long, nonstandard hours and the impact that this has on other aspects of the individual's life, such as child care arrangements, is also highlighted in the literature as the main cause of fatigue for police officers (Vila, 2006). While the literature has identified the issues of fatigue, there are few studies that offer possible solutions to reduce the level of fatigue among police officers. In practice however, the New Zealand police force uses job rotation. That is, after officers have been on the front line for three to six months, they are transferred to less stressful roles, such as motorway patrol, to allow them to have a break before returning to the front line (Interview notes, 2016).

Another occupation in which fatigue is an issue is nursing. Here the literature not only identifies fatigue as a result of working long hours, but also as a result of working in a challenging work environment. This form of fatigue is known as compassion fatigue. Yoder (2010) and Keidel (2002) note that compassion fatigue is a unique form of burnout that particularly affects those in the caregiving profession. Compassion fatigue was initially identified in the nursing literature but expanded in the psychology and trauma stress literature as being identical to Secondary Traumatic Stress Disorder (STSD) (Stebnicki, 2000). STSD is recognised as the natural behaviours and emotions that result from knowing about a traumatising event experienced by a suffering person (Figley, 2002; Bride, Radey, & Figley, 2007). STSD is also common among counsellors but was previously referred to as a form of burnout, (Fahy, 2007). Bride et al. (2007) highlight that despite experiencing STSD, clinicians continue to be committed to their work. Throughout the psychological literature there is frequent mention of STSD in articles written by Figley, who adopted the concept and renamed it as compassion fatigue as it was seen as more user friendly (Coetzee & Klopper, 2010). Therefore, from a psychological perspective STSD has been identified as compassion fatigue with recognised causes; however, there has been a failure to identify solutions to the problem. Instead, it is regarded as a norm within the psychotherapist and social worker professions (Adam et al, 2006; Figley, 2007).

Notwithstanding the fact that compassion fatigue has been largely overlooked, there has been some attempt to understand when and how it occurs. Alkema, Linton, and Davies (2008) state that compassion fatigue is the result of long-term exposure to the suffering of others, that is, having to listen to traumatic events experienced by others with little to no emotional support in the workplace. There is a discussion in the literature that suggests that compassion fatigue only affects those who are highly motivated to bring about change and healing in the lives of the suffering (Gentry, 2002). Kristensen, Borritz, Villadsen, and Christensen (2005) notes that compassion fatigue is common among nurses and those who work within the human service sectors.

The literature also discusses that compassion fatigue is a form of burnout experienced by caregivers and human service workers (Negash & Sahin, 2011). It implies that it only applies to those who care for people. However, this is incorrect; compassion fatigue also affects professions such as veterinarians. A veterinarian is a doctor for animals. Much like doctors, they experience high amounts of stress caused from working long hours, relationships with peers, animals, lack of resources and having to provide euthanasia to animals (Gardner & Hini, 2006). There is an increase in the literature that looks at compassion fatigue outside of the human services sector, such as veterinarians. This is because the literature is beginning to identify other factors besides caring for people that contribute to or can cause compassion fatigue. Negash et al. (2011) discuss how compassion fatigue can be a symptom of other stressors such as work and family conflict.

The literature consistently reports that occupations in the health and community service sector are stressful (Dollard & McTernan, 2011). Trimpop, Kirkcaldy, Athanasou, and Cooper (2000) identify that there is a relationship between fatigue and psychological distress. This could clarify why counsellors, psychologists, doctors and veterinarians often develop substance or alcohol abuse habits, opting to self-medicate and treat their own injuries instead of reporting issues such as compassion fatigue or other injuries (Fahy, 2007; Gabel & Gerberich, 2002). Ultimately, this results in problems such as misjudgements, clinical errors, poor treatment and serious issues of effective care passed on to the patients (Rossi et al., 2012) A reoccurring theme within the literature is that fatigue, including compassion fatigue and burnout, is identified among different professions. There is knowledge on what it is, however, there appears to be no support from managers or methods identified to manage fatigue or burnout; rather, it is just overlooked. This contributes to those in high stress professions self-medicating through alcohol or medication to try to subdue the problem. Inbar et al. (2003) discuss the idea of ‘helping the helpers’, suggesting that more needs to be done to help those who work in health care professions to reduce the amount of stress, burnout and fatigue those professionals deal with.

Prevalence of compassion fatigue in the health sector

Compassion fatigue was first identified in the nursing literature, but it is not limited to nurses. Compassion fatigue affects police officers, hotline workers, mental health workers and any person who works with traumatised people (Conrad et al., 2006). Stress is also identified in the literature as a normal and natural response to working with traumatised people (Duggleby & Wright, 2007; Killian, 2008). There is a large body of laboratory data showing beyond a doubt that fatigue impairs human performance (Gaba & Howard, 2002).Current literature focuses on the prevalence of fatigue amongst doctors and nurses within the health sector. However, there is very little research that identifies fatigue or compassion fatigue amongst caregivers. Fatigue is one of the most common complaints of people working in the primary health sector (Aaronson, Teel, Cassmeyer, & Neuberger, 1999). Fatigue in the health sector affects both doctors and nurses within the medical profession. Sleep deprivation, extended hours and extreme fatigue are all common occurrences (Gaba & Howard, 2002; Fisman, Harris, Rubin, Sorock & Mittleman, 2007).

Fatigue occurs differently amongst doctors and nurses. Firstly, in relation to doctors, fatigue occurs often because it is the “norm” that doctors frequently work long hours on a regular basis. Junior doctors often work anywhere between 47-72 hours a week as part of a company/industry mechanism to teach these doctors how to deal with pressure (Gander, Purnell, Garden & Woodward, 2007). The literature also suggests the long hours of work are needed to expose junior doctors to a broad spectrum of cases (Gander, Purnell, Garden, & Woodward, 2007; Gaba et al., 2000). Furthermore, a New Zealand survey of anesthetists reported that of those surveyed 86 percent of respondents reported at some stage of their careers they had made an error due to fatigue (Gander, Merry, Miller, & Weller, 2000). This alone highlights the importance of ensuring fatigue is managed better within the health sector. In New Zealand, junior doctors went on strike after failing to reach an agreement over working conditions. In total, 70 percent of junior doctors are members of the New Zealand Resident Doctor Association union and when they decided to strike it meant that they only had enough senior doctors to provide urgent care (NZ Herald, 2017). Junior doctors are starting to fight back against the long hours as they no longer find this acceptable as doctors. The norm for New Zealand junior doctors is to work 60 hours a week for 12 days straight before they are given a break (NZ Herald, 2017). The literature fails to identify solutions for fatigued doctors as long hours are regarded as a normal way of working and something that doctors must become used to.

Secondly, in relation to nursing, which is the largest segment of the healthcare workforce (Maytum, Heiman, & Garwick, 2004), shift work is standard practice and stress and fatigue are common (Yuan et al., 2011). Shift work has been identified amongst multiple professions as one of the main causes of fatigue (Violanti et al., 2008; Peacock, 1983; Vila, 2006; Lerman et al., 2012). Kaine & Ravenswood (2014) argue that in New Zealand, fatigue amongst nurses occurs due to the high patient to nurse ratio. This high ratio results in nurses working on average 55 minutes a day extra in order to fulfil their responsibilities in the workplace (Scott, Hwang, & Rogers, 2006). This is highlighted in the nursing literature, however budget restrictions and staff shortages have resulted in nurses also working beyond their regular hours in order to cover shifts (Yuan et al., 2011). This is partially caused by an aging workforce and stimulated by growing shortages (Bohle, Di Milia, Fletcher, & Rajaratnam, 2008). The nursing literature primarily focuses on specific types of nurses in relation to compassion fatigue, in particular ontology nurses and nurses who work in palliative care, that is, caring for the terminally ill (Bush, 2009; Keidel, 2002). The literature does not look at all nurses only those nurses who specialize in dealing with severely sick or dying patients Compassion fatigue often appears suddenly and it is not identified until nurses have reached the limit of their capacity to care and are unable to sustain it any further (Keidel, 2002). A nurse experiencing compassion fatigue may have a change in job performance, an increase in the number of mistakes made and a noticeable change in personality (Hooper et al., 2010). Creating emotional distance is a mechanism used by nurses and caregivers in an attempt to protect themselves; however, this can lead to nurses and caregivers responding to clients in negative ways (Fischer et al., 2013). The literature shows that nurses who work nightshift or longer than 12.5 hours in one shift have a higher chance of becoming fatigued then those who work during the day (Lerman et al., 2012; Yuan et al., 2011). Providing care can be both highly rewarding and highly stressful (Adams, Boscarino, & Figley, 2006). Similar to the literature found on doctors within the health sector, the nursing literature uses the term ‘cost of caring’. The term is used to identify that compassion fatigue is something that is associated with the role of a nurse. Nurses at times will experience compassion fatigue and it is a “norm” within the health sector.

Working conditions and characteristics of the occupation ‘Caregiver’

Caregiving provides a sense of reward, satisfaction and companionship for those who do it (Chen, Ngo, & Park, 2013). The occupation of a caregiver involves providing day-to-day caregiving activities such as bathing, feeding and interacting with residents (Czuba, 2015; Human Rights Commission, 2012 & Moghimi, 2007). Caregiving is seen as a low-skilled and undervalued job in which there are no formal qualifications required to work in aged care facilities (Martin, 2007; Ravenswood & Douglas, 2014; Ravenswood & Harris, 2016). It is argued, however, that caregiving is a skilled job but one that is undervalued by society (Badkar, Callister &Didham, 2009). Furthermore the literature identifies that work that involves caring pays less than any other kinds of work (England & Folbre, 1999). This is related to the gender gap in pay; it is known that more women than men do caring work (England et al., 1999; Ravenswood, Markey, 2017).

There are two forms of caregiving: The first is family caregivers who take on the role of caregiver for family members who have become ill. The responsibilities may include complex physical and medical tasks, advocacy, decision making and emotional support (Hudson, Remedios & Thomas, 2010). These caregivers do not get paid for this work and do it because the family member requires assistance. The second is non family caregivers who work in residential care facilities or in the health and disability sector. This study focuses on paid caregivers within aged care, hospice and health and disability sectors. Caregiving work has stressful aspects, but it also has positive aspects such as the caregiver feeling useful and appreciated in the role (Pinquart & Sorensen, 2003).

While palliative caregivers have been identified in the literature as the most likely to experience compassion fatigue, those who look after dementia patients are also identified as having a high risk of suffering from compassion fatigue (Chappell et al., 2002). Similar to the nursing literature, the literature on caregiving focuses on particular types of caregivers to draw attention to compassion fatigue. In New Zealand, 92 percent of the caregiving workforce is female of which the average age is 45 years old (Ravenswood, et al 2014). Callister (2014) reported that between 1991 and 2013, New Zealand-born caregivers increased from 12,417 to 27,849 while overseas born caregivers increased from 2,844 to 12,882. Kaine et al. (2014) also highlight the precarious and insecure nature of work associated with caregiving. It is argued that caregiving employment offers “flexibility” that gives workers a work/life balance (Bohle, Quinlan, Kennedy, & Williamson, 2004). However, high unemployment, lack of qualifications and difficulty in changing jobs can cause some to be “locked in” to an occupation that no longer seems desirable (Aronsson, Gustafsson, & Dallner, 2000). This can lead to both burnout and compassion fatigue. There are similarities between nurses and caregivers throughout the literature: both have a high risk of experiencing compassion fatigue as they both provide caring to people as a job. Similar to a nurse, a caregiver will continue their role beyond their own tolerance until they are overwhelmed (Teel et al., 1999; Hooper et al., 2010). Likewise, when a caregiver experiences fatigue, it begins to affect the care recipient and caregiver relationship (Teel et al., 1999). This can lead to the possibility of both caregivers and nurses experiencing what is called the “boiled frog” syndrome. The “boiled frog” syndrome is discussed throughout the literature and it refers to the idea that if you place a frog in cool water and gradually heat it up, the frog will remain in the pot until it dies (Gini, 1998; Hannif, Lamm, Lo, & Lu, 2006; McKee, Johnston, & Massimilian 2006).

What this symbolises for both caregivers and nurses is that they are unaware of the effect their job has on them until it is too late. Or they are aware of the situation but see no point complaining. It is not until they have reached breaking point that they realise something is wrong. The literature points out that other aspects of a caregiver’s life can influence the likelihood of developing compassion fatigue (Adams et al., 2006). However, there is minimal literature that focuses not just on the caregiver’s role at work, but also their role outside of work. Bush (2009) discusses how caregivers at times feel that they are working two jobs: firstly as a caregiver and then coming home to their families to play a similar role. It is possible that caregivers could experience fatigue or burnout from this, however, there is no literature that focuses on this aspect of caregiving.

Causes of fatigue

Fatigue manifests itself in various forms and therefore is not easily identifiable by a single test or function (Satio, 1999). Fatigue is often mistaken for depression or burnout when diagnosed (Schneider, 2003). Nevertheless, fatigue can be seen as both a cause of or as a result of depression and can mask or mimic it (Schneider, 2003). Fatigue is a feature of depression, however, not all people who experience fatigue are depressed (Clark, 2002). Work Safe New Zealand identifies shift work as a common cause of fatigue and identifies physical exertion, sleep disruption and circadian disruption as common factors in the onset of fatigue (Department of Labour, 2003). Violanti et al., (2008) further discuss that working other than a regular day shift (9am-5pm) can be a potential occupational stressor. This is because shift work can cause disturbances to circadian rhythms and cause fatigue, which can decrease the level of performance and subjective response a person has (Peacock, Glube, Miller, & Clune, 1983). Those with responsibilities outside work may also find these harder to achieve in a disturbed work routine. For example doing the cleaning in a house when others are trying to asleep, is clearly counterproductive overall. Mismatched sleep patterns in a household is rarely mentioned in the literature because studies tend to focus on workplaces.

Shift work is identified in the literature as a common cause of fatigue in multiple professions especially those working at night (Courtney, Francis, Paxton, (2010). Residential homes and hospitals are required to operate 24/7, which means that they are required to have staff working different shifts. Shifts normally range from 7am-3pm, 3pm-11pm, 11pm-7am and then short shifts in between. However personality, age, marital status, behavioural and health variables are all factors that may influence whether or not a person wants to do shift work (Bohle & Tiilley, 1998). There are a wide variety of factors that may affect the fatigue of shift workers, the strongest predictor of dissatisfaction for shift work being work/non-work conflict (Bohle et al., 1998; Bohle & Tilley, 1993). While shift work is unavoidable in some workplace settings, it could be managed better within those professions. The literature has only been able to identify the solution of job rotation, which at present does not always work (Inbar & Ganor, 2003). Possible solutions could be hiring specific workers for night and day shifts, so those who want to work nights are able to. This is based on the idea that many factors influence attitudes towards shift work.

As mentioned, fatigue is often mistaken for burnout and compassion fatigue is defined in some of the literature as a unique form of burnout (Alkema, Linton & Davis, 2008; Bride, Radey & Figley, 2007). However, burnout can occur when one is unable to achieve one’s goals, which results in frustration, a sense of loss of control and diminishing morale (Yoder, 2010). This differs from compassion fatigue because compassion fatigue affects a person in a similar way to post-traumatic stress disorder; that is, being unable to save an individual from harm can result in guilt and distress (Yoder, 2010). The evidence suggests that compassion fatigue strongly affects those within the health sector, more specifically nurses, doctors and caregivers. In some cases, the caregiver loses interest in being empathetic towards those who are suffering as a reaction to being overwhelmed (Abendroth, 2011). At the same time, there is an association between depression and caregiver burden (Schneider, 2003). However, either form of fatigue can lead to increased absenteeism, decreased performance and higher turnover for the organisation (Hooper et al., 2010). This is not suitable for the organisation because it means that it will have to expand already scarce resources to recruit and train new staff (Chiller & Crisp, 2012). Furthermore, it puts remaining staff at risk of burnout or fatigue because they are more likely to have to work overtime, stay longer and experience a higher workload to compensate for those who are not at work.

Burnout in relation to compassion fatigue

The current literature discusses that compassion fatigue and burnout are overlapping concepts; therefore, it is important to differentiate between the two. Sabo (2006) identifies burnout as the process in which the professional's attitudes and behaviours change in a negative way in response to job strain. Burnout can result in depression, fatigue, sense of failure, loss of motivation and poor productivity (Kop, Euwema, & Schaufeli, 1999). Burnout can result in healthcare professionals treating patients and others in an uncaring manner, as well as result in a high turnover of staff (Aycock & Boyle, 2009). Burnout occurs because of excessive and prolonged levels of job stress (Conrad & Kellar-Guenther, 2006). Burnout is seen as a response to interpersonal stress on the job, which can result in changes in attitude and behaviour towards others (Ibikunle, Umeadi, & Ummunah, 2012). In comparison, compassion fatigue is caused by prolonged, continuous and intense contact with patients (Coetzee & Klopper, 2010). Compassion fatigue can occur suddenly with very little warning when compared to burnout, which occurs over time (Coetzee et al., 2010). Empirical studies on burnout reveal that it is prevalent among professionals (Sprang, Clark, & Whitt-Woosley, 2007), while compassion fatigue is typically reserved for caring professionals, paraprofessionals and volunteers (West, 2015). Burnout and compassion fatigue are similar in the sense they can both create feelings of helplessness, loneliness, anxiety and depression (Conrad et al., 2006). Stress results in burnout, which can manifest as compassion fatigue, and it is possible for a person to experience both compassion fatigue and burnout at the same time (Craig & Sprang, 2010). While it is discussed in the literature that those who are more caring and empathetic are more likely to suffer from compassion fatigue (Edwards, 1995), there are no traits identified in the literature that makes a person more susceptible to experiencing burnout than others. The key difference between the two is that burnout is caused by the individual's inability to cope with constant work stresses, compared to compassion fatigue which is primarily caused by dealing with continuous contact with people (Ibikunle et al., 2012).

The 'Caregiving Burden' – The cost of caring

Burnout and compassion fatigue research has its roots in caregiving and service occupations where the relationship between the provider and the recipient is at the core of the profession (Fischer et al., 2013). Caregivers are required to constantly balance their personal lives with family and their caregiving roles which can be overwhelmingly stressful (Chen et al., 2013). Compassion fatigue implies a state of psychic exhaustion. This is associated with the 'cost of caring' and evolves in caring professions where workers are in close contact with others (Boyle, 2011). A reoccurring theme within the current literature identifies that caregiver fatigue can also affect the patient and the caregiver's relationship with patients (Chen et al., 2013; Hooper et al., 2010; Teel et al., 1999). This also occurs amongst nurses. When nurses are caring and compassionate, their patients are satisfied; however, there is a link between patient dissatisfaction and the fatigue and stress of the care-giver – when nurses experience fatigue or stress, their patients are likely to feel dissatisfaction (Hooper et al., 2010). Caregivers need to be constantly prepared to handle unpredictable situations and obligations (Yuan et al., 2011). 'Caregiving Burden' is defined as the overall impact of the physical, psychological, social and financial demands of caregiving. It is commonly referred to in the literature as the 'cost of caring' (Chen et al., 2013; Given et al,, 2004; Teel, Press, Lindgren, & Nichols, 1999).

The literature frequently uses the term and the idea behind it as being directly related to caregiving; however there is a difference between the caregiver burden and caregiving in general because caregiving refers to activities and experiences involved in providing help and assistance to those who are unable to provide for themselves (Etters, Goodall, & Harrison, 2008). Similar to nursing, the literature shows that caregivers who work specifically with dementia patients experience a greater level of burden and are more likely to experience fatigue (Chappell & Reid, 2002; Etters et al., 2008). However, while the literature looks at different types of nurses and whether they experience compassion fatigue more than other nurses, there is little literature that looks specifically at different types of caregivers. Most of the literature identified examines palliative caregivers in relation to compassion fatigue. Therefore further research could be undertaken to provide comparisons between different types of caregivers. Compassion fatigue is reported more by women than by men, who are more likely to report burnout than compassion fatigue (Fischer, 2013). This could be because caregiving is a female dominated profession. The literature could possibly look into whether compassion fatigue affects males and females differently.

Resilience and compassion satisfaction

Resilience is defined as the competence to cope and adapt in the face of adversity and the ability to bounce back when stressors become overwhelming (Pidgeon, Ford, & Klaassen, 2014). Resilience also reflects the ability to maintain a stable equilibrium (Bonanno, 2004). It is argued that resilience can be taught, especially to health professionals; however, individuals that possess a set of characteristics such as empathy, pro-social behaviour, positive self-image and the ability to organise daily responsibilities tend to cope with stress better (McAllister & McKinnon, 2009). It is suggested that those who are more resilient are less likely to become fatigued or suffer burnout from job demands. This does not mean that such individuals will not ever experience it. When there is a continuation of constant stress on top of an already demanding workload, resilience can be put to the test (Inbar & Ganor, 2003). This can affect health professionals such as hospice nurses who encounter more patient deaths than any other nurse speciality (Ray, Wong, White, & Heaslip, 2013). Resilience is under-researched in the literature, especially within the health sector. If resilience is taught to health professionals, it may reduce burnout and fatigue; however, it may also prolong a health professional’s experiences of burnout or fatigue (Sprang et al, 2007).

Compassion satisfaction is the opposite of compassion fatigue. Compassion satisfaction is the positive feeling one receives from completing tasks well (Klappa et al., 2015). Alternatively, compassion satisfaction is the positive benefit a person gets from working with those who are suffering (Conrad et al., 2006). A person can either experience compassion satisfaction or compassion fatigue – it is not possible to experience both at the same time. There is a cost to caring: while a person may experience compassion satisfaction within their profession, it is more than likely that stress from wanting to help those who are suffering will result in the person becoming fatigued (Sexton, 1999).

Research Gaps

To summarize, the research gaps that have been identified based on the current literature are as follows:

- While there has been ample research on fatigue, there has been little research on compassion fatigue among caregivers.
- There is a lack of knowledge that looks at the cost figure associated with fatigue, in particular the emotional and physical cost associated with caregiving.
- There has been little research on work/life balance among caregivers.
- Shift work has been identified in the literature as a common cause of fatigue but there has been a lack of research that identifies solutions to minimise this.
- There has been a lack of research that looks at whether resilience can be taught to those in the health professions to minimise burnout and fatigue.
- More could be done to assess and understand Cumulative Care Load – the combination of paid and unpaid responsibilities on staff.

Conclusion

It is evident that the occupational health and safety (OHS) of caregivers is rarely mentioned in the health sector literature, especially in relation to fatigue. Moreover, other forms of fatigue, such as compassion fatigue, have only recently been identified in the literature and only among nurses (Bush, 2009). Future research could look at how compassion fatigue affects both male and females and if there are any similarities or differences. Therefore, there is a need to undertake research that looks at different forms of fatigue experienced by caregivers in different workplace settings. The current literature focuses on nurses who experience fatigue rather than caregivers. In New Zealand, there is a gap in the literature regarding compassion fatigue amongst caregivers. As the population of New Zealand is ageing and requires more individualised care, the level of caregiving is growing. Caregivers experience emotional stress and decreased morale and life satisfaction (Moghimi, 2007). The role of a caregiver is physically and emotionally challenging. The literature commonly refers to the term ‘Caregiver Burden’ as a consequence associated with caregiving (Chappell et al., 2002). ‘Caregiver Burden’ refers to the overall impact of the physical, psychological, social and financial demands of caregiving (Chen & Park, 2013). Fatigue erodes the caregiver’s ability to function at an optimum level (Showwalter, 2010).

When this occurs, it puts both the caregiver and the patient at risk because fatigue interferes with the caregiver being able to do his/her job effectively (Showwalter, 2010). In addition, the current literature concentrates on fatigue among senior medical professionals as a result of caring for terminally patients while offering no thorough examination of the fatigue experienced by caregivers undertaking different roles. Therefore, the proposed study will provide useful insights into whether or not caregivers experience fatigue in the same way as senior medical professionals Professional managers in the care sector have very little evidence-based research to draw on, and this must be having a detrimental impact on the ability to run operations effectively and take care of staff.

Chapter Three: Methodology and methods

Introduction

As discussed in the literature review, it is well known that fatigue, and compassion fatigue in particular, are prevalent in (but not limited to) the health sector (Adams, Boscarino & Figley, 2006; Dollard & McTernan, 2011; Figley, 2002; Kop, Euwema & Schaufeli, 1999). The literature review identified other occupations that also have a prevalence of fatigue and compassion fatigue, such as policing. While there has been ample research on fatigue, there has been little research on fatigue and compassion fatigue amongst caregivers. Shift work is identified in the literature as a common cause of fatigue and yet there are few definitive studies that identify solutions to minimise it. Finally, there is little known about the economic and social costs associated with fatigue in the caregiving sector.

This study examines both fatigue and compassion fatigue amongst three different types of caregivers: aged care caregivers, palliative care caregivers and disabled adult caregivers. This study focuses solely on caregivers and not nurses as most of the literature on fatigue has centred on nurses only (Yoder, 2010; Yuan et al, 2011). This chapter introduces and defines aspects of ontology, epistemology and methodology whereby an interpretive descriptive approach using a qualitative methodology was selected as being appropriate to identify if and under what circumstances caregivers experience fatigue. Qualitative data was gathered using a semi-structured interview schedule in order to answer the central research question: “Do caregivers experience fatigue, including compassion fatigue, and under what circumstances?”.

Methodology

Drawing on similar exploratory studies focused on the health care sector (Britten, 2007; Hunt, 2009; Neergaard et al., 2009; Thorne, 2000; Thorne et al., 2004), it was appropriate that this study followed similar ontology, epistemology, and research methods. The approach taken in this study was an interpretivist approach. Ontology is concerned with what constitutes reality; that is, researchers need to take a position regarding their perceptions of how things really are and how they really work (Gray, 2013; Scotland, 2012). The ontological position of interpretivism is relativism (Crotty, 1989; Scotland, 2012). Relativism is the idea that reality is subjective and changes from person to person (Gray, 2013). As this research is investigating fatigue among caregivers and why it occurs, relativism was a suitable approach. It is subjective because no two caregivers are the same and whether or not a caregiver experiences fatigue is dependent on the person. Qualitative research often takes the position that interpretive understanding is the only possible way to uncover the meaning of a phenomenon (Thorne, 2000). This contrasts with the positivist approach, which argues that reality consists of what is available to the senses, that is, what can be seen, smelt and touched (Gray, 2013).

Epistemology provides a philosophical background for deciding what kinds of knowledge are legitimate and adequate. It is concerned with how knowledge can be created, acquired and communicated (Crotty, 1989; Gray, 2013; Scotland, 2012). Epistemology can include objectivism, constructivism or subjectivism. For this research, the epistemology used was subjectivism, which is based on real world phenomena (Crotty, 1989; Scotland, 2012). Subjectivism attempts to comprehend others' understanding of what they do and the meaning they ascribe to their actions. This research seeks to comprehend caregivers' understanding of fatigue and whether or not they experience fatigue within the workplace.

The interpretive descriptive approach uses themes and patterns from the participants' experiences to derive an understanding of the phenomena (Forbes et al., 2012). This approach was chosen because it enables an exploration of the perceptions of being a caregiver and provides details based on the experiences of caregivers on whether or not they experience fatigue.

Researching fatigue among caregivers

Given that the focus of the study is on the participant's perspective of fatigue, a qualitative method was adopted. Hunt (2009) identifies that qualitative research methods are increasingly being utilized by researchers within the healthcare sector. Neergaard, Olesen, Andersen, and Sondergaard (2009) also argue that qualitative research in the health sector has led to the introduction of a vast array of qualitative methodologies. Qualitative descriptive studies involve presenting facts of the case in everyday language (Sandelowski, 2000; Neergaard et al., 2009). Qualitative research is defined as an approach that emphasizes the collection of descriptive data in natural settings (Babchuk & Badiee, 2010). Qualitative methods also provide context in which data are collected in a real life setting. By collecting qualitative data, one has the ability to analyse how and why things happen instead of merely focusing on a snapshot in time (Johnson, 2001; Sandelowski, 2010). An important difference between qualitative methods and quantitative methods is outlined by Throne (2000) who maintains that qualitative research is more concerned with uncovering the knowledge of how people think and feel about circumstances in which they find themselves rather than making judgements as to whether or not those thoughts and feelings are valid.

This study is also exploratory and draws on descriptive interview data from caregivers located in different workplaces. It is common to use qualitative description in this type of study given that the aims are to describe the caregiver's experiences and feelings. Therefore, using similar terminology to the participants will make the research easier to understand should it be read by any other caregivers.

As discussed below, the analysis of the interview data will be thematic. Thematic analysis is used to identify all data that relate to already classified patterns (Aronson, 1995). It focuses on identifiable themes and patterns of living or behaviour. Aronson (1995) discusses how thematic analysis combines and catalogues related patterns into sub themes. The transcribing will be completed by solely the researcher.

Sample

For this study five caregivers from different workplaces were interviewed. The selection criteria for the caregivers was that they had to have worked for a minimum of two years in either aged care, disabled adults care or palliative care and be over the age of 16. Participants were chosen using a backwards snowball sampling technique. Information on the study was left with managers in selected service providers and if anyone was interested in participating, they were given the researcher's contact details. Those who contacted the researcher were then given further information about the study and asked to sign a consent form. This method of acquiring participants presented difficulties in that it took some time to get an initial response and *ipso facto* it was then difficult to get five committed participants. Overall, it took just under three months to successfully get five participants who were willing to be interviewed and subsequently signed the consent form. Below is a table that outlines the participants' characteristics and provides an overview of their experience and type of caregiving. As can be seen from the table, all participants are female. This is no surprise as 90 percent of the caregiving workforce is female dominated (Badkar et al., 2009).

Table 1: Overview of the participants

Participant	Male/ Female	Experience	Type of Caregiver	Staff to Resident Ratio
1	Female	5 years in the same organisation working with people with intellectual disabilities.	Casual support worker for disabled adults. Currently on maternity leave and will not be returning to work.	3 staff to 8 residents.
2	Female	12 years in the same organisation working with people with intellectual disabilities.	Community support worker for disabled adults.	2 staff to 6 residents
3	Female	7 years as a caregiver. 5 years in current role as a caregiver.	2 years in palliative care. 5 years in aged care.	2 staff to 12 residents
4	Female	5 years in the current organisation in total. Worked for 3 years before taking a break. Returned and has since worked for 2 years.	Caregiver	2 staff to 7 residents, 8 if there is a respite resident.
5	Female	20 years' experience. Worked in current organisation for 15 years.	Aged care caregiver as well as palliative care.	2 staff to 12-15 residents.

Data collection

The data collection took place over a period of eight weeks. The method chosen was semi-structured, face-to-face interviews that were approximately 30 to 60 minutes long. The interview data were collected using an audio recording device. This ensured that the researcher was able to fully focus on what the participants were saying. It also meant that minimal note taking was needed during the interviews. Gill, Stewart, Treasure, and Chadwick (2008) maintain that one of the interviewer's most important skills is the ability to listen to what participants are saying; that is, participants are able to recount their experiences fully with no unnecessary interruptions.

Interviews are the most commonly used qualitative technique in the healthcare setting (Britten, 2007). Given that this is an exploratory study, a semi-structured interview schedule in which interviews were conducted face-to-face was used as the most appropriate method of obtaining in-depth views and opinions on this topic. In addition, a semi-structured interview schedule was useful in that the order of questioning could be changed depending on how the interview was developing with participants (Johnson, 2001). Using semi-structured interviews with open-ended questions gives participants an opportunity to discuss their answers more in depth. This structure also allows the researcher to probe for detailed descriptions and clarification to gain an understanding of the participants' lived experiences (Gray, 2013). Gill et al. (2008) state that semi-structured interviews are most frequently used in healthcare as they provide participants with some guidance on what to talk about. It is also argued that face-to-face interviews provide a deeper understanding of social phenomena and are appropriate when exploring the perceptions and views of the interviewees (Britten, 1995; Wackerbarth, Streams, & Smith, 2002; Gill et al., 2008; Lamm, 2014). In comparison, surveys require larger participation rates and do not necessarily capture sufficient in-depth data that would be relevant to this research topic.

In the interview process, the participants were all asked the same questions and how they responded to them determined if additional questions were asked. The questions were grouped under the following headings: Firstly, questions sought to provide an overview of the participants. Secondly, participants were asked about their work-related experiences as caregivers, not only in their current organisation but also throughout their career as a whole. Thirdly, participants were asked about their experiences of fatigue as caregivers. These questions also provided a brief insight into the lives of the caregivers outside of work. The fourth and final group of questions provided the participants with an opportunity to add anything else they wanted to disclose.

Data analysis

For this study thematic analysis was used to analyse the data. Fereday and Muir-Cochrane, (2006) define thematic analysis as the search for themes through a description of the phenomenon. This process involves identifying themes by reading the data and grouping the themes into categories for analysis. Because the study involved a small sample of five participants, the thematic analysis was conducted manually by the researcher. As stated, the interview schedule was grouped into four categories: overview of the caregiver; work-related experiences of the caregiver; experiences of fatigue; and final questions. These four categories were used to generate key themes based firstly on the individual participant and then on the group of participants. The analysis began with the interview field notes that were taken in order to gain an impression of the main themes during the interviews. When transcribing the interviews, an analysis of the data also took place and allowed the researcher to build on the themes as well as identify any questions that were missed during the face-to-face interviews.

The data analysis can be broken up into four stages:

1. Transcribe the interviews
2. Analyse the individual transcript based on the four question categories
3. Analyse all participant transcripts based on the four question categories
4. Identify themes through thematic analysis.

1: Transcribe the interviews

An audio recording device was used during the interview process with the five participants and the transcription of the interviews was completed by the researcher for this study. Although transcription is a time-consuming process that involves typing interviews out word for word, it provides researchers with an opportunity to immerse themselves in the data and allows a deeper understanding of the topic (Stuckey, 2014). The decision to transcribe all the interviews was made because the sample size was small with only five participants. Once the transcripts were typed up, the interviews were anonymised in that any identifying factors were removed and replaced with participant numbers.

2: Analyse the individual transcript

The semi-structured interviews were divided into the four question categories, which made it easier to analyse each interview. Each interview was analysed individually in order to gain an understanding of each participant and to identify key themes.

3: Analyse all participant transcripts

Once transcripts had been analysed individually, they were then compared as a whole. This allowed key themes to be identified throughout all five interviews. The four main question categories were then broken into detailed sub-categories which could be used for the discussion of findings.

4: Identify key themes through thematic analysis

Key themes were identified from the sub-categories during the analysis of all participant transcripts. The purpose of this process was to narrow down the key themes in relation to the research question; that is, whether caregivers experience fatigue and if so, whether they experience fatigue, compassion fatigue or both.

Reliability, bias and protocols

An interview protocol was developed so that the participants could anticipate the interview process, how long the interview would take and the post-interview information that they would receive. Safety measures were included in the interview protocol, for example, that the researcher would not interview participants in their own home. The interviews were also recorded and transcribed solely by the researcher.

The purpose of reliability is to produce stable and consistent results. When determining the reliability of participants, the focus is on trustworthiness, that is, whether or not participants are telling the truth (Golafshani, 2003). Reliability is concerned with the consistency, stability and repeatability of a participant's account and the researcher's ability to collect and record information (Brink, 1993). For this study, reliability was ensured by asking all the participants the same questions from each of the four question categories. All interviews were recorded on an audio device to minimise the researcher's need for note taking and to allow the researcher to listen to what the participants were saying.

A study's validity is concerned with whether the research truly measures what it intends to measure, as well as whether the findings are accurate and truthful (Brink, 1993; Golafshani, 2003). The researcher in this study has a background in caregiving, which could blur the lines of validity. However, for the purpose of this study, the researcher did not disclose her background to the participants. Furthermore, the researcher did not interview participants that she knew (see Brink, 1993).

With regard to bias, there is the risk of the 'Hawthorne effect', whereby the behaviour of the interviewee will change as a result of being the subject of attention (Srigley, Furness, Baker, & Gardam, 2014; McCambridge, Witton, & Elbourne, 2014). In other words, people sometimes have a tendency to change their behaviour or what they say when they know they are being observed (Sedgwick & Greenwood, 2015). This creates bias in that participants being interviewed may say what they think the interviewer wants to hear rather than describing what has actually happened to them (Srigley, 2014). Furthermore, a small participation rate and the use of convenience sampling can create bias. This study originally had six potential participants; however, when the sixth participant continued to postpone the interview, the decision was made to remove this participant and to focus on the five other participants instead. Despite this small sample size, there was no opportunity for convenience sampling as the researcher used a backwards snowball sampling technique so those who were interested contacted the researcher instead of the researcher contacting potential participants. However, the researcher is familiar with the caregiving industry and knows people in the industry, which could create bias. This was overcome in that the researcher did not interview people in the industry that she knew or who knew of her (Suri, 2011).

Ethics

Ethics approval for this study was granted on the 23rd of February 2017 by the AUT Ethics Committee. The ethics application included the purpose of the research, its history and the research design as well as assurances of confidentiality and anonymity. Information that was going to be supplied to the participants was also submitted, including the consent form, the participant information sheet, the confidentially agreement and the interview guidelines. A copy of the researcher safety protocol was also attached.

The AUT Ethics Committee stipulated that the researcher was not to inform the participants that she had worked as a caregiver and would not discuss any of her personal experiences. To ensure the participants' anonymity, participants were not identified in their interview transcriptions. When specific quotes are used in the report, the participants are given numbers instead of names to maintain confidentiality.

Conclusion

In summary, this study uses a similar research design to other studies in the healthcare sector. The main reason for this is because many healthcare researchers aim to understand why particular issues occur in the healthcare sector rather than the rate at which they occur. This research investigates if fatigue occurs amongst five caregivers involved in aged care, palliative care and with disabled adults and under what circumstances. Undertaking an exploratory, descriptive, qualitative approach using semi-structured interviews was deemed the most suitable research approach. To reduce bias and ensure reliability and validity, participants were all interviewed using the same semi-structured interview questions and the researcher did not disclose her experience within the caregiving industry. The next chapter presents and discusses the data and analysis.

Chapter 4: Findings

Introduction

The objective of this study is to identify if fatigue is evident amongst caregivers, in particular compassion fatigue and under what circumstances. This chapter presents and discusses the findings based on the five interviews that took place with caregivers from different sectors (aged care, disabled adults and palliative care). This chapter is comprised of four sections. The first section provides an overview of the caregivers who were interviewed for this research as well as details about their lives. The second section discusses the work-related experiences of these caregivers. This section aims to gain an insight into what each caregiver has experienced in their current organisation and during their career as caregivers. The third section focuses on fatigue and whether or not the caregivers have experienced fatigue or experience symptoms of fatigue. It also provides a brief insight into each caregiver's life outside of work. The final section presents further information disclosed by the caregivers as well as their opinions on the recent court case settlement for caregivers. The findings are analysed, organised and categorised into the themes based on each section discussed below.

Overview of the caregivers

The table below outlines the main characteristics of the five caregivers who took part in this study. The caregivers have had between 5 and 20 years' experience in the caregiving industry. A reoccurring theme is that all caregivers interviewed are female. Three out of the five caregivers have worked in the same organisation throughout their role as caregivers. The terminology around their job titles is slightly different; those who work with intellectually disabled residents are referred to as casual support workers or community support workers, while those who work with the elderly and in aged care are referred to only as caregivers. The main reason that these participants became caregivers is because they like helping people. Four out of the five who were interviewed took on the role because they liked people or because they had previous experience caring for family members. One participant took the job because she did not want to work in a supermarket; however, over time she embraced the role and has become a more caring caregiver.

Table 2: Characteristics of the participants

Name & gender	Number of years' experience in total	Current role & years of employment in position	Reason for becoming a caregiver
Participant 1 Female	5 years	Casual support worker for 5 years. Works with people who are intellectually disabled.	Likes helping people
Participant 2 Female	12 Years	Community support worker for 12 years. Works with people who are intellectually disabled.	Had family members who she cared for previously who were disabled.
Participant 3 Female	7 Years	Caregiver for 5 years. Works in aged care with dementia residents.	Needed a job and had the option of working in a supermarket or becoming a caregiver.
Participant 4 Female	5 years	Caregiver for 2 years. Works with elderly people.	Sees herself as a caring person and likes doing it.
Participant 5 Female	20 years	Caregiver/palliative care for 15 years. Works in aged care with Alzheimer's residents and provides palliative care.	Did not think she was bright enough to do anything else and really likes people so thought she would give it a try.

Work related experiences of caregivers

The purpose of this section is to present what the participants have experienced during their career as caregivers. It focuses on the participants as a group and then discusses them individually based on the current role they are working in. One of the aims of undertaking the interviews was to gain an understanding of what these caregivers experience in their workplaces.

Highs and lows of the job

One of the main themes identified from the interview data was that all the caregivers really enjoy taking care of the residents. Spending time with the residents and getting to know the people they are taking care of is the highlight for all caregivers. When discussing negative work related experiences, differences emerged between caregivers. The two caregivers who work in aged care with dementia and Alzheimer's residents had the same theme. "*It was a real eye opener at first to see. I just thought when people got old they just went to a rest home but to see what actually happens to them as in the illness and stuff like that was an eye opener" – Participant 5.*

The two aged care caregivers noted that residents passing away or having their health deteriorate is a negative work experience. There were other instances of negative work experiences. For example, Participant 1 described a time where a resident's wallet went missing and she was blamed for it. However after the theft was identified she was not given an apology and there was no acknowledgement by her team leader that they made a mistake. Participant 1 described the situation as making her feel "really stink". Participant 2, who was also a disabled adult caregiver, was on sick leave for two months and during that time she stated that she really missed her job and desperately wanted to return to work. In another example, the caregiver working with the elderly had problems around the poor management practices in the organisation. All participants discussed different experiences that have affected them but the two aged care workers had very similar responses. No caregivers discussed more than one negative experience during the interviews.

Table 3: Staff to resident ratio

Participant & type of caregiver	Number of staff	Number of residents
1 Disabled adults	3	8
2 Disabled adults	2	6
3 Aged care	2	12
4 Elderly caregiver	2	7 or 8
5 Aged care/ palliative	2	12-15

When comparing staff to resident ratios among caregivers, it is clear that those caregivers who work in aged care have a higher number of residents to care for. The ratio doubles for aged care caregivers in comparison to disabled adult caregivers. All participants work very similar hours, ranging from 7am-3pm, 3pm-10pm, 3pm-11pm, 7am-1pm, 4pm-8pm. The only difference is that the disabled adult workers have shifts which are termed sleepovers. This means that they work from 10pm-7am and are paid to sleep at work. This compares with other caregivers who have an 11pm-7am shift which is called the night shift, during which they are required to stay awake.

Workload

For disabled adult caregivers, the workload was described as "*Pretty easy*" (Participant 1) and only challenging when they are short staffed. In comparison to the aged care workers, Participant 5 described stated that, "*The workload sucks, I'm not happy with that it's too much work.*" All caregivers agreed that the workload is manageable but that this also depends on the residents and staff. However the aged care workers suggested that the workload would be even more manageable if the workers in the proceeding shift prior did not leave them all their work. All of those who were interviewed are required to provide the same amount of care. Each caregiver is responsible for the daily needs of the residents, cooking, cleaning and spending time with the residents the only difference being that three participants have 6-8 residents between 2-3 caregivers, while two participants have between 12-15 residents between 2 caregivers. According to Participant 3, "*That's just how it is, it comes with the occupation.*" All caregivers agreed that the workload has increased over the years with the majority of the caregivers determining that the increase in workload is due to the deterioration of the residents over time.

Experience of fatigue

This section aims to identify if the participant caregivers have experienced fatigue or symptoms of fatigue and to provide a brief insight into what they do outside of work. The participants were not asked if they have experienced fatigue; instead, they were asked questions around fatigue and tiredness. The aim was to encourage participants to describe how they are feeling.

All participants interviewed admitted that they have experienced tiredness as a caregiver. Participant 1 described her tiredness from having to do multiple 24-hour shifts and pointed out that she has no choice but to do the shifts: "*They make you do it.*" She added that she is unable to refuse the shifts because she does not want to make "trouble". Participant 2 stated that *"sometimes the workload impacts on you"*; however, she put her tiredness down to not getting enough rest, not sleeping well and not eating well. Other participants who were interviewed described how they, "*Just don't have time for the residents I can't be bothered and I shouldn't be feeling like that"* (Participant 4). Having to work long shifts and working with new staff or staff who do not do their fair share of the work is another factor mentioned by caregivers that causes them to feel tired. "*You just feel really tired like, do I really want to be here today?"* (Participant 5). The hours of work are clearly a main contributor to the tiredness of the caregivers. A common theme among the caregivers was that working non-standard hours and working long shifts contributes to their tiredness. Dealing with the workload of being a caregiver also relates to the tiredness of the caregivers.

When comparing the physical aspect of the role of a caregiver and the emotional aspect of dealing with the residents on a daily basis, the general consensus amongst the participants was that both factors contribute to their tiredness. All participants agreed that the physical aspect of caring for frail or slow residents, such as lifting, transferring and changing the residents, puts them under strain. Residents having falls, deteriorating health or behavioural changes which also impact on the tiredness of the caregivers: "*It's hard because you see what they were before. You could manage them and you could do more but now it's getting more difficult"* (Participant 2). In terms of the emotional aspect of providing care, the caregivers are all clearly affected in the same way. The residents affect the caregivers' emotional wellbeing when their health deteriorates, when residents pass away and for the aged care caregivers, the repetitive behaviour that is associated with residents who have Alzheimer's is also draining. *"You want them to get better and you do all you can to make them better but sometimes it doesn't happen"* (Participant 3).

Participant 5 has had experience in palliative care and pointed out that she really enjoys that aspect of her job because it means that she is caring for residents until the end. *"It's always sad when you know the person isn't going to live long, it can be really sad and you don't want anything to happen to them because you are fond of them"*(Participant 5). This poses the question of whether caregivers care too much. The participants were asked if they thought they cared too much and all caregivers responded with yes; however, some went more into detail than the others: *"You look after them all and when something happens to them you get really upset it affects you"* (Participant 5). *"Yes I do care as a caregiver, that's just who you are, you care about the residents"* (Participant 2). *"It's not a job where you can just switch off and go home, there's always something* *on your mind, you wonder if a resident is ok”* (Participant 3). It is evident that the caregivers all care about who they look after. Each caregiver is affected differently but they all agreed that it is the residents that affect them the most. What happens to the residents directly impacts the way the caregivers feel: *“*Sometimes *you don’t want to stay there, you don’t want to do that job because you know the next person is going to pass away and you have to deal with it”* (Participant 5).

Participants were asked what coping mechanisms they use to overcome their tiredness. Most expressed that they do not have any mechanisms to cope with this. One participant expressed that she takes the occasional sick day when she feels very tired. Another participant prays when she is tired and another goes to the gym. While all participants accommodated their tiredness differently, all of the participants believed feeling tired all the time was just part of the job. The participants did not have any coping mechanisms to deal with tiredness while they were working or within their workplace, such as changing job roles or job hours temporarily. None of the participants mentioned anything work related to cope with their tiredness because of the stigma that it comes with the job.

Work life balance and support

All caregivers were asked if they feel they receive enough support from their managers. All five participants answered no. Participants expressed that they feel their managers could listen to them more and that there is too much expected of them in their job. One participant in particular emphasised that management is very demanding and has no idea what the caregivers do: “*Management are only good to you when they want something other than that they just sit on you, they don’t really care otherwise”* (Participant 4). Another participant maintained that management has a role and is needed but it should make an effort to see things from the caregivers’ perspective. All but one of the participants stated that they are unable to say no to their managers if they are asked to work overtime or extra shifts. Reasons for this vary among the caregivers. One participant pointed out that caregivers would not be asked to extend their hours if it was not absolutely necessary, while others suggested that if they said no, it would cause trouble.

Only one of those interviewed felt that she has a work/life balance and the only reason for this is because she has reduced her hours from full time to part time. *“I’ve cut my hours back to part time so I feel I have more of a balance now”* (Participant 2). All other caregivers feel that they do not have a work/life balance: *"I don't really make attempts to keep one to be honest. I just take it week by week"* (Participant 3). It was also pointed out by participants that although they would like a work/life balance, they do not know how to create one.

Participants' lives outside of work are also very busy. Three out of the five participants have children. When they are not at work, they attend to their family, clean the house, look after the children and fulfil various other responsibilities. All three mothers interviewed agreed that this is the nature of their lives. The two participants who are not mothers discussed how they spend their free time relaxing: *"Sometimes I just spend the whole day sleeping, I'm just too tired to do anything"* (Participant 3). *"I spend my day off catching up with stuff and sometimes just doing nothing"* (Participant 4).

Final words

In this section, participants' further thoughts and disclosures – either related to fatigue or the workplace – are presented. It also outlines participants' reactions to the recent court case settlement in regards to the increased pay for caregivers for the equal pay settlement. Although the settlement was signed on the 2nd of May 2017, information about the settlement was released prior to this and therefore a question regarding the settlement was added during the interview process.

When adding her further thoughts on the subject of fatigue, Participant 1 pointed out that she lives an hour away from work, meaning that she has a very long and tiring day. She expressed her concern that being tired could result in bad repercussions for the residents, such as making medication errors, but added that her situation is the 'norm'. Participant 2 discussed the fact that her management has implemented a new policy that restricts the amount of hours a person can work. Under the policy, workers can only work a maximum of 100 hours in a fortnight and following that their hours will be reduced to no more than 80 hours for the following pay period. *"It's a good thing in a way because the residents need care and sometimes workers are too overworked"* (Participant 2). Other participants discussed how the residents' families could make more of an effort to come and see their loved ones because it makes a big difference to the residents' wellbeing. Participant 5 maintained that families should not rely on the caregivers: *"The family come in and they want you to look after mum or dad as if that's the only person in the home"* (Participant 5).

It is evident that caregivers are not doing their jobs for the money because they are paid poorly, with some only getting the minimum wage. All participants maintained that the new pay rise that came into effect in July 2017 is overdue and that they all deserve it. They all expressed happiness to be finally recognised for their work. *"It's a job some people don't value, they don't think it's worth that much but if we didn't have rest homes and people had to look after them, they may change their mind"* (Participant 5). Participants all agreed that while a pay rise is a good thing, it will not be enough to make their lives more comfortable; however, paying the bills will be easier. Other participants pointed out that the pay rise will not change the workload they experience as caregivers.

Conclusion

The main characteristics of the participants were that all five are female. All participants also have the same job description with the only difference being the title they hold. All participants expressed that the highlight of their role is spending time with residents and getting to know them. This is important because it led to the question of whether caregivers care too much. When asked, all participants agreed that they do in fact care too much. The low point for the participants was expressed as concern over the residents' deteriorating health or residents passing away. Therefore, there is a direct relationship between how the participants feel and what is happening to the residents.

The main finding in this study is that while none of the participants directly mentioned the word "fatigue", all caregivers described symptoms and feelings of both fatigue and compassion fatigue. Although the staff to resident ratio differs between the participants, they all expressed that they experience tiredness and that the hours of work increase their level of tiredness. The physical aspect of being a caregiver, including showering, lifting and the day-to-day care of the residents, causes tiredness for the participants. Their emotional wellbeing is also affected when residents' health deteriorates or they pass away. It is clear that what happens to the residents directly affects the way caregivers feel. All five caregivers maintained that they are not supported by their managers.

This study promotes the concept that caregivers experience fatigue and fatigue factors which are directly linked to the care residents receive. As discussed in the next chapter, these findings could be used as a base for further research on the subject of caregiver fatigue. A larger study could be completed to further confirm the relationship between caregivers and fatigue.

Chapter 5: Discussion

Introduction

The chapter discusses the findings of this study regarding fatigue and the role of the caregiver and relates these findings to the identified themes and the relevant the literature. The key themes are presented in the table below. This chapter focuses on the overview of the caregiver, work related experiences of caregivers, experiences of fatigue and concludes with the Health and Safety at Work Act 2015 and how it affects workers with fatigue.

Key Themes

The key themes that are identified in this chapter are firstly that caregiving is a female dominated occupation. The female participants that took part in this study have worked as caregivers for their respective organisations for extended periods of time and regard caregiving as providing stable employment. Secondly, there is a common theme around why people choose to be caregivers. The participants of this study all confirmed that their choice to be caregivers is not directly related to money; rather it is related to the residents that they look after. All participants stressed that the residents are their prime concern, to the extent that they generally care too much for them. A third important theme is that although the workload of the participants continues to increase, surprisingly they all find it manageable. This contributes to the fourth theme that focuses on the fatigue that all the participants have experienced in their workplaces without recognising it. Fifthly, the lack of managerial support is also a contributing factor that affects the way participants feel in their workplace. All participants agreed that their workplaces provide no coping mechanisms in support of their job roles. The sixth theme identified in this chapter is that the participants feel that they have no work/life balance in their lives. The findings suggest that the participants associate the way they are feeling with the stigma of being a caregiver; that is, caregivers should not expect more in their role – any difficulties they face reflect the fact that “that’s what being a caregiver is about”. This can help explain why the participants are unable to recognise that they are experiencing symptoms of fatigue, compassion fatigue or burnout.

Table 4: Overview of themes

Interview Categories	Themes Identified
Overview of the caregiver: questions eliciting details about participants' roles as caregivers	• Female dominated • Stability of employment • Conditions around pay (Equity case in effect as of 1st July 2017)
Work related experiences of the caregiver: questions eliciting insight into participants' experiences in their organisations and within their career as caregivers	• Reason for being caregivers related to the residents they care for • All find their workload manageable even though they all feel their workload has increased over the years
Experiences of fatigue: questions to determine if the participants have experienced fatigue or symptoms of fatigue in their role as caregivers; questions to gain insight into the participants' lives outside of work	• All have experienced fatigue, tiredness, feelings of wanting to give up work or not go to work • All think they care too much but that this is part of the job of being a caregiver • No coping mechanisms for dealing with their tiredness or how they are feeling from work • Felt unsupported by management • No work/life balance

Overview of the caregiver

One of the obvious themes identified in this study is that the five caregivers interviewed are all female and while this is not uncommon given that the caregiving workforce is predominantly female, it relates to the debate on gender inequality. According to Badkar et al. (2009), caregiving is a highly gendered occupation in which 92 percent of caregivers are female, with most caregivers being employed to look after the elderly. This may be associated with the fact that caregivers generally require no formal qualifications to undertake the role – out of the five caregivers who were interviewed, only one holds qualifications that are directly related to the job, while all others have no work related qualifications at all. Subsequently, the role of a caregiver is undervalued and identified as low skilled (Martin, 2007; Badkar et al., 2009). This situation was highlighted in an enquiry by the Human Rights Commission into caregivers, which identified that caregivers are undervalued and experience low pay conditions as well as pay disparity (Human Rights Commission, 2012). It is common knowledge that caregivers are under-paid for the work they provide. While they may feel emotionally rewarded for their work and valued by the residents they care for (Human Rights Commission, 2012), they are not financially rewarded for the role they undertake. However this may change based on the pay equity settlement that came into effect on the 1st of July 2017. Caregivers will now receive recognition for their work as well as pay rises which will continue to increase till 2021. Prior to July 1st 2017 caregivers were paid anywhere from $15.75 an hour to $18 an hour. The majority of caregivers only received a pay rise when the minimum wage increased. Therefore, it would be interesting to see if firstly, the sector remains female dominated and secondly, if this sector continues to hire people without qualifications. It will also be interesting to see if there is a shift in the perception around caregivers and whether or not the role becomes more valued by society. Another key theme identified is stability of employment in that four of the five participants have remained in the same job role and with the same workplace between 5 to 15 years. Participants 2 and 5 have been in the same job role for the longest, with Participant 2 having been in the same job for 12 years and Participant 5 for 15 years. This suggests that typically, caregivers tend to stay in the same job and the same workplace for long periods of time. This also suggests that caregivers are motivated by intrinsic rewards rather than extrinsic rewards; that is, caregivers feel that the role they provide has a positive effect on the residents and it makes them feel useful and appreciated (Pinquart et al., 2003). However, Aronsson et al. (2000) argue that lack of qualifications and difficulty in changing jobs can cause some to caregivers be "locked in" to an occupation they no longer find desirable. This is not evident amongst the participants because they all appear to enjoy their job. The participants were asked why they became caregivers, with four of those interviewed providing similar reasons: firstly, they like caring for people; secondly they see themselves as caring people; and thirdly, they previously had family members in care or required care which inspired them to become caregivers. Participant 3 had a different reason for becoming a caregiver. She chose to become a caregiver because at the time it was a better option for her: *"I had the choice of working in a rest home or working in a supermarket, so I chose to be a caregiver"* (Participant 3). Over time her perception of being a caregiver has changed and she now enjoys her role as a caregiver.

Work-related experiences of caregivers

Another theme identified among all caregivers is that the pleasure they get out of their job is directly related to looking after the residents in their care. While caregiving is seen as a stressful job, it still provides the caregivers with positive experiences (Pinquart et al 2003).

The participants expressed different opinions on what they regard as negative work experiences, with these experiences being dependent on the caregiver and their place of work. For the aged care caregivers, the negative experiences are related to the residents passing away or deteriorating in health. The remaining caregivers regard their negative experiences as being directly related to how they are treated within their organisations. One caregiver described being away from work as a negative experience: *"I cried to come back to work, I missed working and I missed seeing the clients"* (Participant 2).

There is a dichotomy of opinion in that all participants feel their workload is manageable and yet they feel their workload has increased over the years, particularly as the health of residents deteriorates. The literature identifies what is called the "boiled frog" syndrome; namely, if a frog is placed in a pot of cool water and the water is subsequently heated, the frog will stay in there until it dies (Gini, 1998; Hannif et al,. 2006; McKee et al., 2006). This analogy is relevant to the participants as it appears that they are unaware of the negative impact their job is having on them and continue to work until they are no longer able to work and are forced to take a break. Teel et al. (1999) describe how caregivers will continue their role beyond their own tolerances until they become overwhelmed. This relates to the participants of this study because although they admit that their workload has increased over the years, they still believe that it is manageable, dependent on the number of residents. Interestingly, when examining the staff to resident ratio and the workload of the five participants, it is clear that the ratio is different amongst the participants, despite them all agreeing that their workload is manageable.

Experience of fatigue

All five participants experience tiredness as caregivers. Saito (1999) defines fatigue as the state of being tired and maintains that the intensity of work affects the appearance of fatigue. The main contributor to the participants' tiredness was identified as working non-standard hours and long shifts. Shift work is identified across multiple professions as a main cause of fatigue (Lerman et al., 2012; Peacock, 1983; Violanti et al., 2008). Shift work can disturb circadian rhythms, decrease a person's level of performance and affect sleeping patterns (Peacock et al., 1983; Violanti et al., 2008). The participants pointed out that they feel tired because of their hours of work. Bohle et al. (1998)

highlight a number of factors that influence whether or not a person wants to do shift work, including personality, age and material status. These factors are not relevant to this study as all participants who work shift work have no choice in the matter; that is, they must do the shifts that are given to them. Future research could look into solutions to manage this issue, such as the effectiveness of different rotating rosters or optimal staffing levels.

The participants were asked whether they feel tired or exhausted from the physical aspect of being a caregiver or from the emotional aspect of being a caregiver. All five participants responded that both affect their levels of tiredness. The participants pointed out that the physical aspect of caregiving, which includes lifting, transferring and providing day-to-day care, is physically exhausting. They also pointed out that their emotional wellbeing is impacted when the health of the residents deteriorates, their behaviour changes or when a resident dies. In other words, what happens to the residents directly impacts the way the participants feel, Sexton (1999) maintains that there is a cost to caring: a person will experience satisfaction within a caring profession but will also experience stress and fatigue from wanting to help those who are suffering. According to Participant 5:*"Sometimes you don't want to stay there, you don't want to do that job because you know the next person is going to pass away and you have to deal with it."* Compassion fatigue is the result of long-term exposure to the suffering of others (Coetzee et al., 2010; Alkema et al. 2008). Because it appears suddenly, it is not until the caregiver has reached the limits of their capacity to care that they become unable to sustain it any further (Keidel, 2002). During the interviews, compassion fatigue was evident amongst some of the participants, despite the fact that they never specifically mentioned it. According to Participant 4, *"Yes but I also feel like I can't be bothered, like I just don't want to have time for the residents when I shouldn't be feeling that way."* The interviews made it clear that participants experience guilt, distress and possibly depression because of their sense of helplessness and inability to care for the residents when their health deteriorates: *"It's sad to watch them like that and know that there is nothing you can do"* (Participant 3). Gander et al. (2011) state that fatigue is the inability to function at the desired level, while Yoda (2010) maintains that compassion fatigue affects a person in the same way as post-traumatic stress disorder. The participants have clearly experienced both fatigue and compassion fatigue throughout their careers as caregivers due to a combination of working long hours and shift work within a challenging environment. However, the participants did not express any awareness of their fatigue as they are so accustomed to their working conditions that they regard their situation as normal.

This theme led to the question, *"Do you think you care too much?"* All five caregivers were unanimous in their response to this question, responding with "yes". Thus another common theme amongst the participants is that they all feel that they care too much but regard this as a characteristic that makes them good caregivers. According to Participant 2, *"As a caregiver that's just who you are, you care about the residents".* The literature highlights the nature of a caregiver as being someone who cares – it is an essential aspect of the job (Given et al., 2004; Teel et al., 1999). It can be assumed that the participants have often received comments about their deep level of care and therefore were very quick in their response to the question. All participants made statements that reflect the 'cost of caring': *"That's just how it is, it comes with the occupation. I have not heard of a rest home where staff have it easy"* (Participant 3).

A further common theme identified in the findings is that none of the participants feel they have clear coping mechanisms to deal with their job role or to deal with how they are feeling. Some participants stated that as a form of coping, they take the occasional sick day, whereas another participant prays and another occasionally goes to the gym. Hooper et al. (2010) discuss how fatigue can lead to absenteeism, decreased performance and higher turnover.

It should be noted that while the participants did not necessarily use the term "fatigue" they talked about being "tired" and that being tired most of the time was an unavoidable fact of being a caregiver. Another theme identified amongst the participants is that they feel they lack the support of their managers. In the interviews they discussed the fact that their managers do not listen to them and expect too much of them, and that they feel unable to say no to their managers in regards to working extra shifts.

Only one of the five participants (Participant 2) feels she has a work/life balance and this is because she has reduced her hours from full time to part time. None of the other four participants feel that they have a work/life balance at all. Bush (2009) maintains that caregivers essentially work two roles: firstly as caregivers in their job role and secondly in the role as caregivers for their families. The three participants who have children highlighted their role as mothers outside of work, as well as their family responsibilities. However, they maintained that they accepted their dual roles as a fact of life. When the caregivers were asked to describe what they do outside of work aside from any family responsibilities, the comment, *"I'm just too tired to do anything"* was recurrent. Aside from Participant 2, the remaining participants find it difficult to attend to their personal lives and would like a work/life balance; however, they do not see this a possibility because of the demanding nature of their jobs.

The Health and Safety at Work Act 2015

The changes in The Health and Safety at Work Act 2015 are regarded as the biggest upheaval of health and safety requirements in 20 years. The changes came about because of the Royal Commission of Inquiry into the Pike River Coal Mine tragedy of 2012. Firstly, safety in the workplace is no longer solely the responsibility of the employer. This means that workers now have a responsibility to protect themselves and others from harm and they must comply with policies and procedures in their organisation. The Act includes the "reasonably practicable" concept which relates to what is considered reasonable for a business to do Health and Safety at Work Act, 2015). Worker fatigue is mentioned in the Act and this has relevance to caregivers. However, as mentioned above, it is no longer the employer's sole responsibility to manage it. Work Safe NZ suggests that organisations should create a fatigue policy. This policy should be used for workers, managers and supervisors and it should include information regarding lengths of shift, average weekly hours and procedures for reporting and managing fatigue (Work Safe NZ, 2017). It became clear in the interviews that none of the organisations the participants work for have a fatigue policy in place. While all participants described symptoms of fatigue, none were able to identify it as a condition that they experience. This highlights the need for training in organisations to inform and teach caregivers about fatigue and how to manage it. However, in the case of the participants, there is no support from management. All five participants described symptoms of both fatigue and compassion fatigue and management are either unaware of this situation or choose to ignore it. There needs to be better communication between the participants and their managers around managing and minimising fatigue as The Health and Safety in Work Act 2015 requires both employers and employees to take responsibility for it and to take reasonable steps to minimise it.

Conclusion

The aim of this study was to explore whether caregivers experience fatigue, in particular compassion fatigue. This study found that caregivers do experience fatigue; however, what is even more concerning is the fact that they may not realise that they are experiencing it. This chapter highlighted the main themes identified and the relevance they had to current literature. The following chapter discusses the implications of the study, limitations of the study and future research recommendations.

Chapter 6: Conclusion and Implications

Introduction

This chapter discusses the implications of the study, the limitations of the study, which include using qualitative research with a small sample size predominantly based in the South Auckland region. All participants are New Zealand born and all are female. The data was also collected, analysed and transcribed by one researcher only. This chapter concludes with future research recommendations that include using a wider population sample that also includes male as well as women caregivers. It is also recommended that future study is extended to take into consideration the change in pay for caregivers as a result of the recent pay equity case. Finally it recommends that caregivers and managers are taught to be aware of fatigue and that coping mechanisms are developed to support caregivers in response to the recent Health and Safety at Work, 2015 that emphasises the need for safer working conditions in organisations.

Implications

This study aimed to identify if caregivers experience both fatigue and compassion fatigue. The study found that not only do caregivers experience fatigue and compassion fatigue, but also that they are completely unaware that they do so. This lack of self-reflection may explain why this subject is overlooked throughout the literature. These findings highlight the importance of teaching caregivers and management about fatigue and how to deal with it through coping mechanisms.

The findings suggest that caregivers experience fatigue and compassion fatigue within their roles in the same way that nurses do. While the fatigue experienced by nurses has received attention in the literature, the fatigue experienced by caregivers has not. Hence, this study fills an important gap in the literature. However, while the caregivers interviewed in this study were able to describe the symptoms of fatigue and compassion fatigue, they are clearly unable to recognise these types of fatigue within themselves. This may result from the fact that they believe their experiences are “part of the job”, and also because when they finish work most have families to attend to leaving little time to dwell on their own fatigue. However, the spill over effect of fatigue into the participants’ personal lives is evident. The themes identified in this study are consistent with the current literature; however, this study makes a clear case that caregiver fatigue is comparable to that of nurses, a subject which as yet has received no attention in the literature.

Limitations of the research

Although this study provides a number of useful insights in the area of fatigue among caregivers, there are nonetheless limitations that need to be acknowledged.

Firstly, this study used qualitative research methods and the backwards snowballing technique. Information was left with selected service providers and caregivers who were interested contacted the researcher. The study sample was relatively small as only those who were interested and met the criteria were selected. In total there were five participants, which reflected the difficulty in finding interested participants in the timeframe this study allowed.

The design of the study, therefore, may have impacted the findings, in particular the method of recruiting participants and collecting the data. The recruitment was based predominately in the South Auckland area due to the time restriction in finding participants and the number of organisations willing to make information available to potential participants. It is possible that the experiences of caregivers is different in other areas of Auckland and New Zealand as a whole and it may therefore be useful for further research to explore fatigue amongst caregivers on a larger scale within New Zealand.

Secondly the data was collected, analysed and transcribed by one researcher. The researcher's lack of experience in interviewing participants may have affected the way participants responded to the questions. Furthermore, as mentioned above, due to the time frame only five female caregivers were interested in participating in the study and met the criteria. The five participants are all New Zealand born; that is, no immigrants were interviewed. This may have been a result of the backwards snowballing technique used and the possibility that immigrants who work as caregivers in the targeted organisations did not understand the information provided. There were no male participants for this study. While caregiving comprises a highly female dominated workforce, the lack of male participants should still be regarded as a limitation.

Taking into consideration the above limitations, this study still provides a very useful understanding of fatigue amongst caregivers. No prior research has been undertaken in this area and this study therefore contributes to the body of knowledge concerning caregivers and fatigue.

Future research

As mentioned, more wide scale research on fatigue among caregivers is required and these findings could be used as the basis for further investigation into both fatigue and compassion fatigue among caregivers. It is suggested that future research extend the scope of this study to encompass a wider population of caregivers throughout New Zealand that includes not only female but also male caregivers. Using a wider population sample would strengthen the findings that this study has highlighted by providing a more comprehensive understanding of the nature of caregiver fatigue within the workplace. Including males within the sample would also help determine if gender has a part in caregivers' experience of fatigue Furthermore, future research could be adapted and extended to take into consideration the change in pay within the caregiving workforce. It would be interesting to investigate whether the recent increase in pay changes caregivers' perspective on their work and whether it minimises their level of fatigue or adds to their already increasing workload. In addition, this study found that those participants who are mothers as well as caregivers have an extremely busy life with little time to themselves. Those who are not mothers expressed that they are too tired to do anything on their days off. Therefore, looking in more in detail at caregivers' work/life balance could also prove crucial in providing solutions to the current lack of relaxation time available to caregivers and the cumulative fatigue that caregivers can experience both within and outside their work.

Secondly, there appears to be a lack of coping mechanisms available for caregivers who are feeling overwhelmed or fatigued in their job role. Future research could be aimed at teaching caregivers how to identify that they may be experiencing fatigue, compassion fatigue or burnout, as well as teaching management how to recognise fatigue amongst their organisation's workers. The findings of this study show that that the participant caregivers receive little support from managers and future research that focuses on coping mechanisms for caregivers could help relieve the tension between caregivers and management and thus benefit organisations.

Finally, there appears to be a lack of knowledge among both employers and caregivers in regards to the Health and Safety at Work Act 2015. While WorkSafe New Zealand has produced guidelines on how organisations can manage fatigue, future research could look at developing a fatigue model for residential care organisations in order that fatigue and compassion fatigue can be better managed. Caregiving can be a demanding occupation and developing mechanisms to minimise fatigue in residential care organisations would mean organisations are taking all practicable steps to minimise work-place hazards and reduce harm.

Conclusion

This study adds to the body of knowledge that highlights the challenges caregivers face within their job role and supports previous research on caregivers, such as that undertaken by, for example, the Human Rights Commission (2012) and Ravenswood, et al, (2014). More importantly it includes compassion fatigue at part of the general discourse on fatigue and in doing so broadens the scope of the research. The findings of this small study reveal that caregivers experience fatigue within their workplaces regardless of what type of caregiver they are or the staff-to-resident ratio. More importantly, caregivers are unaware that they are experiencing fatigue because their level of fatigue is normalised. While no caregivers interviewed identified that they are fatigued, they described symptoms of fatigue, compassion fatigue and burnout.

This study highlights the lack of knowledge around fatigue and also the lack of support that caregivers receive because of the stigma that is associated with the job role. It also highlights the lack of knowledge around legislation relevant to caregiver’s health and safety. Educating caregivers and employers appears to be the best way to help minimise fatigue in the workplace.

It is evident from this study that until recently, caregivers were not recognised for their work and dedication to their role. The pay rise for caregivers that became active on 1st July 2017 goes some way in recognising the demanding role of a caregiver. Although this study was conducted with a small sample size, the findings confirm that fatigue and compassion fatigue are evident amongst caregivers. Future research could be undertaken on a larger scale to strengthen these findings and to increase the body of knowledge around both fatigue and the role of caregivers. Finally, society’s perception of caregivers needs to change and people need to be educated on the important role of caregivers within organisations.

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Appendix A: Ethics Approval

23 February 2017

Felicity Lamm
Faculty of Business Economics and Law

Dear Felicity

Ethics Application: 17/21 **An exploration of fatigue among caregivers**

Thank you for submitting your application for ethical review. I am pleased to confirm that the Auckland University of Technology Ethics Committee (AUTEC) has approved your ethics application for three years until 20 February 2020.

The committee suggests:

- That the researcher reflects on the potential for phrases like “emotional stuff” to diminish what is potentially very serious.
- In the spirit of reciprocity, consider offering a small token of appreciation (e.g. supermarket voucher).

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 20 February 2020;
- 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 20 February 2020 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, we ask that you 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,

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

Cc: dpe.harris@hotmail.co.nz

Appendix B Tools (A) Participant Information Sheet

Participant Information Sheet

9th January 2017

An exploration of Fatigue among Caregivers

An Invitation

Hello, my name is Dannii Harris, I am a student at AUT University completing my Master's degree through the Human Resource Management and Employment Relations discipline. I wish to invite you to participate in this research study which contributes toward the completion of my dissertation as part of my Master's degree. Your participation in this study is voluntary and you may withdraw at any given time, prior to the completion of data collection (add collection date).

What is the purpose of this research?

The purpose of this research is to obtain qualitative data in order to explore fatigue among caregivers. The research aims to contribute new insights towards the under-researched area of the working conditions of caregivers and in particular, the different forms of fatigue experienced by caregivers. This research will result in a Dissertation. There is also a chance it may result in a research article, journal article, academic publications or presentations and/or conference article.

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

You have been identified personally by myself, or by a third party, as qualifying to participate in this research. You have been selected as a possible candidate as you have been recognized as meeting the selection criteria (working as either an aged care caregiver, disabled adult caregiver or hospice caregiver, experiencing fatigue in the workplace and working in this area for a minimum of a year).

What will happen in this research?

The research project involves 5 face-to-face interviews conducted by myself as the researcher, and you as the participant. Should you choose to participate in the research process, you will be invited to attend the interview lasting 30-60 minutes, where you will be asked questions relating to your role as a caregiver and experiencing fatigue in the workplace. Questions will be open ended to allow for full discussion of your experiences. The interview will be held in a location mutually agreed upon. The data will be recorded by a voice recording device. All data will be kept in a secure location and may be used for additional post-dissertation purposes relating to this study. I will be the only person to have access to the recorded interview. The anonymous transcript may be shared with my supervisor, Felicity Lamn for guidance in the data analysis process. All data collected will be stored securely at AUT, separate from consent forms.

What are the discomforts and risks?

I do not expect any risks to come from your participation. As questions are open-ended regarding your personal experience of caregiving and feelings towards the research agenda, please feel free to answer in your own time and to a comfort level which suits you. You may stop the interview at any time, or ask to move on from any question. I do not believe any questions will take you outside of your comfort zone, however if they do, a free, professional, face-to-face counselling service is available, up to a maximum of three sessions. Details of this service are as follows;

- To utilise this service, drop into any center WB219 or AS104 or phone 921 9992 (city campus) or

  921 9998 (north shore campus) to make an appointment.

- Let the receptionist know you are a research participant.

- Provide my contact details as mentioned below and the research project you are involved in to

  make your appointment.

- You can find out more information regarding the counsellors and counselling on their website

http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing

- Current AUT students also have access to the counselling services and online counselling as part of

  their normal service delivery.

- Should you require any further information please do not hesitate to ask myself or my

  supervisor involved in this research project. Contact details are provided below.

- This counselling provision cannot accommodate crisis work, so in that situation you would need

  to access your own health provider or Community Mental Health Services as soon as possible.

What are the benefits?

The benefit of participating in this research is to give you an opportunity to provide data which has the potential to increase the knowledge base and literature on fatigue among caregivers. It will also assist me as it contributes towards the completion of my Dissertation as part of the AUT MBus program.

How will my privacy be protected?

As mentioned above, the details of the interview will remain confidential. You will not be identifiable in any way. You have the option to obtain a copy of the transcript resulting from this interview, by selecting the appropriate option in the 'Consent Form'.

What are the costs of participating in this research?

There are no financial costs. The interview could take 30-60 minutes of your time. Transport time to the interview location and getting comfortable may extend that time.

What opportunity do I have to consider this invitation?

Participants will be given 2 weeks to consider their participation in this research. You may accept or decline prior to this time frame.

How do I agree to participate in this research?

I will provide a consent form at the time of interview, or prior as requested, for you to sign and return to me.

Will I receive feedback on the results of this research?

You will be given the option of receiving a copy of the summary of findings on completion of the research study. You also may choose to receive a copy of the transcript once the interview has been transcribed These may be obtained by selecting the appropriate option on the 'Consent Form'.

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 Project Supervisor, Felicity Lamn, Felicity.Lamn@aut.ac.nz, 64 9 921 9999 ext 5906.

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

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Dannii Harris

DPE.Hariis@hotmail.co.nz

Project Supervisor Contact Details:

Felicity Lamn

64 9 921 9999 ext 5906

Felicity.Lamn@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 23rd February 2017, AUTEC Reference number 17/21

Appendix B Tools (B) Consent Form

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Consent Form

Project title: ***An exploration of fatigue among Caregivers***

Project Supervisor: ***Felicity Lamn***

Researcher: ***Dannii Harris***

○ I have read and understood the information provided about this research project in the Information Sheet dated (Add date here)

○ 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 the interviews will be audio-taped and transcribed by the researcher (Dannii Harris). If individual quotes are used in the final report, names will be changed to maintain confidentiality.

○ 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 summary of findings once completed (please tick one): Yes○ No○

○ I wish to receive a copy of the Transcript once available (please tick one): Yes○ No○

Participant's signature:
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Participant's name:
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Participant’s Contact Details (if appropriate):

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Date:

Approved by the Auckland University of Technology Ethics Committee on 23rd February 2017 AUTEC Reference number 17/21

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

Appendix B Tools (C) Interview Schedule

Interview Schedule from Caregivers

Overview of the caregiver: Questions providing detail about the particular caregiver being interviewed.

1. How long have you been working as a caregiver for and how long have you been in your current role?
2. What is your current role?
3. What made you want to be a caregiver?

Work related experiences of the caregiver: Questions to gain an insight into what the caregiver has experienced not only in their organisation but also within their career as caregivers.

4. What has been the highlight of your time as a caregiver?
5. Have you had any negative experiences as a caregiver? Has anything happen to you personally or affected you personally from these negative experiences.
6. How do you feel about your workload as a caregiver?
7. What is the ratio of staff to residents?
8. Do you think your workload is manageable?
9. Do you think your workload has increased over the years?

Experiences of fatigue: Questions that look more into if the caregiver has experienced fatigue, or if they have experienced symptoms of fatigue. Brief insight into their life outside of work. These questions are used to determine if the caregiver is possibly taking on too much.

10. Have you experienced tiredness as a caregiver?
11. Interviewer: Do you feel more tired or exhausted from the physical work of the caregiver or more so from the emotional side of dealing with patients/clients?
12. What do you do to overcome this?
13. How do you keep a work life balance as a caregiver? Do you think you have a work life balance?
14. Do you think you care too much?
15. Can you tell me a little bit about your life outside of work?
16. Do you feel you get enough support from your managers?

Final Question: Leaves it open for caregivers to add anything else they wish to disclose.

17. Is there anything else about fatigue in your workplace that you want to comment on?
18. How do you feel about the recent court case settlement regarding caregivers?